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Hand Function in Palestinian People with Rheumatoid Arthritis: An Exploratory Mixed Methods Study

by

Hisham Ahmad Deeb Arab Alkabeya BSc MSc

Thesis for the degree of Doctor of Philosophy

July 2020

University of Southampton

Abstract

Faculty of Environmental and Life Sciences
School of Health Sciences
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An Exploratory Mixed Methods Study

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Background

Rheumatoid arthritis (RA) is the most prevalent, chronic, inflammatory arthritis and is a debilitating disease that leads to pain, joint damage, and functional disability. For those with RA, loss of general functional ability largely depends on hand function. There is limited research available on hand function and its impact on the daily life of people with RA in Palestine. This project, therefore, was designed to explore this subject in-depth, that is to say, hand function and the factors influencing hand functional disability among Palestinian people with RA.

Methods

An exploratory mixed-methods research design employed in two sequential phases, was adopted for this PhD project and the International Classification of Functioning, Disability and Health (ICF) was used as the theoretical framework. This was underpinned by a pre-study phase, which included a systematic review of the factors associated with hand functional disability in RA. Phase One (Qualitative) involved five focus group discussions with 20 Palestinians with RA, who were recruited using a purposive sampling technique. Focus group data were analysed using a modified form of content analysis (specifically, the condensation procedure) to identify concepts of hand functioning important to Palestinians with RA. The findings from the focus groups were then used to inform the design and conduct the second phase of this project. Phase Two (Quantitative) was a multicentre, cross-sectional observational study conducted to examine hand function and related variables among Palestinian people with RA. The study comprised a convenience sample of 67 patients. The data were collected by both self-reported and clinician assessed objective performance-based measures and analysed statistically using SPSS software (Statistical Package for Social Sciences version 25).

Results

The systematic review study (pre-study phase) revealed that evidence from the existing literature was insufficient to advise on the environmental and personal factors that might influence hand function in RA. In Phase One, the qualitative data analysed from the focus group interviews revealed 32 hand functioning concepts considered to be important for Palestinians with RA. Activity and participation comprised the largest number of concepts (16 concepts), followed by body function and structure (7 concepts), personal factors (5 concepts), and finally, environmental factors (4 concepts). The above findings informed the discussion on the appropriate hand functional outcome measure(s) to use within the Palestinian context and identified the important personal and environmental variables in relation to hand function in daily living. The findings from the cross-sectional study in Phase Two identified that Palestinian patients with RA have reduced grip strength, limited hand mobility and hand pain remains a problem. Furthermore, hand functional disability in various levels were detected in 85% of the patients studied. Finally, the bivariate analyses also revealed that hand functional disability was associated with different aspects of functional dimensions, which indicated that hand functional disability in RA is complex.

Conclusions

Findings from this PhD project suggest that hand function problems are prevalent in Palestinian patients with RA, form an important aspect of their patient experience and significantly impact their daily lives. In addition, the thesis results also revealed that hand functional disability is associated with different aspects of functional dimensions. Future longitudinal research would provide useful data about hand functional abilities over time and would allow causal factors amenable to change to be identified.

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Research Thesis: Declaration of Authorship

Print name: Hisham Ahmad Deeb Arab Alkabeya

Title of thesis: Hand function in Palestinian people with rheumatoid arthritis: An exploratory mixed methods study

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
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6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
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    - Arab Alkabeya H, Hughes A-M and Adams J (2019) Factors associated with hand and upper arm functional disability in people with rheumatoid arthritis: A systematic review. Arthritis Care Res 71(11): 1473-1481
    - Arab Alkabeya H, Sankah BEA, Hughes A-M and Adams J (2019) Measurement properties of patient-reported hand function measures in rheumatoid arthritis: a systematic review protocol. Phys Ther Rev 24(3-4): 60-65
    - Arab Alkabeya H, Daibes J, Hughes A-M and Adams J (2020) The Arabic Arthritis Self-Efficacy Scale-8 (ASES-8): A valid and reliable measure of evaluating self-efficacy in Palestinian patients with rheumatoid arthritis. Disabil Rehabil, 1-7

Signature: Hisham Arab Alkabeya Date…………………

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Abbreviations

Abbreviation	Definition
AAUP	Arab American University-Palestine
ACR	American College of Rheumatology
ADL	Activities of Daily Living
AIMS	Arthritis Impact Measurement Scales
ASES	Arthritis Self-Efficacy Scale
AUROC	Receiver Operating Characteristic Curves
AXIS	critical appraisal checklist to assess the quality of cross-sectional studies
BCI	Brief COPE Inventory
bMHQ	brief Michigan Hand Outcomes Questionnaire
BMQ	Beliefs about Medicines Questionnaire
BRS	Brief Resilience Scale
COREQ	Consolidated Criteria for Reporting Qualitative Research
CRP	C-reactive Protein
DALYs	Disability-Adjusted Life Years
DAS-28	Disease Activity Score with 28-Joint Counts
DASH	Disabilities of the Arm, Shoulder and Hand
DHI	Duruoz Hand Index
DIP	Distal Interphalangeal
DMARD	Disease Modifying Anti-Rheumatic Drug
ESR	Erythrocyte Sedimentation Rate
EULAR	European League Against Rheumatism
FG	Focus Group
GAD	Generalised Anxiety Disorder
GAT	Grip Ability Test
GBD	Global Burden of Disease
GRAMMS	Good Reporting of A Mixed Methods Study
HAQ	Health Assessment Questionnaire
HL	Health Literacy
HLA	Human Leukocyte Antigen
ICF	International Classification of Functioning, Disability and Health
ICHI	International Classification of Health Interventions
IP	Interphalangeal
IPQ	Illness Perception Questionnaire
Lt.	Left

Abbreviation	**Definition**
MCP	Metacarpophalangeal
MHQ	Michigan Hand Outcomes Questionnaire
MoH	Ministry of Health
MRI	Magnetic Resonance Imaging
MSA	Modern-Standard Arabic
MSPSS	Multidimensional Scale of Perceived Social Support
MT	Metatarsophalangeal
n	number
NGOs	Non-Governmental Organisations
NICE	National Institute for Health and Care Excellence
NIS	New Israeli Shekel
NRS	Numeric Rating Scale
OA	Osteoarthritis
OMERACT	International Initiative to Improve Outcome Measurement in Rheumatology
OT	Occupational Therapy
PGA	Patient Global Assessment
PHQ-2	Patient Health Questionnaire (depression scale)
PHQ-4	Patient Health Questionnaire
PIP	Proximal Interphalangeal
PIS	Participants Information Sheet
PPI	Patient and Public Involvement
PRISM	Preferred Reporting Items for Systematic reviews and Meta-Analyses
PROMIS	Patient-Reported Outcomes Measurement Information System
PROSPERO	International Prospective Register of Ongoing Systematic Reviews
PSR	Palestinian Rheumatology Society
PT	Physiotherapy
QuickDASH	shortened version of the DASH
RA	Rheumatoid Arthritis
RAAD	Rheumatoid Arthritis Articular Damage
RAPID	Routine Assessment of Patient Index Data
RCTs	Randomised Control Trials
RF	Rheumatoid Factor
ROM	Range of Motion
Rt.	Right

Abbreviation	Definition
SDAI	Simplified Disease Activity Index
SF-36	Short Form 36-Item Health Survey
SHFT	Sollerman Hand Function Test
SILS	Single-item health literacy screening
SODA	Sequential Occupational Dexterity Assessment
SOFI	Signals of functional impairment
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TEMPA	Upper Extremity Function Test for the Elderly
TNF	Tumour Necrosis Factor
UNRWA	United Nations Relief and Work Agency
VAS	Visual Analog Scale
WHO	World Health Organisation

Research staff abbreviations

Abbreviation	Definition
HA	Mr. Hisham Arab Alkabeya, PhD candidate
JA	Professor Jo Adams, Professor of Musculoskeletal Health within Health Sciences, University of Southampton
AMH	Dr. Ann-Marie Hughes, Associate Professor within Health Sciences, University of Southampton
JD	Ms. Jumana Daibes, PhD candidate and Lecturer, Faculty of Allied Medical Sciences, Arab American University-Palestine
SE	Dr. Sean Ewings, Research Fellow within Southampton Statistical Sciences Research Institute, University of Southampton

Chapter 1 Introduction

1.1 Introduction

This study is concerned with hand function among Palestinians living with rheumatoid arthritis (RA), with a specific focus on the factors that contribute to hand function in their Activities of Daily Living (ADL). From my personal experience as a physiotherapist and based on the views of my colleagues in the rehabilitation setting, Palestinian people with RA are usually not referred to rehabilitation services, and those who do self-refer, often present with severe hand functional disability. A preliminary exploration of the literature found no evidence to inform on the impact of RA on hand function and the factors that contribute to hand functional disability among Palestinian people. This led to the development of this programme of research. This chapter introduces the background and rationale of the research study and presents the aims and structure of the thesis.

1.2 Background and rationale

RA is the most prevalent chronic inflammatory arthritis and is a debilitating disease that, if left untreated, leads to pain, joint damage, functional disability, reduced health-related quality of life and premature death (Uhlig et al. 2014). Globally, there are approximately 20 million prevalent cases and 1.2 million incident cases (Safiri et al. 2019). Over the last 20 years, management strategies of RA have changed dramatically, focusing on early diagnosis and early intervention, and treatment involves disease modifying anti-rheumatic drugs, as well as access to biological and biosimilar medicines. With this therapeutic approach, most patients can be treated effectively, as it leads to reduced disease activity, functional disability and joint damage than beforehand (Carpenter et al. 2017; Nam et al. 2017). Nevertheless, many patients still experience functional disability (Karpouzas et al. 2017), which can deteriorate, despite suppression of the disease activity (Seto et al. 2013).

In RA, a great deal of loss of functional ability depends on hand function (Johnsson and Eberhardt 2009). The importance of hand function in RA is underlined by the fact that RA has a predilection for the hands and that hand function plays an essential role in performing ADL. In 80-90% of cases, the hands of those with RA are affected (Durmus et al. 2013), which results in joint stiffness, swelling, pain, Range of Motion (ROM) limitation, deformity and muscle weakness (Horsten et al. 2010). These impairments have a formidable impact on hand function and the performance of ADLs (Dellhag and Burckhardt 1995; Vliet Vlieland et al. 1996), and causes hand functional disability for a substantial percentage (81%) of people with RA (Bodur et al. 2006). In spite of new drug advances and targeted medical treatment, recent reports show that hand function problems still persist and deteriorate overtime in this patient population (Johnsson and Eberhardt 2009; Toyama et al. 2014; Rydholm et al. 2018; Bremander et al. 2019). Whilst some available evidence suggests that measures of disease activity do not fully reflect the regional impact of RA on the hands, others also report that hand functional tests are sensitive enough to reflect improvement in regional specific functional ability in hands, secondary to treatments in RA (Eberhardt et al. 2008; Bremander et al. 2019). It has been argued, therefore, that hand functional assessment should be included as a distinct element of the global assessment of RA (Eberhardt et al. 2008; Bremander et al. 2019). Furthermore, hand function domain (i.e. fine hand use) is included in the International Classification of Functioning, Disability and Health (ICF) core set categories to be evaluated in RA (Stucki et al. 2004). Therefore, it is important to measure, interpret and evaluate hand function in clinical practice and research.

The term hand functional assessment has been used to represent a wide range of assessment techniques and is often used inconsistently (Kimmerle et al. 2003). Traditionally, assessment of hand function in RA has included measures of hand impairments such as joint motion and stability, whereas the ability to perform ADLs that involve the hands has been evaluated using self-reported and performance-based tests (Poole 2019). However, measures of hand impairments are limited to reporting how well patients perform their ADLs, and do not capture the full extent of patient disability (Waljee et al. 2010). In addition, for RA patients, the level of hand disability in daily life may be of greater importance than the level of impairment (van Lankveld et al. 1998; Nicklasson and Jonsson 2012). Therefore, self-reported and performance-based tests are commonly used with RA patients to evaluate the functional ability of their hands. However, there has been a continues debate about the relative advantages of performance-based versus self-reported approaches for hand functional assessment (Metcalf et al. 2007). Despite this debate, recent evidence supports the use of self-reported hand function questionnaires among RA patients, which is in line with a world-wide rheumatology trend towards patient-centred care (Gossec et al. 2015).

Many self-reported questionnaires designed specifically to measure hand functional ability among those with rheumatic disease are available (Poole 2011); however, there is lack of consensus amongst researchers regarding which to use in rheumatic hand conditions (Klokker et al. 2016). Additionally, most of the measures available also vary quite considerably in terms of the concepts they measure. Similarly, these measures have been predominantly developed in Western countries and none have included patients from different countries or sociocultural contexts in the development process. Based on the above, it may be questioned whether the content of these questionnaires covers the spectrum of problems related to hand function that patients with RA in non-Western countries face. Evidence has shown that the concept of hand functioning may differ according to the sociocultural context (Thumboo et al. 2017). It is also important to recognise that these measures have been developed primarily to measure the consequences of the disease on activity and participation levels, and may not address all relevant aspects of hand function such as environmental and personal factors, which are associated with hand functional ability in those with RA (Chung et al. 2011; Andrade et al. 2016). Content analysis of self-reported hand functional measures, including those used with the RA population, have shown that these measures have addressed function in terms of impairment, activity and participation level with limited consideration of environmental factors (van de Ven-Stevens et al. 2015). Therefore, these measures may not reflect the important aspects of hand function important for patients with RA. However, developing a questionnaire for people with RA that covers all of the important aspects of hand function is a time consuming and expensive process.

It would therefore be valuable to define what should be measured to facilitate the decision as to what the appropriate tool(s) to assess hand function in RA are. To achieve this goal, the ICF can be used, as this is a globally agreed framework used to define the typical spectrum of functional problems among patients with RA (WHO 2001). The ICF categories are too detailed to be used in daily practice, therefore, for patients with RA, the ICF core set, which contains the most relevant functioning categories, has been developed (Stucki et al. 2004). However, this core set describes functioning and disability in general, and was not developed to address hand function specifically. Importantly, patients were not involved in the development of the RA core set, and successive validation studies have reported additional categories that were not covered by the ICF core set (Stamm et al. 2005; Coenen et al. 2006). Similar to the process of developing the ICF core set for RA patients, the ICF core set for hand conditions has also been developed (Rudolf et al. 2010; Rudolf et al. 2012), and although patients were involved in this process, it was not clear if RA patients were included. Of note, the ICF core set of hand conditions was developed in Western countries (i.e. Germany) and therefore, the concepts of hand function important for patients living in a different sociocultural context may have been overlooked. As pointed out earlier, the concepts of hand function may differ according to the sociocultural context (Thumboo et al. 2017) and, to date, there has not been a qualitative study explicitly designed to explore these concepts important for patients with RA.

A robust and extensive systematic literature review was conducted and recently updated (Appendix A) by the researcher, indicating that there is no evidence to address the clinical characteristics of Palestinian people with RA and their hand function outcomes, or even their general functional status. Whilst the data published has provided valuable information about hand function in RA patients, it has been reported that hand function outcomes in RA tend to be different across countries (Chung et al. 2011; Su et al. 2017). This therefore indicates that country-specific factors may contribute to the burden this disease places on sufferers, and subsequently influence hand function outcomes. Palestine has one of the most complex settings worldwide. Indeed, review studies from Palestine show that a complex combination of political, socioeconomic and cultural factors have influenced the health outcomes of the Palestinian people over the last decade (Giacaman et al. 2009; Mataria et al. 2009; Saca-Hazboun and Glennon 2011; Keelan 2016). These factors may contribute to the burden of those with RA and consequently influence hand function outcomes among Palestinian people with RA. Accordingly, transferring the results obtained from international published RA studies that include hand function outcomes might not be applicable to the Palestinian population. Therefore, an in-depth investigation is necessary and justified to understand the impact of RA on Palestinian patients' hand function outcomes. While there is a critical need to explore the impact of RA on Palestinian patients' this issue, it would be valuable to initially explore the concepts valued by

Palestinian people with RA in terms of hand function in daily life. Exploring these concepts would facilitate discussion and enable recommendations on the most appropriate outcome measure(s) to be used for patients' research and by clinical staff to be made.

Rehabilitation interventions targeting the hands in cases of RA (such as exercises and splints) have focused predominantly on reducing hand impairment instead of using a multidimensional approach. Furthermore, there is insufficient evidence to make firm conclusions about the effectiveness of these interventions (Beasley 2012). Current evidence suggests that hand functional disability in RA is multifactorial, that is to say, it is influenced by many variables, including disease status, and environmental and personal factors (Chung et al. 2011; Andrade et al. 2016). Therefore, to improve hand function in the RA population, careful consideration of all of the factors that contribute to hand function in ADLs should be identified before such an intervention is developed. However, an overview of these factors, which are associated with hand function in daily life, has yet to be systematically reviewed and reported. Furthermore, the influence of environmental and personal factors on hand function in ADLs among RA patients remains unknown. Therefore, there is a need to explore the important environmental and personal factors experienced by Palestinian people with RA that are both facilitators and barriers in relation to their hand function in daily living tasks. Identifying these factors would assist in identifying the most appropriate outcome measure(s), in order to explore their influence on hand function and assess their status. It was therefore proposed that a qualitative study would be required in order to identify the environmental and personal factors. In addition, the qualitative study would also inform the selection of the most appropriate hand function measure(s) to be utilised within the main study, which describes the impact of RA on hand function and defines the factors associated with hand functional disability among Palestinian patients.

1.3 The research aims

This thesis was inspired by clinical experience and intended to shed light on hand function and its associated factors that contribute to hand functional disability among Palestinian people with RA. The research employed a mixed method, sequential exploratory design. A qualitative focus group and quantitative cross-sectional study were conducted to address the following aims:

1) To explore and identify the concepts of hand function important for Palestinian people with RA.
2) To examine hand function and the related variables among Palestinians with RA.

1.4 Significance of this doctoral research

This is the first study to explore hand function and the factors that influence hand function in ADLs among Palestinian individuals with RA. The outcomes of this research will impact on health professionals with a special interest in hand rehabilitation and people from Palestine living with hand RA. This study has deepened the understanding of hand function and its influencing factors in a unique sociocultural setting; Palestine, and also provided a better insight into the needs of Palestinian people with RA. Furthermore, this is the first study to provide a descriptive experience of Palestinian people with RA, in terms of what they identify as the important concepts of hand function. Consequently, this should help inform decisions as to the most appropriate outcome measure(s) to be used in the Palestinian context. This work should also enhance hand function assessment, and subsequently lead to a better and more timely allocation of resources required to manage hand function problems. Importantly, this study explored both environmental and personal factors as facilitators and barriers in relation to hand function, and thus provides an additional unique perspective on these important contexts. The relative importance of these factors in relation to hand function in ADLs has been investigated and reported here, adding to the body of understanding in this area. This doctoral work has also provided a basis and possible structure for approaching therapeutic intervention research that targets hand function. Since the study focused on the Palestinian context, the findings and implications of this research are timely and will contribute to the improvement of healthcare and hand therapy practice for Palestinians with RA. In addition to the benefits for those in the Palestinian context, the findings from this doctoral project could also be valuable for non-Western countries when used as a benchmark to evaluate their own RA populations. Finally, it is envisaged that evidence from this research project will increase the awareness of hand functional problems and their link to RA management among rehabilitation professionals and policy makers.

1.5 Structure of thesis

This thesis reports the findings of a mixed method study conducted to understand hand function in Palestinian people with RA and the associated factors contributing to hand functional disability in this patient population. This research used two phases to meet its aims. In addition, a pre-study phase, which included a systematic review, was conducted to lay the foundation of this thesis (Figure 1-1). This thesis is structured around seven chapters (including the current chapter), which comprise a literature review, a systematic review, a methodology section, a qualitative study (focus group), a quantitative study (cross-sectional) and an overall discussion and conclusion chapter. Detailed outlines for each chapter are shown in Table 1-1.

The next chapter will explore the background and context of the whole PhD project.

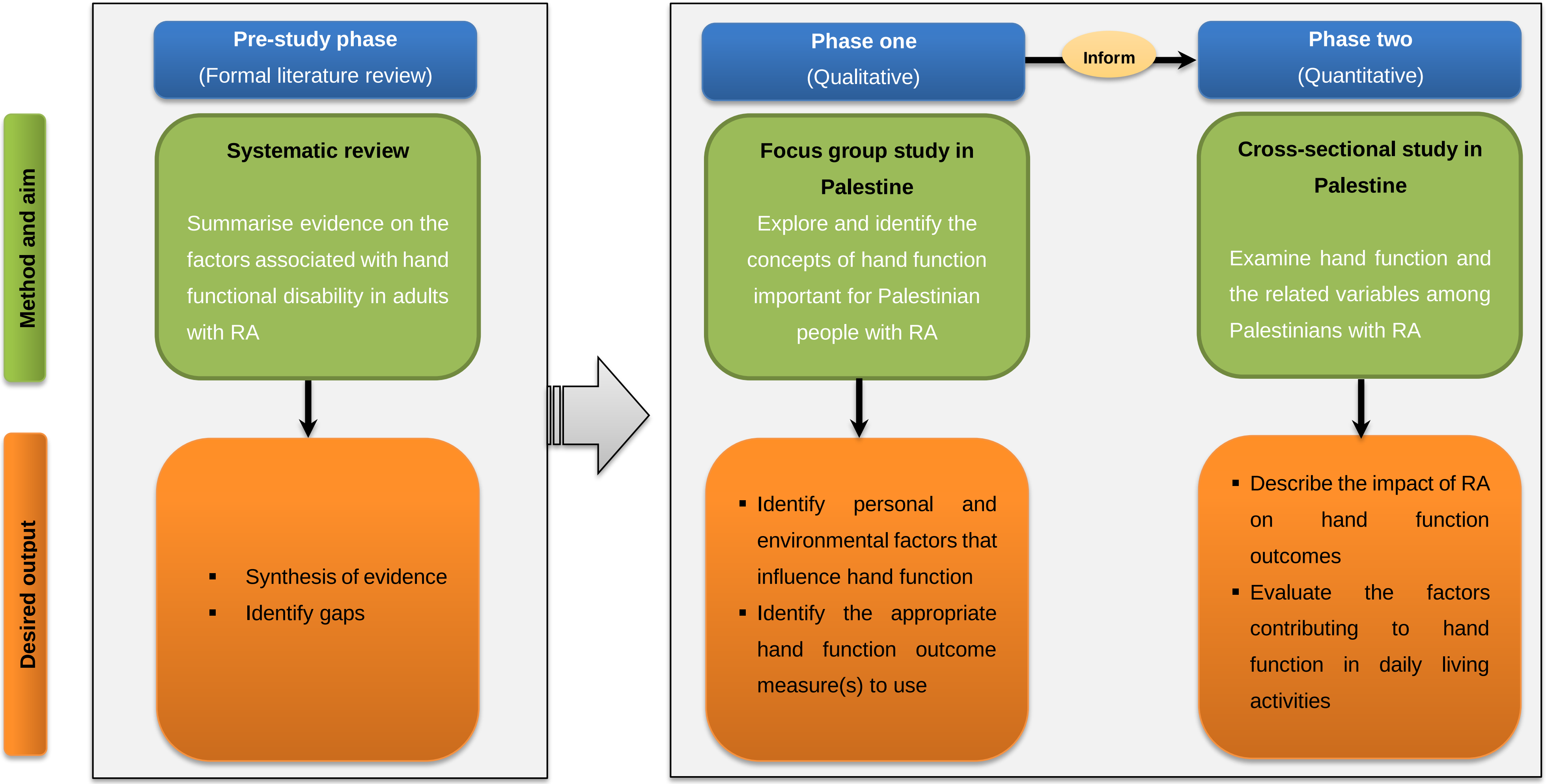


Figure 1-1 Overview of PhD research

Table 1-1 Details of each chapter in the thesis

Chapter	Title and outline
1	**Introduction**
	This chapter outlines a brief research background and the rationale for the research. The aims and significance of the PhD project are clearly discussed.
2	**Background and context**
	This chapter comprehensively explores the background and context of the PhD study. It contains three parts; which provides background information about RA, examine the existing body of knowledge concerning hand function in RA, and outline the study context alongside addressing the gaps in the literature that reinforce the need and significance of the PhD study.
3	**Factors associated with hand functional disability in people with RA: A systematic review**
	This chapter details a systematic review, which was performed to determine the current reported evidence within observational studies on the factors associated with hand functional disability in RA. The findings of this review are discussed and gaps in the literature are identified.
4	**Methodology and methods**
	This chapter explains the methodological approach for the programme of the research study and the selection of a study paradigm underpinning the investigations in the entire thesis. The rational for using mixed methods research are discussed and the research phases are outlined. Specific methods for each study included in the thesis are presented in the corresponding chapters of each investigation.
5	**Concepts of hand functioning important for Palestinian people with RA: A focus group study**
	This chapter presents a qualitative study that explores the concepts of hand functioning important for Palestinian individuals with RA. Findings of this study provided evidence on the appropriate hand function outcome measure(s) useful for the Palestinian RA population as well as identify the important environmental and personal factors that influence their hand function.
6	**Hand function and related variables in Palestinian people with RA: A cross-sectional study**
	This chapter presents the quantitative observational study that investigated hand function and defined the relationship between hand functional disability and influencing factors among Palestinian people with RA. The findings of this study are discussed within the context of current evidence.
7	**General discussion and conclusions**
	This chapter integrates and summarises the findings from the previous chapters. It also discusses the thesis strengths and limitations, implications of findings and directions for future research.

Chapter 2 Background and context

2.1 Chapter overview

This chapter is divided into three parts and is designed to provide the foundational evidence for the thesis. The first part provides background information on the nature of RA, its epidemiology, diagnosis, outcome measurements and management. The second part examines the existing literature surrounding hand function in RA and, lastly, the final part explains the context of the present thesis and highlights the research gap.

2.2 Part 1: Rheumatoid arthritis

RA is an inflammatory, systemic autoimmune and chronic disease of which the exact cause is unknown (Hochberg et al. 2009; Scott et al. 2010). Through an immune-mediated mechanism, RA causes symmetrical synovitis of the joints and hyperplasia, autoantibody production, as well as cartilage and bone destruction, which results in functional limitations and aesthetic changes to the synovial joints (McInnes and Schett 2011). Patients' symptoms range from pain and morning joint stiffness to functional impairments. Furthermore, a range of extra-articular manifestations such as problems with the skin, eyes, heart, lungs, and the renal, nervous and gastrointestinal systems can also occur as a result of RA (Young and Koduri 2007; Cojocaru et al. 2010).

RA is shown to have significant physical, psychosocial and economic burdens on people living with it and, as explained in the literature, this leads to difficulties performing ADLs, reduced work performance, work disability and a decreased health-related quality of life, as engaging in leisure activities and social participation are more challenging (Cutolo et al. 2014; Uhlig et al. 2014). Additionally, RA has also been reported to considerably increase the risk of mortality in people living with the disease (Carmona et al. 2010).

2.2.1 Prevalence and incidence of rheumatoid arthritis

Several epidemiological studies into RA have been published, which have proposed that there is a variation in the occurrence of the disease among different populations

(Alamanos and Drosos 2005; Rudan et al. 2015). For example, studies conducted in Northern Europe and North American regions estimated that there is a prevalence of 0.5-1.1% (Alamanos and Drosos 2005). Similarly, a variation in the prevalence rate was reported in low and middle-income countries, with the lowest prevalence rate having been observed in Eastern Mediterranean countries (0.37%) and the highest in Latin American low and middle-income countries(1.25%) (Rudan et al. 2015). Potential explanations for the variation in the reported prevalence rates include differences in RA diagnosis, behavioural factors, environmental exposure and genetic factors (Carmona et al. 2010). However, the global prevalence of RA is reported to be somewhat lower (~ 0.24%) with about 1.2 million annual incident cases (Cross et al. 2014; Safiri et al. 2019). The number of prevalent cases is three times higher in women compared to men (Cross et al. 2014), and this increases with age, peaking in the 60-64 age group for both males and females (Safiri et al. 2019). A recent report has shown that from 1990 to 2017, the global prevalence and incidence rates of RA increased by 7.7% to 8.2% (Safiri et al. 2019). Possible reasons for this increase could be due to the fact more systematic assessments of RA epidemiological data have been conducted recently and the growth in ageing populations globally.

2.2.2 Aetiology

Although many theories have been proposed concerning possible causative factors for RA, the initiating cause of RA remains unknown. However, RA is recognised as a complex genetic disease, indicating that several genes, environmental factors, and chance factors act to cause pathological consequences (Klareskog et al. 2009; Carmona et al. 2010; Smolen et al. 2016). For example, epidemiological studies have shown that having a family history of RA increases the risk of developing RA by three to five times (Frisell et al. 2013; Somers et al. 2013; Jiang et al. 2015). The heritability of RA was found to be approximately 50% for those with seropositive results, as these tests show the presence of antibodies, such as rheumatoid factor and anti-cyclic citrullinated peptide, which are believed to cause the symptoms of RA, but were lower (~20%) among seronegative individuals (Frisell et al. 2013). Findings of a twin study have estimated the relative contribution of genetic factors to RA to be about 50%, leaving the remaining part to environmental and chance factors (MacGregor et al. 2000).

Genetic analysis studies have identified more than a hundred loci associated with RA risk, most of which implicate immune mechanisms (Smolen et al. 2016). The genes in the human leukocyte antigen (HLA) region strongly determine the susceptibility of RA (Weyand and Goronzy 2000). However, genetic variation of the HLA region explains approximately 40% of susceptibility to RA (Brooks 2006). Cohort studies exploring the role of genetic factors in determining disease severity have reported conflicting results. For instance, whilst Viatte et al. (2015) and Reneses et al. (2011) reported that some HLA genotypes were associated with more disease activity and more aggressive erosive disease, Gossec et al. (2004) reported that HLA genotypes were neither associated with the disease course nor its severity. Differences in sample size, genetic technologies used and follow up periods may have influenced the above research findings. Thus, the use of modern genetic technologies combined with appropriately powered clinical cohort studies will advance and reshape the understanding of the impact of genetics on the disease course and severity.

Based on population and twin studies, it was anticipated that non-inherited factors play a role in the aetiology of RA. Therefore, not all those who are genetically susceptible to RA develop the disease. For that reason, factors such as sex, hormones, infection, smoking, diet and sociodemographic factors have been of interest in determining whether the presence of such triggers will give rise to immunological abnormality, and subsequently to the clinical features of RA (Carty et al. 2004; Liao et al. 2009; Alpizar-Rodriguez and Finckh 2017). The higher prevalence of RA in women, especially during the postpartum period and lactation (Babushetty and Sultanpur 2012), as well as the frequent improvement in the disease during pregnancy, has led to the identification of the possible role hormones play in susceptibility to the disease. However, a recent review concluded that many studies regarding hormonal factors showed controversial results (Alpizar-Rodriguez and Finckh 2017). Similarly, contrasting results as to whether oral contraceptives decrease the risk of developing RA have also been reported. Whilst some studies reported a significant association (Doran et al. 2004), other studies, including a meta-analysis, concluded that oral contraceptives had no protective effect for women at risk of RA (Klareskog et al. 2009; Qi et al. 2014). Within the male population, a case-controlled study suggested that low testosterone levels increases the susceptibility to RA (Pikwer et al. 2014). In summary, it can be concluded that the contribution of biological mechanisms, specifically hormones, to the risk of developing RA are not fully understood.

In addition to genetic factors, there has also been a long-standing interest in the possible role that infectious agents play in triggering RA. For instance, infections from viruses such as rubella, parvovirus and the Epstein-Barr virus, as well those from bacteria (e.g. Mycobacteria and Mycoplasmas), have been proposed as triggering factors for RA (Carty et al. 2004). In addition, geographical clustering is a common feature of infectious diseases and, based on the possible associations between infectious agents and RA, the impact of this on RA has been described (Silman et al. 2000). For example, from a recent observational study on geographical clustering, the majority of RA cases were reported to occur sporadically and, from the inconclusive study findings, it was suggested that infectious agents may not be responsible for causing RA (Alpizar-Rodriguez and Finckh 2017). Environmental factors such as smoking, and dietary and socioeconomic factors have been increasingly studied as possible risk factors that trigger RA. However, the findings of observational studies exploring the association of these factors and the development of RA are inconsistent (Alpizar-Rodriguez and Finckh 2017).

In summary, RA is a systematic disease affecting the synovium, with debateable and inconclusive aetiological factors that influence the susceptibility and course of the disease. More studies into the influence of genetics on RA may shape future research and, along with the importance of understanding the aetiology of the disease, in depth knowledge about the disease pathogenesis is valuable to the understanding of the cellular and articular changes that occur as a result of the disease and its progression.

2.2.3 Pathogenesis

Although different signalling pathways have been proposed for the pathogenesis of RA, the exact signalling pathway is still unresolved. Through an immune-mediated mechanism, RA causes synovial inflammation and hyperplasia, autoantibody production, and cartilage and bone destruction, which results in functional limitations and aesthetic changes to the joints (McInnes and Schett 2011). This happens following the invasion of the synovium by an antigen that triggers an antibody-antigen reaction and stimulates the production of various immune modulators (cytokines and effector cells). The complex interaction between immune modulators is responsible for the joint damage that starts at the synovial membrane and covers other structures of the synovial joints. Synovitis is caused by the activation of local, migrant, or both, mononuclear cells (including T cells, B cells, plasma cells, dendritic cells, macrophages and mast cells) and by angiogenesis (Smolen and Steiner 2003). As inflammation persists, the synovial lining becomes hyperplastic and the synovial membrane expands and forms villi (Smolen and Steiner 2003). In the chronic disease phase, the pannus (destructive vascular granulation tissue), which differentiates RA from other forms of inflammatory arthritis, extends from the synovium, causing bone damage. Furthermore, the lysosomal enzymes secreted by neutrophils, synoviocytes and chondrocytes cause destructive changes in the joint cartilage (Smolen and Steiner 2003; Crawford 2015). Figure 2-1 illustrates the pathological articular changes that can occur in RA.

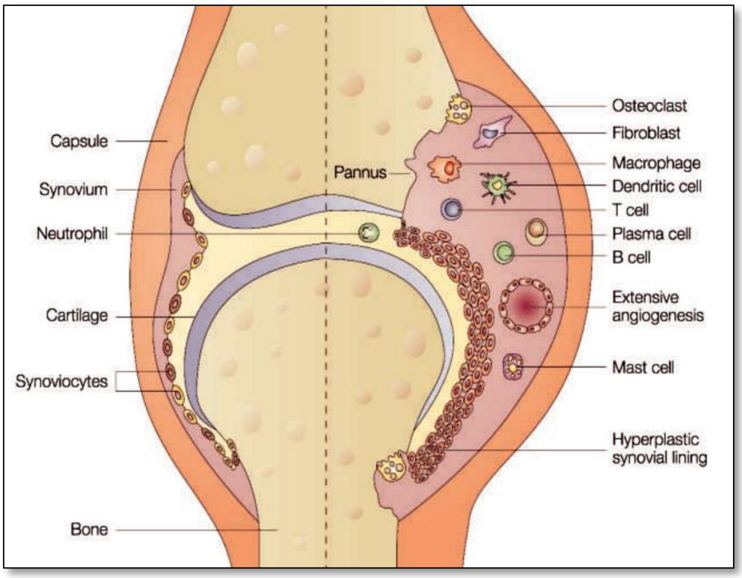


Figure 2-1 The joint affected by rheumatoid arthritis shows increased inflammation and cellular activity. Reproduced with permission from Springer Nature (Nature Reviews Drug Discovery) in Smolen and Steiner (2003)

2.2.4 The disease onset and clinical presentation

Clinical manifestations of RA are considerably heterogeneous, as age onset and degree of joint involvement vary greatly (Feist and Burmester 2013; Jeffery 2014). In addition, the course the disease takes may also vary according to the existence of or lack of several variables, including genetic components, autoantibodies and the severity of inflammation (Gossec et al. 2010). However, three patterns of RA have been identified, and these are: (i) Monocyclic (single attack followed by stable remission; 10% of RA patients) (ii) Polycyclic (variable duration and severity of attack; 45% of RA patients) and (iii) Progressive (constant, persistent course; 45% of RA patients) (Smith 2002).

The onset of articular symptoms of RA is generally insidious and the extent of articular involvement usually described as monoarticular, oligoarticular or polyarticular, with pain, soft tissue swelling, stiffness, and occasionally warmth (Feist and Burmester 2013). Initially, the distinctive features of RA symptoms are that they are usually gradual and affect the hands and the small joints of the feet symmetrically. Contrary to the above, the sudden onset of RA might also occur in up to 30% of patients, an issue which is frequently common in elderly people (Hochberg et al. 2009; Jeffery 2014). It is worth noting that RA can affect any synovial joint, however the joints most commonly involved initially are the metacarpophalangeal joints (MCP), proximal interphalangeal joints (PIP), wrist, and metatarsophalangeal joints (MTP) (Scott et al. 2010; Feist and Burmester 2013). Figure 2-2 shows the most common joints affected by RA.

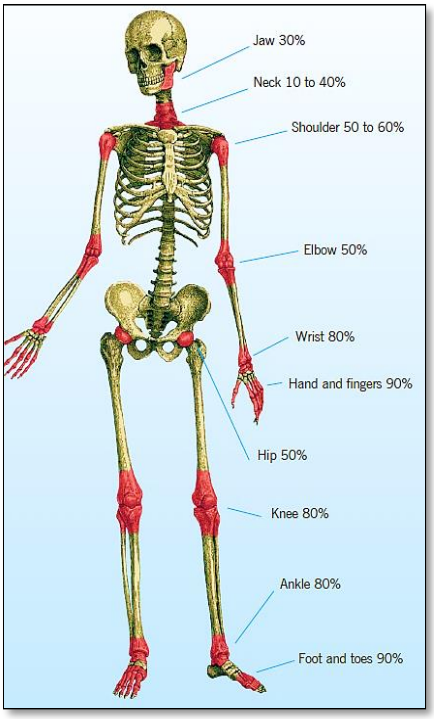


Figure 2-2 Percentages of joints commonly affected in rheumatoid arthritis. Reproduced with permission from Newbourne Group (Primary Health Care) in Oliver (2010).

Clinical symptoms of pain, swelling, and stiffness were considered fundamental keys to classifying RA earlier in the disease course (Aletaha et al. 2010). RA pain is commonly severe during the proliferative and early destructive stages (Smith 2002), with reports of women recording higher pain levels than men (Ahlstrand et al. 2015; Malm et al. 2015; Thyberg et al. 2016). Joint swelling results from a combination of an increase in synovial fluid, proliferation of the synovial membrane and blood flow (resulting in warmth and occasional redness) (Hochberg et al. 2009). The most common characteristic feature of a swollen joint is that when palpated, the joint has a ‘boggy’ feel in which fluids can be displaced by pressure in two planes (Crawford 2015). RA patients often report a marked stiffness of the joints in the morning or following a period of inactivity, which has been reported to last for more than 60 minutes (Schumacher et al. 2004). However, stiffness enduring ≥30 minutes increases the likelihood of RA diagnosis with a sensitivity (ability of the test to correctly identify those patients with the disease) of 74-77% and specificity (ability of the test to correctly identify those patients without the disease) of 48-52% (van Nies et al. 2015). In addition to articular manifestations, RA can lead to periarticular symptoms including tendinitis, tenosynovitis, epicondylitis, and carpal tunnel syndrome (Feist and Burmester 2013). Individuals with RA may attempt to protect their painful, swollen and stiff joints by immobilising them, which over time can lead to deformities and, subsequently, disability (Crawford 2015).

Although RA primarily affects the musculoskeletal system, the systemic inflammation properties may affect other body tissues and organs (Extra-Articular). Indeed, a range of extra-articular features can occur as a result of RA (Table 2-1) affecting the skin, eyes, heart, lungs, as well as the renal, nervous and gastrointestinal systems (Young and Koduri 2007; Cojocaru et al. 2010), and these extra-articular manifestations can occur at any age after the disease onset (Cojocaru et al. 2010). Predictors of extra-articular occurrence are not fully available, however, they are associated with men, smokers, more severe disease and higher levels of inflammatory biomarkers (Young and Koduri 2007; Cojocaru et al. 2010). RA nodules are the most common extra-articular features, and are present in up to 30% of RA patients, whereas other extra-articular features occur in only 1% or less of these patients (Young and Koduri 2007).

Table 2-1 Extra-articular features of rheumatoid arthritis (Cojocaru et al. 2010)

Manifestation	Complication
Skin	Subcutaneous nodules, Vasculitis and Erythema
Pulmonary	Pleural effusions, Pleuritis, Nodules and Interstitial lung disease
Gastrointestinal	Intestinal infarction
Cardiac disease	Pericarditis, Myocarditis and Nodules in the aortic or mitral valves
Ocular	Scleritis and Episcleritis
Neurological	Peripheral neuropathy and Mononeuritis multiplex
Renal disease	Mesangial glomerulonephritis
Haematological	Anaemia, Neutropenia, Thrombocytopenia, Thrombocytosis Eosinophilia, and Haematological malignancies
Oral	Oral dryness and Salivary gland swelling

2.2.5 Diagnosis and outcome measures of rheumatoid arthritis

To reiterate, clinical expressions of RA vary greatly between patients. Moreover, the signs and symptoms of RA cover a wide-ranging spectrum and vary from pain, stiffness and swelling to functional impairments (Heidari 2011; Crawford 2015). Although a few sets of criteria were recommended for RA diagnosis (Visser et al. 2002; van der Helm-van Mil et al. 2007; Salehi et al. 2013), to date, a valid diagnostic criteria for RA has not yet been established (Aggarwal et al. 2015). Clinical diagnosis of RA is a greatly individualised process and this makes it fundamentally hard to create uniform diagnostic criteria (Aggarwal et al. 2015). Therefore, RA diagnosis is grounded on a subjective combination of clinical symptoms, laboratory tests, and knowledge about the epidemiology of RA.

Considering the absence of a specific test to diagnose RA, the majority of treatment trials published in the last two decades (van der Helm-van Mil and Huizinga 2012) included patients who fulfilled the 1987 American College of Rheumatology (ACR) classification criteria of RA (Arnett et al. 1988). The ability to correctly identify those patients with RA (i.e. sensitivity) in the earlier stages was a major limitation of the 1987 ACR criteria, therefore the 2010 ACR/European League Against Rheumatism (EULAR) criteria was developed for differentiating patients who may progress to RA (Aletaha et al. 2010). Although the new ACR/EULAR criteria has an acceptable sensitivity level (Humphreys et al. 2013), it has been recommended that the currently available classification criteria be revised, as they may provide false-positive results (i.e. low specificity) (Aggarwal et al. 2015). However, RA is diagnosed based on phenotypic features and not on the explicit pathological process that is core to the phenotype (Gossec et al. 2010; van der Helm-van Mil and Huizinga 2012).

The complexity of the pathogenic processes underlying RA has led to difficulty in finding a single representative outcome measure. Therefore, different measures have been used to evaluate the RA disease outcome variables. To standardise these measures, the International Initiative to Improve Outcome Measurement in Rheumatology (OMERACT), with involvement from the EULAR, the World Health Organisation (WHO), and the International League Against Rheumatism, have proposed a core set of variables that include: pain, patient global assessment, physical function, swollen and tender joint counts, laboratory measurement of acute phase reactants, physician global assessment, and radiographs of joints (Boers et al. 1994). In addition, fatigue was added to the core data set in 2003 after an OMERACT meeting with major input from RA patients (Kirwan et al. 2003). Table 2-2 provides a brief description of the outcome measures in RA. Since different RA patients show unique clinical presentations, no single variable accurately mirrors every patient’s disease activity at any given point in time (Salomon-Escoto et al. 2011). Consequently, several composite indices have also been developed that incorporate various individual core variables into a single score, such as the Disease Activity Score With 28-Joint Counts (DAS-28) (Prevoo et al. 1995).

Table 2-2 Outcome measures in rheumatoid arthritis

Measure	**Description**
Pain	▪ Pain is the dominant complaint in patients with RA and can be used to predict long-term outcome (Malm et al. 2015). ▪ Pain VAS has been widely used to assess pain in RA because of its simplicity and flexibility (Hawker et al. 2011). ▪ Limitations to the use of pain VAS include: low-literacy populations and elderly people may have difficulty completing the pain VAS and it cannot be administrated by telephone, limiting its usefulness in research (Hawker et al. 2011). ▪ Pain numerical rating scales have been identified as a possible useful alternative (Hawker et al. 2011).
Physical function	▪ Physical function is usually referred to “the ability to move one’s body parts purposefully to achieve a task” (Hochberg et al. 2009). ▪ In RA clinical trials, the HAQ is predominantly employed to assess physical function status (Orbai and Bingham 2015). ▪ Evidence generally indicates an acceptable degree of psychometric properties of HAQ (Oude Voshaar et al. 2011). ▪ Key shortcomings of the HAQ include low responsiveness, content coverage and density problems, and poor ability to detect extremes in functioning (ceiling and floor effect problem) (Stamm et al. 2006; Adams et al. 2010; Oude Voshaar et al. 2015). ▪ The PROMIS has taken an initiative to develop, validate, and standardise item banks to measure physical function (Cella et al. 2007). ▪ Grounding on the PROMIS physical item bank, a 20-items physical function short form has been developed for patients with RA, which showed excellent psychometric properties compared with the HAQ (Oude Voshaar et al. 2015).
Fatigue	▪ Fatigue is intrusive, overwhelming, invisible symptom of the disease that can have a severe impact on patients’ quality of life (Carr et al. 2003). ▪ The MAF, SF-36, FACIT, ordinal scales, POMS, and VAS have a reasonable evidence of validation for measuring fatigue in RA (Hewlett et al. 2007).

FACIT: Functional Assessment Chronic Illness Therapy-Fatigue; HAQ: Health Assessment Questionnaire; MAF: Multidimensional Assessment of Fatigue scale; POMS: Profile of Mood States; PROMIS: Patient-Reported Outcomes Measurement Information System (PROMIS); SF-36: Short Form 36-Item Health Survey; VAS: Visual Analog Scale

Table 2-2 (Continued)

Measure	**Description**
Patient/ physician global assessment	▪ The patient/physician global assessment are simple patient-completed or provider-completed VAS, measuring the overall way RA affects the patient at a point in time. ▪ Rating disease activity by this method is practical for use in the clinic as long as training for clinician or patients is not highly required (Anderson et al. 2011). ▪ Patient global assessment may be influenced by the patient literacy level and has inadequate agreement level with provider global assessment, indicating that patient perceptions of disease activity may be different with those of provider (Makinen et al. 2008).
Swollen /tender joint counts	▪ The swollen joint count is related to the amount of inflamed synovial tissue, and the tender joint count is linked more with the level of pain provoked by palpation. ▪ The 28-joint count was recommended to quantify tender and swollen joint count (Anderson et al. 2012). ▪ Joint counts generally have been recognised to be poor in term of reproducibility and relative efficiency (Sokka and Pincus 2005).
Acute phase reactants	▪ The Creative protein (CRP) and erythrocyte sedimentation rate (ESR) are the recommended (Aletaha et al. 2010) and universally employed acute phase reactants to assess disease activity in clinical trials (Salaffi and Ciapetti 2013). ▪ Acute phase reactants have poor prognostic value for disability (Malm et al. 2015), and may not change despite clinical improvements (Sokka and Pincus 2005).
Radiography	▪ Conventional radiography is considered the standard method in examining the degree of anatomical abnormalities in RA (Heidari 2011). ▪ Ultrasound and magnetic resonance image are the best to predict the progression to clinical RA from undifferentiated inflammatory arthritis (Colebatch et al. 2013). ▪ Joint structural damage shown in radiography has little predictive value for disability (Pincus 2006), and has diminished in the context of modern treatment (Carpenter et al. 2017).

2.2.6 Management of rheumatoid arthritis

While there is currently no cure for RA, management of this autoimmune disease aims to improve disease, physical and psychosocial outcomes (NICE 2018). To achieve these goals, the National Institute for Health and Care Excellence (NICE) has provided guidance for the management of RA and recommends that people with RA should have access to support from a diverse group of health professionals within the multidisciplinary team (e.g. rheumatologists, physiotherapy, and occupational therapy) (NICE 2018). This model of care is considered the best clinical practice and is recommended by 60% of the current treatment guidelines for RA (Mian et al. 2019). Despite widespread recommendations for the multidisciplinary approach, there is a lack of consensus on the setting, content and format of this management approach. Furthermore, a recent systematic review and meta-analysis which investigated the effectiveness of multidisciplinary team care found limited evidence regarding disability, disease activity, or quality of life in people with RA (Bearne et al. 2016). This review highlighted the importance of new research investigating the optimal composition and cost-effectiveness of multidisciplinary care for RA patients.

Although there is no standard management approach for RA, current management is based on a combination of pharmacological and non-pharmacological approaches.

2.2.6.1 Pharmacological management

Pharmacological approaches to RA management depend on combinations of different medications. First-line treatment includes nonsteroidal anti-inflammatory drugs (e.g. naproxen) and glucocorticoids (e.g. prednisolone) which aim to relieve pain and decrease inflammation. The second-line treatment includes Disease Modifying Anti-Rheumatic Drugs (DMARDs) that focus on the suppression of disease activity by targeting the underlying disease process. There are two main types of DMARDs, including conventional (non-biological) and biologics (Guo et al. 2018). Conventional DMARDs include methotrexate, leflunomide, hydroxychloroquine and sulfasalazine. Biological DMARDs include Tumour necrosis factor inhibitors (TNF) such as etanercept (Enbrel), infliximab (Remicade), and adalimumab (Humira); and non-TNF biologics such as T-cell targeted therapies (e.g. Abatacept), IL-6 inhibition (e.g. Tocilizumab) and B-Cell depletion and inhibition antibodies (e.g. Rituximab). Several reviews have been conducted that demonstrate the effectiveness of second-line treatments in early and established RA (Nam et al. 2017; Hughes et al. 2018).

Although there are many clinical guidelines for RA management, a recent systematic review of RA management guidelines concluded that five general principles should be followed for the effective pharmacological management of RA (Mian et al. 2019). These include starting with DMARDs as soon as possible after the diagnosis, using methotrexate as an initial treatment option, monitoring disease activity regularly, providing biological DMARDs for patients with persistent, active disease who have already received methotrexate, and achieving remission or low disease activity. However, the choice of treatment relies on several factors such as patients' tolerability, disease progression, availability of medication and cost.

2.2.6.2 Non-Pharmacological management (rehabilitation care)

Despite the effectiveness of the drugs available to people with RA, functional disability still persists. Cohort reports from the rheumatology literature on the subject of RA patients treated with DMARD and biological agents have documented that a considerable percentage (53%) exhibited residual disability (Karpouzas et al. 2017), and functional disability can deteriorate despite suppression of disease activity (Seto et al. 2013). These observations suggest that people with RA continue to experience physical, psychological and social participation consequences; thus, they are in need of long-term care, consisting not only of drug therapy but also rehabilitation (Vliet Vlieland 2003; Hammond 2004b; Vliet Vlieland 2007). The majority of clinical guidelines for the management of RA, therefore, emphasise the use of rehabilitation care in addition to the use of drug therapy (Mian et al. 2019). Rehabilitation care of people with RA aims to manage the consequences of disease. Although there is no fully agreed or widely used definition or model of rehabilitation, rehabilitation can be defined as “an educational, problem-solving process that focuses on activity limitations and aims to optimise patient social participation and well-being, and so reduce stress on carer/family” (Wade 2005). In rheumatology, a structured approach to rehabilitation management was proposed by Stucki and Sangha (1998) and modified by Steiner et al. (2002). This approach has several advantages as it comprehensively reviews the consequences of disease, relates specific problems to relevant factors, defines the goals for therapy, and improves interventions by linking them to results during the rehabilitation process (Steiner et al. 2002).

In rheumatology literature, there are review studies that provide a summary of different rehabilitation interventions for patients with RA (Vliet Vlieland 2003; Hammond 2004b; Christie et al. 2007; Vliet Vlieland 2007). These reviews have concluded that the evidence to support both the short-term and long-term effects of the majority of rheumatology interventions is lacking, and that there is a shortage of studies that compare the different attributes of rehabilitation interventions. However, recent systematic reviews have indicated strong evidence for the beneficial effects of patient education, self-management, and cognitive behavioural approaches among RA patients (Carandang et al. 2016; Siegel et al. 2017). Hammond (2004b) recommended six types of interventions for RA based on their potential to improve physical, psychological, self-efficacy and pain reduction. Examples of rehabilitation interventions reported by Hammond (2004b) are presented in an adapted format in relation to the ICF framework (Table 2-3). Importantly, each intervention strategy is not mutually exclusive. Moreover, Hammond (2004b) recommends the use of cognitive behavioural education interventions to gain long lasting improvement in function.

Table 2-3 Examples of rehabilitation interventions in relation to the International Classification of Functioning, Disability and Health (ICF) domains

ICF domains		Example of intervention
Functioning and disability	Impairment	Strengthening exercises Physical modalities (e.g. thermal and electrical therapy)
	Activities and participation	ADL assessment and training Work and leisure interventions
Context	Environmental	Provision of orthosis and prostheses Adaption of home or work environment
	Personal	Cognitive behavioral therapy Patient education and self-management

ADL: Activities of Daily Living

The reviews of rehabilitation interventions for people with RA vary considerably in their scope, which also makes it difficult to produce a uniform list of all rehabilitation interventions. However, the ICF model allows a reasonable classification of the focus or target of any intervention (Wade 2005). Based on a newly developed classification, namely "The World Health Organization's International Classification of Health Interventions (ICHI)" (Fortune et al. 2018), these intervention can be grouped into (i) body system and function (ii) activity and participation (iii) environmental and (iv) health-related behaviours. The ICHI is not yet finalised and still being tested in different countries and contexts, but based on preliminary evidence, it has the potential to facilitate the classification of rehabilitation interventions in rheumatology, as well as enhance the ability to explore and understand the effects of different attributes of rehabilitation interventions.

2.2.7 Summary

RA is a chronic systemic autoimmune disease that mainly affects the synovial joints, particularly in the hands, and is associated with progressive disability, socioeconomic burden and premature death. Patients with RA experience difficulties performing ADLs, as hand function plays an essential role in this. The next section of this thesis will therefore provide a critical review of hand function in RA.

2.3 Part 2: Hand function in rheumatoid arthritis

This section of the background presents and critically reviews research evidence on hand function in RA. Initially, the nature of hand involvement in RA and its impact on functional abilities of the hands are discussed. The concept of hand function in relation to the WHO's ICF (WHO 2001) and the validity of the ICF core sets for assessing hand function in RA are also discussed. This is followed by an examination of the approaches used to evaluate hand function in RA. Finally, rehabilitation interventions targeting the hand in RA are outlined and the factors that may influence hand function in RA are then discussed in relation to the ICF domains. This section concludes with a summary of the literature review.

2.3.1 Hand involvement in rheumatoid arthritis

Hand involvement is the classic early sign of RA and the issues with the hand joints and tendons is well documented in 75% of people with RA (Ilan and Rettig 2003). The major cells affected by RA are the synovial and cartilage cells (Scott et al. 2010). The inflammatory response in the synovium and pannus formation results in the destruction of the articular cartilage and capsule (Smolen and Steiner 2003; Sharif et al. 2018). During the active phase of RA; pain, swelling and limitation of motion of the MCP and interphalangeal (IP) joints can occur in the hands. Synovitis within the MCP joints may result in the weakening of the dorsal and radial structures and the collateral ligaments can become lax, which in turn may decrease radial deviation of the wrists and associated ulnar deviation of the fingers (Khurana and Berney 2005). The IP joint involvement can present as various deformities with examples being boutonniere and swan neck deformities, which occur because of ligamentous loosening. A boutonniere deformity develops when the central slip of the extensor tendon is lax, together with concomitant volar displacement of the lateral bands. In a boutonniere deformity, there is flexion at the PIP joint and hyperextension at the distal interphalangeal (DIP) joints. A swan neck deformity is a result of hyperextension at the PIP joints and flexion at the DIP joints (Khurana and Berney 2005; Soeroso 2006). This deformity may occur due to disruption of the extensor tendon at the DIP, with secondary shortening of the central extensor tendon (Soeroso 2006). The rheumatoid thumb can show similar effects including flexion deformity at the MCP joint and hypertension of the IP joint (Sharif et al. 2018).

The involvement of the wrist is common in people with RA and affects up to 50% of patients within the first two years after the onset of the disease, with an increase of up to 90% after ten years (Trieb and Hofstatter 2009). Typical wrist deformities include volar subluxation of the hand, together with a sliding at the radiocarpal joint and carpal bones radial deviation (Ilan and Rettig 2003; Feist and Burmester 2013). The stability of the wrist is supported by soft tissue (e.g. the radiocarpal ligaments, intercarpal ligaments) and since RA majorly affects the synovium, many of these stabilising structures are affected (Ilan and Rettig 2003; Trieb and Hofstatter 2009). The resulting instability and mechanical tension of the ulnar head can ultimately cause the rupture of carpal extensor tendons (Ilan and Rettig 2003; Feist and Burmester 2013). Moreover, tenosynovitis in the wrist can result in increasing pressure within the carpal canal, leading to carpal tunnel syndrome, and ulnar nerve entrapment (Chim et al. 2014). Figure 2-3 shows the typical deformities due to involvement of the hand in RA.

The inflamed synovium may infiltrate the tendons surrounding the capsule which causes tenosynovitis. This may cause tendon dissolution and the further weakening of the tendons that cross over the bony spicules, with a resultant increase in the possibility of tendon rupture (Kim and Jung 2007). The distal end of the ulna is the most frequent site for extensor tendon rupture. People with RA may suddenly lose finger extension or flexion because of tendon rupture (Soeroso 2006). Trigger finger can also occur due to synovial proliferation, which leads to nodule formations on the tendons, and subsequently trapping the tendon in a flexed position (Khurana and Berney 2005).

Figure 2-3 Patient with rheumatoid arthritis presenting with a radial deviation (right wrist), swan-neck deformity (digits 3 right and 5 both sides) and boutonniere deformity (digits 2–4 left). Reproduced with permission from Oxford University Press (Oxford Textbook of Rheumatology) in Feist and Burmester (2013).

2.3.2 The impact of rheumatoid arthritis on hand function

Hand impairment and functional disability are common features of RA (Romero-Guzman et al. 2016; Su et al. 2017). A considerable percentage of patients develop hand deformity during the first and second years of RA (43%, 56% respectively) (Johnsson and Eberhardt 2009). Most predominant deformities are due to ulnar deviation of the MCP joints (Adams et al. 2004; Adams et al. 2005a; Johnsson and Eberhardt 2009), boutonniere and swan neck deformity (Eberhardt et al. 1991; Johnsson and Eberhardt 2009) and Z-deformity of the thumb (Feist and Burmester 2013). Despite the remarkable advances in the pharmacotherapy of RA, a recent longitudinal study reported that hand deformities persisted and still progressed over time among RA patients actively treated with biological and non-biological DAMRDs, even when the RA was well controlled (Toyama et al. 2014). A recent cross-sectional study reported that more than 70% of RA patients actively treated with biological and non-biological DAMRDs, and with a mean disease duration of 11.72 (SD 8.29), presented at least one wrist or hand deformity (Rodrigues et al. 2019).

Deficits such as reduced grip strength and ROM have been also reported in the early stage of RA (Adams et al. 2004; Adams et al. 2005a; Bjork et al. 2006; Bjork et al. 2007; Goodson et al. 2007; Odegård et al. 2007; Rydholm et al. 2018). Moreover, women with RA have reported lower pressure pain thresholds and hyperalgesia (Friden et al. 2013). Impairments of the dominant hand is reported to be greater than the non-dominant hand (Adams et al. 2005a), and men are reported to have greater impairments than women (Bjork et al. 2006; Ahlmén et al. 2010). Despite the above, the relevance of dominance in the development of hand impairments is still debated amongst researchers (Mody et al. 1989; Eberhardt et al. 1991; Adams et al. 2005a; Ebru et al. 2013).

Deformities, together with loss of ROM and strength, can have a major impact on hand function and, consequently, the ability to accomplish daily life activities (Adams et al. 2004; Bjork et al. 2006; Hörnberg et al. 2007; Johnsson and Eberhardt 2009). Current observational studies have reported that hand function outcomes were substantially worse when compared to healthy referents, although patients had low disease activity (Bjork et al. 2007; Erol et al. 2016; Kinikli et al. 2016; Packer et al. 2016; Romero-Guzman et al. 2016; Sferra da Silva et al. 2018). Few published studies have also considered the longitudinal hand functional abilities in the RA population (van Lankveld et al. 1998; Dellhag and Bjelle 1999; Bjork et al. 2006; Eberhardt et al. 2008; Toyama et al. 2014; Thyberg et al. 2016; Rydholm et al. 2018; Bremander et al. 2019). However, most of these studies had methodological problems (e.g. small sample sizes and recruiting participants with varying disease duration), thus compromising the findings. Another challenge in understating the impact of RA on hand function over time is that the majority of these studies employed generalised health outcome measures such as the Health Assessment Questionnaire (HAQ) or had a narrow scope focusing on hand impairment measures such as grip strength and ROM. In short, a generalised measures of disability may not reflect what an individual can do with their hands on a daily basis. Furthermore, these measures are unlikely to detect and assess changes in hand function over time (Adams et al. 2010). Indeed, Waljee et al. (2010) argued that hand impairment measures do not capture the full extent of patient disability. Although the progression of hand function over time remains unclear, recent longitudinal studies conducted among RA patients treated with current intensive therapeutic regimes have demonstrated that hand function deteriorated progressively, even in patients in remission or those with low disease activity (Johnsson and Eberhardt 2009; Toyama et al. 2014; Rydholm et al. 2018; Bremander et al. 2019).

Hand function in RA is multifactorial and influenced by personal and environmental factors (Chung et al. 2011; Andrade et al. 2016). Therefore, functional ability in the hand cannot be isolated from the individual context, the experiences of the disease process nor the psychological impact of the disease. Comparative studies on the impact of RA have reported that disease severity, extra-articular manifestations, functional disability, and quality of life tend to be different across countries (Adebajo and Reid 1991; Drosos et al. 1992; Veerapen et al. 1993; Hameed and Gibson 1996; Dadoniene et al. 2003). Similarly, hand function outcomes in RA also tend to vary between countries (Chung et al. 2011; Su et al. 2017). A study comparing British and Chinese patients with early RA reported that, comparatively, the Chinese group showed higher disease activity, less satisfaction of their hands' appearance, greater dominant hand deformity and less overall hand function when measured with the Michigan Hand Outcomes Questionnaire (Su et al. 2017). As the aforementioned, evidence has generally shown that the expression and impact of RA differs between countries, it implies that country-specific factors such as socioeconomic and healthcare system related factors might contribute to the burden of the disease, and subsequently influence hand function outcomes. Accordingly, the available data regarding the impact of RA on hand function may not reflect or contribute to the understanding of the impact of RA on hand function in a specific context.

It is noteworthy that most of the available studies on hand function in RA were carried out in high-income countries, particularly Western countries, which leaves a gap in the understanding of this phenomenon in developing and non-Western countries. Similarly, several reports have also highlighted the scarcity of epidemiological studies on RA in developing and non-Western countries (Halabi et al. 2015; Ally et al. 2016). This is coupled with the fact that RA patients from developing countries are often diagnosed late, have limited access to therapy and usually present with active disease (Halabi et al. 2015; Ally et al. 2016). Therefore, hand functional problems are likely to be more severe among patients from low-income and developing countries, since these countries have fewer resources to manage the medical, social and surgical consequences of uncontrolled RA.

In summary, despite new drug advances and targeted medical treatment, hand function problems persist and are exacerbated progressively overtime. Many ADLs require hand use, and this makes hand function an important component of RA disability. Johnsson and Eberhardt (2009) reported a great deal of loss of daily life function among RA patients, as they depended on hand function. Therefore, it is important to measure, interpret and evaluate hand function in clinical practice and trials. Indeed, hand function tests have been found to be sensitive to treatment response in RA (Eberhardt et al. 2008; Bremander et al. 2019), so this is now possible to do.

2.3.3 The concept of hand function

Hand function depends on the complex interaction of anatomical integrity, mobility, muscle strength, sensation, coordination and absence of pain (McPhee 1987). As pointed out earlier, impairments in physical components (e.g. ROM, strength) of hand function can lead to difficulties in accomplishing daily life activities. However, there can also be psychosocial consequences due to impairment. For instance, altered hand appearance and activity performance can lead to stress and a lack of desire to engage in social contexts (Nicklasson and Jonsson 2012). Furthermore, the function of the hand depends on the person and context (Kimmerle et al. 2003; Black 2011; Nicklasson and Jonsson 2012). For that reason, hand function can be defined as the ability to perform ADLs (Fowler and Nicol 2001) including physical, psychological and social aspects of functioning (Engstrand 2016). Therefore, to understand the limitations of hand function, it is important to consider the consequences of hand function limitations in connection to a specific context (Rudolf et al. 2012). Furthermore, clinicians and researchers need to use a framework to guide their hand functional assessment and therapy (Kimmerle et al. 2003). The ICF provides a globally accepted, widely used and useful frame of reference to understand hand functioning.

2.3.3.1 Representation of hand function guided by the International Classification of Functioning, Disability and Health (ICF)

The ICF provides a global language and conceptual basis for the definition and measurement of human health and disability. Human functioning according to the ICF is the “dynamic interaction between a person’s health condition, environmental factors and personal factors” (Figure 2-4) (WHO 2001). The ICF consists of two parts (a) Functioning and Disability and (b) Contextual Factors (WHO 2001). The Functioning and Disability part contains the following components; “Body Functions and Structures (impairments)”, “Activity (limitations) and Participation (restrictions)”. In the ICF model, activity is defined as the execution of a task or action by an individual, whereas participation refers to the person’s involvement in a life situation. Contextual Factors contains the components “Environmental Factors” and “Personal Factors”, which can influence the interactions between impairments, activity limitations and participation restrictions.

The ICF contains more than 1,400 categories, each allocated to the previous components, except for the component “Personal Factors”, which has not yet been classified. To determine which domains and categories of the ICF should be addressed when assessing RA patients’ hand function, it is necessary to recognise which components of the ICF are relevant to this population. Furthermore, since the ICF classification is composed of more than 1,400 categories, it is predominantly valuable as an academic tool, not as a daily practice tool. Therefore, to facilitate the application of the ICF in clinical practice and determine the ICF categories relevant to RA patients, a comprehensive ICF core set of recommended outcomes for RA (Stucki et al. 2004) has been created. Additionally, the ICF core set of recommended outcomes for hand conditions has also now been developed (Rudolf et al. 2010; Rudolf et al. 2012).

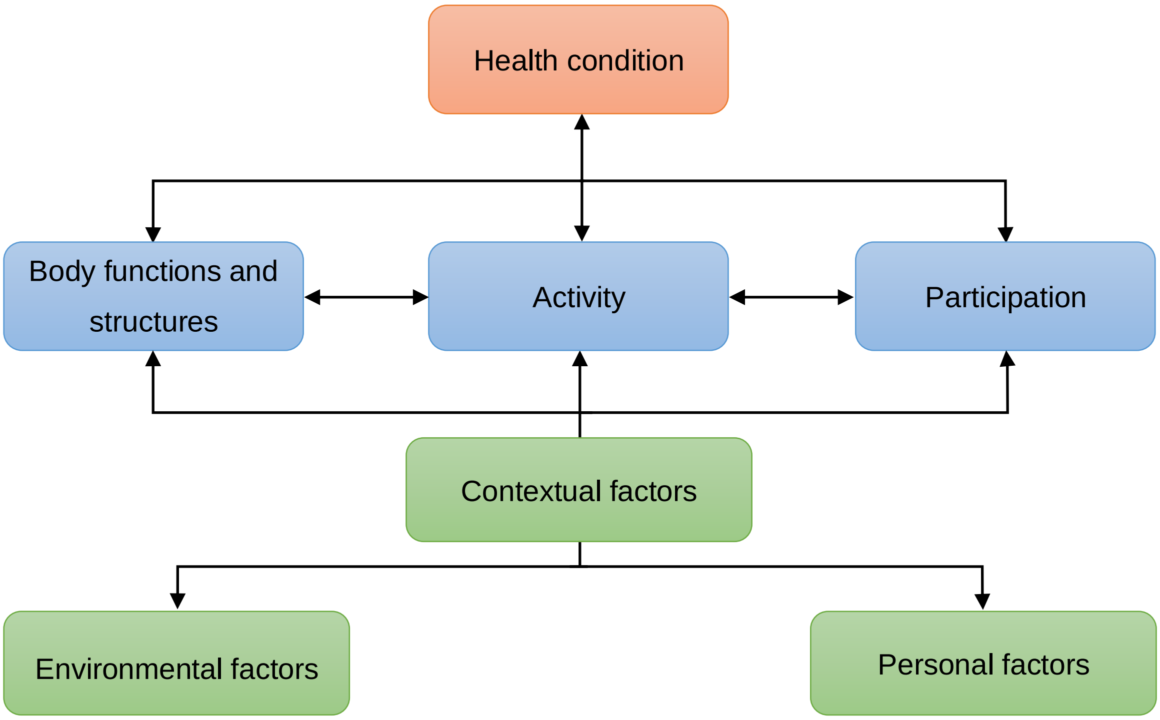


Figure 2-4 Interactions between the components of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001)

2.3.3.2 The validity of the International Classification of Functioning, Disability and Health (ICF) core sets for hand function assessment

ICF Core Set for RA defines classical problems with functioning among patients encountered in comprehensive assessments or in clinical studies (Coenen et al. 2006). Although the ICF core set for RA has been developed with the aim to create a short list of ICF categories that are important for patients with RA (Stucki et al. 2004), it has several limitations. The ICF core set for RA outlines “what to measure” but does not define “how to measure”, and more importantly, patient perspectives were not included in its development (Stamm et al. 2005; Coenen et al. 2006). When assessing daily functioning in patients with RA, it is essential to include the patient perspective, since personal values for outcomes are known to vary between and within patients and professionals (Hewlett et al. 2001; Hewlett 2003). Moreover, subsequent qualitative studies have reported additional categories that are not covered by the ICF core set (Stamm et al. 2005; Coenen et al. 2006). Furthermore, a reliability study documented low to moderate interrater and intrarater reliabilities (47% and 59% agreement, respectively) of the ICF RA core set (Uhlig et al. 2007). Another responsiveness study by Uhlig et al. (2009) documented that the ICF RA core set showed moderate responsiveness (i.e. only 20% of patients showed an improvement with at least one response level averaged through all ICF categories) in RA patients treated with DMARDs over a six-month period.

The content validity of the ICF RA core set has been tested by occupational therapists (Kirchberger et al. 2007b), physiotherapists (Kirchberger et al. 2007a), psychologists (Kirchberger et al. 2008), and physicians (Gebhardt et al. 2010) and from these studies, it was concluded that the ICF RA core was not yet comprehensive, as it was missing some categories (e.g. psychosocial). Chung et al. (2011) evaluated the RA core sets for assessing the functional outcomes of the rheumatoid hand in a sample of 142 RA patients and reported that the ICF RA core set was less effective in assessing changes in hand function in patients with RA over time. This is because the ICF RA core set was developed to describe general functioning and disability, and specific hand related function and disability categories might be missing from the ICF RA core set. From the evidence given above, it is apparent that further investigations are warranted to revise the ICF RA core, to enhance content validity and reliability and ensure hand function categories are fully considered.

The comprehensive and brief ICF core set for hand conditions was developed, employing three phases including a systematic literature review, qualitative focus groups study and experts consensus (Rudolf et al. 2010; Rudolf et al. 2012). The ICF core set for hand conditions does not focus on a determined health condition but refers to the body part (i.e. hand). This core set facilitates the description of hand function in clinical practice by providing a list of categories relevant to people with hand injury and disorders. Although the ICF core set for hand conditions was limited in terms of defining “how to measure” the included outcomes, an assessment set for functioning based on the brief ICF Core Set for hand conditions has recently been developed based on a systematic literature review and experts consensus (Kus et al. 2017). This will facilitate the assessment and the comparability of hand functioning-related information.

Whilst the views of German patient were included in the qualitative phase of the development of the ICF core set for hand conditions, it is not clear whether those patients also included people with RA. Therefore, it has the following limitations (i) it is possible that the perspectives of RA patients regarding hand functioning have not been considered and (ii) German views may not be representative of the wider community. This is because the choice and meaning of hand usage and activity are influenced by sociocultural values and beliefs (Black 2011). In people with hand osteoarthritis (OA), Thumboo et al. (2017) reported differences in perspective between Asian and European individuals in relation to hand function. Furthermore, qualitative evidence has shown that contextual factors including personal and environmental factors are important in relation to hand functioning among RA patients with hand deformities (Nicklasson and Jonsson 2012). These factors may differ from one context to another. For example, poverty as an environmental factor that could affect functioning in RA people was not addressed in the European context (Stamm et al. 2014), but was an important concept in the African context (South Africa) (Schneider et al. 2008). Studies that have aimed to validate the comprehensive and brief ICF core set for hand conditions have mostly included patients with hand injuries, with no information given about whether the participants included RA patients (Kus et al. 2011; Kus et al. 2012). Although these studies have demonstrated the validity of the ICF core set for hand conditions, it was found that additional categories such as sleep function and individual attitudes toward others were not covered. To the author’s knowledge, the validity of the ICF core set of hand conditions in RA has not yet been established.

To date, the literature lacks a qualitative study explicitly designed to explore the concepts of hand functioning important for people with RA. While many problems might be common among patients with hand conditions, patients’ experiences are different (Stamm et al. 2014), and some problems are unique to the individual and context (Nicklasson and Jonsson 2012). Consequently, researchers and clinicians should consider their patients’ perspective of meaningful hand function to identify “what to measure”, as opposed to solely using the ICF core sets currently available.

2.3.4 Assessment of hand function in rheumatoid arthritis

Although clinical assessment of hand function and disability remains complex and debateable (Goodson et al. 2007; Waljee et al. 2010), it is essential to measure the progression of hand disability in RA to understand the impact of the disease, determine the treatment strategies and evaluate the interventions. The term functional assessment has been used to represent a wide range of assessment techniques and is often used inconsistently (Kimmerle et al. 2003). Using the ICF terms, RA patients’ hand function limitations are evaluated by measuring impairments (i.e. ROM, grip strength and dexterity), whilst those in hand activity are documented using performance-based and patient-reported outcome measures (PROMs) (Poole 2019).

Hand impairment measures focus on reflecting the consequences of the disease at the bodily musculoskeletal level. Although impairment measures are relatively simple to obtain, they are reported to be limited in demonstrating how well patients perform their ADLs and, to some degree, they do not often capture the full extent of patient disability (Waljee et al. 2010). For RA patients, the level of disability in daily life may be of greater importance than the level of impairment (van Lankveld et al. 1998; Nicklasson and Jonsson 2012). Reports in the literature have provided contradictory results regarding whether hand impairments and activity limitations are linked or not. For instance, Adams et al. (2004) suggested that grip strength is an accurate indicator of upper limb ability in early RA. Similarly, Andrade et al. (2016) reported that grip strength was associated with upper limb activity limitations, however, Goodson et al. (2007) documented that pinch and grip strengths only have weak associations with hand activity limitations. Discrepancies reported in the literature may be a result of the differences between assessment methods and study populations. The relationship between hand impairments and activity limitations or participation restrictions is complex; minor limitations in hand impairment may lead to substantial activity limitations or participation restrictions, but major limitations may not. As a result, it is important to assess not only hand impairments, but also the impact of the hand impairment on individuals' hand activities and participation.

Performance-based measures such as the Jebsen Taylor Hand Function Test (Jebsen et al. 1969) and Grip Ability Test (GAT) (Dellhag and Bjelle 1995) require patients to perform prescribed functional tasks. In contrast, PROMs are subject-completed questionnaires which require the patient to rate his/her overall performance on a predetermined set of functional tasks. Examples of these measures include the Cochin Hand Function Scale (Duruoz et al. 1996), and the Michigan Hand Outcomes Questionnaire (MHQ) (Chung et al. 1998).

There has been an ongoing debate regarding the relative advantages of performance-based versus self-report approaches for hand function assessment (Metcalf et al. 2007). Theoretical advantages of performance-based measures, when compared with self-report questionnaires, were shown to include better reproducibility and less susceptibility to external influences such as culture, language, and education (Goodson et al. 2007; Metcalf et al. 2007). However, performance-based measures include tasks that supposedly simulate real life tasks, although these might not be meaningful to the patients' real life tasks (Metcalf et al. 2007). The results obtained are effort dependent, which may be influenced by mood. In addition, these measures cover a narrow spectrum of hand functioning (Stamm et al. 2004b), and often do not account for important end points such as pain and patient satisfaction (Waljee et al. 2010). In addition, they may not reflect the patient's ability to carry out ADLs (Fowler and Nicol 2001).

In contrast to performance-based approaches, PROMs of hand function do not require special equipment, are easier to administrate and are self-administered with the advantage of eliminating observer bias. These questionnaires represent the patients' perception of their hand function, and allows for the identification of functional deficits and the establishment of patient-centred care (Naughton and Algar 2019). In rheumatology practice, self-reported questionnaires have enjoyed increasing use during the shift towards patient-centred care (Gossec et al. 2015). Despite an increase in the use of hand function PROMs by clinicians and researchers, there is a belief among some practitioners that the information obtained through PROMs is subjective, less reliable and not as accurate as that obtained from performance-based measures (Michener and Leggin 2001). This is because it is often argued that the validity of PROMs is threatened by a self-reporting bias, in which patients respond to questions inaccurately or falsely (Althubaiti 2016). The issue of self-reporting bias has been widely discussed in healthcare research and there are many reasons individuals might offer biased estimates of self-assessed hand function, ranging from misunderstanding questionnaire items due to reading difficulties to social-desirability bias (respondents want to present themselves in a positive light) (Metcalf et al. 2007). Current evidence suggests that PROMs of hand function are also liable to be influenced by the patent's socioeconomic factors (e.g. education and income) and dominant hand involvement (Finsen 2015; Kachooei et al. 2015). Consequently, respondents may overestimate or underestimate their hand functional abilities, which introduces measurement error into reported outcomes. However, the assumption that PROMs may be less reliable compared to performance-based measures is misguided, as both types of measurements can suffer from the same threats to reliability (Metcalf et al. 2007). If any form of self-reported or performance-based measure is badly designed with poor psychometric properties, it will not provide reliable data. Existing evidence suggests that several PROMs that are designed to evaluate hand function have desirable psychometric properties, including a relatively high level of reliability (Wormald et al. 2019).

Indeed, both approaches (self-report and performance-based) to hand functional assessment have advantages as well as limitations. Studies among RA patients that have compared self-reported and performance-based measures of hand function have reported a low to high association between the two approaches (O'Connor et al. 1999; Adams et al. 2004; Sahin et al. 2006). This suggests that these measures do not provide equivalent information about a patient’s hand functional status. Therefore, on interpreting performance-based measures, clinicians should be mindful that changes in performance-based measures might not be reflected by similar changes in self-report measures. In fact, it was suggested that performance-based measures can complement self-report ones in clinical practice (Rallon and Chen 2008). Rallon and Chen (2008), however, pointed out that self-reported measures are adequate to evaluate a patient’s hand function, as they offer simple and inexpensive ways of obtaining unique piece of information that represent the patient’s perspective. However, it is challenging to determine which PROMs should be selected to evaluate hand function in RA within a specific context.

2.3.4.1 Selection of hand function Patient Reported Outcome Measures (PROMs)

There is a wide variety of PROMs that evaluate hand function in rheumatic hand conditions. Some of these are generic such as the HAQ (Fries et al. 1982) and the Arthritis Impact Measurement Scales (AIMS and AIMS2) (Meenan et al. 1980; Meenan et al. 1992), which include items on the use of the hands. However, these measures are limited to a few items, due to the large scope of the assessment, and were not originally designed to assess the hand (Aktekin et al. 2011; Poole 2011). O'Connor et al. (1999) argued that generalised measures such as the HAQ are not sensitive enough to accurately represent hand function and disability in day-to-day tasks. Reports more recently conducted have shown that generalised measures are less responsive when compared with hand performance measures and hand specific self-reported questionnaires (Eberhardt et al. 2008; Adams et al. 2010). However, more specific outcome instruments such as the Cochin Hand Function

Scale (Duruoz et al. 1996), the Michigan Hand questionnaire (MHQ) (Chung et al. 1998), the Disabilities of the Arm, Shoulder and Hand (DASH) (Hudak et al. 1996), and the shortened version of the DASH (QuickDASH) are valid measures for assessing hand function in patients with RA (Poole 2019).

There is a lack of consensus about what constitutes the most appropriate PROMs for measuring hand function in rheumatic hand conditions (Klokker et al. 2016). However, determining the most appropriate self-report tool is guided by the psychometric properties of the tool, its relevance to the patient, and feasibility (Boers et al. 2014; Naughton and Algar 2019). There have already been efforts to review the literature on the outcome measures used in the context of hand injury and disorders (Changulani et al. 2008; Schoneveld et al. 2009; van de Ven-Stevens et al. 2009; Wormald et al. 2019). While these reviews provided valuable information about the purpose and psychometric properties of several outcome measures, they are limited in providing RA specific data. However, a scoping search identified two relevant review studies reporting the psychometric properties of hand function PROMs used in the arthritis population (Poole 2003; Poole 2011). According to these reviews, PROMs used with the arthritis population generally lack psychometric testing and vary in feasibility. However, both reviews are outdated and presented evidence of the measurement properties of only a few outcome measures based on data available from the arthritis population in general, not specific RA evidence. Besides, these reviews were not conducted systematically and did not use a quality assessment of the evidence, thus, their results are not conclusive. Therefore, a systematic review protocol has been developed and published to describe hand function PROMs used with RA population, which appraises their methodological quality and psychometric properties using an up-to-date method (Arab Alkabeya et al. 2019b). The published content of this protocol is provided in Appendix B. Notwithstanding, a recent review demonstrated that the DASH (Hudak et al. 1996), QuickDASH (Beaton et al. 2005), and MHQ (Chung et al. 1998) have the best-published psychometric properties across different patient populations including RA (Wormald et al. 2019).

It is important that hand function PROMs used in clinical practice or trials demonstrate adequate measurement properties, such as validity and reliability, for the population they intend to assess. Validity is related to the degree to which a PROM measures the construct it is intended to measure. The Consensus-based standards for the selection of health status measurement instruments (COSMIN) (Mokkink et al. 2010) distinguish three aspects of validity including:

i) Content validity: The degree to which the content of a PROM is an adequate reflection of the construct to be measured. Content validity includes face validity (the degree to which (the items of) a PROM indeed look(s) as though they are an adequate reflection of the construct being measured).

ii) Construct validity: The degree to which the scores of a PROM are consistent with hypotheses (e.g., relationships to scores of other instruments or measures) based on the assumption that a PROM validly measures the construct being measured.

iii) Criterion validity: The scores of a PROM are an adequate reflection of a ‘‘gold standard’’.

Content validity is the most important measurement property that should be considered when a questionnaire is selected as an outcome measure. It is essential to ensure that an instrument measures all the relevant aspects of an outcome or construct (Terwee et al. 2018). The content of hand function PROMs commonly used in hand therapy practice (including those used with RA patients) vary widely in terms of the concepts included, and how they address the functioning of the impairment, activity and participation level, with limited consideration of environmental factors (van de Ven-Stevens et al. 2015). Previous studies conducted to link hand function PROMs to the ICF categories or ICF core set for hand conditions reported that none of the existing measures fully cover all the domains of functioning (Coenen et al. 2013; Farzad et al. 2014; Naughton and Algar 2019). Coenen et al. (2013) demonstrated that hand function PROMs generally capture only parts of the functioning aspects important to patients with hand injuries. Oksuz et al. (2017) reported that the DASH, QuickDASH and MHQ reflect 30%, 16.32% and 10.2%, respectively, of problematic hand activities for Turkish people with a hand injury. Therefore, existing hand function PROMs may not capture all aspects of hand functioning important for patients with RA. Whilst new measures specifically designed to assess aspects of hand functioning that are important for patients with RA could be developed, the development and validation of new measures is a time consuming and expensive process. Furthermore, considering the individual and cross-cultural variations in hand use (Black 2011), it is difficult to construct a questionnaire that encapsulates all hand activities (Oksuz et al. 2017). A preferable approach might be to qualitatively examine RA patient’s perspectives of hand functioning which will facilitate the selection of the most appropriate measure. To date, no qualitative study has been explicitly designed to explore the perspectives of RA patients regarding this important issue.

Although the published literature including RA patients has been devoted to understanding underlying hand impairments or activity limitations, it is also necessary to evaluate the impact of hand-use difficulties on individuals’ participation. One qualitative study that recruited patients with experience of living with hand deformities due to RA indicated that there is no direct relationship between the experience of participation and the capacity to perform hand activities (Nicklasson and Jonsson 2012). Therefore, participation outcomes in relation to hand use must also be assessed and not predicted implicitly from other levels of assessments. To the author’s knowledge, no reviews have recognised instruments that assess RA patients’ participation in relation to hand-use difficulties. This could be related to the fact that activity and participation components are considered as one category in the ICF with a lack of distinction between their definitions (Piskur et al. 2014). This would make it difficult to clearly operationalise these different concepts in measurements (Farzad et al. 2014). Studies which have investigated the content of hand function PROMs such as the DASH and MHQ have reported that these measures have addressed both activity and participation level of hand functioning (Metcalf et al. 2007; Dixon et al. 2008; Farzad et al. 2014). Therefore, currently available self-report questionnaires allow the researchers and clinicians to assess not only hand-related activity limitations, but also aspects of participation restrictions.

Finally, the feasibility of an instrument in terms of availability, administrative burden and interpretability is considered crucial in the selection of measures (Boers et al. 2014). Therefore, in the hand therapy field, the use of hand function PROMs questionnaires that can be integrated into daily practice with a low administrative burden is recommended, and it is also advised that patients are able to complete them easily and quickly (Marks 2020).

2.3.5 Rehabilitation of hand function in rheumatoid arthritis

Rehabilitation interventions targeting the hand in RA are used to help individuals maintain functional performance during ADL, mediate symptoms and prevent deformities (Bobos et al. 2019). These include treatments such as exercise, splints (orthosis), physical agent modalities (e.g. electro-therapy and thermal modalities), joint protection and provision of adaptive equipment, although the amount of evidence supporting the effectiveness of these treatments is insufficient (Beasley 2012). Recent systematic reviews which examined the effect of joint protection programmes (Bobos et al. 2019) and exercise interventions (Williams et al. 2018) on hand function among RA patients reported a lack of evidence and stated that it is not currently possible to establish a conclusive answer on the effectiveness of these interventions. However, these reviews have reported that the results of randomised control trials (RCTs) generally support the use of these interventions for improving hand function in RA. In contrast, the results of RCTs generally do not support the use of splints for the treatment of RA in hands (Healy et al. 2018).

Although the importance of hand function in RA is generally acknowledged, there is little evidence regarding the optimal content and mix of rehabilitation interventions targeting the hand. This lack of knowledge can be explained by the complexity of hand function problems among RA patients. In cross-sectional studies, it was concluded that multiple variables might cause and explain hand functional disability in people with RA (Chung et al. 2011; Andrade et al. 2016). Therefore, improvement of hand function in the RA population requires the consideration and comprehension of many factors that play a role in obtaining and maintaining hand function in ADL.

2.3.5.1 Factors associated with hand function in rheumatoid arthritis

The limitations of hand function in ADLs among RA patients are often accompanied by a combination of impairments that are classed as body functions and structures on the ICF such as ROM, strength and pain. Moreover, contextual factors (environmental and personal) may play an imperative role in the occurrence and impact of hand function problems. Several studies have reported on the impairment variables which are associated with hand function in RA patients (Adams et al. 2004; Sahin et al. 2006; Eberhardt et al. 2008; Özeri et al. 2008; DedeoĞLu et al. 2013; Durmus et al. 2013; BİRcan et al. 2014; Erol et al. 2016; Kinikli et al. 2016). Although these studies have reported an association between hand function and impairment variables, the strength of this reported association was not consistent and contradictory findings were noticed. For instance, Adams et al. (2004) reported a strong negative correlation ($r=-.810$, $p<.001$) between dominant hand power grip strength and hand function, as measured by Disabilities of the Arm, Shoulder and Hand (DASH). Whereas Kinikli et al. (2016) reported a moderate correlation ($r=-.432$, $p=.019$) between dominant hand power grip strength and hand function, as measured by Duruoz Hand Index (DHI). Belghali et al. (2017) and Birtane et al. (2008) reported no association ($p>.05$) between hand function and hand radiological (X-ray) changes, whereas Dogu et al. (2013) and Özeri et al. (2008) reported a weak to moderate correlation ($r=.231$, $p=.03$; $r=.517$, $p=.019$; consecutively). Differences in outcome measures, methodological approaches, patients' characteristics and sample size might explain the variation in the reported results.

With RA patients, quantitative and qualitative evidence suggest that environmental and personal factors are crucial in determining the limitations of hand function in ADL. A cross-sectional study of 81 RA patients demonstrated that work activity, as an independent environmental variable was associated with hand-related activity limitations (Andrade et al. 2016). In a qualitative study, RA patients with hand deformities stated that social environmental attitudes negatively affected their participation (Nicklasson and Jonsson 2012). Similarly, a qualitative study by Stamm et al. (2010) indicated that environmental factors were reported by RA patients to affect their everyday activities. Although published qualitative reports have identified different categories of environmental factors which influence RA patients overall functioning (Stamm et al. 2005; Coenen et al. 2006; Stamm et al. 2014), the relative importance and influence of these factors might vary according to the settings and culture and, to date, this has not yet been explored or reported. Furthermore, the identified environmental factors are related to the RA patients overall functioning and might not provide specific hand related data.

WHO describes personal factors as internal factors, which 'may include gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character and other factors that influence how disability is experienced by the individual' (WHO 2001). A qualitative study recruiting RA patients with established hand deformities demonstrated that personal factors influenced how patients managed their hand related activity limitations and participation in social activities (Nicklasson and Jonsson 2012). Furthermore, a qualitative interview study concluded that personal factors have a major effect on everyday activities among RA patients (Stamm et al. 2010). Recently, a cross-sectional study recruiting a large sample of RA patients (*n*=737), aimed to study whether self-efficacy and pain acceptance mediate the relationship between pain and performance of valued life activities (Ahlstrand et al. 2016). Using univariate regression analyses, the study results showed that personal factors were significantly associated with the performance of valued life activities, and that this partially mediates the relationship between RA related pain and performance of valued life activities. Kuhlow et al. (2010) suggested the importance of exploring the association of personal factors such as self-efficacy and illness perception, as they have potential to explain activity limitations and participation restrictions among RA patients.

Despite the fact a few researchers have explored personal factors through consensus processes (Grotkamp et al. 2012), systematic reviews (Geyh et al. 2011), or qualitative interviews with RA patients (Dur et al. 2015), the identified personal factors have not yet been classified according to the ICF “taxonomy”. Indeed, in two validation studies based on qualitative data from RA patients, several personal factors were identified as meaningful which are not covered by the ICF RA core sets (Stamm et al. 2005; Coenen et al. 2006). Furthermore, 12 personal factors identified through a qualitative study with RA patients were not comprehensively covered by any one individual self-reported measure (Dur et al. 2015). However, in previous published research, personal factors were explored in relation to general functioning among RA patients, although this does not provide specific hand related data; and thus, it is suggested that important personal factors in relation to specific hand functional outcome must be explored further.

To date, a review of existing evidence to establish what is currently known about the factors associated with hand function in ADL has not yet been conducted. Therefore, a systematic overview of factors associated with hand function in patients with RA is timely and imperative. Such an overview could provide information that is useful for developing new interventions to improve hand function in people with RA. The literature suggests that important environmental and personal factors in relation to hand function in RA patients deserve specific attention. However, these factors have not been explored and identified in relation to hand function in ADL. Exploring and identifying these factors may assist in the designing of bespoke and tailored multidimensional interventions for individuals with RA.

2.3.6 Summary

This part of the thesis has provided a critical overview of hand function in RA. Despite the effectiveness of the medications available to people with RA, current evidence identifies that hand functional problems persist and deteriorate over time. Furthermore, evidence reveals that hand function outcomes differ across countries, indicating that country-specific factors may influence hand function. Therefore, it is important to consider the functional consequences of RA on hands in a specific context. The next part provides the background context of this thesis in Palestine.

2.4 Part 3: Study context

Palestine is an Arab country located in the Middle East. It consists of the West Bank and Gaza Strip, and is home to a population of more than 4.8 million people (60.2% live in the West Bank and 39.8% in the Gaza Strip) (Figure 2-5). With reference to recent data, Palestinian society remains a young society, with 38.7% of the population under 15 years, and 3.3% over 65 years old. Most Palestinians are Muslim (94%), with the remainder being predominantly Christian (6%) and only a few identifying as Jews (Palestinian Central Bureau of Statistics 2017). According to the Human Development Report (2019), Palestine is classified as a “lower middle-income economy” (119 of 182 countries in 2018).

In Palestine, health is influenced by a complex combination of political, socioeconomic, and cultural determinants (Giacaman et al. 2009; Mataria et al. 2009; Saca-Hazboun and Glennon 2011; Keelan 2016). Palestine has one of the most complex contexts in the world, because of the on-going Palestinian-Israeli conflict, which began in 1948. The Lancet Palestinian Health series by Giacaman et al. (2009) and a recent WHO (2019) report demonstrated that occupation by the Israeli state is the greatest factor that has determined the extent Palestinians have health problems, as it has distorted and fragmented the Palestinian health system. Restrictions on movement imposed by multiple Israeli checkpoints and the separation wall act as obstacles to health and inhibit the ability of most Palestinians to access healthcare, particularly those living in rural areas (WHO 2019). To date, the Palestinian healthcare system remains controlled by Israel in terms of healthcare budgets, border crossings, entry permits and pharmaceutical imports and exports.

In addition to occupation, there is a general problem of low quality healthcare services, as a result of a shortage of skilled healthcare providers, limited financial support, and weak institutional capacity for monitoring and assessment (Giacaman et al. 2009). Importantly, there is a lack of effective coordination between health sectors in Palestine, which has resulted in poor referral practices and the overlapping of services (Giacaman et al. 2009; Mataria et al. 2009). Furthermore, healthcare services in Palestine remain both considerably physician oriented and biomedically focussed, which may pose a significant barrier to effective medical treatment for patients in general.

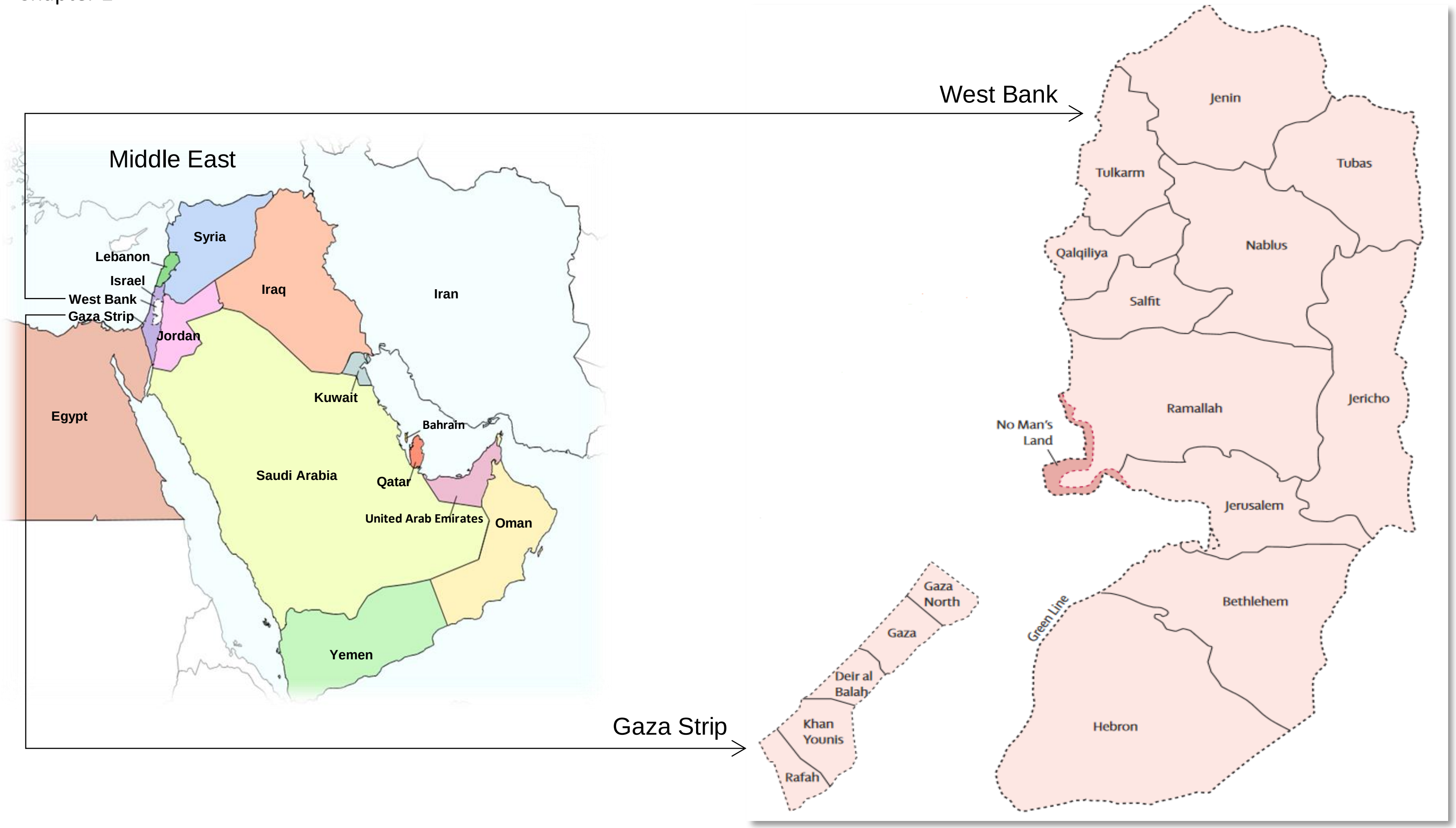


Figure 2-5 The administrative divisions of Palestine (West Bank and Gaza). Reproduced with permission from Elsevier (The Lancet Journal) in Giacaman et al. (2009)

2.4.1 The Palestinian healthcare system and rheumatology care

The Palestinian healthcare system is complex and fragmented. In Palestine, four main providers deliver primary, secondary, and tertiary healthcare: the Palestinian Ministry of Health (MoH), non-governmental organisations (NGOs), United Nations Relief and Work Agency (UNRWA), and the private sector (see Figure 2-6). The MoH is the main provider of both Palestinian healthcare (providing universal healthcare through hospitals and health centres at the primary, secondary and tertiary levels) and primary healthcare services operating more than 60% of the 732 primary healthcare clinics (Palestinian Ministry of Health 2019).

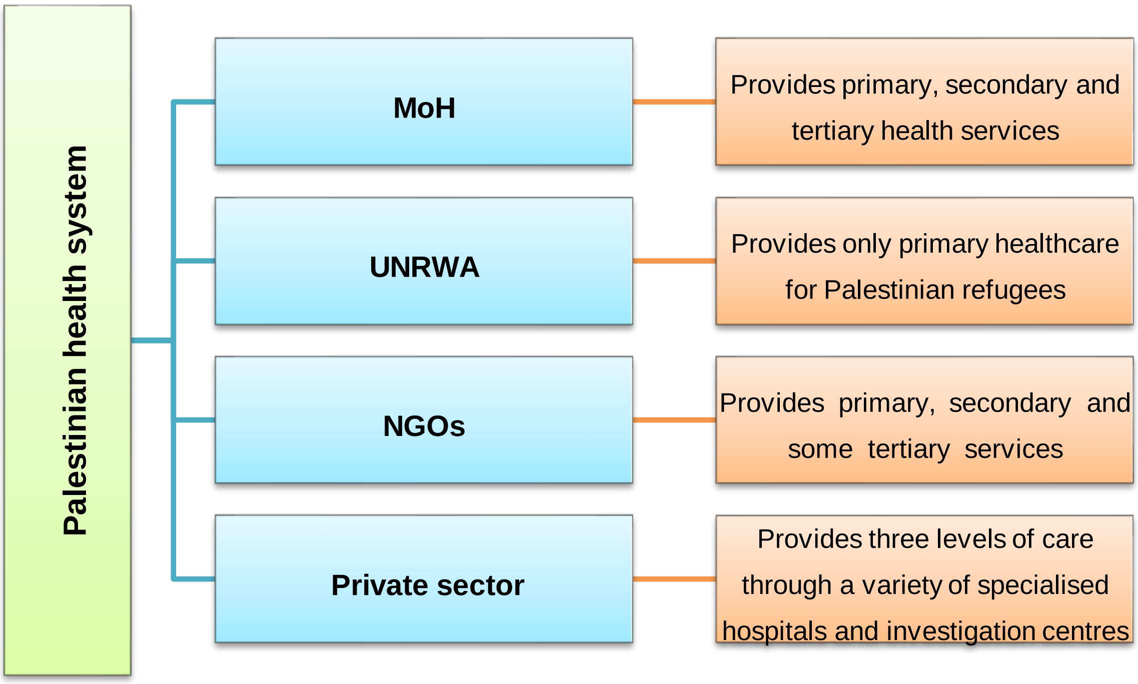


Figure 2-6 Components of the Palestinian health system

The Palestinian MoH annual reports are conventionally focused on the number of beneficiaries who use the services, the number of hospitals/beds and primary healthcare centres, and the number of health professional personnel, with no information about rheumatology services (Palestinian Ministry of Health 2017, 2019). However, with reference to the Palestinian Rheumatology Society (PSR), rheumatology services are mainly provided by the Palestinian MoH outpatient clinics and to a smaller extent by the private sector through private physician offices (personal communication). For the northern part of West Bank, there are three rheumatology outpatient clinics, which belong to the Palestinian MoH. They operate one day per week and are covered by one rheumatologist. The central and southern part of West bank have one rheumatology clinic each, covered by two rheumatologists. The rheumatology services provided by the MoH outpatient clinics include mainly medical consultations and the provision of medication. According to the latest statistics by the PSR, there are seven qualified registered rheumatologists in the West Bank. However, data on rheumatology services and the number of rheumatologists in the Gaza Strip are unavailable.

The Palestinian healthcare system is complex and fragmented and lacks financial support, physical infrastructure and human resources. The number of rheumatologists is insufficient to meet the needs of the community, therefore many Palestinian people with RA do not receive appropriate medical care, and RA is either unrecognised or inadequately treated. For example, many Palestinian people with RA experience delayed referral to rheumatology clinics, and a considerable number of them are treated by orthopaedic consultants or general practitioners. These clinical observations are coupled with the fact that Palestinian people with RA have limited access to rehabilitation services such as physiotherapy and have to pay privately for these services. Although data on RA treatment in Palestine is limited, the PSR have reported that Palestinian patients receive analgesics, glucocorticoids, and conventional and biological DMARDs. These medications are not provided free of charge but may be partly subsidised by the MoH for some people who have government insurance. Even with health insurance, out of pocket costs for RA medications are high, reaching more than 1,000 NIS (New Israeli Shekel – approximately 200 pounds), while the average monthly income of a family in Palestine is 2,320 NIS (~ 500 pounds) (Palestinian Central Bureau of Statistics 2017). Therefore, it is evident that many Palestinian people with RA are unable to afford their medication costs.

2.4.2 Rheumatoid arthritis in Palestine

The relatively higher burden of non-communicable diseases (e.g. cardiovascular and cancer) other than RA that are more prevalent in Palestine, which means that the latter is perceived as less important in the broader healthcare picture. This is reflected in the Palestinian MoH reports, which lack information about RA or musculoskeletal diseases (Palestinian Ministry of Health 2017, 2019). However, the “Global Burden of Disease (GBD) 2017” study showed that the prevalence (0.27%) and annual incidence rate (15.3 cases per 100000) of RA in Palestine increased significantly (~12%) from 1990-2017 (Safiri et al. 2019). Despite the low prevalence of RA in Palestine, it is ranked as the 42nd highest attributable disease to global disability (Cross et al. 2014), and musculoskeletal diseases (including RA) are among the top ten leading causes of disability in the Middle East (Watad et al. 2017). The GBD 2017 study assessed the burden of RA using disability-adjusted life years (DALYs). It was reported that the DALYs rate increased by 8.2% in Palestine during the period of 1990-2017. This is higher than the reported increase of DALYs rate at the regional level (6%) and in contrast to the global DALYs rate, which decreased during this period (-3.6%) (Safiri et al. 2019).

Data on RA patients from the Middle East and Arab countries are inadequately reported and poorly addressed (Halabi et al. 2015), and Palestine is no exception. A thorough systematic literature search (conducted in January 2017 and updated on March 2020) did not reveal any published literature reporting the clinical characteristics, hand function outcomes or even general functional status of Palestinian people with RA (Appendix A). In a bibliometric analysis of rheumatology research in Arab countries, Bayoumy et al. (2016) reported that no publications on the subject in Palestine were found between 1976 to 2014. There were, however, a few studies on RA from other Arab countries (Al-Salem and Al-Awadhi 2004; Badsha et al. 2008; Chaaya et al. 2012; Alawneh et al. 2014; Lutf et al. 2014; Alam et al. 2018; Namas et al. 2019), but these had several shortcomings, including methodological limitations, and focused mainly on RA disease activity, without assessing or reporting on patients' functional outcomes. Despite the above-mentioned flaws, these studies did show that the severity and clinical manifestations of RA vary greatly across Arab countries. For instance, whilst studies from Jordan (Alawneh et al. 2014) and United Arab Emirates (Badsha et al. 2008; Namas et al. 2019) reported more severe patterns of RA, those from Qatar (Lutf et al. 2014; Alam et al. 2018), Kuwait (Al-Salem and Al-Awadhi 2004) and Lebanon (Chaaya et al. 2012) showed less severe patterns. A large part of the variability between these studies in terms of RA severity and clinical manifestations may be related to methodological differences. In addition, part of the variability may be due to differences in healthcare systems and socioeconomic determinants. A recent cross-sectional study which recruited 895 RA patients from five Arab countries (Jordan, Lebanon, Qatar, Saudi Arabia and United Arab Emirates) reported variations in the RA treatment used, due to differences in the healthcare systems and patients' profile across these countries (Dargham et al. 2018). A higher use of biological DMARDs was recorded in the Gulf countries (e.g. Qatar and Saudi Arabia), where health care services (including medication) are free or highly subsidised by the government for citizens. Furthermore, patient-related factors such as age and comorbidities were reported to influence the choice of RA medications in these countries (Dargham et al. 2018).

Like many countries in the Middle East, Palestine lacks RA treatment recommendations (Halabi et al. 2015). This leaves rheumatologists to manage RA based on personal preference, with no clearly defined treatment targets or care pathway, which could eventually lead to a large variability in clinical care. However, it appears that many rheumatologists from Middle Eastern countries that lack RA management guidelines adhere to international guidelines. A recent study conducted in Saudi Arabia, which lacks RA management guidelines, showed that Saudi rheumatologists adhere to international guidelines (Omair et al. 2017). While the use of international recommendations for RA management appear to be useful and largely applicable, they may not be completely appropriate for countries in the Middle East, which have some unique characteristics such as financial limitations and differently structured health systems (Al Saleh et al. 2015). However, the use of currently available international, national and regional guidelines on RA (Mian et al. 2019) may provide a useful starting point for the development of treatment guidelines tailored to the Palestinian patient population and health system.

The alarming increase in the prevalence and DALYs rate of RA in Palestine, demands that urgent research be conducted in this cultural setting. Since RA mostly affects the hands, and the loss of functioning in RA is largely dependent on hand function, exploring the impact of RA on hand function among Palestinian patients deserves specific examination. This examination will provide a better understanding of the impact of RA on hand function among Palestinian patients and their treatment needs.

2.4.3 Hand function in Palestinian people with rheumatoid arthritis: Study rationale

As discussed in the previous section, research into the consequences of RA on hand function and the factors that contribute to hand function in ADL has not been conducted in Palestine. A review of the current literature demonstrated that hand functional problems in RA persist and progressively worsen over time despite new drug advances (section 2.3.2). Although published data provide valuable information about the impact of RA on hand function, evidence suggests that hand function outcomes in RA tend to vary between countries. This indicates that country-specific factors may contribute to the burden of disease and consequently impact on hand function outcomes. Considering the unique context of Palestine, as discussed earlier, directly transferring the results obtained from RA trials might not be valid. Therefore, an in-depth investigation to understand the impact of RA on Palestinian patients' hand function is both necessary and justifiable.

While the examination of the functional consequences of RA on the hands of Palestinians with RA is required, concepts of hand functioning important for patients with RA remains unknown, and the available ICF core sets for RA or hand functioning may not cover all of the aspects of functioning important to people with RA (section 2.3.3.2). Furthermore, the concepts of hand functioning, as previously discussed, differ between diverse sociocultural contexts (Thumboo et al. 2017). Therefore, there is a need to understand the Palestinian patients' perspective of meaningful hand function, in order to define "what to measure". It is expected that this would facilitate decisions on the appropriate measure(s) to use within the Palestinian context.

When deciding on an appropriate approach to evaluate hand function, clinicians can be guided by the evaluation of hand impairments or activities and participation. As highlighted previously (section 2.3.4), measures of hand impairments may not provide information about the ability to use the hands for self-care, work and leisure activities. Following the previous discussion on the selection of hand function PROMs (section 2.3.4.1), when considering which ones to use in Palestine, it is worth considering that they have been developed based on Western culture. Consequently, the available outcome measures might have inadequate content validity for Palestine. This is because the nature and accomplishment of functional activity is generally determined by culture and setting (Badley 2008). Cultural context may also determine the range of tasks executed, and these tasks may differ according to societal involvement. For instance, using a rosary (Figure 2-7), which is a string of beads for keeping count of prayers, is a common daily life activity for the majority of Palestinians, and this requires substantial hand skills. Similarly, most

Palestinian women wear Al-Hijab (a head cover) daily, which also requires functional hand use. The praying activity performed five times a day by Muslims also requires extensive hand use. In praying, hand movements and weight bearing through the upper limbs are required to perform the prostrating (sujud) activity and return to standing. Palestinians with RA might face difficulties accomplishing these activities due to RA affecting their hands, and these hand activities are not represented in self-reported questionnaires developed with and for Western cultures. As a result, measuring the impact of RA on Palestinian patients' hand function using the currently available measures may not reflect what Palestinian people feel are their valued activities. From another perspective, developing a questionnaire which involves all of the cultural activities is also not an achievable goal (Oksuz et al. 2017). Consequently, exploring the concepts of hand functioning important for Palestinian individuals with RA would facilitate the discussion and recommendations of the most appropriate PROMs to use.

Figure 2-7 Normal use of a rosary (Image: authors own)

Evidence suggests that hand function in RA is influenced by multiple factors, however, there is a gap in the general knowledge in terms of understanding the factors that are associated with hand function in RA. To this end, a systematic review of the factors associated with hand function in RA is warranted, in order to shed light on this important issue. Even though this review is not related to the Palestinian context, it will provide an insight into the methodological issues regarding hand function assessment that are addressed in this thesis. In addition, the findings of this review provide insight into what important factors should be considered when evaluating hand function among Palestinian people with RA. Previous evidence highlights that RA patients' personal and environmental factors deserve more systematic consideration in clinical research, however, important environmental and personal factors in relation to hand function have not yet been identified. Considering the unique political, socioeconomic and cultural determinants that influence health in Palestine, important environmental and personal factors as both facilitators and barriers experienced by Palestinians with RA in relation to their hand function in daily living tasks deserve specific examination. Exploring and identifying the contribution of these factors in relation to hand function will facilitate the creation of a bespoke and multidimensional treatment plan for Palestinian people living with hand RA that addresses the relevant factors contributing to meaningful function and participation.

2.4.4 Summary

To date, the impact of RA on hand function and the factors contributing to hand function in ADLs among the Palestinian patients is not available nor documented. Therefore, to report, evaluate and treat the limitations of daily activities and restrictions in participation, it is important to explore what the most typical problems in the daily lives of Palestinian patients, as a result of RA affecting their hands, are. One vital goal now is to explore the concepts valued by Palestinians with RA, in terms of hand activities and functioning in daily life, using the ICF as a global framework and using a qualitative research method to gain meaningful in-depth contextual data on people's experiences and perceptions. Exploring these concepts would facilitate discussions and recommendations on the most appropriate outcome measure(s) to facilitate the setting of patient-oriented treatment goals and the establishment of appropriate interventions needed for Palestinian people with RA. Furthermore, this approach will allow the exploration and identification of environmental and personal factors that influence hand function in ADL, and subsequently assess and evaluate their influence on hand function.

2.5 Chapter summary

This chapter has introduced the background literature and study context to facilitate the understanding of the research phenomenon. Although some attention has been paid to assessing hand function in RA and the factors associated with hand functional disability, no published review has addressed the factors that contribute to hand functional disability in RA. In the next chapter (Chapter 3), the factors associated with hand functional disability are reviewed using a systematic review approach.

Chapter 3 Factors associated with hand functional disability in people with RA: A systematic review

3.1 Chapter overview

This systematic review was published in the Arthritis Care & Research Journal in 2019 (Arab Alkabeya et al. 2019a). The published content is provided in Appendix C. The following chapter provides a detailed description of the systematic review, including additional materials not submitted for publication. In addition, a detailed systematic search strategy is outlined and a summary of the available literature for the factors associated with hand functional disability is introduced. Best-evidence analysis was performed to provide a summary overview. The study findings are presented using a narrative, graphical and tabular summary which is then discussed, appraised and interpreted.

3.2 Introduction and objectives

The introductory literature review that informed Chapter 2 found that a systematic overview of factors associated with hand functional disability in patients with RA is lacking. Since the focus of rehabilitation interventions is to maintain and improve hand function abilities for people with RA (Hammond 2004a), it is important to identify the factors that influence the impact of RA disease on hand function in ADLs. Consequently, a review of the existing evidence was conducted to establish what is currently known about the factors associated with hand functional disability. With such an overview, hand function interventions for people with RA can be improved by considering these factors during the intervention. While this review is not related to the Palestinian context, it is considered important to inform the investigations that underpin this thesis in many ways. By gathering and summarising information about potential factors that contribute to hand functional disability in RA, this review will provide guidance as to which important factors should be considered when evaluating hand function among Palestinian RA individuals. The findings of this review will crucially identify factors which are not addressed within the current literature, as well as the methodological issues regarding hand function assessment, allowing both to then be considered in this thesis.

This study aimed to provide a comprehensive synthesis of the evidence reported within observational studies regarding the factors associated with hand functional disability in patients with RA in a real-world setting, rather than in RCTs. The objectives of this systematic review were to:

1) Summarise and provide a comprehensive synthesis of the evidence of the factors associated with hand functional disability in patients with RA.

2) Investigate if a significant association exists and, if so, the strength of the association between hand functional disability and influencing factors in patients with RA.

3) Identify areas where further research is required.

In the present review, hand functional disability is used to denote the hand-related activity limitations and restrictions to participation. It is important not only to explore if an association exists between hand functional disability and the factors, but also to interpret the strength of the relationship. In terms of the studies which explored the association between the assessed factors and hand function using correlation analysis, correlation coefficients were interpreted, as shown in Table 3-1. In the context of this review, to facilitate the understanding of the approach used to report the relationships between the assessed factors and hand function, the term “associated” is used to denote a relationship that is statistically significant and the term “no association” or “not associated” are used to denote a relationship that is not statistically significant.

Table 3-1 Interpretation of correlation coefficients (Mukaka 2012)

Correlation coefficient	Interpretation
.91 to 1.00 (−.91 to −1.00)	Very high
.71 to .90 (−.71 to −.90)	High
.51 to .70 (−.51 to −.70)	Moderate
.31 to .50 (−.31 to −.50)	Low
.00 to .30 (.00 to −.30)	Negligible

3.3 Methods

The Joanna Briggs Institute Guidelines for Systematic Reviews of Association (Moola et al. 2015) were used to direct the review process and the PRISM (Preferred Reporting Items for Systematic reviews and Meta-Analyses) Guidelines were used to ensure appropriate reporting (Moher et al. 2009). The completed PRISMA checklist is provided in Appendix D.

3.3.1 Forming a review question

The problem addressed by a systematic review should be specified in the form of a well-formulated, unambiguous and structured question before starting the review. The use of the PEO (population, exposure, and outcome) mnemonic is recommended when conducting systematic reviews for association (Moola et al. 2015). Considering these three components, the question (i.e. what are the factors associated with hand functional disability in people with RA?) of the present review has been formulated (Table 3-2).

Table 3-2 Components of the research question

Component	Research question
Population (type of participants)	Rheumatoid arthritis
Exposure of interest (independent variable)	Associated factors
Outcome or response (dependent variable)	Hand function

Following the development of a systematic review question, reviewers should search for existing systematic review protocols and completed reviews to avoid duplication (Moher et al. 2014). Therefore, prior to commencing the present systematic review, the International Prospective Register of Ongoing Systematic Reviews (PROSPERO) database was searched to avoid duplication of the potential review evidence. From this search, no on-going or completed systematic reviews were identified (Table 3-3).

Table 3-3 Search strategy at the PROSPERO online portal (Search date 22/2/2017)

Search terms	Results
TI Hand	37
TI Rheumatoid arthritis	71

3.3.2 Protocol development and registration

As soon as the research question is framed, the research protocol can be developed. Developing a systematic review protocol before undertaking the review ensures that the systematic review is sensibly planned, and that what is planned is clearly documented before the review begins, thus enhancing the trustworthiness of the results (Moher et al. 2015). Typically, a protocol for a systematic review outlines the methods for searching the literature, the eligibility criteria, the data extraction method and form of analysis (Murphy et al. 2009). Recently, the Preferred Reporting Items for Systematic reviews and Meta-Analyses for Protocols (PRISMA-P) has been published (Shamseer et al. 2015). The PRISMA-P aims to assist in the preparation and reporting of a well-reasoned protocol for a systematic review. Therefore, for this systematic review, a protocol was constructed using the PRISMA-P guidelines. This protocol was then registered with PROSPERO Reviews in May 2017 (protocol reference: CRD42017065856).

3.3.3 Eligibility criteria

The focus of the question will help to define the inclusion and exclusion criteria. The eligibility criteria determine which studies will be included in the review, and they generally consist of two categories: study characteristics and report characteristics (Moher et al. 2009). Specifically, the eligibility criteria may encompass the study design, participants, interventions, outcomes, comparisons, timing, setting and language (Shamseer et al. 2015). In the present review, the types of studies, participants, outcomes, language and publication status that were considered for inclusion are detailed in Table 3-4.

Table 3-4 Description of the eligibility criteria

Criterion	Description
Types of studies	Published, peer-reviewed observational studies presenting data on the association between hand functional disability and one or more factors were included. Longitudinal cohort studies and any cross-sectional studies from different time points but collected on the same samples were also included. Conference abstracts, dissertations, psychometric studies (i.e. validity, reliability and responsiveness) of hand function outcome measures, and studies of RA hand treatment or surgery were excluded.
Participants	Participants with the diagnosis of RA, either according to ACR criteria (Arnett et al. 1988) or 2010 ACR/ EULAR criteria (Aletaha et al. 2010) for RA. Studies including participants diagnosed according to seropositive criteria only (i.e. testing positive for the presence of antibodies that are hypothesised to cause symptoms of RA) were excluded, because seropositive criteria are mainly based on the presence of antibodies such as rheumatoid factor (RF), which can occur in other autoimmune conditions and chronic infection.
Types of outcomes	Studies that have used standardised measures of hand functional disability outcome measures (either subjective or objective measures) commonly used with persons with rheumatic diseases, have psychometric support, and evaluate hand-related activity limitations and/or participation were included. Articles that have used self-reported hand function subscales from generic disability measures or hand functional disability outcome measures of impairment only were excluded. This is because generic disability measures are not designed to provide detailed feedback on hand function and include insufficient coverage on hand use.
Language	The true effect of excluding articles based upon language is not fully clear. Moher et al. (1996) reported remarkable effects on the results of a systematic review. Conversely, Juni et al. (2002) found little effect of excluding studies published in languages other than English on summary treatment effect estimates. Because of the uncertainty regarding the consequences of excluding studies upon language (i.e. language bias), the exclusion of studies based on language should be justified (Bown and Sutton 2010). For this systematic review, language was limited to English as translation expenses were not available.
Publication status	As mentioned previously studies should include participants with the diagnosis of RA according to the ACR criteria. The ACR criteria were published in March 1988; therefore, the search was restricted for studies published from January 1990 up to the present.

3.3.4 Information sources

In the present review, the literature was searched systematically using the following databases: MEDLINE, EMBASE, CINAHL, PsycINFO, AMED and Web of Sciences. These databases were selected because they have unique, individual features that helped the author to conduct a comprehensive search and retrieve as many relevant published articles as possible. A description of these databases is presented in Table 3-5. A secondary search was performed in Google Scholar to enhance the optimal discovery of the most highly relevant articles that, for whatever reason, may not have been included in the previous search platforms. Additionally, other sources of citations included checking reference lists from the studies already retrieved, citation searching, and consultation with experts, in order to identify any additional relevant articles and limit the publication bias (Booth et al. 2016). Accordingly, the reference lists of all of the studies meeting the inclusion criteria in this systematic review were hand-checked to capture any additional eligible studies. Using Google Scholar, forward citation searching was performed for the current review. Key studies that were identified by the database searches and selected as meeting the inclusion criteria were used to carry out citation searching. Finally, the supervisory team were consulted to identify any new articles and make sure that all of the relevant articles had been included.

Grey literature is a term that refers to information available in either print or electronic literature that has been produced by government, academia, business and industry and which is not controlled by a commercial publisher (Grey Literature Network Service 2017). This can include materials such as unpublished studies, conference abstracts, government and agency reports, as well as unpublished dissertations (Bellefontaine and Lee 2013). Studies retrieved from the grey literature may balance the literature by minimising the effect of publication bias, consequently, enhancing the results of systematic reviews (McAuley et al. 2000; Higgins and Green 2011). Therefore, excluding studies that are from the grey literature limits the researcher’s ability to review a portion of the evidence available, which in turn might threaten the review’s validity (Conn et al. 2003). However, it is difficult to locate or retrieve studies from the grey literature, and the studies retrieved have questionable scientific quality, since the methodological quality has not been checked as part of the peer review process (Conn et al. 2003; Pappas and Williams 2011). The literature has also been said to provide inconsistent findings with regard to the influence of included and excluded grey literature (Conn et al. 2003). As a result, there is still an ongoing debate about the importance of including unpublished studies retrieved from the grey literature in systematic reviews and meta-analysis. For this systematic review, the grey literature was not searched, since the inclusion criteria specified that only published peer reviewed articles would be included.

Some systematic reviews topics may be concentrated in a few key journals, therefore searching these journals may be particularly useful in finding additional articles not indexed in electronic databases (Armstrong et al. 2005). However, hand searching is a time-consuming process. This was reported by Greenhalgh and Peacock (2005) who found that a month was needed to extract the 24 articles that made the final systematic review report, as a result of hand-searching key journals. Currently there are about 100 rheumatology journals (OMICS International 2017). Therefore, a hand-searching strategy was not thought to be feasible within the time allocated to accomplish this systematic review.

3.3.5 Search strategy

The search strategy is a component of systematic reviews that is crucial, since the validity of the review findings are related to the comprehensiveness and reproducibility of the literature search (Khan et al. 2011; Murad et al. 2014; Gough et al. 2017). Therefore, developing the skills needed for searching databases and consulting with an experienced medical librarian to develop a search strategy and obtain advice on selecting the citation databases was recommended by the main systematic reviews guides (Lefebvre et al. 2011; Aromataris and Riitano 2014). Accordingly, the researcher attended two tutorial workshops, which were conducted by an experienced medical librarian at the University of Southampton, on the subject of searching literature systematically. Additionally, the supervisory team, who are experts in rheumatology and hand function research, were consulted regarding the comprehensiveness of the list of free-text words terms, and subject headings retrieved from the literature. Furthermore, three meetings were held with an experienced medical librarian at the University of Southampton to examine and refine the search strategy developed for this systematic review.

Table 3-5 Selected databases for the literature search

Database	Description
MEDLINE (Medical Literature Analysis and Retrieval System Online)	Medline is one of the largest bibliographic databases that contains more than 24 million citations to journal articles in the biomedical sciences; it covers more than 5600 international journals published since 1946 (Medicine 2017).
EMBASE (Excerpta Medica dataBASE)	Embase is a large bibliographic database, with more than 32 million citations from almost 8300 currently published journals published since 1947 and requires a subscription for access. Embase includes more than six million records and 2900 journals that are not covered by MEDLINE (Elsevier 2017).
CINAHL (Cumulative Index of Nursing and Allied Health Literature)	CINAHL is a comprehensive research database that contains more than 5.3 million citations to journal articles related to midwifery, nursing, occupational therapy, physiotherapy, podiatry, health education and other related subject areas. it covers more than 770 international journals published since 1937 (Ebscohost 2017).
AMED (Allied and Complementary Medicine Database)	AMED is a bibliographic database produced by the Health Care Information Service of the British library. The database covers topics that can be difficult to research, including complementary medicine, palliative care, and allied professions. AMED covers nearly 600 journals from 1985 to the present. The scope of journals is generally European, and content is updated monthly. Many of the journals included in AMED are not indexed in any other biomedical database, which makes it a key database for those conducting systematic reviews (Vardell 2016).
PsycINFO (Psychological Information Database)	PsycINFO is an excellent resource devoted to peer-reviewed literature in behavioural science and mental health. It contains nearly 4 million bibliographic records, indexing of more than 2500 journals (99% of which are peer-reviewed) published since 1800 (American Psychological Association 2017).
Web of Sciences	Web of Science covers over 12,000 journals in the sciences, social sciences, arts, and humanities. It includes the Science Citation Index Expanded (1970-present), Social Sciences Citation Index (1970-present) and Arts & Humanities Citation Index (1975-present) (Yong-Hak 2013).

Searching the literature is an iterative process that includes multiple stages to ensure the identification of all relevant studies (Khan et al. 2011; Aromataris and Riitano 2014). Traditionally, a concept-based, subjective approach is used for the development of a search strategy in systematic reviews (Hausner et al. 2015). The key characteristic of a concept approach is largely dependent on a number of factors including the systematic review teams' experience and knowledge of the databases structure, the thesaurus (controlled vocabulary), the research topic, and the researchers' subject knowledge (Jenkins 2004).

However, the structure of the search strategy usually follows the research question components, that is, the key terms articulated in the question are identified to create a concept map (Lefebvre et al. 2011; Aromataris and Riitano 2014). For this purpose, a variety of sources are used to identify a thesaurus (i.e. index terms or subject headings) and keywords or free-text words for the concepts determined (Aromataris and Riitano 2014). A thesaurus, which is usually called a controlled vocabulary, is a list of preselected terms created by librarians and database indexers to index publications in databases (Petrova et al. 2012; Booth et al. 2016). The controlled vocabulary can be retrieved by conducting a simple search using the main key concepts to retrieve key articles to see how they were indexed using the thesaurus. However, databases use a unique controlled vocabulary (e.g. MEDLINE (MeSH), EMBASE (EMTREE)) to index their articles; thus, indexing terms need to be adapted to each database (Lefebvre et al. 2011; Aromataris and Riitano 2014). Many databases offer the ability to 'explode' subject terms to automatically include more detailed terms in the search, which should be used in a search strategy if appropriate (Lefebvre et al. 2011). Free-text words are terms that are not sourced from an existing controlled vocabulary (Petrova et al. 2012). They can be retrieved by scanning the title and abstract of the key articles selected through the preliminary searches using the main concepts identified. They can also be used flexibly across many databases, and have the ability to apply truncations ('*' or '$'), and wildcards ('?'), and adjacency searches.

Keywords and search terms of a search strategy should be carefully created to ensure that the search will be balanced between being sensitive and specific (Lefebvre et al. 2011; Impellizzeri and Bizzini 2012; Aromataris and Riitano 2014). For the purpose of establishing a comprehensive search strategy to identify as many pertinent publications as possible, a search strategy should involve a combination of both subject terms (‘exploded’ where appropriate) and a variety of free-text words terms (Lefebvre et al. 2011; Aromataris and Riitano 2014). Once both free-text words and indexing terms have been collected, Boolean operators (e.g. AND, OR and NOT) and adjacency (ADJ and NEAR) can be used to combine the terms together appropriately.

Although a concept approach is recommended by the Cochrane Collaboration (Lefebvre et al. 2011) and Joanna Briggs Institute (Aromataris and Riitano 2014), it remains unclear how to decide if the strategy is complete and which terms to include in the search strategy (Hausner et al. 2012; Hausner et al. 2015; Bramer et al. 2017). This is because the content of search strategies is fundamentally constructed on expert opinions; thus, it can be considered to be methodologically weak (Bak et al. 2009). Recently, efforts have been made to establish an objective (Hausner et al. 2015), and a blended (objective and expertise opinion) (Bramer et al. 2017) approach for the development of a search strategy in systematic reviews, while simultaneously making an assessment of search strategies to identify errors (Sampson et al. 2009). These initiatives offer several potential advantages over a conceptual approach; however, their validity and practicability are still questionable.

In the present review, the search strategy was developed using the concept approach. In this approach, the inclusion of all of the research question elements to structure the search strategy are deemed unnecessary, and even undesirable (Lefebvre et al. 2011). This belief was supported by Ho et al. (2016), who found that a higher number of studies were obtained when the search strategy was based on two elements of the research question. Considering the question of this review, two components have been identified: “Rheumatoid arthritis”, and “Hand function”. Thereafter, a list of free-text words and subject headings were retrieved from key articles that were identified by conducting a simple search using the previously mentioned two components.

These components were combined using Boolean logic: (hand Function) AND (rheumatoid arthritis). Subject headings (e.g. MESH headings) were used to describe the concepts of “hand function”, and “rheumatoid arthritis”, if available, otherwise, text words were used. Furthermore, subject headings were exploded where appropriate. Titles and abstracts were searched in all of the databases used, except for the Web of Sciences, where only a title search was completed, as an abstract search was not possible. The search strategy was formulated in MEDLINE and adapted for use in other databases after consultation with an experienced medical librarian. Published filters were used to identify studies published in the English language from January 1990 up to 17th March 2017. An example search strategy for MEDLINE is shown in Table 3-6. The full strategy used for identifying the relevant literature is presented in Appendix E.

Table 3-6 Search strategy in MEDLINE through Ebscohost

#	Search terms
S1	((TI hand or TI hands) N3 (TI activit* OR TI abilit* or TI function* OR TI perform* OR TI skill* OR TI impair* OR TI disabilit*)) OR ((AB hand OR AB hands) N3 (AB activit* OR AB abilit* OR AB function* OR AB perform* OR AB skill* or AB impair* OR AB disabilit*))
S2	((MH "Hand+") OR (MH "Hand Deformities") OR (MH "Hand Strength")) AND ((TI ADL OR TI “daily activit*” OR TI “activity limitation*” OR TI “activities of daily living”) OR (AB ADL OR AB “daily activit” OR AB “activity limitation*” OR AB “activities of daily living”))
S3	S1 OR S2
S4	(MH "Arthritis, Rheumatoid") OR (TI RA) or (AB RA) OR (TI "Rheumatoid Arthritis") OR (AB "Rheumatoid Arthritis")
S5	(MH "Arthritis, Juvenile") OR (TI "Juvenile Arthritis") OR (AB "Juvenile Arthritis")
S6	S4 NOT S5
S7	S3 AND S6
S8	limit S7 (English language , yr="1990 -Current")

3.3.6 Managing citations

In the context of systematic reviews, researchers have to manage large number of citations identified through electronic databases searches. Furthermore, searching multiple databases often results in the retrieval of many duplicate references. This is due to the overlap of journals between databases. Furthermore, the nature of the publishing cycle in the field of healthcare may increase the number of duplicate references, because full-text publications and conference abstracts reporting the same data are often retrieved simultaneously (Kwon et al. 2015). Therefore, many systematic review guidelines recommend using bibliographic software to record and manage references (CRD's 2009; Higgins and Green 2011). By using bibliographic software such as EndNote and RefWorks, authors of systematic reviews are able to accurately report the findings of electronic databases and to ensure that the method used for pooling studies for inclusion in a systematic review is valid and reliable (Lorenzetti and Ghali 2013; Kwon et al. 2015). Generally, bibliographic software functions can assist researchers in importing, sorting, retrieving references, removing duplicate references, apprising and coding references for eligibility of a systematic review, and creating a citation during the writing-up phase (King et al. 2011).

In this systematic review study, literature search results were exported to a single EndNote® (version X7) library. Then duplicate records were deleted using the EndNote automatic de-duplication option. Since the de-duplication option of EndNote has been reported to have low sensitivity (Kwon et al. 2015; Rathbone et al. 2015), this option was supplemented by hand-searching for duplicates. However, hand-searching may lead to the removal of references that should not be removed, therefore the whole process of deleting duplicate citations was repeated twice using two different EndNote libraries. Using such a method is thought to minimise the possibility of removing references that should be included.

3.3.7 Study selection

Following the previous step, the study selection process was completed in two stages (Figure 3-1). The first stage included only examining the titles and abstracts of the search results. The purpose of this step was to eliminate all clearly ineligible publications. The second stage encompassed a full-text review of articles that appear to meet the inclusion criteria. This was also employed in cases when a decision could not be made based on the title and abstract alone. At this stage, articles were eliminated based on the exclusion criteria. Then the reference lists of the studies included were scanned to identify additional studies. Furthermore, key studies that were identified and selected as meeting the inclusion criteria were used to carry out citation searching.

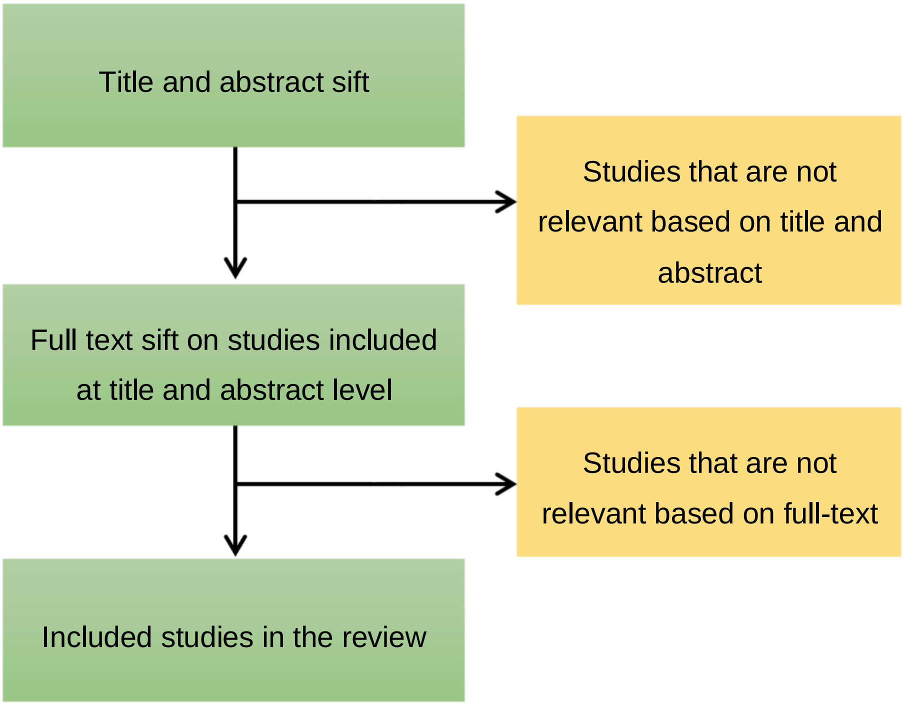


Figure 3-1 Study selection process. Amended from Booth et al. (2016)

Owing to the subjective nature of the study selection process, it is recommended to include at least two reviewers (CRD's 2009; Higgins and Green 2011; Impellizzeri and Bizzini 2012), as this minimises random errors and biases (e.g. pre-formed opinions may result on including or excluding certain studies) (CRD's 2009). In the current review, the selection process was completed solely by the researcher, however, the supervisory team were consulted when any ambiguity arose.

3.3.8 Data extraction

Pertinent data were extracted and documented by the researcher and cross-checked by the supervisory team for completion and accuracy. A predesigned data extraction form was used to extract the following data:

1) General information (author and year of publication)
2) Characteristics of participants (sample size, disease duration, age and gender)
3) Study characteristics (design)
4) Hand function outcome measures
5) Factors
6) Association between factors and outcome

3.3.9 Quality assessment

The extent to which a systematic review conclusion can be trusted depends on several factors. Importantly, it depends on whether the results from the included studies are valid (Mallen et al. 2006; Higgins and Green 2011). As a result, assessing the quality of the included studies is an essential component of systematic reviews. Quality is a complex and multidimensional concept, which is related to the design, conduct, and analysis of a study, its generalisability, or quality of reporting (Juni et al. 2001). However, quality includes two main dimensions: internal and external validity. Internal validity is usually referred to as methodological quality (Higgins and Green 2011), and external validity is related to the degree of generalisability or applicability of a study's results to other circumstances (Juni et al. 2001). Methodological quality focusses on the risk of bias and refers to the degree to which the study's design, conduct, and analysis can possibly prevent bias and systematic error (Higgins and Green 2011). On the other hand, reporting quality is related to how well a published article presents the methods and results in line with international standards (Downes et al. 2016; Harrison et al. 2017). Poor reporting in studies makes it difficult to assess the risk of bias and the quality of the study design. For that reason, tools assessing the quality of studies should include items related to the quality of reporting, the quality of design and the risk of bias (Downes et al. 2016).

Three types of tools are available to evaluate the methodological quality of observational studies including scales, checklists, and checklists with a summary judgement (Sanderson et al. 2007). Scales provide a summary numerical score, usually obtained as a total score for many items. Scales however, can be problematic, since calculating a summary score involves assigning 'weights' to different items in the scale; as a result they may fail to identify studies at increased risk of bias (Higgins and Green 2011; O'Connor et al. 2015). Checklists consist of only a list of items, whereas checklists with a summary judgement provide a general qualitative assessment of the study's quality (e.g. high, moderate and low) (Sanderson et al. 2007). Checklists are widely used in the literature and they provide a transparent evaluation of the quality components (Shamliyan et al. 2010).

In the context of observational studies, no agreed "gold standard" quality assessment tool is currently available (Shamliyan et al. 2012). Many reviews were unable to provide recommendations as to what should be used for carrying out quality assessments of observational studies (Katrak et al. 2004; Sanderson et al. 2007; Shamliyan et al. 2010; Jarde et al. 2012; Shamliyan et al. 2012). All of these reviews have generally concluded that most tools were not developed using specified empirical research, have limited validity and reliability evidence, and that there is a wide variety of tools to choose from. Furthermore, none of the available tools discriminate poor reporting from the quality of the studies, and there is no consensus on which content domains should be taken into account. This is coupled with the fact that very few tools address conflict of interest or the sample representativeness aspect (Sanderson et al. 2007; Shamliyan et al. 2010; Jarde et al. 2012). Finally, the majority of the available tools are not applicable to cross-sectional studies (Katrak et al. 2004; Sanderson et al. 2007; Jarde et al. 2012). Due to the above-mentioned shortcomings, scholars (Sanderson et al. 2007; Shamliyan et al. 2010) and editors (Lang and Kleijnen 2010) have recommended the development of a quality assessment tool for observational studies.

The quality and risk of bias of the studies included in this research were assessed using a critical appraisal checklist, in order to assess the quality of the cross-sectional studies (AXIS) (Downes et al. 2016). As mentioned previously, the quality assessment tools available are not applicable to cross-sectional studies and the AXIS tool is the only available appraisal tool specifically designed to assess cross-sectional studies (Downes et al. 2016). The following sections will describe the AXIS tool and the process of assessing the quality of the included studies.

3.3.9.1 The critical appraisal checklist to assess the quality of cross-sectional studies (AXIS)

The Axis tool was developed through empirical research combining a comprehensive review and Delphi panel. It comprises 20 items that focus mainly on the presented methods and results, with each item rated as either “Yes”, “No” or “Don't know” (Table 3-7). The 20 items are grouped into five sections: (i) introduction (one item); (ii) methods (10 items); (iii) results (five items); (iv) discussion (two items) and (v) other (two items). Seven questions (1, 4, 10, 11, 12, 16 and 18) included in the AXIS tool are related to the quality of reporting, seven questions (2, 3, 5, 8, 17, 19 and 20) are related to the study design quality and six questions (6, 7, 9, 13, 14 and 15) are related to the risk of bias. This tool has the benefit of providing the opportunity to assess each individual aspect of study design, in order to give an overall evaluation of the quality of a study. By offering this subjectivity, AXIS provides the possibility of distinguishing the quality of reporting and risk of bias when making judgements on the quality of a study.

Although the AXIS tool was developed to evaluate the methodological quality of cross-sectional studies, it can be used to evaluate other types of observational studies such as case-control and cohort studies. This is because the questions are relatively generic and can be interpreted and scored according to the study design being evaluated. The researcher contacted the developer of AXIS (M Downes) via email to ask whether any questions included in the tool should be modified for cohort and case-control studies. However, it was recommended that no questions be changed when using the AXIS tool, as it is suitable for appraising different observational designs such as prevalence, incidence and risk factors (personal communication). Furthermore, the review team found it easy to interpret and score AXIS questions according to the type of study under investigation.

The AXIS was recently developed, therefore limited evidence exists supporting its validity and reliability. However, a recently published protocol for a systematic review of observational studies of antibiotic resistance in ethnic minority groups was reported using AXIS as a tool to evaluate the study's quality (Lishman et al. 2017). Because of the rigorous method used to develop the AXIS, its simplicity, as well as the availability of a comprehensive explanatory manual, which aids the reviewers when interpreting the questions, AXIS has the potential to be widely used in the systematic reviews of observational studies in the future.

Table 3-7 Appraisal of Cross-sectional Studies (AXIS) (Downes et al. 2016)

Question	Yes	No	Don't Know
Introduction			
1) Were the aims/objectives of the study clear?			
Methods			
2) Was the study design appropriate for the stated aim(s)?			
3) Was the sample size justified?			
4) Was the target/reference population clearly defined? (Is it clear who the research was about?)			
5) Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?			
6) Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?			
7) Were measures undertaken to address and categorize non-responders?			
8) Were the risk factor and outcome variables measured appropriate to the aims of the study?			
9) Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?			
10) Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)			
11) Were the methods (including statistical methods) sufficiently described to enable them to be repeated?			
Results			
12) Were the basic data adequately described?			
13) Does the response rate raise concerns about non-response bias?			
14) If appropriate, was information about non-responders described?			
15) Were the results internally consistent?			
16) Were the results presented for all the analyses described in the methods?			
Discussion			
17) Were the authors' discussions and conclusions justified by the results?			
18) Were the limitations of the study discussed?			
Other			
19) Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?			
20) Was ethical approval or consent of participants attained?			

3.3.10 Synthesis of evidence

One option for the synthesis of evidence is to include a meta-analysis. Nevertheless, heterogeneity is a common problem in observational studies, limiting statistical pooling of the data (Moola et al. 2015). When a meta-analysis is not feasible, a narrative approach can be used to synthesise data (Popay et al. 2006; CRD's 2009). A narrative approach relies mainly on the use of words and text to summarise and explain the findings of the synthesis. Furthermore, researchers may use a graphical and tabular summary for data synthesis (Moola et al. 2015). However, using a narrative approach can be problematic, because the researcher may select or emphasise some findings over others when describing the data (Reeves et al. 2011). Therefore, one guideline published on the conduct of narrative synthesis has identified different techniques which can be used to enhance the robustness of the synthesis (Popay et al. 2006). The decision, about which of these techniques is appropriate, depends on the nature of the review being conducted.

The present review aims to summarise the findings from the research using a wide range of designs (e.g. cross-sectional and longitudinal studies), which need to be combined to provide a conclusion. As a result, the best-evidence synthesis approach was found to be suitable based on the nature of this review. Best-evidence synthesis is a qualitative evidence ranking based on the method developed by Slavin (1995), which is widely used and contemporaneous (Yusuf et al. 2010; Veenhof et al. 2012). As in the case of meta-analysis, best evidence synthesis aims to provide methodological rigor to evidence synthesis by clearly and succinctly articulating the synthesis standards (Suri and Clarke 1999). In short, best-evidence synthesis identifies the strength of a relationship based on the type, quantity, quality, and consistency of the evidence available to support a relationship between variables (Tompa et al. 2016). A ranking system (Table 3-8) proposed by Van Tulder et al. (2003), and utilised in subsequent systematic reviews (Yusuf et al. 2010; Veenhof et al. 2012), was considered for this purpose. Initially, the studies were categorised according to the type of study design. The favoured design was a cohort study followed by a case-control design and, lastly, a cross-sectional design. After that, the studies were ranked according to their overall methodologic quality score. Consistency in this ranking system means that the factor was significantly associated with hand function, with the same direction of association.

Table 3-8 Best-evidence synthesis (Van Tulder et al. 2003)

Level of evidence	Description
Strong	Generally consistent findings were presented in multiple high-quality cohort studies
Moderate	One high-quality cohort study and at least two high-quality case–control studies, or when at least three high-quality case–control studies show generally consistent findings
Limited	Generally consistent findings were found in a single cohort study, or in maximum two case–control studies, or in multiple cross-sectional studies
Conflicting	Less than 75% of the studies reported consistent findings
No evidence	No study could be found

3.4 Results

3.4.1 Study selection

The search of the selected databases resulted in the retrieval of 1,254 citations (MEDLINE 395; EMBASE 566; CINAL 122; AMED 54; PsychINFO 18; Web of Knowledge 99), and other source searches yielded 17 citations (Google Scholar). After removal of duplicate citations, 764 articles remained. Following that, screening of citation titles and abstracts excluded 703 citations from the review. From the remaining 61 citations, 41 were excluded for the following reasons:

1) Citations were not peer reviewed (i.e. thesis or conference abstracts)
2) Hand function data were not reported or separate analysis for RA participants was not available
3) Participants were not diagnosed according to the ACR or 2010 ACR/EULAR criteria
4) Hand function was not evaluated using hand specific outcome measures (i.e. generic disability measures or a hand function subscale from generic disability measures) or impairment measurement of hand function was used

As presented in the PRISMA flow diagram (Figure 3-2), 20 articles that met all of the inclusion criteria were identified, and thus included in the present review. Hand searching of these articles resulted in the retrieval of one additional article (Taştekin et al. 2006) which was published in Turkish, and therefore excluded. Forward citation tracking and consulting the experts in this systematic review team did not yield any further articles for inclusion in the review.

3.4.2 Study characteristics

The articles in the review were based on 19 independent studies of people with RA. Fifteen (75%) of the 20 articles were cross-sectional (Jonsson and Larsson 1990; O'Connor et al. 1999; Adams et al. 2004, 2005b; Sahin et al. 2006; Birtane et al. 2008; Özeri et al. 2008; Horsten et al. 2010; Aktekin et al. 2011; DedeoĞLu et al. 2013; Dogu et al. 2013; Durmus et al. 2013; BİRcan et al. 2014; Andrade et al. 2016; Belghali et al. 2017), two were case-control (Erol et al. 2016; Kinikli et al. 2016), and three studies were cohort (van Lankveld et al. 1998; van Lankveld et al. 1999; Eberhardt et al. 2008).

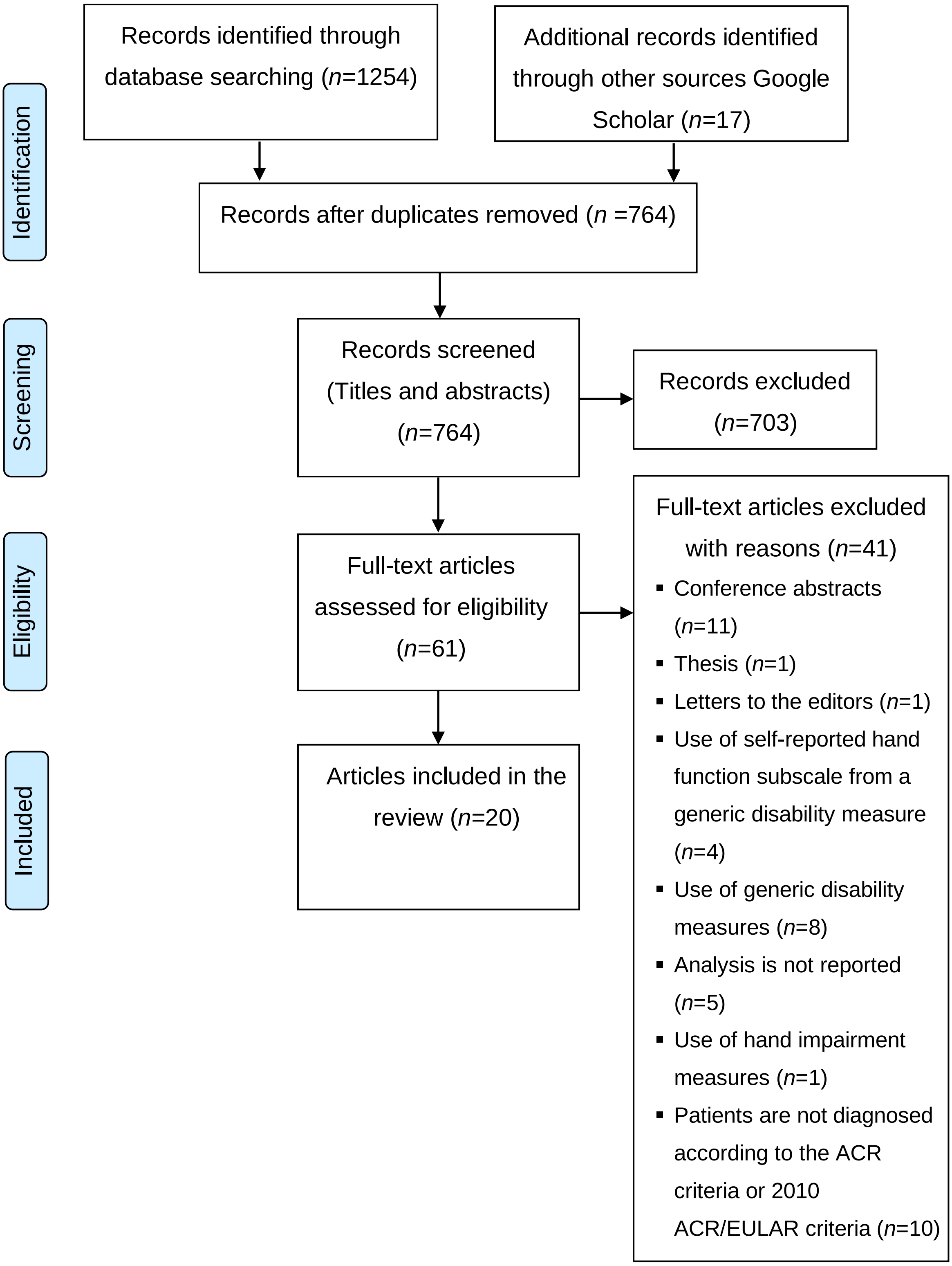


Figure 3-2 PRISMA flow chart

Case-control and cohort studies included in this review presented cross-sectional data on the association between factors and hand function. For instance, Eberhardt et al. (2008) reported the associations between the factors identified and hand function only at the end of study. Conversely, van Lankveld et al. (1998) only reported the associations at the study baseline stage. Since case-control and cohort studies included in this review presented cross-sectional data regarding the association between factors and hand function, all of studies were considered to be cross-sectional, resulting in at best limited evidence in the best-evidence synthesis. In a similar systematic review study, the authors considered case-control studies to be cross-sectional, since the data presented were cross-sectional (Veenhof et al. 2012).

Two articles (van Lankveld et al. 1998; van Lankveld et al. 1999) used the same group of participants, but the factors assessed for association with hand function were different. However, both articles reported the same associations between hand function and age, gender and disease duration. Therefore, the results of both articles with regards to the associations between hand function and age, gender and disease duration were considered as one body of evidence in the analysis. A full overview of the study characteristics of the included studies is presented in Table 3-9.

3.4.3 Characteristics of the samples

Although 20 articles were included in the present review, two articles (van Lankveld et al. 1998; van Lankveld et al. 1999) used the same group of participants. Therefore, this review identified data from 19 unique study samples. The sample size ranged from 25 (O'Connor et al. 1999) to 200 participants (Horsten et al. 2010). The majority of the participants (56%–100%) in the studies were women and the mean age ranged from 45.07 to 70 years (with the SD ranging 2.4-14.15 years). Two studies only included female participants (Özeri et al. 2008; Dogu et al. 2013). The mean disease duration ranged from 7 months to 21 years (with the SD ranging from 1.7 months-15.4). One study did not provide details about the mean disease duration (Erol et al. 2016). Although the recruitment settings were poorly reported in many of the included studies, those studies that did report the recruitment setting cited outpatients’ rheumatology and/or rehabilitation clinics.

Table 3-9 The characteristics of the articles included, ordered by publication date

Author (year)	Study Design	Study population	HF assessment	Results: associations with low hand functional abilities	Statistical analysis	Quality score
Belghali et al. (2017)	Cross-sectional	▪ Sample size (*n*=100, F=85, M=15) ▪ Mean age (55 ±12 years) ▪ Mean disease duration (9±7 years)	bMHQ ↑	▪ Associations with older age (above 65 years), longer disease duration (above 2 years), high disease activity (DAS-28), presence of deformities, high ESR level, not receiving rehabilitation services (PT, OT and splint), and medical treatments (biological medication and surgery). ▪ No association with gender, physical functioning, living condition, educational level, laterality, job, presence of extra-articular manifestations, immunological blood tests (RF, ACPA and ANA), structural damage to the hand, symptomatic and conventional DMARDs	Spearman correlation	45%
Kinikli et al. (2016)	Case-control	▪ Sample size (*n*=29, F=20, M=9) ▪ Mean age (51.5±8.6 years) ▪ Mean disease duration (9.6±7.4 years)	DHI ↓	▪ Associations with low power grip strength and endurance of the DH	Spearman correlation	30%
Erol et al. (2016)	Case-control	▪ Sample size (*n*=33, F=24, M=9) ▪ Mean age (46.4±11.1 years) ▪ Mean disease duration (Not reported)	DHI ↓	▪ Associations with DH high tenosynovitis severity and number of DH deformities ▪ No association with immunological blood test (RF), hand overuse, and DH bone erosion, bone edema, and synovitis	Mann–Whitney U test, Spearman correlation	50%

Table 3-9 (Continued)

Author (year)	**Study Design**	**Study population**	**HF assessment**	**Results: associations with low hand functional abilities**	**Statistical analysis**	**Quality score**
Andrade et al. (2016)	Cross-sectional	▪ Sample size (*n*=81, F=74, M=7) ▪ Mean age (54 ± 2.4 years) † ▪ Mean disease duration (12 ± 2.2 years) †	SODA ↑	▪ Associations with low DH power grip strength, DH limited ROM, low mental health status and presence of DH deformities ▪ No association with age, gender, upper limb ROM deficit, DH tip pinch strength, pain intensity during SODA tasks, vitality, stiffness intensity, fatigue intensity, dexterity, disease duration, classification of functional status (ACR), general health status, work situation and work activity	Linear regression analysis	55%
BİRcan et al. (2014)	Cross-sectional	▪ Sample size (*n*=65, F=55, M=10) ▪ Mean age (55±11years) ▪ Mean disease duration (10.2±8.2 years)	GAT ↓	▪ Associations with long duration of morning stiffness, low physical functioning, high pain intensity during ADL, high stiffness intensity, increase of DH ROM flexion deficit, high disease activity (DAS-28), and low power grip strength of both DH and NDH ▪ No association with gender, pain intensity at rest, gender, number of deformities in both hands, disease duration, and NDH flexion ROM deficit	Mann–Whitney U test, Spearman correlation	60%
Dogu et al. (2013)	Cross-sectional	▪ Sample size (*n*=83, F= 83, M=0) ▪ Mean age (45.07±14.15 years) ▪ Mean disease duration (8.46±5.68 years)	DHI ↓	▪ Associations with weak power grip and pinch strengths (lateral, tip, and tripod) and more hands' structural damage ▪ No association with hands' bone mineral density	Pearson correlation	65%

Table 3-9 (Continued)

Author (year)	**Study Design**	**Study population**	**HF assessment**	**Results: associations with low hand functional abilities**	**Statistical analysis**	**Quality score**
Durmus et al. (2013)	Cross-sectional	▪ Sample size (*n*=80, F=62, M=18) ▪ Mean age (52.86±9.43 years) ▪ Mean disease duration (6.99±4.42 years)	▪ MHQ ↑ ▪ DASH ↓	▪ MHQ & DASH: Associations with high CRP level (only MHQ), high level of ESR (only DASH) high pain intensity (at rest, in ADL, and bodily pain), high disease activity (DAS-28 and PGA), high swollen and tender joints count, low physical functioning level, low social functioning, low Rt and Lt hand power grip strength, low emotional function, low vitality level, low mental health status, and low general health status ▪ MHQ: No association with ESR level ▪ DASH: No association with CRP level	Pearson correlation	60%
DedeoĞLu et al. (2013)	Cross-sectional	▪ Sample size (*n*=102, F=78, M=24) ▪ Mean age (52.8±10.5 years) ▪ Mean disease duration (13.55±9.03 years)	DHI ↓	▪ Associations with high disease activity (DAS-28), low physical functioning level, more joint article damage (RAAD), high pain intensity, limited functional mobility (hands and upper limbs), more hands' structural damage, long disease duration, low power grip strength and low pinch strengths (tip, lateral and tripod) ▪ No association with RF level	Mann–Whitney U test, Spearman correlation	45%

Table 3-9 (Continued)

Author (year)	**Study Design**	**Study population**	**HF assessment**	**Results: associations with low hand functional abilities**	**Statistical analysis**	**Quality score**
Aktekin et al. (2011)	Cross-sectional	▪ Sample size (*n*=166, F=130, M=36) ▪ Mean age (52.5±12.6 years) ▪ Mean disease duration (10.6±8.1 years)	DASH ↓	▪ Associated with high disease activity (DAS-28, CDAI,SDAI, PAG and PhGA), low physical functioning level, low social functioning, high swollen and tender joints count, high level of ESR and CRP, high body pain intensity, low mental health status, low emotional function, low vitality and low general health status	Pearson correlation	40%
Horsten et al. (2010)	Cross-sectional	▪ Sample size (*n*=200, F=150, M=50) ▪ Mean age (59.7±10.7 years) ▪ Mean disease duration (5.9±2.7 years)	DASH ↓	▪ No association with disease duration	Chi square test	75%
Özeri et al. (2008)	Cross-sectional	▪ Sample size (*n*=30, F=30, M=0) ▪ Mean age (47.4±8.8 years) ▪ Mean disease duration (7.11±5.3 years)	DHI ↓	▪ Associations with long disease duration, high pain intensity at hand and wrist, high disease activity (PGA), high tender joints count (RAI), limited DH wrist flexion ROM, low power grip strength, more hands' structural damage, limited functional mobility and high CRP level ▪ No association with duration of morning stiffness, lateral pinch strength, ESR level, MCP flexion ROM, PIP flexion ROM, DIP flexion ROM, swollen and tender joint count and total score of swelling	Spearman correlation	40%

Table 3-9 (Continued)

Author (year)	**Study Design**	**Study population**	**HF assessment**	**Results: associations with low hand functional abilities**	**Statistical analysis**	**Quality score**
Eberhardt et al. (2008)	Cohort	▪ Sample size (*n*=49, F=37, M=12) ▪ Mean age (54.9±12.2 years) ▪ Mean disease duration (15±10 years)	GAT ↓	▪ Associations with weak power grip and tip pinch strength, low physical functioning level, and limited functional mobility ▪ No association with disease activity (DAS-28)	Spearman correlation	55%
Birtane et al. (2008)	Cross-sectional	▪ Sample size (*n*=48, F=38, M=10) ▪ Mean age (52.56±13.02 years) ▪ Mean disease duration (9.08±6.73 years)	DHI ↓	▪ Association with high disease activity (DAS-28) ▪ No association with disease duration, age, gender, and structural damage of the hands	Spearman correlation, Pearson correlation	50%
Sahin et al. (2006)	Cross-sectional	▪ Sample size (*n*=42, F=34, M=8) ▪ Mean age (55.1 ± 12 years) ▪ Mean disease duration (7.2±6.5 years)	▪ DHI ↓ ▪ SHFT ↑	▪ DHI & SHFT: Associations with low power grip strength, low physical functioning level, low lateral pinch strength, increase of ulnar deviation angle, and more hands' structural damage (erosion and joint space narrowing)	Correlation analysis- not specified	40%
Adams et al. (2005b)	Cross-sectional	▪ Sample size (*n*=110, F=81, M=29) ▪ Mean age (57±13.85 years) ▪ Mean disease duration (7±1.7 months) †	DASH ↓	▪ Associations with older age and long disease duration	Pearson correlation	55%

Table 3-9 (Continued)

Author (year)	**Study Design**	**Study population**	**HF assessment**	**Results: associations with low hand functional abilities**	**Statistical analysis**	**Quality score**
Adams et al. (2004)	Cross-sectional	▪ Sample size (*n*=36, F=25, M=11) ▪ Mean age (58±14 years) ▪ Median disease duration (7.5 months)	▪ DASH ↓ ▪ GAT ↓	▪ DASH: Associations with low power grip strength, low tripod pinch grip, and DH limited wrist ROM ▪ GAT: Associations with low power grip strength, low tripod strength, DH limited wrist ROM, and of increase ulnar deviation angle ▪ DASH: No association with ulnar deviation angle, NDH wrist ROM ▪ GAT: No association with NDH wrist ROM	Spearman correlation	65%
van Lankveld et al. (1999)	Cohort	▪ Sample size (*n*=94, F~59, M~35) ▪ Mean age (56.34 ±11.87) ▪ Mean disease duration (13.33±10 years)	SODA ↑	▪ Associations with high disease activity (DAS-28), long disease duration, high pain factor score (3 measures of pain intensity), high impairment factor score (number of deformities, power grip strength, and structural damage) and decreasing activity behaviour ▪ No association with age, sex and adaption behaviour (pacing)	Pearson correlation	45%

Table 3-9 (Continued)

Author (year)	Study Design	Study population	HF assessment	Results: associations with low hand functional abilities	Statistical analysis	Quality score
O'Connor et al. (1999)	Cross-sectional	▪ Sample size (*n*=25, F= 14, M=11) ▪ Mean age (70±7.7) ▪ Mean disease duration (21±14 years)	▪ SHFT ↑ ▪ SODA ↑	▪ SHFT: Associations with long disease duration, low physical functioning level, limited flexion ROM of DH and limited extension ROM of DH and NDH ▪ SHFT: No associations with pain intensity during SODA tasks, pain intensity in DH and NDH, limited flexion ROM of NDH, ulnar deviation angle of both DH and NDH, age, and sex ▪ SODA: Associations with long disease duration, high pain intensity during SODA tasks, low physical functioning level, limited flexion ROM of both DH and NDH, limited extension and flexion ROM of both DH and NDH, and an increase of DH and NDH ulnar deviation angle ▪ SODA: No associations with DH and NDH pain intensity, age, and sex	Spearman correlation, Pearson correlation	50%
van Lankveld et al. (1998)	Cohort	▪ Sample size (*n*=94, F~59, M~35) ▪ Mean age (56.34±7.7) ▪ Mean disease duration (13.33±10 years)	SODA ↑	▪ Associations with long disease duration, more hands structural damage, low power grip strength, increase number of deformities of both hands, limited flexion ROM of the fingers (thumb, index, middle, ring and little finger), limited wrist ROM (flexion, extension, ulnar deviation, radial deviation, supination, and pronation), increase number of painful joints, high pain intensity ▪ No association with age, gender, and ESR level and number of swollen joints	Pearson correlation	40%

Table 3-9 (Continued)

Author (year)	**Study Design**	**Study population**	**HF assessment**	**Results: associations with low hand functional abilities**	**Statistical analysis**	**Quality score**
Jonsson and Larsson (1990)	Cross-sectional	▪ Sample size (*n*=77, F= 46, M=31) ▪ Mean age (65±14.2) ▪ Mean disease duration (19±15.4 years)	SHFT ↑	▪ Associations with older age, long disease duration, increase number of in hospital days, and limited functional mobility of hand and upper limb ▪ No association with treatment cost	Regression analysis	25%

↑: Higher score of the outcome measure denotes better hand function; ↓: Lower score of the outcome measures denotes better hand function †: Estimated mean values using Hozo et al. (2005) method; ACPA: Anti-citrullinated Peptide Antibodies; ACR: American College of Rheumatology; ADL: Activities of Daily Living; ANA: Anti-nuclear Antibodies; bMHQ: brief Michigan Hand Outcomes Questionnaire; CDAI: Clinical Disease Activity Index; CRP: C-reactive Protein; DAS-28: Disease Activity Score; DASH: Disabilities of the Arm, Shoulder and Hand; DH: Dominant Hand; DHI: Duruoz Hand Index; DMARDs: Disease Modifying Anti-rheumatic Drugs; ESR: Erythrocyte Sedimentation Rate; F: Female; GAT: Grip Ability Test; HF: Hand function; Lt.: left Hand; M: Male; MHQ: Michigan Hand Outcomes Questionnaire; NDH: Non dominant hand; OT: Occupational Therapy; PGA: Patient s' global assessment of disease activity; PhGA: Physician's global assessment of disease activity; PT: Physiotherapy; RAAD: Rheumatoid Arthritis Articular Damage; RAI: Ritchie Articular Index; RF: Rheumatoid Factor; ROM: Range of Motion; Rt.: Right Hand; SDAI: Simplified Disease Activity Index; SHFT: Sollerman Hand Function Test; SODA: Sequential Occupational Dexterity Assessment

3.4.4 Types of hand function outcome measures

From the 20 articles included, seven hand function measures and four self-reported measures, including the brief Michigan Hand Questionnaire (bMHQ) (Waljee et al. 2011), Michigan Hand Questionnaire (MHQ) (Chung et al. 1998), Disabilities of the Arm, Shoulder and Hand (DASH) (Hudak et al. 1996), and Duruöz Hand Index (DHI) (Duruoz et al. 1996) were identified. Three performance-based hand function tests were used: Sequential Occupational Dexterity Assessment (SODA) (van Lankveld et al. 1996), Grip Ability Test (GAT) (Dellhag and Bjelle 1995), and Sollerman Hand Function Test (SHFT) (Sollerman and Sperling 1978). Four studies evaluated hand function using two outcome measures: self-reported and performance-based measures (Adams et al. 2004; Sahin et al. 2006), self-reported measures only (Durmus et al. 2013), and performance-based measures only (O'Connor et al. 1999). As shown in Figure 3-3, DHI and DASH were the more frequently used outcome measures, followed by SODA, GAT, and SHFT, and the least used were MHQ and bMHQ. In the study by Andrade et al. (2016), hand function was evaluated using both the SODA and the Upper Extremity Function Test for the Elderly (TEMPA) (Johanne et al. 1993); however, the results of association between the TEMPA and other variables were not considered in this review analysis, because the evidence supporting the use of TEMPA with the RA population is currently limited (Andrade et al. 2016).

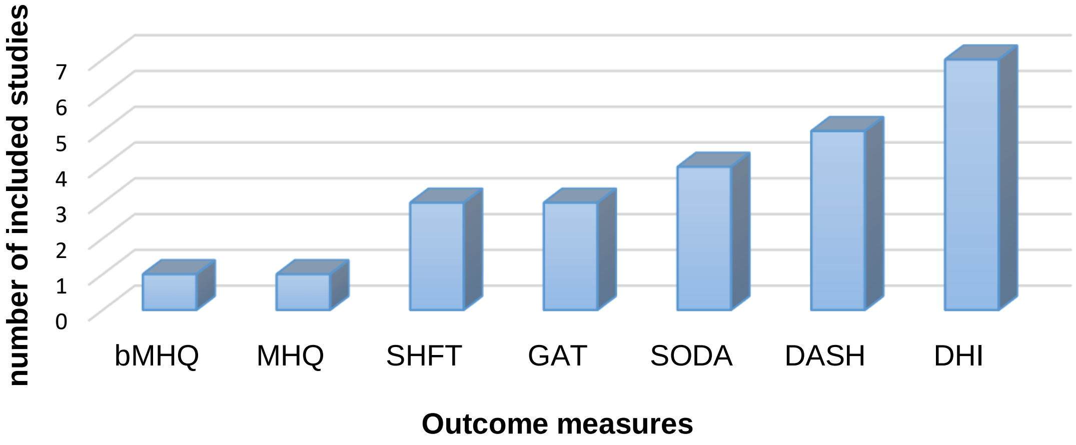


Figure 3-3 Frequency of use of each hand function outcome measure in included articles

3.4.5 Methodological quality

One reviewer (JA) involved in this review was the author of two out of twenty of the articles included in the review. However, to ensure that the quality assessment process was unbiased, the quality assessment of these two articles were completed by the researcher and the second reviewer (AMH) only.

The initial scoring between the researcher and the first reviewer (JA) and the researcher and the second reviewer (AMH) of the included studies had an agreement rate of 73% (146/200) and 81% (162/200), respectively. Disagreement was mainly prevalent in the “sampling frame” domain (item 5), because the sample frame was not clearly reported in the included studies. After four meetings between the researcher and the reviewers, a consensus was achieved on all the initial disagreements and the third reviewer was not required to solve any disagreements. The items, which had been rated as “Don't know” at the initial scoring, were later rated as “Yes” or “No” after reaching a consensus. The overall scores of methodological quality, and the quality scores for reporting, design and risk of bias domain of the included studies are presented in Table 3-10.

The overall quality assessed by the reviewers as the total percentage of quality appraisal items endorsed for each study was high (≥ 60%) for five studies (25%) (Adams et al. 2004; Horsten et al. 2010; Dogu et al. 2013; Durmus et al. 2013; BİRcan et al. 2014). The mean quality score over the 20 included articles was 49.5%, with a range of 25% to 75%. The risk of bias items (6, 7, 13, and 14) were inadequately met by the included studies, including those with overall high quality scores, with the exception of the study by Horsten et al. (2010). The study by Horsten et al. (2010) was the only study to meet items seven, thirteen and fourteen, and item six was only met by Dogu et al. (2013). Consequently, only one study was deemed to have a high methodological quality (67%) in terms of the risk of bias domain (Horsten et al. 2010). However, this study explored the association between only one factor (i.e. disease duration) and hand function. Unlike the risk of bias domain, 80% (*n*=16) of the included studies had a high score for reporting quality domain. The mean quality score for reporting domain was 75%, with a range of 29% to 100%. Therefore, the overall high-quality scores for the included studies appears to be due to the high reporting quality scores.

Table 3-10 Quality assessment using AXIS tool of the articles included, ordered by publication date

#	Author (year)	Question																				Quality			
		Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Overall	Report	Design	Bias
1	Belghali et al. (2017)	Y	Y	N	Y	N	N	N	N	N	Y	N	Y	N	N	Y	Y	Y	Y	N	N	45%	86%	29%	17%
2	Kinikli et al. (2016)	Y	Y	N	Y	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	Y	Y	30%	43%	43%	0%
3	Erol et al. (2016)	Y	Y	N	Y	N	N	N	Y	N	Y	N	Y	N	N	Y	Y	Y	N	N	Y	50%	71%	57%	17%
4	Andrade et al. (2016)	N	Y	Y	Y	Y	N	N	Y	Y	Y	N	N	N	N	Y	N	Y	Y	N	Y	55%	43%	86%	33%
5	BİRcan et al. (2014)	Y	Y	N	Y	N	N	N	Y	N	Y	N	Y	N	N	Y	Y	Y	Y	Y	Y	60% †	86%	71%	17%
6	Durmus et al. (2013)	Y	Y	N	Y	Y	N	N	N	N	Y	Y	Y	N	N	Y	Y	Y	Y	N	Y	60% †	100%	57%	17%
7	Dogu et al. (2013)	Y	Y	N	Y	N	Y	N	Y	Y	Y	N	Y	N	N	Y	Y	Y	Y	N	Y	65% †	86%	57%	50%
8	DedeoĞLu et al. (2013)	Y	Y	N	Y	N	N	N	N	N	Y	N	Y	N	N	Y	Y	Y	N	Y	N	45%	71%	43%	17%
9	Aktekin et al. (2011)	Y	Y	N	Y	N	N	N	Y	Y	N	N	Y	N	N	Y	Y	N	N	N	N	40%	57%	29%	33%
10	Horsten et al. (2010)	Y	Y	N	Y	Y	N	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	75% †	100%	57%	67%
11	Özeri et al. (2008)	Y	Y	N	Y	N	N	N	N	N	Y	N	Y	N	N	Y	Y	Y	N	N	N	40%	71%	29%	17%
12	Eberhardt et al. (2008)	Y	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	N	N	Y	Y	Y	N	N	N	55%	86%	43%	33%
13	Birtane et al. (2008)	Y	Y	N	Y	N	N	N	N	N	Y	Y	Y	N	N	Y	Y	Y	N	N	Y	50%	86%	29%	17%
14	Sahin et al. (2006)	Y	Y	N	Y	N	N	N	N	N	Y	N	Y	N	N	Y	Y	Y	N	N	N	40%	71%	29%	17%
15	Adams et al. (2005b)	Y	Y	N	Y	N	N	N	Y	Y	N	Y	Y	N	N	Y	Y	Y	N	N	Y	55%	71%	57%	33%
16	Adams et al. (2004)	Y	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y	N	Y	65% †	100%	57%	33%
17	van Lankveld et al. (1999)	Y	Y	N	Y	N	N	N	N	N	Y	N	Y	N	N	Y	Y	Y	Y	N	N	45%	86%	29%	17%
18	O'Connor et al. (1999)	Y	Y	Y	Y	Y	N	N	N	N	Y	Y	Y	N	N	N	Y	Y	N	N	N	50%	86%	57%	0%
19	van Lankveld et al. (1998)	Y	Y	N	Y	N	N	N	N	N	Y	N	Y	N	N	Y	Y	Y	N	N	N	40%	71%	29%	17%
20	Jonsson and Larsson (1990)	N	Y	N	Y	Y	N	N	N	N	Y	N	N	N	N	Y	N	N	N	N	N	25%	29%	29%	17%

Y: Yes; N: No, Q: Question; †: High quality

3.4.6 Data synthesis

Factors tested for association with hand function have been categorised based on the ICF framework and health related factors. The ICF classification is structured into four broad domains including:

1) Body function and structure (e.g. range of motion, power grip strength).
2) Functional status (i.e. activity limitation and participation restriction such as physical functioning).
3) Personal (e.g. age, gender).
4) Environmental (e.g. work activity).

Health related factors included health condition factors (e.g. disease duration) and general health status.

3.4.7 Overview of all factors

The frequency of the factors tested for association with hand function are mapped in Figure 3-4 to Figure 3-8. The majority (80%) of the studies were concerned with body function and structure factors. Thirteen unique body function and structure factors were assessed for association and are outlined in Figure 3-4. Power grip strength, composite disease activity and structural damage (radiographic) were the most frequently assessed factors in eleven, eight and seven independent studies, respectively. Functional status factors included physical functioning, social functioning and the emotional role. The former factor was assessed in eight studies and the other two factors were assessed in two separate studies (Figure 3-5). Few personal factors were assessed for association, and most of those factors were assessed in a single study, with the exception of age and gender, which were assessed in seven independent studies (Figure 3-6). Of the five environmental factors assessed for association, only the work activity factor was assessed in three studies and the remaining five factors were assessed in a single study (Figure 3-7). Four health condition factors including disease duration, RF factor, ACR functional classification and extra articular manifestations were assessed. Disease duration was explored in eleven studies, whereas RF was explored in three studies and the latter two factors were explored in a single study (Figure 3-8). Lastly, general health status was explored in three studies.

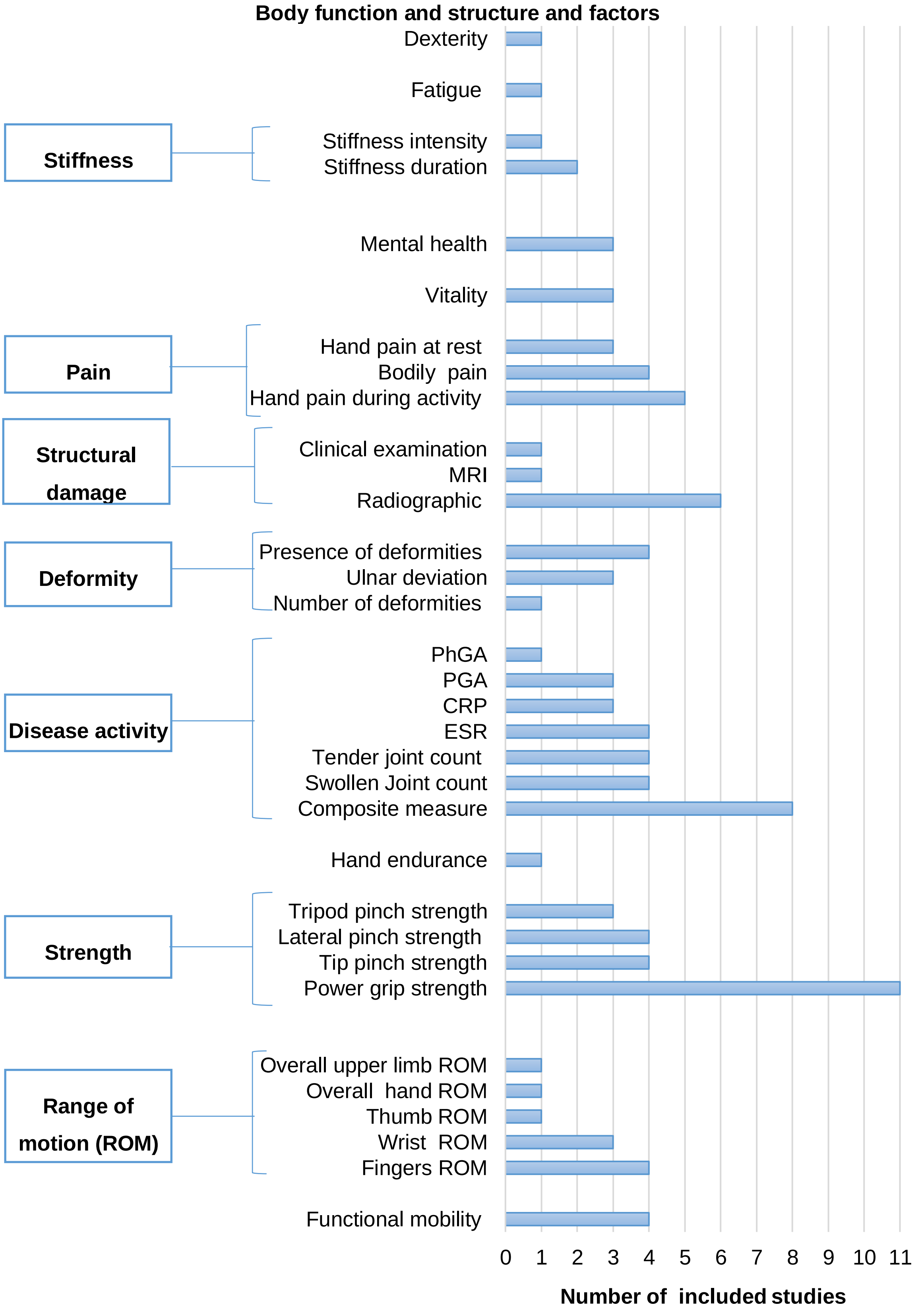


Figure 3-4 Frequency of body function and structure factors tested for association with hand function

CRP: C-reactive Protein; ESR: Erythrocyte Sedimentation Rate; MRI: Magnetic Resonance Imaging, PGA: Patient Global Assessment; PhGA: Physician Global Assessment

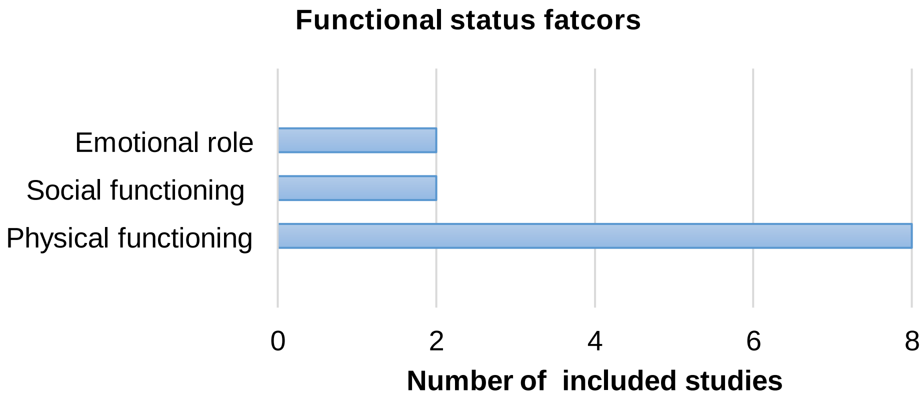


Figure 3-5 Frequency of functional status factors tested for association with hand function

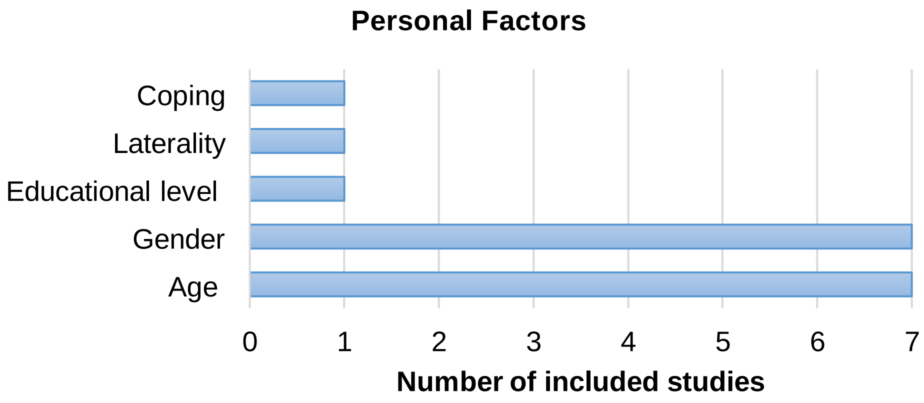


Figure 3-6 Frequency of personal factors tested for association with hand function

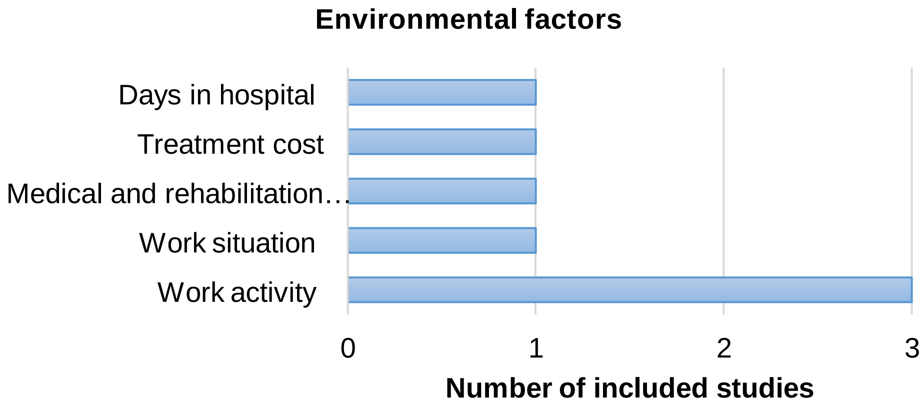


Figure 3-7 Frequency of environmental factors tested for association with hand function

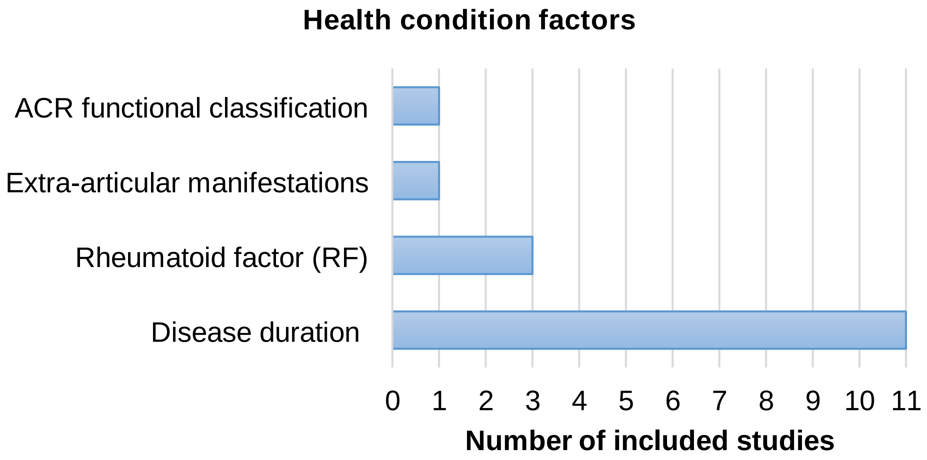


Figure 3-8 Frequency of health condition factors tested for association with hand function

3.4.8 Methodological considerations for best-evidence synthesis

The studies included exhibited marked heterogeneity in terms of patient characteristics, outcome measures, statistical analysis, and substantial differences in reporting of results. Consequently, meta-analysis was not possible and best-evidence synthesis (Slavin 1995) was used. It was evident from the studies assessing the association between hand function and factors related to body function and structure, that there was a marked variation regarding methods of measuring body function and structure factors, as well as how to describe and report them. For instance, Adams et al. (2004) assessed the dominant hand and non-dominant hand wrist flexion-extension active motion and documented the results of association for each hand separately. Whereas van Lankveld et al. (1998) assessed wrist flexion and extension separately and reported the association between hand function and the mean value of extension and flexion ROM for both hands. Therefore, factors that have been measured and reported in the same manner were considered common if supported by evidence from more than one study, otherwise, the results were considered inconclusive.

Studies that have used two hand function tools reported, at times, association between the factor and only one tool. For example, the CRP level was associated with the MHQ and not with the DASH (Durmus et al. 2013). For studies that used two tools to evaluate hand function and reported an association between a factor and one tool, but no association with another tool, the following conditions were applied:

1) If the study used a generic hand function tool (e.g. DASH) and hand specific tool, then only the results of the latter were considered.
2) If the study used two specific hand function tools, then the results of the tool that had been used more frequently in the included studies were considered.

3.4.9 Factors related to hand function

Factors that were common across the included studies based on the methodological considerations outlined previously were determined, thereafter best-evidence synthesis was performed using the ranking system presented in Table 3-8. However, extensive details regarding the association between hand function and all of the factors identified from the included studies are presented in Appendix F.

3.4.9.1 Body function and structure factors

A summary of all of the body function and structure factors considered for best evidence analysis is presented in Table 3-11.

- **Grip and pinch strength**

As presented in Table 3-11, limited evidence was found regarding the association between hand strength (power grip, tripod pinch, tip pinch and lateral pinch) and hand function. All of the studies which assessed the association between hand function and power grip strength and tripod pinch strength consistently reported a statistically positive significant association, regardless of the measurement or analysis methods. However, it was observed that there were discrepancies in relation to the strength of correlation between hand function measures and strength measurements. For power grip strength, the highest correlation ($r=-.810$, $p<.001$) was reported for the dominant power grip strength (Adams et al. 2004), and the lowest correlation ($r=-.399$, $p<.01$) was reported for the non-dominant power grip strength (BİRcan et al. 2014). Similarly, the strength of correlation between tripod pinch strength and hand function ranged from low ($r=-.344$, $p=.0001$) (Dogu et al. 2013) to high ($r=-.802$, $p<.001$) (Adams et al. 2004). A low to moderate correlation was reported by studies that explored the association between hand function and the mean value of both hands' tip pinch and lateral pinch strength when three consecutive measures were taken. For tip pinch strength, correlation ranged from low (*r*=−*.35, p*<*.05*) (Eberhardt et al. 2008) to moderate (*r*=−.640, *p*<.001) (DedeoĞLu et al. 2013), while lateral pinch strength correlation ranged from low (*r*=−.402, *p*=.0001) (Dogu et al. 2013) to moderate (*r*=−.640, *p*<.00) (DedeoĞLu et al. 2013).

There was inconclusive evidence to support the findings of Andrade et al. (2016) that the correlation between dominant hand tip pinch strength and hand function is not statistically significant. Similarly, the findings of Özeri et al. (2008) were inconclusive regarding the correlation between the mean value of both hands' lateral pinch strength measured in one trial and hand function was not statistically significant.

- **Range of motion**

Marked variation was observed regarding the methods of evaluating ROM measurements, as well as how to describe and report them. As a result, only two ROM measures were considered for best-evidence synthesis; the remaining ROM results were considered inconclusive. Regarding best-evidence synthesis, limited evidence was found for the association between the finger flexion deficit of both the dominant and non-dominant hands and hand function. Two studies reported a statistically negative significant association between finger flexion deficit of the dominant hand and hand function. The strength of correlation ranged from negligible (*r*=.267, *p*<.05) (BİRcan et al. 2014) to high (*r*=−.71, *p*<.01) (O'Connor et al. 1999). However, the same studies (O'Connor et al. 1999; BİRcan et al. 2014) reported that the correlation between finger flexion deficit of the non-dominant hand and hand function was not statistically significant.

Table 3-11 Overview of findings regarding associations of body function and structure factors with hand function

Factors	Association found(reference)‡	No association found(reference)‡	Level of evidence
Strength			
Power grip (mean value of both hands)	One HQ [7] and three LQ [2, 8, 19]		Limited
Power grip (dominant hand)	Two HQ [5, 16] and one LQ [14]		Limited
Power grip (non-dominant hand)	Two HQ [5,16]		Limited
Lateral pinch (mean value of both hands)	One HQ [7] and one LQ [8]		Limited
Tip pinch (mean value of both hands)	One HQ [7] and one LQ [8]		Limited
Tripod pinch (mean value of both hands)	One HQ [7] and one LQ [8]		Limited
Range of motion			
Dominant hand fingers flexion deficit	One HQ [5] and one LQ [18]		Limited
Non-dominant hand fingers flexion deficit		One HQ [5] and one LQ [18]	Limited
Disease activity			
Composite measure (DAS-28)	Two HQ [5, 6] and five LQ [1, 8, 9, 13, 17]	One LQ [12]	Limited
Swollen joint count	One HQ [6] and one LQ [9]	One LQ [20]	Conflicting
Tender joint count	One HQ [6] and two LQ [9, 20]		Limited
ESR	Two LQ [1, 9]	One HQ [6] and two LQ [11, 19]	Conflicting
CRP	One HQ [6] and two LQ [9, 11]		Limited
PGA	One HQ [6] and one LQ [9]		Limited

Table 3-11 (Continued)

Body Structure and function factors	Association found (reference)‡	No association found (reference)‡	Level of evidence
Deformity			
Presence of deformities in dominant hand	Two LQ [3,4]		Limited
Presence of deformities in both hands	One LQ [1]	One HQ [5]	Conflicting
Ulnar deviation of dominant hand	One HQ[16] and two LQ [14,17]		Limited
Ulnar deviation of non-dominant hand	One HQ [16] and one LQ [17]		Limited
Mental health	One HQ [6] and two LQ [4, 9]		Limited
Fatigue	One HQ [6] and one LQ [9]	One LQ [4]	Conflicting
Structural damage (radiographic)	One HQ [7] and three LQ [8, 11, 14]		Limited
Pain			
Bodily pain (VAS)	Two LQ [19, 8]		Limited
Bodily pain (SF-36)	One HQ [6] and LQ [9]		Limited
Hand pain during activity (SODA tasks)	Two LQ [18, 19]	One LQ [4]	Conflicting
Hand pain during activity (VAS)	Two HQ [5, 6]		Limited
Hand pain at rest (VAS)	One HQ [6] and one LQ [11]	One HQ [5] and LQ [18]	Conflicting
Stiffness			
Duration	One HQ [5]	One LQ [11]	Conflicting
Intensity	One HQ [5]	One LQ [4]	Conflicting

HQ:High Quality; LQ:Low Quality; ESR:Erythrocyte Sedimentation Rate; CRP: C- Reactive Protein; PGA:Patient Global Assessment; VAS:Vsual Analog Scale; SF- 36: Short- Form 36 Health Survey; SODA:Sequential Occupational Dexterity Assessment. ‡: The reference number in these tables corresponds to the number given to each study in Table 3-10

The results of association between hand function and ROM measures, which were considered inconclusive, can be grouped into wrist, fingers, thumb and overall ROM measures. For the wrist ROM, van Lankveld et al. (1998) reported a statistically significant positive correlation between hand function and wrist ROM when the mean values of wrist ROM for both hands were explored for associations. Likewise, Adams et al. (2004) reported a statistically significant positive correlation between hand function and active wrist flexion-extension ROM of the dominant hand, but not with the non-dominant hand. Also, Özeri et al. (2008) reported a statistically positive significant correlation between the dominant hand wrist flexion-extension ROM and hand function.

Regarding finger ROM, van Lankveld et al. (1998) found a low negative correlation between finger II-V flexion deficit, as measured by a ruler and hand function (range: $r=-.30$ to $r=-.37$, $p<.01$). However, Özeri et al. (2008) reported that the correlation was not statistically significant between hand function and flexion-extension ROM of MCP, PIP and distal DIP of the dominant hand when measured by the goniometer. Regarding thumb ROM, van Lankveld et al. (1998) found that thumb flexion ROM was weakly correlated (i.e. low) ($r=-.38$, $p<.01$) with hand function. Finally, a linear regression analysis conducted by Andrade et al. (2016) showed that hand function correlated positively with the overall dominant hand ROM, but not with the overall dominant upper limb ROM.

- **Disease activity**

There is limited evidence for the association between hand function and disease activity measured by the composite disease activity score, tender joint count, CRP level, and patients' global assessment of disease activity. The strength of correlation between these disease activity measures and hand function ranged from low to moderate. However, there is conflicting evidence regarding the association between hand function and disease activity measured by ESR level and swollen joint count. Aktekin et al. (2011) reported a moderate negative correlation ($r=.645$, $p<.05$) between hand function and disease activity, as evaluated by the physician's global assessment, however this finding is inconclusive.

- **Pain**

There is limited evidence regarding the association between hand function and bodily pain intensity, regardless of the methods of measuring pain. Bodily pain was measured using the pain scale of the SF-36 and VAS, and it showed a statistically significant negative correlation with hand function, which ranged from low (r=.477, p=.0001) (Durmus et al. 2013) to high (r=−.759, p<.05) (Aktekin et al. 2011). Hand pain during activity was measured using VAS and the sum of the painful tasks from the SODA. Limited evidence was found for the association between hand function and pain intensity during activity measured by VAS. The strength of correlation ranged from negligible (r=.261, p<.05) (BİRcan et al. 2014) to moderate (r=.603, p=.0001) (Durmus et al. 2013). However, conflicting evidence was found regarding the association between hand function and the sum of the painful tasks during the SODA tasks. Two studies reported a statistically significant negative correlation between hand function and the sum of painful tasks during the SODA tasks (van Lankveld et al. 1998; O'Connor et al. 1999), and one study reported that the correlation was not statistically significant (Andrade et al. 2016). Furthermore, conflicting evidence was found regarding the association between hand function and hand pain intensity at rest, as measured by VAS. Finally, the association found between the composite pain score and hand function by van Lankveld et al. (1999) was inconclusive.

- **Hand deformity**

Limited evidence was found for the association between hand function and the ulnar deviation angle of both the dominant and non-dominant hands. The strength of correlation between hand function and the ulnar deviation angle of the dominant hand ranged from low (r=.353, p=.035) (Adams et al. 2004) to moderate (r=−.64, p<.01) (O'Connor et al. 1999). The strength of correlation between hand function and ulnar deviation of the non-dominant hand was moderate (range: r=.517 to .57) (O'Connor et al. 1999; Adams et al. 2004). Limited evidence was found for the association between hand function and the presence of dominant hand deformities. Two studies reported a statistically significant negative association between hand function and the presence of dominant hand deformities (Andrade et al. 2016; Erol et al. 2016). However, there is conflicting evidence for the association between the presence of deformities in both hands and hand function (BİRcan et al. 2014;

Belghali et al. 2017). Lastly, the results from van Lankveld et al. (1998) showed that an increase in the number of deformities in both hands, which is associated with limited hand function, was inconclusive.

- **Structural damage**

Structural damage was evaluated by a radiographic (x-ray) method and different scoring systems were used. Because these scoring systems did not assess the same joints of the hands (Boini and Guillemin 2001), only the studies which have used the same scoring system were considered for best evidence analysis. As a result, there was limited evidence that more structural damage (radiographic) scored by the modified sharp score (van der Heijde 1999) was positively associated with reduced hand function. The strength of correlation ranged from negligible (*r*=.231, *p*=.03) (Dogu et al. 2013) to high (*r*=-.72, *p*<.0001). However, Belghali et al. (2017) reported that the association between hand function and structural damage evaluated using the Sharp score was not statistically significant. Studies that used the Larsen score (Larsen et al. 1977) and the modified Larsen score (Larsen 1995) reported contradictory findings (van Lankveld et al. 1998; Birtane et al. 2008). However, these results were inconclusive.

By quantifying structural damage using MRI, Erol et al. (2016) reported a moderate correlation between a high tenosynovitis score and limited hand function (*r*=.522, *p*=.003). Furthermore, they reported that the correlation was not statistically significant between hand function and erosion score, bone oedema score and synovitis score. The strength of correlation between structural damage measured by Rheumatoid Arthritis Articular Damage (RAAD) and hand function was found to be low (*r*=.438, *p*<.001) (DedeoĞLu et al. 2013). However, these results were inconclusive.

- **Fatigue**

Conflicting evidence was found regarding the association between hand function and fatigue when measured by the SF-36 vitality subscale. Two studies reported low (*r*=−.335, *p*<.05) to moderate correlation (*r*=−.538, *p*=.0001) between hand function and fatigue (Aktekin et al. 2011; Durmus et al. 2013). However, linear regression analysis conducted by Andrade et al. (2016) showed that the association between hand function and fatigue (measured with SF-36 vitality subscale) was not statistically significant. One study explored the association between fatigue intensity, which was measured by VAS, and hand function (Andrade et al. 2016). It was reported that the correlation was not statistically significant, however, this finding is inconclusive.

- **Mental Health**

There is limited evidence regarding the association between mental health status and hand function. The strength of correlation was low (range: $r=-.423$, $p<.05$ to $r=-.468$, $p=.0001$) (Aktekin et al. 2011; Durmus et al. 2013).

- **Stiffness**

There is conflicting evidence in terms of the association between stiffness duration and hand function (Özeri et al. 2008; BİRcan et al. 2014). In addition, there is conflicting evidence regarding the association between stiffness intensity and hand function (BİRcan et al. 2014; Andrade et al. 2016).

- **Dexterity**

Andrade et al. (2016) reported that the association between dexterity and hand function was not statistically significant. However, this result is not enough to draw a conclusion.

- **Hand endurance**

A study by Kinikli et al. (2016) was the only study which assessed the association between hand endurance and hand function and reported a moderate correlation ($r=-.543$, $p=.002$). Hence, this result was considered inconclusive.

- **Functional mobility**

Studies which explored the association between functional mobility and hand function reported a positive correlation, which ranged from a moderate ($r=.51$, $p<.01$) (Eberhardt et al. 2008) to high ($r=.84$, $p<.05$) (Jonsson and Larsson 1990). However, functional mobility in these studies was evaluated using different outcome measures. Two studies were found to evaluate functional mobility using the Signals of functional impairment (SOFI); one study used the total score of the SOFI scale (DedeoĞLu et al. 2013), whilst the other only used the hand items score (Eberhardt et al. 2008). As a result, the current evidence is insufficient to confirm the strength of correlation between hand function and functional mobility.

3.4.9.2 Functional status factors

Limited evidence was found in terms of the association between hand function and the level of physical and social functioning (Table 3-12). Although all of the studies used the HAQ to evaluate general physical function, two studies (Aktekin et al. 2011; Durmus et al. 2013) used the physical functioning subscale of the SF-36 in addition to the HAQ. The strength of correlation between physical functioning and hand function ranged from low ($r=-.41$, $p=.05$) (O'Connor et al. 1999) to high ($r=.876$, $p<.001$) (DedeoĞLu et al. 2013). The social functioning subscale of the SF-36 was used to evaluate social functioning and the strength of correlation was relatively moderate. Finally, limited evidence was found regarding the association between emotional status and hand function, with the strength of correlation ranging from negligible ($r=.254$, $p=.023$) to moderate ($r=-.588$, $p<.05$) (Aktekin et al. 2011; Durmus et al. 2013).

3.4.9.3 Personal factors

There was conflicting evidence with regard to the association between age and hand function (Table 3-12). Of the seven studies that explored the association between hand function and age, three studies reported a statistically significant negative correlation, which ranged from negligible ($r=.054$, $p<.05$) (Adams et al. 2005b) to low ($r=.4$, $p<.05$) (Jonsson and Larsson 1990). In terms of hand function, seven studies reported that the difference between men and women was not statistically significant (i.e. hand function is not associated with gender). As a result, limited evidence is documented in the best-evidence synthesis. The association between hand function and pacing coping strategy (a tendency to adapt the level of physical activity when confronted with limitation) (van Lankveld et al. 1999), educational level and laterality (the preference people show for one side of their body over the other) (Belghali et al. 2017) was also not statistically significant. However, decreased activity (tendency to avoid physical activity when confronted with pain) as a coping strategy was found to be correlated ($r=-.37$, $p<.01$) with hand function (van Lankveld et al. 1999). Nevertheless, the evidence to support these results was inconclusive.

Table 3-12 Overview of findings regarding associations of functional status, personal, environmental, and health-related factors with hand function

Factors	Association found(reference)‡	No association found(reference)‡	Level of evidence
Functional status			
Physical functioning (HAQ)	Two HQ [5, 6] and five LQ [8, 9, 12, 14, 18]	One LQ [1]	Limited
Physical functioning (SF-36)	One HQ [6] and one LQ [9]		Limited
Social functioning	One HQ [6] and one LQ [9]		Limited
Emotional role	One HQ [6] and one LQ [9]		Limited
Personal factors			
Age	Three LQ [1,15, 20]	Four LQ [4, 13, (17+19) †, 18]	Conflicting
Gender		One HQ [5] and six LQ [1,4, 13, (17+19) †, 18, 20]	Limited
Environmental factors			
Work activity	Three LQ [1, 3, 4]		Limited
Health-related factors			
Disease duration	Seven LQ [1, 8, 11, 15, (17+19) †, 18, 20]	Two HQ [5, 10] and two LQ [4, 13]	Conflicting
Rheumatoid factor (RF)		Three LQ [1, 3, 8]	Limited
General state of health	One HQ [6] and one LQ [9]	One LQ [4]	Conflicting

HAQ: Health Assessment Questionnaire; HQ:High Quality; LQ:Low Quality. ‡: The reference number in these tables corresponds to the number given to each study in Table 3-10. †:Study 17 (van Lankveld et al. 1999) and 19 (van Lankveld et al. 1998) were considered as one body of evidence, since both studies reported the findings from the same sample of RA patients with regard to the association between SODA and disease duration, age and gender

3.4.9.4 Environmental factors

Limited evidence was found that hand function is not associated with work activity (Table 3-12), as only three studies reported that the association between work activities (type of employment or job) and hand function was not statistically significant (Andrade et al. 2016; Erol et al. 2016; Belghali et al. 2017). The association between hand function and treatment cost (Jonsson and Larsson 1990), work situation (Andrade et al. 2016), living condition and medical treatment by symptomatic and conventional DMARDs (Belghali et al. 2017) was also not statistically significant. The number of days spent in hospital (Jonsson and Larsson 1990), hand specific treatments and biological treatment were found to be associated with hand function (Belghali et al. 2017). However, these results were insufficient to draw conclusions.

3.4.9.5 Health-related factors

There was conflicting evidence regarding the association between hand function and disease duration and general health status (Table 3-12). Of the eleven studies which assessed the association between disease duration and hand function, seven studies reported a statistically significant negative correlation which ranged from negligible (r=.091, p<.05) (Adams et al. 2005b) to moderate (r=.604, p<.01) (Özeri et al. 2008). Three studies assessed the association between overall health status and hand function (Aktekin et al. 2011; Durmus et al. 2013; Andrade et al. 2016). Only the study by Andrade et al. (2016) reported that the correlation was not statistically significant. Three studies reported that the association between Rheumatoid factor (RF) and hand function was not statistically significant (DedeoĞLu et al. 2013; Erol et al. 2016; Belghali et al. 2017), consequently, limited evidence is reported in the best-evidence synthesis. The association between hand function and extra-articular manifestations (Belghali et al. 2017) and ACR functional classification (Andrade et al. 2016) was not statistically significant. However, the evidence to support these results was inconclusive.

3.5 Discussion

3.5.1 Overview of the studies

To the best of the research team's knowledge, this is the first systematic review that has provided an overview of factors associated with limited hand function in people with RA. After a systematic search, twenty published articles were critically reviewed, and common factors associated with limited hand function were compiled into a best-evidence synthesis. The studies included used either self-reported and performance-based measures of hand function, or both. This probably influenced the results of this review, since, performance-based measures cover a narrow spectrum of hand function and may not reflect hand abilities accurately (Stamm et al. 2004b). Furthermore, performance-based and self-reported measures of hand function are not strongly associated (Rallon and Chen 2008). Therefore, more studies need to be performed into hand function in people with RA using standardised measures of hand function, preferably, self-reported measures. However, currently available outcome measures for hand function lack psychometric testing and vary in feasibility, validity, reliability and responsiveness (Poole 2011). Consequently, no specific instrument can be recommended to measure hand function in rheumatic hand conditions (Klokker et al. 2016).

From reviewing the literature, it is evident that there is a lack of consistency in measures used in reporting hand impairments, leading to a limited ability to make comparisons between the studies. For instance, measuring and reporting ROM was inconsistent between the studies included, and the majority of the studies did not provide a clear description of what was being measured (i.e. active or passive ROM). In addition, there were deficiencies associated with hand impairment outcome measurements, such as reporting hand deformities without details about the assessment or grading methods. Based on these observations, the present review calls for the development and adherence to protocols when making assessments of hand impairments in the RA population. Furthermore, agreed consistency in reporting hand function is also now required. In this regard, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendations, which provide guidance to authors on how to improve reporting of observational studies (von Elm et al. 2007), can help to improve the quality of reports of observational studies investigating hand function in people with RA. Separately reporting data for both the dominant and non-dominant hands will allow a comparison of results between studies, and subsequently contribute towards resolving disputes regarding the impact of RA on the dominant and non-dominant hand.

The marked variation in the quality of reporting within the included studies resulted in the need to apply best-evidence synthesis to provide a summary and conclusion. It is worth noting that evidence for such associations is based on a relatively small number of cross-sectional studies for the majority of factors, making conclusions tentative. This is because most of the included studies (75%) are of low methodological quality and have a small sample size. Additionally, this may make the synthesis of evidence susceptible to change with the addition or deletion of articles from the analysis, since, the number of studies affects the strength of the evidence. However, all of the studies in the present review are cross-sectional, consequently only limited evidence of associations between the factors and hand function could be reported. Since cross-sectional study designs form the lowest level evidence according to the ranking system of the best-evidence synthesis, the relative importance of this point of the review results is negligible.

The consequence of the limited and conflicting level of evidence of associations reported in the present review imply that further high-quality cohort studies with a large sample size are needed, so that the strength of association can be determined, rather than relying on a few studies as the evidence base. In future, well-designed longitudinal, preferably cohort studies, will allow for a more conclusive understanding of the relationship between hand function and different disease, personal, and environmental factors over time.

In evaluating the studies identified in this review, it was observed that there were no consistent trends in relation to the strength or significance of associations between hand function measures and the factors assessed. However, this review was limited by the wide variation in the included study’s sample size (range: *n*=25 to 200) and statistical analysis, as well as the hand function assessments used across the studies, making comparisons difficult and possibly impacting upon the strength of the associations reported. This is due to the fact that sample size is a major determinant of the risk of reporting false-negative findings (Type II error) (Jones et al. 2003; Biau et al. 2008). Accordingly, sample size may have affected the results of associations reported in the included studies, since small associations are significant in studies with a large sample size and not in studies with a small sample size. In this case, the impact of using different statistical methods means that not all studies presented the size of the association (i.e. presented only the P-value or mean values of hand function for different groups); consequently, it is difficult to preclude that the results of the present review are biased as a result of this.

The potential impact of the quality of the studies included on the current findings was addressed by assessing the quality of the reporting and risk of bias. Although the quality of the reporting was satisfactory for the majority of the studies identified in this review, almost all of the studies failed to account for and minimise systematic errors (i.e. biases). The results in Table 3-10 suggest that any conclusions from this review could be at risk of bias, due to the weaknesses in the studies included. Improving the selection and reporting of the study participants, especially the response rates and information about non-respondents would address these biases and should be incorporated into future research.

Finally, attention should be given to the disagreement (27% and 19%) between the reviewers regarding the methodological quality of the study. This disagreement may have been reflected in the quality of reporting of the studies, as discussed above, which may have led to differences in the interpretation of the methodological criteria. Furthermore, the extensive scoring ability that the AXIS tools provides may have influenced the interpretation. Reducing the scoring options to “yes” and “no, and not including “don't know”, may increase the simplicity of use of the AXIS and may minimise the disagreements between reviewers. Lastly, it is important to note that the use of consensus meetings to debate and resolve disagreements was an integral part of this review.

3.5.2 Findings

3.5.2.1 Body function and structure factors

The results of this review showed that many factors related to body function and structure were significantly associated with limited hand function. Grip strength is routinely recorded in rheumatology clinical trials as a valuable indicator of disability (Lillegraven and Kvien 2007; Toussirot 2010), and has been shown to predict later hand function (Bjork et al. 2007) and to substantially contribute to hand function improvements (Hall et al. 2017) in people with RA. In this review, more than half of the included studies assessed the association between power grip strength and hand function, and all of them reported statistically significant relationships, regardless of the measurement or reporting method. This confirms what has been suggested previously, specifically, that power grip strength is a reliable indicator of hand function in the RA population, therefore clinicians can have confidence in this finding, which is consistently reported in high-quality studies. The literature review by Helen et al. (2005) reached a similar conclusion, that is to say, that power grip strength can provide an accurate guide to hand function in different populations. Although scholars have attempted to develop normative power grip strength data for people with RA (Fraser et al. 1999), there is no consensus regarding the normative power grip strength in the RA population, and a bilateral handgrip ratio did not reflect the values for healthy norms (Adams et al. 2005a). In addition, the threshold levels for grip strength, below which hand function becomes limited, are not known (Helen et al. 2005).

Unlike power grip strength, fewer studies have supported the association between pinch strength measures and hand function. Additionally, two studies, which were not included in the best evidence synthesis, reported no association between hand function and tip pinch (Andrade et al. 2016) and lateral pinch strength (Özeri et al. 2008) was not statistically significant. However, these studies did not report how tip pinch strength and lateral pinch were measured nor how many trials were used to ascertain the outcome score. The evidence suggests that the number of trials and variation of forearm positions affect the outcome score of tip pinch and lateral pinch strength and, as such, are a critical component of accurate strength measurement in research (Stegink Jansen et al. 2003). Consequently, the measurement method of pinch strengths may have affected the results of these studies.

Two studies in this review found that limited hand function was associated with greater finger flexion deficit of the dominant hand (O'Connor et al. 1999; BİRcan et al. 2014). The same studies also found no association with finger flexion deficit of the non-dominant hand. Similar to these results, wrist flexion-extension ROM of the dominant hand was found to be associated with hand function, but not non-dominant hand wrist flexion-extension ROM (Adams et al. 2004). Similar to the results related to ROM measurements, the presence of deformities in the dominant hand was associated with limited hand function. A possible explanation for these observations could be that the dominant hand may be more severely affected than the non-dominant hand (Adams et al. 2004; Adams et al. 2005a; Ebru et al. 2013; Koh et al. 2015), and hand dominance has a substantial effect on hand function (Hodges and Adams 2007). However, there is debate regarding the importance and relevance of dominance in the development of hand impairments (Mody et al. 1989; Eberhardt et al. 1991; Adams et al. 2005a; Ebru et al. 2013).

The results of the association between the presence of deformities in both hands and hand function have been contradictory (BİRcan et al. 2014; Belghali et al. 2017). Differences between studies concerning patients' characteristics, sample size, assessments of hand function and methods used to identify hand deformities may explain the contradictory findings. Importantly, the methods used to identify hand deformities were not reported, so the validity of these methods is questionable. Furthermore, limited evidence was found regarding the association between hand function and ulnar deviation of both the dominant and non-dominant hand. However, before applying the best evidence synthesis, contradictory findings within and between studies were observed regarding the association between hand function and the presence of deformities. For instance, Adams et al. (2004) found a significant association between dominant and non-dominant hand ulnar deviation and the GAT, but not with the DASH. O'Connor et al. (1999) study reported an association with the GAT, but not with the SHFT; whereas Sahin et al. (2006) found a significant association between the SHFT and the dominant hand ulnar deviation. These results, in part, may exemplify how the choice of hand function assessment can influence the results. Stamm et al. (2004b) stated that hand function assessment tools place different emphases on their measurements. However, these studies are not statistically powered (statistical power is related to the ability of a study to detect a difference if a difference really exists); thus, the results are susceptible to type II errors during analysis (Jones et al. 2003; Biau et al. 2008).

Disease activity variables have been found to be associated with hand function except in the cases of ESR and swollen joint count, which were found to provide conflicting evidence. An explanation for this observation may be that different hand function assessment tools cover different spectrums of functioning (Stamm et al. 2004b), and people with RA show unique and different clinical presentations; thus, no single disease activity variable can accurately mirror every patient's disease activity at any given point in time (Salomon-Escoto et al. 2011). For example, high disease activity measured by DAS-28 was associated with limited hand function; however, one study reported no association (Eberhardt et al. 2008). The authors of this study considered that this might have been a result of the fact their sample included those with severe hand dysfunction. A similar study which evaluated hand function using the same hand function performance-based measure documented low correlation (BİRcan et al. 2014). Simply put, performance-based measures usually register the time to complete the tasks and ignore hand impairments and compensatory movements if they do not affect the time needed to complete the task (Adams et al. 2005a; Goodson et al. 2007). In this way, changes in disease severity may not influence the level of hand function (Fowler and Nicol 2001). Consistent with recent reports which have explored the association between disease activity and activity limitations in RA patients (Ji et al. 2017; Karpouzas et al. 2017), this review’s results suggest that disease activity as a modifiable parameter significantly contributes to hand function.

Although the disease activity measured by the DAS-28 was found to be significantly associated with hand function, the strength of the correlation was not consistent between the studies, as it ranged from low to moderate. As previously highlighted, variations in the studies identified in this review may have influenced these studies’ results. However, inconsistent trends/findings in relation to the strength of association may indicate that estimating hand function based on disease activity may not be clinically useful. Indeed, evidence from RA longitudinal studies have demonstrated that functional disability (Seto et al. 2013) and hand functional impairments (Toyama et al. 2014) can deteriorate despite the controlling and suppression of disease activity. However, there is also evidence that RA hand function assessments are more sensitive to improvements due to treatment, more than other clinical measures (Eberhardt et al. 2008). Therefore, the assessment of hand function may add important information to evaluations done with traditional assessment methods.

Pain in RA is the main treatment target for patients and clinicians (van Tuyl et al. 2017), and the most important modifiable symptom that is addressed, due to its prevalence and impact. The results from RA cohort studies conducted during an era when biological treatments were available demonstrated that pain still remains a problem and influences the performance of valued life activities (Ahlstrand et al.

2015; Thyberg et al. 2016). In the present review, limited evidence was found that a higher intensity of general pain and hand pain during an activity is associated with limited hand function, and conflicting evidence was found regarding the association with hand pain at rest. This indicates that hand pain during activity may substantially contribute to limited hand function. In line with these results, a recent longitudinal report on a Swedish RA cohort study indicated that general pain was higher than hand pain during activity, which in turn was higher than hand pain at rest (Thyberg et al. 2016). The authors considered that higher levels of hand pain during activity than at rest may explain on-going hand related activity limitations. Interestingly, the evidence was conflicting in terms of the association between hand function and hand pain during activity measured by the sum of the painful tasks from the SODA tasks. O'Connor et al. (1999) stated that RA patients may learn to live and function despite on-going pain, which might explain why the sum of painful tasks from the SODA tasks was not significantly associated with hand function. Another explanation for this finding could be the fact that a patient’s interpretation of pain changes over time if they have chronic musculoskeletal pain (Damsgard et al. 2011). For that reason, patients’ interpretations of pain during SODA tasks may have influenced the results.

The reviewed studies indicate a link between structural damage and hand function, and that an increase in radiographic joint damage is associated with an increase in hand functional limitations. This result aligns with the review articles (van der Heijde 2001; Hazes 2003; Scott et al. 2003; Bombardier et al. 2012) and recent cohort studies (Navarro-Compan et al. 2015; Gherghe et al. 2016), that radiographic joint damage accounts for much more activity limitation, and that this association is strong in later RA. However, when considering the whole body of evidence, regardless of the method used for quantifying radiographic joint damage, the level of evidence was found to be conflicting. This suggests how the choice of radiographic outcome measure for hands can influence the results. Therefore, it was reasonable to consider the method used for quantifying radiographic joint damage for the best evidence analysis to obtain robust results. Although radiographic joint damage was found to negatively affect hand function, the relative importance of structural damage may be of little meaning in future research. This is because a recent report of two cohort studies in the UK demonstrated that radiographic joint damage has diminished in the context of modern treatment (Carpenter et al. 2017).

The fact that conflicting evidence was found regarding the association between hand function and stiffness duration and intensity is remarkable, since, stiffness is a symptom widely experienced by patients with RA, and has considerable effects on daily life, work performance and quality of life (da Silva et al. 2011; Phillips and Dow 2012; Mattila et al. 2014). Indeed, a long duration of stiffness was found to be associated with greater activity limitation (Schneeberger et al. 2010). The Dellhag and Burckhardt (1995) study, which was conducted during the pre-biological era and recruited participants diagnosed according to seropositive criteria, found that a high stiffness intensity was associated with limited hand function. Aside from the methodological explanations (i.e. only cross-sectional studies with relatively small sample sizes were included), the methods used to measure stiffness may explain the conflicting evidence found. Although there are no standardised measures of stiffness (Cutolo 2011; van Tuyl et al. 2014), methodological details about the approaches used to this were not clear in the included studies. Evidence from a systematic review of stiffness measures demonstrated that there is limited evidence to support the validity of the currently available stiffness measures (van Tuyl et al. 2014). Furthermore, qualitative evidence suggested that RA patients experience stiffness differently, and reported stiffness in terms of impact rather than in terms of duration or severity (Orbai et al. 2014; Halls et al. 2015). As a result, progress has been made to develop an outcome measure to evaluate stiffness impact (Orbai et al. 2014; Halls et al. 2015).

Regarding fatigue, conflicting evidence was found regarding its association with hand function. One low quality study (Andrade et al. 2016) did not find an association, whereas two other low quality studies did identify an association between them (Aktekin et al. 2011; Durmus et al. 2013). This can perhaps be explained by the relatively low number of participants (n=81) in relation to the type of analysis (i.e. linear regression) used in this study. Although there is debate about the sample size required for linear regression analysis (Austin and Steyerberg 2015), this study used a fixed sample size, without considering the number of independent variables (n=18) which may have impacted upon these results. In contrast to this study, Kuhlow et al. (2010) conducted linear regression analysis with a larger sample size (n=239), and found that fatigue was strongly associated with activity limitation when assessing RA patients using HAQ. Fransen et al. (2002) reported a moderate association ($r=-.52$, $p<.0001$) between fatigue assessed using the SF-36 and activity limitations assessed using the MHQ. To sum up, fatigue may influence hand function in people with RA, but even tentative conclusions cannot be drawn from the included studies.

Finally, mental health assessed using the SF-36 was found to be associated with hand function in the included studies. A systematic review and meta-analysis regarding the impact of RA on quality of life and assessed by the SF-36 reported that a reduced mental health status is prevalent in those with RA, and found to be substantially reduced in comparison to other physical illnesses and the general population (Matcham et al. 2014). However, studies which have explored the association between mental health, using the SF-36 assessment, and activity limitations, assessed using HAQ, reported dissimilar results. For instance, Fransen et al. (2002) reported that poor mental health was associated ($r=-.30$, $p<.0001$) with a greater level of activity limitations. Conversely, Kuhlow et al. (2010) found no association between mental health and activity limitations. Differences in sample size, analysis procedure and patients' characteristics may have influenced these studies' results. Although these studies reported dissimilar results, in the context of modern treatment, psychosocial variables such as mental health appear to dominate the prediction of activity limitations more than traditional measures such as disease activity (Kronisch et al. 2016). Since the included studies did not emphasise psychosocial variables as being factors for hand function, it is suggested that these amendable factors deserve more consideration in future research.

3.5.2.2 Functional status

In terms of functional status, there was limited evidence that reduced hand function is associated with poor physical function, social function and emotional role. Although functioning in the ICF is a very broad concept, the association found between hand function and functional status measures emphasises the effect of hand disability on both low and high levels of functioning. This is simply because physical function measures such as HAQ measure activity limitations (low level), whereas social functioning and emotional role scales measure participation restrictions (high level) (Stucki and Cieza 2004). The strength of association between hand function measures and physical function assessed by the HAQ was better than that between hand function measures and the SF-36. This is due to the fact that, out of the 20 questions in the HAQ, 12 are upper limb and hand specific questions, whereas the SF-36 questions focus on generic physical health functioning. Another reason may be related to the ability to score the HAQ using two different approaches (the first approach considers the use of aids and devices, and the second approach does not) (Bruce and Fries 2003). However, inconsistent trends in relation to the strength of association between hand function and functional status measures may indicate that general measures of activity limitations and participation restrictions are not sensitive enough to accurately represent hand function in day-to-day tasks. Therefore, hand related activity limitations should be evaluated using tools specifically designed to evaluate hand function in the RA population. In addition, participation outcomes in relation to hand use must be assessed and not predicted implicitly from other levels of assessments. To the author’s knowledge, no reviews have recognised any instruments that assess RA patients’ participation in relation to hand-use difficulties. Therefore, generic participation outcome measures might be of great value for RA patients.

3.5.2.3 Personal factors

Personal factors have been defined as internal factors that determine functioning, as well as individuals’ experiences of disability (WHO 2001). In RA, there is evidence that personal factors have a major effect on everyday activities (Stamm et al. 2010; Nicklasson and Jonsson 2012; Ahlstrand et al. 2016). In this review, few personal factors were explored in terms of their association with hand function. Unfortunately, out of 12 personal factors identified as meaningful for general functioning in RA (Dur et al. 2015), only coping was included as a factor for hand function in one study (van Lankveld et al. 1999); thus, it was not included in the best evidence synthesis. Although scholars have called for exploration into the association of personal factors such as self-efficacy and illness perception, as they have the potential to explain activity limitations and participation restrictions with people with RA (Kuhlow et al. 2010), important personal factors in relation to specific hand function outcome have not been identified. Consequently, important personal factors in relation to specific hand function outcomes should be identified. This is because, by identifying the role of these factors as determinants and modifiers of hand function, it is then possible to facilitate the process when evaluating and planning interventions for people with RA.

In this review, conflicting evidence was found regarding the association between hand function and age. This can be partly explained by the fact that the influence of aging on hand functional abilities was not considered by the included studies. The evidence suggested that hand function decreases in both men and women after the age of 65 years (Carmeli et al. 2003; Metcalf et al. 2008). The age ranges of participants in the studies that reported an association between age and hand function was higher than those studies that reported no association (upper age limit 79.2 years, 68.21 years, respectively). As a result, the significant association reported between age and hand function may be related to the natural decline in hand function. However, other factors related to the characteristics of the included studies may have influenced these findings.

Limited evidence was found that gender is not related to hand function. Since, women with RA report more pain, tend to have weaker muscle strength, and have more pronounced activity limitations compared to men, as assessed by the HAQ (Thyberg et al. 2005; Bjork et al. 2006; Häkkinen et al. 2006; Bjork et al. 2007; Thyberg et al. 2016), one may expect women to have lower hand function levels when compared to men. However, the fact that no association was found between hand function and gender can be explained by a number of different reasons. Firstly, it has been argued that hand function depends on the individual’s ability to develop and use compensatory movements (McPhee 1987). Consequently, women with RA may use different strategies to accomplish daily hand activities. Secondly, women with RA have significantly greater functional mobility (measured using performance-based measure-SOFI) compared to men (Thyberg et al. 2005; Bjork et al. 2006; Bjork et al. 2007). Therefore, women with RA may benefit from this range of motion to accomplish their daily hand activities. Thirdly, grip strength forms just part of a minority of daily hand activities (Adams et al. 2004), and activities which require substantial hand strength may not be represented in both self-reported and performance-based measures of hand function. Fourthly, it has been argued that women with RA perform more activities that require hand use compared to men, and that would explain gender differences in pain (Thyberg et al. 2016). Finally, because functional abilities assessed by the HAQ require strong hands, women with RA may report more disability when measure using this instrument (Thyberg et al. 2005).

3.5.2.4 Environmental factors

The qualitative evidence has suggested that environmental factors play a significant role in hand related activity limitations and participation restriction for RA patients (Nicklasson and Jonsson 2012). Importantly, the social environment of those with RA was found to influence their engagement in daily life occupations and activities (Nyman and Lund 2007; Schneider et al. 2008). However, the relative importance and influence of environmental factors might vary according to the settings and culture. For instance, low-income countries such as those in the Middle East tend to have limited or fewer resources in term of the healthcare system, compared with high-income countries such as the UK. Moreover, social support and beliefs about health and disability may differ across countries. Consequently, environmental factors may differ in the extent to which they increase or decrease the impact on hand function in people with RA. Considering these issues, important environmental factors in relation to hand function outcomes in specific cultures and settings should be identified. This is highly important when evaluating and planning intervention for RA patients with pronounced hand function problems.

Similarly, when considering personal factors, the impact of very few environmental factors has been explored in relation to hand function. In this review, only one factor; namely work activity, was included in the best evidence synthesis, since it was assessed in three independent studies (Andrade et al. 2016; Erol et al. 2016; Belghali et al. 2017). In addition, there was limited evidence indicating that there is no association between work activity and hand function. In alignment with this finding, the evidence from rheumatology research has demonstrated that work activity is not associated with activity limitations when assessed using the HAQ (Kuhlow et al. 2010). However, in this review there was a limited focus on the effect of environmental factors on hand function in the RA population.

3.5.2.5 Health related factors

In terms of health-related factors, conflicting evidence was found regarding the relationship between poor hand function and long disease duration and poor general health status. Long disease duration was expected to be significantly associated with poor hand function, since, hand impairments are prevalent and deteriorate over time in patients with a long disease duration (Horsten et al. 2010; Toyama et al. 2014). In addition to the limitations mentioned earlier concerning the methodologies of the included studies, a possible explanation for this finding may be related to the fact that patients who have experienced a disease for a long period may have adapted to their situation and do not expect any effective treatment to be readily available (Horsten et al. 2010). It has been argued that disease duration may reflect functional statuses related to psychological and social factors that accumulate over time (Palamar et al. 2017). Moreover, in RA, a disease duration of less than 10 years may be meaningless in relation to hand function, and to date, this has not yet been explored or reported on. Cross-sectional studies have concluded that disease activity is the major explanatory factor regarding activity limitations in RA patients with a disease duration of less than 10 years (Toussirot 2010). Accordingly, disease duration may be an irrelevant factor to consider when evaluating hand function, particularly with a disease duration of less than 10 years.

The conflicting evidence found with regard to the association between hand function and general health status was not expected, since activity limitations assessed using the HAQ and general health status assessed using the SF-36 were found to be linked (Hodkinson et al. 2012). Only one study (Andrade et al. 2016) reported no association between hand function and general health status, and this study has methodological flaws (see section 3.4.5). Finally, limited evidence has been found that the RF is not associated with hand function, because the RF can occur in other autoimmune conditions and chronic infection and has a moderate sensitivity (Nishimura et al. 2007), which perhaps explains the findings of this review. Additionally, Carpenter et al. (2017) argued that, in the context of modern treatment, using the RF factor as a clinical marker has little ability to reflect meaningful clinical changes.

3.6 Strength and limitations of the review

A major strength of this review was the use of a comprehensive and inclusive search strategy to minimise the possibility of missing key publications. This was attained by searching many healthcare databases and tailoring the search strategy to each databases' indexing method. Another strength of the review is its use of a comprehensive and predefined system to evaluate the quality of evidence.

However, this review is not without limitations. Firstly, the included studies exhibited marked heterogeneity in terms of outcome measures, factors examined for association with hand function and substantial differences in the reporting of results. This is coupled with the fact that the majority of the included studies were cross-sectional and had a poor methodological quality (average quality 49.5%). Therefore, it cannot be precluded that these shortcomings may have influenced the findings of the present review. Secondly, only the researcher (i.e. one reviewer) screened the titles and abstracts. However, the citations were only considered irrelevant if the title or abstract did not include any information on hand function outcomes. Moreover, the supervisory team (i.e. review team) were consulted where any ambiguity arose during the selection process. Therefore, the possibility of relevant studies having been removed by mistake is low. Thirdly, although the quality assessment tool (AXIS) used in this review was developed based on literature and methodological standards, there is currently limited evidence to support its validity and reliability. However, in the context of observational studies, no agreed “gold standard” quality assessment tool is currently available, and the majority of the quality assessment tools used for observational studies were not developed using specified empirical research, and have limited validity and reliability evidence (Shamliyan et al. 2012). Moreover, the majority of the tools available are not applicable to cross-sectional studies (Katrak et al. 2004; Sanderson et al. 2007; Jarde et al. 2012). In the present review, 75% of articles adopted a cross-sectional design and the remainder presented cross-sectional data; thus, it was reasonable and justifiable to evaluate the methodological quality of the included studies using a tool specifically designed for cross-sectional studies. Finally, searching the grey literature or unpublished studies was not done. Still, it has been argued that there are few studies focusing on hand function in RA patients (Belghali et al. 2017; Palamar et al. 2017); therefore, the number of extra studies that could potentially be identified in grey literature would also be small. In addition, only studies written in English were selected and included in the review. Yet, during the electronic search, the percentage of all of the articles written in other languages was small (8%), consequently, it is unlikely that this percentage would introduce a language bias to the review.

3.7 Chapter summary

This study has summarised the current evidence regarding the factors associated with hand function in RA patients. It has also underlined areas where the methodology is lacking and highlighted potential directions for future research.

There are numerous factors where the current evidence is limited or conflicting. They provide a direction for future research, which should be undertaken using valid and reliable methods of assessment. These factors can be classified as modifiable (e.g. disease activity, hand strength, psychosocial factors) and non-modifiable factors (e.g. age, sex, structural damage). However, focusing on non-modifiable factors offers little added value to improving hand function in people with RA. Therefore, modifiable factors should be of key concern, as some of these factors can be identified and modified by both health professionals and patients using specific strategies and interventions. The results of this review suggest that power grip strength, disease activity and pain are modifiable factors that may have a considerable effect on hand function in people with RA. However, studies have paid little attention to exploring the influence of personal and environmental factors on hand function. Considering the non-modifiable factors, it is unlikely that gender plays an important role in influencing hand function in RA patients. However, because of the cross-sectional design of the studies included in this review, causality between factors and hand function cannot be determined. Before new strategies and interventions are established to improve hand function in people with RA, well-designed longitudinal studies need to be performed to improve the understanding of the influence of factors on hand function. Lastly, important personal and environmental factors in relation to hand function in RA patients need more consideration in future research.

The findings of this review informed the subsequent investigation and underpin this thesis in several ways. Inconsistences and variations between the identified studies, with regard to the measures and reporting of hand function outcomes, highlighted the need to define “what to measure” when evaluating hand function in Palestinian people with RA. Reviewing the literature systematically also confirmed that the current evidence is insufficient to advise on the environmental and personal factors that might influence hand function.

This systematic review, along with the literature review (Chapter 2), has helped to lay the foundations for the thesis. These reviews have provided the background literature, research problem and justification of the study. Based on these foundations, the report can proceed with a detailed description of the research methodology, which is presented in the next chapter (Chapter 4).

Chapter 4 Methodology and methods

4.1 Chapter overview

This chapter provides a general overview of the common paradigms in health research and a more detailed description of the paradigm chosen for this thesis. The paradigm description is followed by a discussion regarding the research design and methodology. The rationale for adopting a mixed methods approach is discussed and a detailed justification offered with regard to the choice of an exploratory sequential design. The strengths and limitations of the research design are discussed, followed by the measures taken to establish the PhD study's validity and rigour. The chapter concludes with the outlining of the individual study phases conducted within this PhD.

4.2 Restatement of the research aims

The main aims of this thesis were to:

1) To explore and identify the concepts of hand function important for Palestinian people with RA.
2) To examine hand function and the related variables among Palestinians with RA.

4.3 Traditional research paradigms and mixed methods

When conducting research, researchers are advised to position their research in a selected paradigm that is compatible with their beliefs about the nature of reality and how to create knowledge (Doyle et al. 2009). This is because the choice of a particular research paradigm influences the subsequent methods used for data collection and analysis (Morgan 2007). The term paradigm has been defined as "a basic set of beliefs that guide action" (Denzin and Lincoln 2018). Several other sources have defined paradigm, and most of them have considered it to be the researcher's worldview (Morgan 2007; Creswell and Plano Clark 2018). However, a research paradigm can also be viewed as a guide that researchers can use to ground their research (Shannon-Baker 2016). Research paradigms have three basic distinct philosophical elements, namely ontology, epistemology and methodology. While ontology refers to the nature of reality (how a researcher views the nature of reality), epistemology deals with the nature of knowledge (the researcher's approach to knowledge generation). Methodology on the other hand refers to the process of conducting the research (the researcher's research strategy) and is distinct from research method, which refers to the specific techniques or tools used to collect and analyse the data (Creswell and Plano Clark 2018; Lincoln et al. 2018).

Traditionally, health researchers have been divided between a positivist scientific model of research (quantitative) and the interpretative or constructivist scientific model (qualitative) (Broom and Willis 2007). These two dominant research paradigms have resulted in two research cultures, one acknowledges the advantage of "deep, rich observational data", while the other accepts "hard, generalisable data" (Johnson and Onwuegbuzie 2004). It is understood that qualitative and quantitative approaches represent incompatible paradigms, due to the fact they are underpinned by different ontological and epistemological standpoints regarding knowledge. The positivist paradigm takes realism as its ontological stance, assuming that there is a single external reality. From the epistemological view, positivism assumes that knowledge is objective, quantifiable, and independent of the researcher. Therefore, researchers adopting the positivist paradigm attempt to put aside their personal beliefs of the phenomena under investigation in an attempt to avoid bias (Doyle et al. 2009). To achieve this, positivism researchers tend to favour deductive quantitative approaches (e.g. randomised control trials), which often include the statistical testing of hypotheses. As a result, positivism methodology is concerned with how variables interrelate, shape events and cause outcomes (Creswell and Plano Clark 2018).

The constructivist-interpretivism paradigm, however, rejects positivist assumptions. An interpretivist-constructivist paradigm has a relativist ontology in which there are multiple socially constructed realities (Krauss 2005; Finlay and Ballinger 2006; Lincoln et al. 2018). In other words, they believe that reality consists of people's subjective experiences of the external world (Creswell and Plano Clark 2018). Epistemologically, interpretivists believe that it is difficult to fully differentiate causes and effects, or separate the investigator from the study, as they consider this to be the main source of reality that is presented (Johnson and Onwuegbuzie 2004). Researchers who adopt a constructivist-interpretivism paradigm tend to use qualitative methods such as in-depth interviews, focus groups and ethnographic observations. Interpretative research is about subjectivity, which adds a rich and comprehensive description of the phenomena under investigation (Broom and Willis 2007).

As has been described earlier, the principal intention of this research was to explore the concepts of hand function important for Palestinian people with RA and to examine hand function and its related variables among this population. These aims could not be fully attained if either quantitative or qualitative methods had been used alone. Therefore, the paradigms that support the use of a single approach, such as positivism and interpretivism were not considered as options. Therefore, it was decided that a mixed methods design would be adopted.

A mixed methods approach involves the use of different methods of data collection, and analysis strategies during different phases of the research. It also requires a paradigm, which allows the adoption of a set of philosophical stances from other paradigms. One of the paradigms which allows such flexibility is pragmatism (Johnson and Onwuegbuzie 2004). Although philosophical stances such as critical realism and transformative perspective are appropriate philosophical stances to consider when combining qualitative and quantitative data in a single study, these paradigms provide little practical guidance in regards to combining qualitative and quantitative data (Shannon-Baker 2016). Therefore, of all the options deliberated, pragmatism was found to be the best fit. To provide support for the validity of this decision, it is important to note that pragmatism has been largely acknowledged to be the dominant philosophy for mixed methods research (Denscombe 2008; Shannon-Baker 2016; Creswell and Plano Clark 2018). For example, Tashakkori and Teddlie (2003) linked pragmatism and mixed methods research in the following points:

- Qualitative and quantitative approaches can be used in a single study and an absolute choice between positivism or constructivism should be discarded
- The research question should be of primary importance more than the method or philosophical stances
- The use of metaphysical concepts of “truth” and “reality” should be abandoned

Pragmatism is also underpinned by the practicality of research, as it enables a researcher to freely choose workable methods that are most appropriate for the purpose of the research rather than being driven by an epistemological or ontological standpoint (Tashakkori and Teddlie 2003; Johnson and Onwuegbuzie 2004; Morgan 2007). Since this thesis is driven by specific research questions and outcomes, freedom in relation to the choice of methods was vital in the planning of each study. As a result, the researcher's position for this research is based on pragmatism. Explicitly, a mixed methods approach was crucial for this research and a philosophical foundation of pragmatism fits well with such an approach (Johnson and Onwuegbuzie 2004; Creswell et al. 2011; Shannon-Baker 2016).

4.3.1 Definition and core characteristics of mixed methods research

Several definitions of mixed methods have been proposed that incorporate different research methods, processes, purpose and philosophical elements (Johnson et al. 2007). Shannon-Baker (2016) defined mixed methods as "a type of inquiry that is philosophically grounded where an intentional mixture of both qualitative and quantitative approaches is used in a single research study". However, there is inconsistency in the literature about exactly what constitutes mixed methods research (Johnson et al. 2007; Doyle et al. 2009; Creswell and Plano Clark 2018). Denscombe (2008) suggested that the core characteristics of mixed methods include:

- Qualitative and quantitative methods within the same research project
- A research design that clearly specifies the sequencing and priority given to the qualitative and quantitative data
- A clear account of how the qualitative and quantitative aspects of the research relate to each other
- Pragmatism as the philosophical underpinning of the research project

4.3.2 Rationale for a mixed methods approach to the current research

The importance of providing a justification for combining quantitative and qualitative approaches within a study has been increasingly highlighted within the literature on mixed methods research. Indeed, authors in the mixed methods research field have enumerated many reasons or rationales for using mixed methods (Bryman 2006;

Doyle et al. 2016). The most commonly identified rationales for mixed methods studies, according to Greene et al. (1989), are presented in Table 4-1.

Table 4-1 Rationales for mixed methods research (Greene et al. 1989)

Rationale	Description
Triangulation	Using quantitative and qualitative methods with the intention of corroborating findings.
Expansion	When there is a need to provide a complete understanding of a research problem. This is usually used when an initial phase provides insufficient or unexplained results.
Development	Using the findings from the initial phase to inform the development of the second phase. This is used to develop instruments or identify unknown variables and requires conducting the two components of mixed methods one after another.
Complementarity	Provides clarification, enhancement or illustration of findings from one method with the findings of another method more comprehensive account of phenomena under study.
Initiation	Discovering paradoxes and contradictions that lead to a re-framing of the research question.

Apart from the suitability of mixed methods to address the aims of this research, the rationale for utilising a mixed methods approach within this study is that of an exploratory (development) and complementary purpose. In this case, the literature review facilitated the exploration of the nature of knowledge and helped to shape the design of the study. Indeed, the initial literature review (Chapter 2) indicated that there were no published data regarding the hand function of Palestinian people with RA, as well as uncertainty regarding the appropriate hand function outcome measures to be used in general, and more importantly, specifically within the Palestinian context. Furthermore, the systematic review (Chapter 3) indicated that there is a lack of evidence regarding the environmental and personal factors influencing hand function in the RA population. This is coupled with the fact that there no qualitative study had explicitly been designed to explore and identify these factors in relation to hand function among RA patients. This lack of information limited the appropriateness of a primarily quantitative approach, since in these situations, it has been recommended to first explore qualitatively to learn what variables and concepts need to be studied and then follow up with a quantitative study to test what was learned from the exploration phase (Creswell and Plano Clark 2018). Greene et al. (1989) labelled this process as “development”, because the results obtained from one method inform another method, specifically when there is a need to make measurement decisions. The qualitative phase of this study revealed a number of personal and environmental factors influencing hand functional disability, and the relative influence of each factor was determined in the subsequent quantitative phase. Given the above considerations, a mixed methods approach was adopted for this thesis. With the aim of achieving complementary exploration, the researcher carefully selected an appropriate mixed methods design from several options, as detailed in the next section.

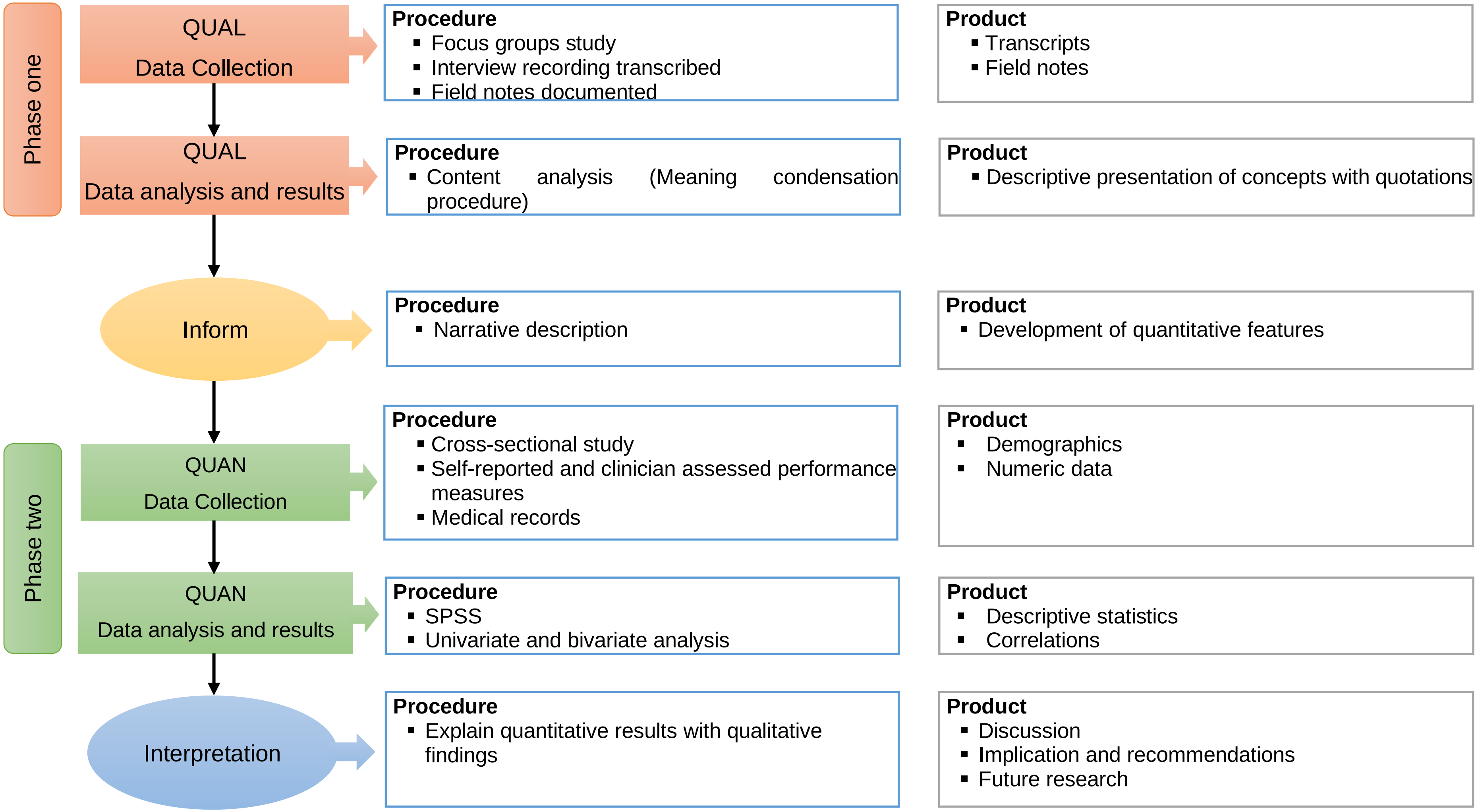
4.4 Research design: A sequential exploratory mixed methods design

A variety of research designs have been published describing the major approaches used in mixed methods research. Indeed, Schoonenboom and Johnson (2017) provided a useful summary of the available mixed methods research design typologies. Creswell and Plano Clark (2018) also described three basic designs commonly used in mixed methods studies, namely, the convergent, explanatory sequential and exploratory sequential mixed method designs. These three main mixed methods designs were considered to address the purpose of this PhD study and an exploratory sequential design was adopted. An exploratory sequential design is a two-phase design that uses the qualitative data collected first to help inform the sequential quantitative method. The sequential approach means that the data collection and analysis of the initial qualitative phase is completed prior to the design and conduct of the second, quantitative phase. In the present study, the first qualitative phase involved a focus group study which explored the experiences of Palestinian individuals with RA in terms of potential environmental/personal barriers and facilitators in relation to hand function, as well as facilitated the discussion regarding the appropriate hand function outcome measures to use in the Palestinian context. The findings of this phase were used to inform the design and conduct a cross-sectional study in the second phase. The two phases were conducted and analysed independently. Figure 4-1 depicts the research design of this sequential exploratory mixed methods study.

There are several reasons this design was selected. Importantly, this design is suitable when the targeted population is under studied and the variables to be measured are not known (Creswell and Plano Clark 2018). By using this design, the researcher assures that the quantitative feature is informed by the participants' perspectives, rather than using what is already available in the published literature. The exploratory design was not chosen to develop a new outcome measure, as the literature identified several valid hand functional measures which the researcher considered appropriate for use in the study, but rather to explore which hand function outcome measure(s) would be suitable in the Palestinian context. Furthermore, this design was selected because there was a need to explore unknown variables (e.g. personal factors) which might influence hand function.

In mixed methods designs, data are intentionally integrated to maximise the advantages and minimise the disadvantages of each form of data (Creswell et al. 2011). Integration may take place at different stages of the research process, from formulating the research question to the final interpretation of findings (Fetters et al. 2013). In line with the research design adopted for this thesis, data integration occurred primarily at the method and data interpretation level. At the method level, the approach built upon the qualitative findings (i.e. concepts and themes inform the subsequent data collection phases) (Fetters et al. 2013; Creswell and Plano Clark 2018). To complete this step, a narrative approach was used to specify how the qualitative findings were used in the design of the quantitative feature. This is detailed in the quantitative phase (Chapter 6). Regarding integration at the data interpretation level, the quantitative and qualitative data were compared and contrasted to identify the similarities and differences between the two forms of data. This appears in the final general discussion chapter (Chapter 7).

Authors of mixed methods research suggest that researchers should clarify which part of their work is given priority (Bryman 2006; Johnson et al. 2007). Indeed, Johnson et al. (2007) suggested that there are three possible options for qualitative and quantitative strands: (i) Equal priority or status (both methods would have equal importance in addressing the research problem), (ii) Quantitative dominant (the quantitative strand takes priority, whilst the qualitative part is a complementary approach to help answer the research questions), (iii) Qualitative dominant (the qualitative strand takes priority, whilst the quantitative work is used as a complement). In keeping with the emergent nature of the adopted research design (i.e. qualitative informs quantitative), both the qualitative and quantitative components were considered equally important. This was because the different methodologies were employed to best answer the study’s various research questions. The uppercase notation of “QUAL” and “QUAN” is used in Figure 4-1 to indicate this.



Procedure
- Focus groups study
- Interview recording transcribed
- Field notes documented

Product
- Transcripts
- Field notes

Procedure
- Content analysis (Meaning condensation procedure)

Product
- Descriptive presentation of concepts with quotations

Procedure
- Narrative description

Product
- Development of quantitative features

Procedure
- Cross-sectional study
- Self-reported and clinician assessed performance measures
- Medical records

Product
- Demographics
- Numeric data

Procedure
- SPSS
- Univariate and bivariate analysis

Product
- Descriptive statistics
- Correlations

Procedure
- Explain quantitative results with qualitative findings

Product
- Discussion
- Implication and recommendations
- Future research

Figure 4-1 Summary of the sequential exploratory mixed approach employed in the current research

4.4.1 Strengths and weaknesses of the sequential exploratory mixed methods design

Creswell and Plano Clark (2018) described the strengths and weaknesses of sequential exploratory designs. In its favour, this design is simple and straightforward to implement and report, and it is the best method when prior knowledge about the research topic is limited. However, this design has some weaknesses, as it requires a considerable amount of time to implement and the analysis of the first qualitative phase should be concluded with findings conducive enough to proceed with the subsequent quantitative phases (Creswell and Plano Clark 2018). One of the main challenges of mixed methods designs in general is that the researcher needs to have sufficient skills in both qualitative and quantitative methods (Cameron 2009). In this case, the PhD researcher had experience in quantitative research and has received training on both quantitative and qualitative research at the University of Southampton, thus having received the appropriate training and support, he felt able to conduct both.

4.5 Validity and rigour in mixed methods research

Validity is important for all research methodologies and has established criteria in quantitative and qualitative research (Bryman et al. 2008). However, the discussion of validity in mixed methods research is still in its infancy (Onwuegbuzie and Johnson 2006; Long 2017). Creswell and Plano Clark (2018) defined validity in mixed methods research as “employing strategies that address potential threats to drawing correct inferences and accurate assessment from the integrated data”. They claimed that since mixed methods research consists of both quantitative and qualitative strands of data, then the research should address the specific types of validity checks associated with both strands. In addition, Creswell and Plano Clark (2018) suggested that validity should be addressed with reference to the type of mixed methods design being used, rather than there being a generic discussion of validity. As a result, they presented a list of potential validity threats in exploratory mixed methods design and also provided strategies to minimise those threats (Table 4-2).

Other scholars have suggested that the term “legitimation” be used instead of validity of mixed methods research, as they believe that this term is acceptable to both quantitative and qualitative researchers (Onwuegbuzie and Johnson 2006). Furthermore, they have described nine types of legitimations, which are thought to enhance the inferences in mixed methods research. O'Cathain et al. (2008) acknowledged that there is a lack of consistency in assessing quality when reviewing published mixed methods research studies and developed the good reporting of a mixed methods study (GRAMMS). GRAMMs focuses on specific mixed method criteria, such as justifying a mixed methods research design and the integration of data and findings but does not comment on how to establish rigour and quality during the research process.

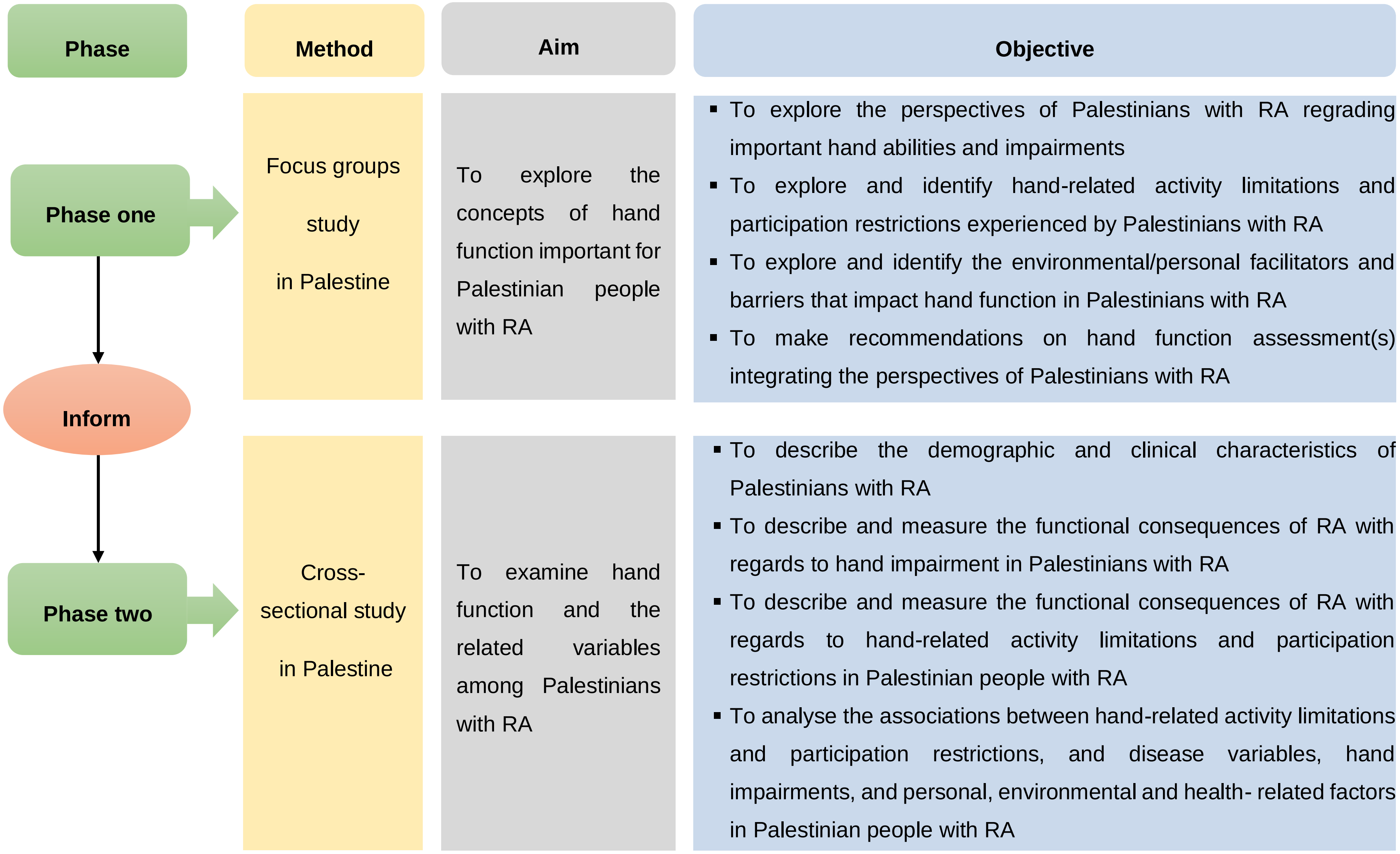
Table 4-2 Validity threats in exploratory mixed methods research design and strategies to minimise them (Creswell and Plano Clark 2018)

Threats	Strategies to minimise threats
Not building the quantitative study based on the qualitative findings	Make explicit how each major qualitative finding is used to inform the development of specific elements of the quantitative feature
Selecting participants for the quantitative study that are the same individuals as the qualitative sample	Use large sample of individuals for the quantitative sample who are different from those in the qualitative sample

In the absence of a consensus on what constitutes validity and quality in a mixed methods study, this PhD study utilised a methods orientated criteria, as advocated by Creswell and Plano Clark (2018). Specifically, separate quantitative and qualitative criteria were utilised to ensure validity measures were applied to the qualitative (focus group study) and quantitative (cross-sectional study) aspects of the study and that strategies were employed in both studies to minimise the threat to its validity. Furthermore, attention was also paid to the GRAMMs mixed methods reporting guidelines.

4.6 Thesis phases

Figure 4-2 provides an outline of the two different phases carried out in this project, as well as their methods, aims and objectives. Each component of the research project is presented as a separate thesis chapter, including specific methods, findings and discussion sections. The final chapter combines the findings from both phases to suggest the potential clinical implications and recommendations, as well as areas for future research.



Phase	Method	Aim	Objective
Phase one	Focus groups study in Palestine	To explore the concepts of hand function important for Palestinian people with RA	▪ To explore the perspectives of Palestinians with RA regrading important hand abilities and impairments ▪ To explore and identify hand-related activity limitations and participation restrictions experienced by Palestinians with RA ▪ To explore and identify the environmental/personal facilitators and barriers that impact hand function in Palestinians with RA ▪ To make recommendations on hand function assessment(s) integrating the perspectives of Palestinians with RA
Phase two	Cross-sectional study in Palestine	To examine hand function and the related variables among Palestinians with RA	▪ To describe the demographic and clinical characteristics of Palestinians with RA ▪ To describe and measure the functional consequences of RA with regards to hand impairment in Palestinians with RA ▪ To describe and measure the functional consequences of RA with regards to hand-related activity limitations and participation restrictions in Palestinian people with RA ▪ To analyse the associations between hand-related activity limitations and participation restrictions, and disease variables, hand impairments, and personal, environmental and health- related factors in Palestinian people with RA

Figure 4-2 Summary of the two phases used in the current research

4.7 Chapter summary

This chapter has provided an overview of the study design and research methodology. Based on this, the overall PhD study design selected was an exploratory mixed methods design within a pragmatic paradigm. This design was chosen to best address the aims of the present study. The initial exploratory qualitative phase was accomplished using a focus group method, with data analysis conducted using content analysis. The second phase of the PhD study involved quantitative data collection using both self-reported and clinician assessed performance-based measures, with different statistical procedures used to summarise the quantitative data. Full details regarding the specific methods and procedures related to each study are provided separately in the subsequent chapters (Chapter 5 and Chapter 6).

Chapter 5 Concepts of hand function important for Palestinian people with RA: A focus group study

5.1 Chapter overview

This chapter describes the focus group study conducted among Palestinian individuals living with RA. The aim and objectives, philosophical stance, study design, ethical consideration, and study plan, including the researchers' skills and patients and public involvement, are discussed. The pilot study, recruitment process, data collection, analytical method, and trustworthiness of the study are then presented. The findings are described according to the ICF framework component related to body function and structure, activity limitations and participation restriction levels, considering both personal and environmental factors. The findings are discussed within the context of previous research, and their subsequent implications for clinical practice and future research, as well as the next phase of this PhD study, are also highlighted throughout. Lastly, the strengths and limitations of the research are discussed, followed by a chapter summary and conclusion.

5.2 Introduction

The initial literature review demonstrated that important personal and environmental factors in relation to hand function had not yet been identified. Furthermore, it was evident the little attention has been given to exploring the influence of personal and environmental factors on hand function in people with RA (Arab Alkabeya et al. 2019a). Additionally, the literature review highlighted that there were no clearly appropriate hand function outcome measures to be used in the Palestinian context. Therefore, a qualitative enquiry was required to explore the perspective of Palestinian people with RA regarding hand function. This exploration informed and facilitated the researcher's discussion and recommendations on the most appropriate hand function outcome measure(s) for the Palestinian RA population. Furthermore, it allowed the important environmental and personal factors in relation to hand function to be explored and identified, and to further evaluate their status and influence on hand function. The Consolidated Criteria for Reporting Qualitative Studies (COREQ) (Tong et al. 2007) was used to guide the development and reporting in this chapter, and the completed checklist is provided in Appendix G.

5.3 Aim and objectives

This study aimed to explore the concepts of hand function important for Palestinians with RA. The specific objectives of this study were to:

1) Explore the perspectives of Palestinians with RA regarding important hand abilities and impairments.
2) Explore and identify hand-related activity limitations and participation restrictions experienced by Palestinians with RA.
3) Explore and identify the environmental/personal facilitators and barriers that impact on hand function among Palestinians with RA.
4) Make recommendations on hand function assessment(s) integrating the perspectives of Palestinians with RA.

5.4 Theoretical paradigm: Subtle realism

The philosophical standpoint of this PhD thesis was acknowledged in Chapter 4, however, researchers who conduct qualitative research should reflect on their own ontological and epistemological positions. This is essential because researchers' underlying belief systems and assumptions affect their approach to the research they conduct (Ballinger 2004). Being aware of their beliefs and preconceptions enables researchers to reflect on the impact they have on their research, the methods they use to collect the data and how they justify their results (Finlay and Ballinger 2006).

To reiterate, there are two main paradigms in research methodology: positivism and constructivism-interpretivism (Krauss 2005; Broom and Willis 2007; Doyle et al. 2009). A paradigm has three main components: ontology (how the researcher views the nature of reality), epistemology (the researcher's approach to knowledge generation) and methodology (the researcher's research strategy) (Creswell and Plano Clark 2018).

A positivist argues that there is "an absolute reality which can be measured, studied and understood" (Duncan and Nicol 2004). A researcher working in a positivist paradigm may adopt a realist position arguing that truth exists independently of the researchers, and knowledge can be generated through direct observations or measurements of the phenomena (Krauss 2005; Andrews 2016). A realist position is more traditionally related to quantitative research (Duncan and Nicol 2004). Considering the aims of this study the researcher's ontological and epistemological beliefs concerning the phenomena under investigation is incompatible with the positivism/realism position. This is because this current component study aims to understand the subjective experiences of a relatively small number of people within a specific context. Therefore, the researcher must reject the positivist/realist stance in this case, as it would limit his ability to explore the participants' subjective experiences, as the nature of individual reality is complex.

On the other hand, the constructivism-interpretivism paradigm asserts that reality is relative and constructed by people who experience a phenomenon of interest (Krauss 2005; Finlay and Ballinger 2006). In contrast to realist epistemologies, the researcher working in this paradigm assumes that a single reality is not obtainable when using an appropriate methodology and methods (Krauss 2005). Adopting the relativism standpoint in qualitative research leads to the conclusion that knowledge about reality can never be definite (Andrews 2016).

The researcher of this study argues that the alternative position of "subtle realism", situated midway between realism and relativism (Mays and Pope 2000; Madill 2008), suits the present study. Subtle realism agrees with the naive realist ontological perspective that an external reality exists but argues that this reality can only be approached indirectly. Regarding epistemology, subtle realism endorses naive realist epistemology in that reality is knowable but also believes that this knowledge depends on our cultural assumptions, and is mostly one representation of "many possible valid accounts" (Madill 2008). Therefore, when adopting the subtle realist position, researchers endeavour to represent reality rather than attempt to attain truth (Mays and Pope 2000). By choosing subtle realism as a philosophical standpoint for this study, the researcher is avoiding the negative implications associated with both realism and relativism philosophy outlined above (Andrews 2016). Subtle realism fits with the researcher's beliefs that hand-related activity limitations and participation restriction concepts are a tangible entity that exist independently of the researcher's view or others' view of it, and although it may not be possible to directly access that reality, subjective experiences can be studied. Furthermore, a position of subtle realism is also compatible with this PhD thesis philosophy, as this study combines research methodologies (Duncan and Nicol 2004).

5.5 Materials and Method

5.5.1 Study design

Qualitative methods are commonly used and have a significant impact on rehabilitation science (VanderKaay et al. 2018). In addition, they are useful for providing in-depth perspectives of patients and ensuring a comprehensive understanding of the phenomena of interest (Bowling 2014). A focus group discussion is one qualitative method that is frequently used to obtain data regarding knowledge, perspectives and attitudes (Plummer-D'Amato 2008; Wong 2008). Focus groups are unstructured group interviews involving a small number of participants that aim to create a focused discussion among the participants in order to generate data (Plummer-D'Amato 2008; Wong 2008; Krueger and Casey 2009; Bowling 2014). This is a well-established research technique during which the participants are guided, facilitated, and encouraged by the researcher to discuss different aspects of specific questions designed by the researchers. Focus groups have the advantage of making use of group dynamics to inspire discussion, gain understanding and generate ideas, in order to explore a topic deeply (Hennink 2007; Krueger and Casey 2009).

The focus group method was chosen to collect data for the following unique advantageous reasons. Firstly, focus groups are particularly recommended for use with RA patients, since it has been demonstrated that they have a greater capacity to comprehensively explore patients' perspectives and reach data saturation compared with individual interviews of the RA population (Coenen et al. 2012) and, therefore, have been successfully used in previous rheumatology research (Coenen et al. 2006; Stamm et al. 2007; Stamm et al. 2014). Secondly, focus groups allow for different perspectives to be expressed in an informal discussion and are therefore ideal for exploring people's experiences (Krueger and Casey 2009). Importantly, focus groups are not designed to reach a consensus, but to elicit a range of experiences, which fits well with the aims of this study. They also challenge the power dynamics frequently found in typical interviews, as they give the participants greater control and turn the interviewer into more of a facilitator. Finally, a focus group has the advantage of generating opportunities to collect data from group interactions which are concentrated on the topic of the researcher’s interest (Krueger and Casey 2009).

Although focus groups were considered to be an appropriate data collection method for the stated advantages, there are a few disadvantages with the method. Notably, dominant members of the group may lead the discussion, and other members can end up simply agreeing or staying silent (Carey and Asbury 2012). However, a mindful moderator can control a dominant participant and encourage a quiet participant by employing different strategies (Wong 2008). It was concluded that the benefits of the focus group method outweighed the negatives in this setting for these individuals.

5.5.2 Ethical considerations

Following a peer review, ethical approval was sought from both the University of Southampton School of Health Sciences (Ethics number: 30278) and the Palestinian Ministry of Health (Ethics number: 162/1265/2017; Appendix H). In both cases, this was granted before the pilot activity and data collection commenced.

The core ethical issues of informed consent, anonymity, confidentiality, security of data and the right to withdraw were followed throughout the interviews. The researcher gave each participant a study participant number, which was not linked with personal data, to ensure anonymity. All of the data, therefore, were anonymised. Personal identifiable information given during group discussions such as professional roles, names and places were substituted in the transcription and any quotations, in order to decrease the risk of tracking back data to the participant. All possible steps were taken to disguise the participants’ identities, so that a reader of the report would be unable to identify the study participants. Informed consent forms included information about the research, expectations about participants’ contributions, assured anonymity (i.e. keeping participants’ identities secret and ensuring a participant would not be traceable from the presented data) and confidentiality. To help with the running of the focus group, before commencing the discussion, discussion ground rules were first stated by the researcher, to clarify what was expected from the focus group participants. For example, it was made clear to the participants that it was fine to agree or disagree with each other, but it was important to respect a range of opinions. It was also made clear that the researcher would be facilitating the discussion rather than participating.

5.5.3 Design and development of the focus group study

Organising focus group interviews generally requires more planning than other types of interviewing (Hennink 2007; Krueger and Casey 2009). To maximise the data obtained from focus groups, careful planning and consideration should be paid to the research workers' skills, the composition of the groups, and the discussion guide (Hennink 2007; Plummer-D'Amato 2008). Therefore, improving the research workers' skills, the initial involvement of the patients and public (PPI) and the inclusion of a pilot study were considered of particular importance to inform this study plan.

5.5.3.1 The researcher's skills

The success of a focus group depends on the researcher's skills. For a focus group study, it is acknowledged that the researcher should have sufficient skills to guide the participants through the discussion, making use of group dynamics to stimulate discussion and to ensure all of the participants join in the discussion (Plummer-D'Amato 2008; Krueger and Casey 2009; Bowling 2014). The researcher of this PhD thesis worked as a physiotherapist and lecturer at the Arab American University in Palestine (AAUP), thus had experience in conducting clinical interviews. However, the process and style of clinical interviews uses a more direct line of questioning that differs from research-based interviews. In addition, the researcher approached this study as a novice qualitative researcher. For the above reasons, prior to the main focus group data collection process, the researcher completed training in both good clinical practice and qualitative interviewing at the University of Southampton. A pilot focus group session was also conducted to test the procedures.

Using computer software specially developed and designed for qualitative data analysis helped to provide the researcher with enhanced data management, shorten analysis timeframes and provides more rigorous coding and interpretation (Jones 2007; Krueger and Casey 2009). Zamawe (2015) suggested that NVivo software (qualitative data management software) could work well with most qualitative research designs and analytical approaches and, based on this, the researcher completed a two-day intensive NVivo training workshop, as the plan was to use NVivo 11™ to support the researcher with the data analysis process.

Conducting focus group discussions usually requires two people; one as a moderator and the other as a note-taker (Hennink 2007; Wong 2008). The research staff in this study were the researcher (moderator) and a female colleague, also a PhD student, who acted as both the note-taker and subsequently, an independent verifier of the data analysis findings. She was a staff member from the Health Sciences Faculty at AAUP who had completed a qualitative research course, received training and education from the researcher on the subject of focus group methodology, as well as the process and analysis procedure. The role of a note-taker in a focus group study is to capture and record the participants' phrases or statements, the order of speaking, and also non-verbal expressions (Hennink 2007; Wong 2008). It is important for the note-taker to capture information from the discussion as accurately as possible and include a sketch of the seating arrangements, and write the participants' names or assigned numbers (Wong 2008). Furthermore, a note-taker needs training and careful instruction on how to recognise and record essential issues during a fast moving group discussion (Hennink 2007). Therefore, the researcher provided the note-taker with background knowledge of the topic discussed and information about the study's aims and objectives. The pilot study also provided an opportunity for the note-taker to improve her skills in capturing important information during the focus group discussion.

5.5.3.2 Patient and Public Involvement (PPI)

PPI has been defined by the INVOLVE group (a national advisory group to support greater involvement in the National Health Service in the United Kingdom) as 'research being carried out "with" or "by" members of the public rather than "to", "about" or "for" them' (Hayes et al. 2012). It is an essential activity in the research process to ensure the acceptability, relevance, and quality of research (Staley 2009; Hayes et al. 2012). Among the arthritis population, PPI has shown to be a promising method to inform the successful design and creation of relevant research projects (Adams and Lempp 2014). There are three approaches to involving patients in research: consultation, collaboration, and user control involvement (Hayes et al. 2012). For this study, the preliminary PPI representatives were consulted during the design stage. A colleague from the Health Sciences department at the AAUP approached two Palestinians with RA (one male, one female) who then met with the researcher using Skype videoconferencing technology to assist in the focus group design. These patients collaborated with the researcher as contributors to the research and were not recruited as research participants. Figure 5-1 shows the output and the links between PPI and the pilot focus group study in informing this study design. The specific output of the PPI and pilot focus group study are presented in Figure 5-2.

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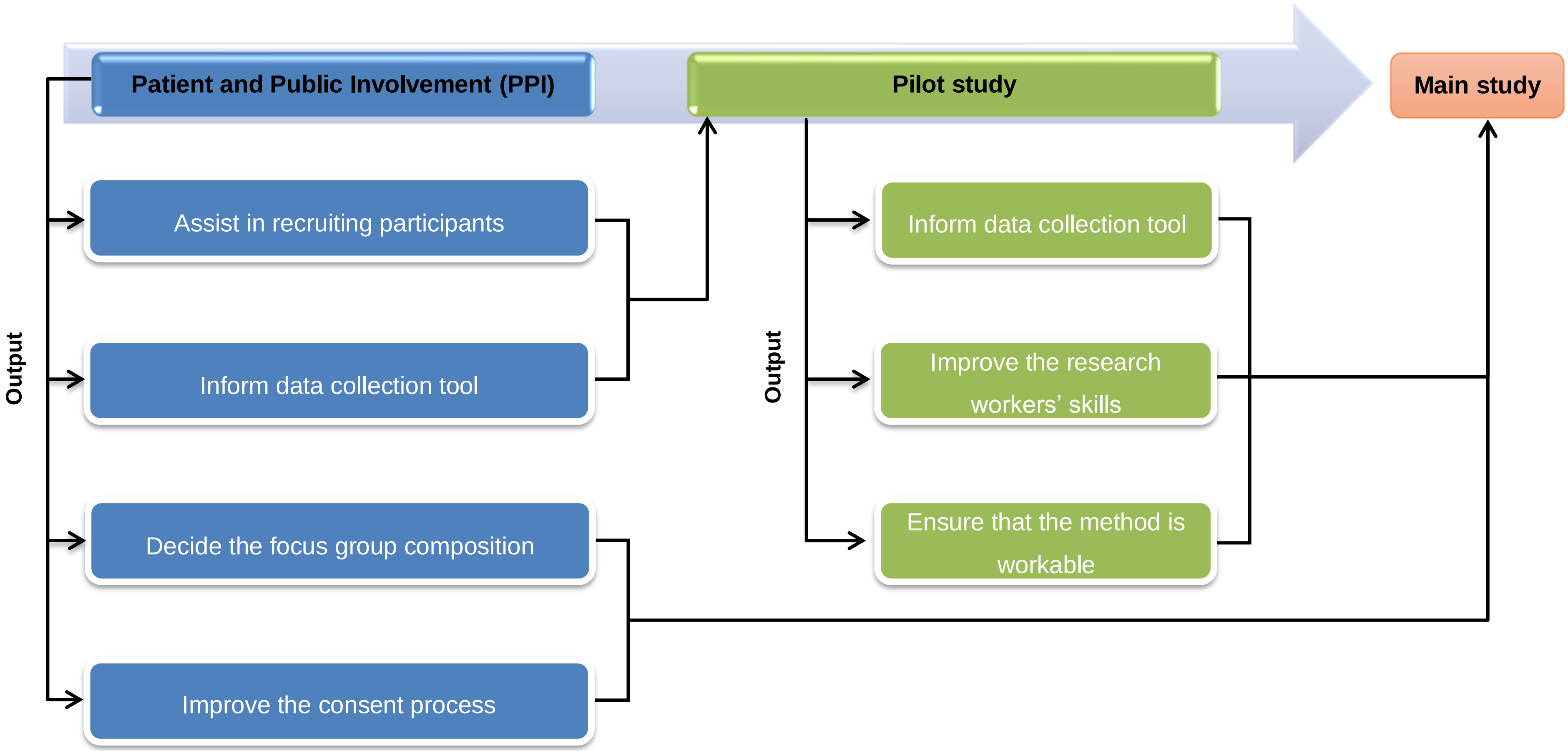
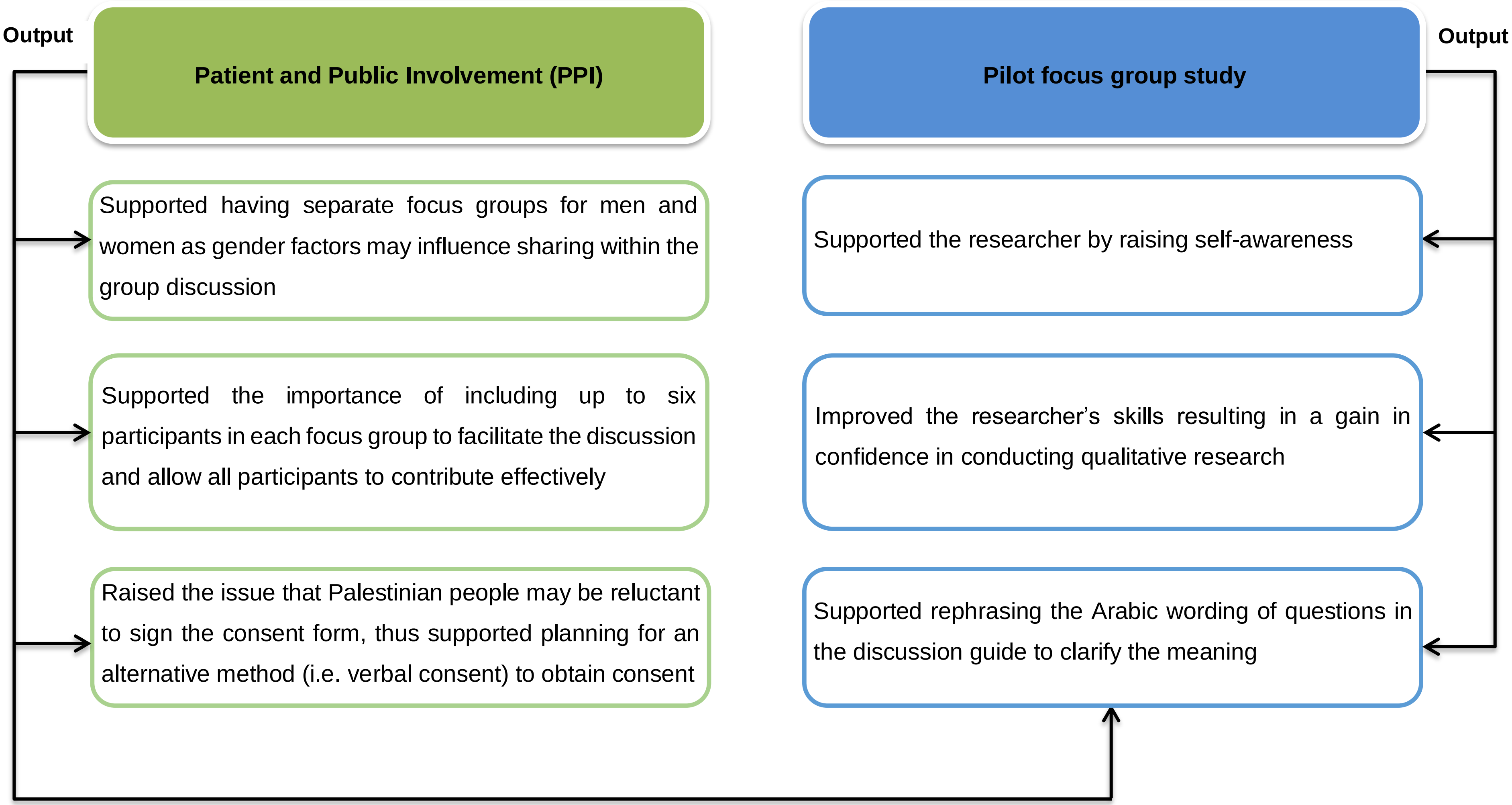


Figure 5-1 Patient and Public Involvement (PPI) and pilot focus group study output and links with the main focus groups study



Patient and Public Involvement (PPI)

Supported having separate focus groups for men and women as gender factors may influence sharing within the group discussion

Supported the importance of including up to six participants in each focus group to facilitate the discussion and allow all participants to contribute effectively

Raised the issue that Palestinian people may be reluctant to sign the consent form, thus supported planning for an alternative method (i.e. verbal consent) to obtain consent

Pilot focus group study

Supported the researcher by raising self-awareness

Improved the researcher’s skills resulting in a gain in confidence in conducting qualitative research

Supported rephrasing the Arabic wording of questions in the discussion guide to clarify the meaning

Figure 5-2 Patient and Public Involvement (PPI) and pilot focus group study key output

5.5.3.3 Pilot focus group study

Conducting a pilot study as part of qualitative research has been recommended for novice researchers (Kim 2010). The principal benefit of doing so is that it provides the researcher with an opportunity to make adjustments and amendments to the main study (Krueger and Casey 2009; Hennink et al. 2011). Furthermore, it helps researchers to improve their skills and gain more confidence when conducting qualitative research (Hennink 2007). For that reason, a preliminary pilot focus group study was conducted at the AAUP which lasted for 77 minutes. Data obtained from this pilot study was not incorporated into the main study data analysis, as the main aims of this pilot study were to inform the main study design and improve the researchers' skills. It was decided prior to the pilto study that if the pilot study had indicated that changes were required to the focus groups, then an amendment would have been requested through the University of Southampton Faculty of Health Sciences Ethics Committee. However, the pilot study did not indicate that any modifications were required to the research design or procedure but did recommend the rephrasing of the Arabic wording of questions to clarify their meaning. The following subsections describe the sample, participant recruitment strategy, discussion guide, and data collection procedure for the pilot focus group study.

- **The sample**

A preliminary pilot focus group study was conducted with three participants diagnosed with RA according to the ACR classification criteria (Arnett et al. 1988). Participants were recruited according to the inclusion and exclusion criteria shown in Table 5-3 and Table 5-4.

- **Participant recruitment strategy**

The personal contacts of a researcher are key resources to leverage and enhance participant recruitment efforts in a pilot study (Joseph et al. 2016). Therefore, key collaborating personnel (a health sciences colleague at the AAUP and a PPI group member) were asked to assist in recruiting participants. They were provided with detailed information about the study aims, process, and inclusion and exclusion criteria. Furthermore, they were given an opportunity to ask questions. They were also asked to give the recruitment pack (Appendix I), which included the invitation letter and participants information sheet (PIS), to the participants who met the inclusion criteria. Potential participants were given at least 48 hours to read and check they understood the PIS and to discuss the study with their families or relatives. Potential participants who were interested in taking part contacted the researcher via a work phone at the AAUP (given in the contact details in the PIS), and were then given further details about the study (i.e. the procedure, the participant's role, the date and time of the focus group) and they also had the opportunity to ask any questions about the study. A verbal agreement to take part was initially obtained from the participant at the end of the phone call.

- **Discussion guide**

In focus group research, the topics of discussion are carefully predetermined and sequenced (Hennink 2007; Wong 2008; Krueger and Casey 2009; Carey and Asbury 2012). Using a discussion guide in a focus group provides the researcher with a framework to ask questions and probe deeper. Furthermore, it increases the comprehensiveness of the data collection and makes data collection more efficient (Hennink 2007; Plummer-D'Amato 2008; Wong 2008; Krueger and Casey 2009). Based on the ICF framework, six open-ended questions were developed and adopted based on the qualitative arthritis literature (including RA and osteoarthritis) as a discussion guide (Coenen et al. 2006; Stamm et al. 2007; Stamm et al. 2009; Coenen et al. 2012; Coenen et al. 2013; Stamm et al. 2014). These open-ended questions required the participants to name their problems in terms of the ICF dimensions (i.e. Body Functions, Body Structures, Environmental Factors, Personal Factors and Activities, and Participation). The questions from the ICF, however, are generic and do not address the hand specifically. Therefore, these questions were carefully reconstructed and modified by the researcher, and checked by the supervisory team, who are experts in the field of arthritis, so they were more specific to hand function (Table 5-1). These guiding questions were translated (by the researcher) into Arabic, using appropriate words and phrases to suit Palestinian culture.

Table 5-1 Focus group interview questions

ICF component	Open-ended questions
Body structures	Please look at the picture of the hand and imagine it is your hand. Would you point to areas on the picture, which either give you problems now or have given you problems in the past with your RA? (See Appendix J)
Body functions	If you think about your hand(s) abilities, what difficulties have you experienced now or in the past due to RA?
Activities & participation	If you think about your daily life, what difficulties do you experience now or have you experienced in the past due to your RA hand(s)?
Environmental factors	If you think about your environment and your living conditions, what factors have you found to help or support you to use your hand effectively now or in the past? (Facilitators) If you think about your environment and your living conditions, what barriers do you experience to use your hand effectively now or in the past? (Barriers)
Personal Factors	If you think about yourself, what helps you to handle your current or past hand(s) problems due to RA?

- **Data collection procedure**

The focus group session was conducted at the Faculty of Health Sciences, AAUP. Shortly before the focus group interview started, the research workers (i.e. researcher and note-taker) organised the room with chairs arranged in a circle. As participants arrived, they were welcomed, given a first name only lapel badge to promote communication within the group, given their travel expenses and asked to take a seat. Participants were informed about the location of the bathroom and invited to use it prior to the focus group session. The participants were invited to help themselves to refreshments.

The researcher welcomed everyone and introduced himself and the note-taker, who was sitting opposite to the researcher, to avoid creating a power block in the circle. The researcher then gave enough information about the aims of the research to allow the participants to feel comfortable with the topic, and to create a relaxed atmosphere. The researcher advised participants that the focus group would last up to two hours and asked if they had any time constraints prior to commencing. The researcher also explained how the session would be recorded using both a paper-based (i.e. note-taker) method and a digital audio recording. To reduce the risk of losing the data, the audio recording equipment was tested before the groups started and measures were taken to ensure the data was audible. The session ground rules (Appendix K) were stated before the focus group session commenced. Participants were then invited to ask any questions regarding the procedure or voice any concerns they may have regarding signing the written consent form (Appendix I) and/or providing verbal consent. However, verbal consent was not required, as the participants were happy to sign the consent form. Following the informed consent phase, each participant (or the researcher if they were unable) filled out a sign-in sheet with a few brief demographic questions including age, gender, employment status, profession, marital status and educational level.

Before starting, the focus group members introduced themselves, to help “break the ice” and build rapport among the group members. The researcher then turned on the digital audio recorder and started the discussion using the discussion guide. The discussion guide was used flexibly to allow a natural flow of conversation. In the process of the discussion, the moderator used a variety of prompt phrases to obtain additional information and encourage more in-depth exploration, these included:

- Could you further elaborate on what you have said?
- Can you tell me more?
- Would you give me an example?

Furthermore, the researcher summarised each time before moving from one question to another. For instance, the researcher said, “Before moving on to the next question, let me see if I have understood your point of view correctly, that is…”. Strategies recommended to control a dominant participant and encourage a quiet participant were employed if needed (Wong 2008). When the group had covered the issues in the guide, the participants were given an opportunity to add anything that had not been asked about. The moderator did this by saying “Is there anything specific anyone would like to share that we have not covered already, but that you particularly wanted to?” Finally, the moderator closed the group by thanking all of the participants.

5.5.4 Setting and context for the focus group

This study involved patients attending the rheumatology outpatient clinic in a governmental hospital in the northern part of Palestine from July to September 2017. The governmental hospital is not explicitly named within this thesis to assist in protecting the anonymity of the participants. The location for recruiting the participants was specifically selected because of its high population, that is 314,866 inhabitants (Palestinian Central Bureau of Statistics 2017), and that fact this resulted in including participants from diverse socioeconomic backgrounds. Furthermore, the governmental rheumatology clinics involved serve a population with high levels of poverty, which is a strength of this study, given the association between sociodemographic status and functional disability in people with RA (Zhao et al. 2015). Additionally, the governmental hospital is located near to the venue where the focus groups sessions were held, thus facilitating the process of recruitment, as well as allowing the participants to reach the venue of the study easily.

To increase the researcher's understanding and familiarisation of the setting prior to conducting the research, the researcher made several visits to the rheumatology clinic. Here, he spent considerable time observing clinical practice at the rheumatology clinic and discussed how medical care was provided with the rheumatologist and nursing staff. These observations and visits were important to enhance credibility (see section 5.6.1) and to build a relationship with the staff responsible for recruiting the participants. For these observations, the researcher made field notes about the types of assessment, the interaction between the patients and healthcare providers, the length of appointments and any impressions the researcher had. From these observations and discussions, the researcher became more aware of the referral services, available treatments, and the rheumatology clinic process for Palestinian people living with hand RA.

Similar to other governmental rheumatology clinics in the northern part of Palestinian, the clinic used in this study was only open one day per week, when more than 50 patients attended. The rheumatology clinic provides medical treatment including assessment by a rheumatology consultant, laboratory tests and medication reviews. In this busy rheumatology clinic, patients had to wait at least two hours before being examined by the consultant, receiving their laboratory test results and getting their medication prescriptions. Although large and with many chairs, the waiting room used for patients seeing the rheumatology consultant was also shared with other patient groups (such as orthopaedic outpatients), so many patients were not always able to find a chair to sit on.

Patients spent most of the time in the clinic waiting for their laboratory tests results, while the examination by the rheumatologists only took five to ten minutes. Despite the presence of a well-established rehabilitation unit within the same hospital as the rheumatology clinic, it was noted that patients were not referred to the rehabilitation services. The main reason for not referring the patients, as explained by the rheumatologist, was that the clinic was too busy to allocate times for referrals. However, another reason could be that healthcare providers are unfamiliar with rehabilitation services. Palestinians with RA in other clinics would have the same experiences in terms of healthcare services, as the services offered are consistent across all rheumatology clinics (personal communication). This is a strength for the wider applicability of the study results, given that many patients are likely to have the same experiences regarding healthcare services. However, the findings of this focus group study may not be transferable to patients receiving healthcare services in the private sector or non-governmental organisations, with respect to their experiences of healthcare services.

The patients attending this clinic were assessed/treated in a private consultation room when seeing the rheumatology consultant. However, it was possible for patients or medical staff to breach the privacy of a patient being examined in the consultation room unintentionally. It was also observed that the nurses’ role was mainly administrative i.e. patient record-keeping, and did not involve offering consultations or treatment. It was also observed that no educational resources were available for the patients in the clinic nor provided by the medical staff. Patients attending this clinic had either been referred there by their general practitioners in the primary healthcare setting or had self-referred.

5.5.5 Sampling strategy

Sampling strategies for qualitative methods have been criticised for being less explicit and often less evident than for quantitative methods (Palinkas et al. 2015). However, the target group selected for focus groups is determined by the aims and objectives of the study. For this reason, focus groups usually employ purposive sampling procedures (Plummer-D'Amato 2008). With RA patients, published qualitative research has frequently employed a maximum variation sampling strategy to explore the lived experiences and everyday function of RA patients (Coenen et al. 2006; Coenen et al. 2012; Stamm et al. 2014). A maximum variation strategy is considered as one type of purposive sampling design, as it aims to ensure that patients with diverse variations are represented in the study sample (Patton and Patton 2002; Palinkas et al. 2015). Therefore, it allows for important common patterns that cut across variations to be identified (Patton and Patton 2002). Although there are no clear guidelines for conducting a maximum variation strategy (Palinkas et al. 2015), it was recommended to depend on the available literature and evidence to decide the variables that might influence the individual’s contribution to the qualitative research (Marshall 1996). In the past, rheumatology qualitative research considered disease duration and age as the most important variables to ensure that patients with both new-onset and long-standing disease experience were included (Stamm et al. 2007; Coenen et al. 2012; Stamm et al. 2014). Therefore, for this study, a maximum variation strategy was employed considering disease duration and age as presented in Table 5-2.

Table 5-2 Participants categories according to disease duration and age

Age categories	Disease duration categories
▪ 18-35 years	▪ 1-5 years
▪ 36-50 years	▪ 6-10 years
▪ ≥ 51 years	▪ ≥ 11 years

5.5.6 Sample size and focus group composition

5.5.6.1 Group size

Group size is an important consideration, since a group with few participants may limit the diversity of the concepts that can be drawn upon. Additionally, a group that involves few participants may run the risk of inadequate interaction (Plummer-D'Amato 2008; Wong 2008). On the other hand, a large group may not allow all members to participate effectively or discourage group members from sharing their experiences and views (Plummer-D'Amato 2008; Wong 2008). However, there is little consensus as to what is the most appropriate sample size for the focus group.

Traditionally, the recommended sample size for a focus group has ranged from 6-12 participants (Wong 2008; Bowling 2014). However, some authors argue for smaller groups of 3-5 participants, especially in health sciences research, as they facilitate closer interaction and communication (Ohman 2005). Because this study aimed to capture in-depth views and experiences, it was deemed that it would be more difficult to seek clarifications with a particularly large group. The feedback from the PPI partners supported the importance of including up to six participants in each focus group to facilitate discussion and allow all of the participants to contribute effectively. Accordingly, prior to commencing the research, it was decided that focus groups would consist of between three and six participants.

There are no rules concerning the optimal number of groups, and this decision may be based on the research purpose, availability of participants, time, cost, and saturation of data (Wong 2008; Carey and Asbury 2012). However, to identify trends across groups, it is recommended to conduct more than one group (Plummer-D'Amato 2008). In rheumatology literature, Coenen et al. (2012) reported that five focus groups including 24 RA patients were sufficient to reach data saturation. Based on this evidence, the researcher aimed to conduct up to six focus groups, in case the total number of participants in all of the conducted focus group sessions was below the target sample of 24 participants.

5.5.6.2 Group composition

When designing a focus group study, it is important to consider the group composition with regards to who participates in each group. Group members in a focus group may be homogeneous in some dimensions and heterogeneous in others (Wong 2008). Homogeneity in a group composition may occur in terms of experiences and gender, but heterogeneity in terms of age and disease duration was aimed for in this research. Homogeneity in terms of experience maximises the extent to which the participants feel comfortable expressing their lived experiences and limits the effect of status differentials within the group on data (Plummer-D'Amato 2008). The feedback from the PPI partners supported having separate focus groups for men and women, as gender factors may influence sharing within the group discussion, so this was enacted (FG session maximum number=6). In the focus group study, some diversity and variation in the composition of the group may enhance discussion (Wong 2008).

5.5.7 Justification of inclusion and exclusion criteria

Palestinian outpatients attending the governmental hospital rheumatology outpatients clinic with a confirmed diagnosis of RA, according to the ACR classification criteria (Arnett et al. 1988), were recruited according to the inclusion and exclusion criteria shown in Table 5-3 and Table 5-4. Briefly, this study aimed to recruit adult patients (men and women) with at least one year's experience of living with hand problems due to RA.

Table 5-3 Inclusion criteria for participants with justification

Inclusion	Justification
Women and men aged ≥18 years	This study aimed to recruit adults (i.e. 18 years and above)
Diagnosed with RA according to the ACR	The ACR criteria is widely used and has robust criteria
Experience of living with hand problems due to RA at least 1 year since diagnosis	Sufficient lived experience
Reporting pain and dysfunction of the hands and/or wrist joints due to RA	Participants have hand problems

Table 5-4 Exclusion criteria for participants with justification

Exclusion	Justification
Had neuromuscular disorders (e.g. stroke, hemiparesis)	These conditions may affect patients' experiences
Had severe or moderate cognitive impairment (e.g. dementia, Alzheimer)	These conditions will affect the ability to recall previous experiences
Patients who are unable to communicate verbally	They will not be able to participate in focus group discussion, and no funds are available for communicators to assist
Patients with severe comorbid illness (e.g. cardiovascular disease, diabetes)	These conditions may affect the patients' experiences

5.5.8 Discussion guide used for data collection

The discussion guide (Table 5-1) described earlier and used for data collection in the pilot focus group study was also used to collect the data collection during the main focus group study. The content and face validity of these questions were assured through feedback from PPI partners and the pilot study. Although all of the questions in the discussion guide were covered by all of the focus groups, the focus group topic guide questions were used flexibly, allowing participants to contribute to the direction of the focus group discussion (Hennink 2007).

5.5.9 Recruitment and data collection procedure

5.5.9.1 Recruitment procedure

Figure 5-3 shows the stages of participant recruitment. Following ethical approval, the researcher approached and discussed the nomination of qualified medical staff (e.g. nurses, physicians) to assist in the recruitment of participants with the rheumatologist in charge of the rheumatology unit. It was important that the nominated medical staff had at least one-year's clinical experience working with RA patients. The nominated staff were provided with detailed information about the study aims, the process, and the inclusion and exclusion criteria. Furthermore, they were provided with information regarding the demographic (i.e. age and disease duration) ranges to be included in the recruitment and were given an opportunity to ask questions. The nominated medical staff used their professional judgment to identify participants who met the stated inclusion criteria for this study. Medical staff were asked to give the recruitment pack to the participants who met the inclusion criteria. If the identified participant was unable to read, or had trouble understanding the information sheets provided, the medical staff read and explained them to the patients.

To avoid logistical problems, which are associated with conducting focus groups research, a fixed future date and time were planned for each focus group. Although this methodology can minimise potential logistical problems, the researcher amended the date and time of focus group sessions when necessary for all the participants interested.

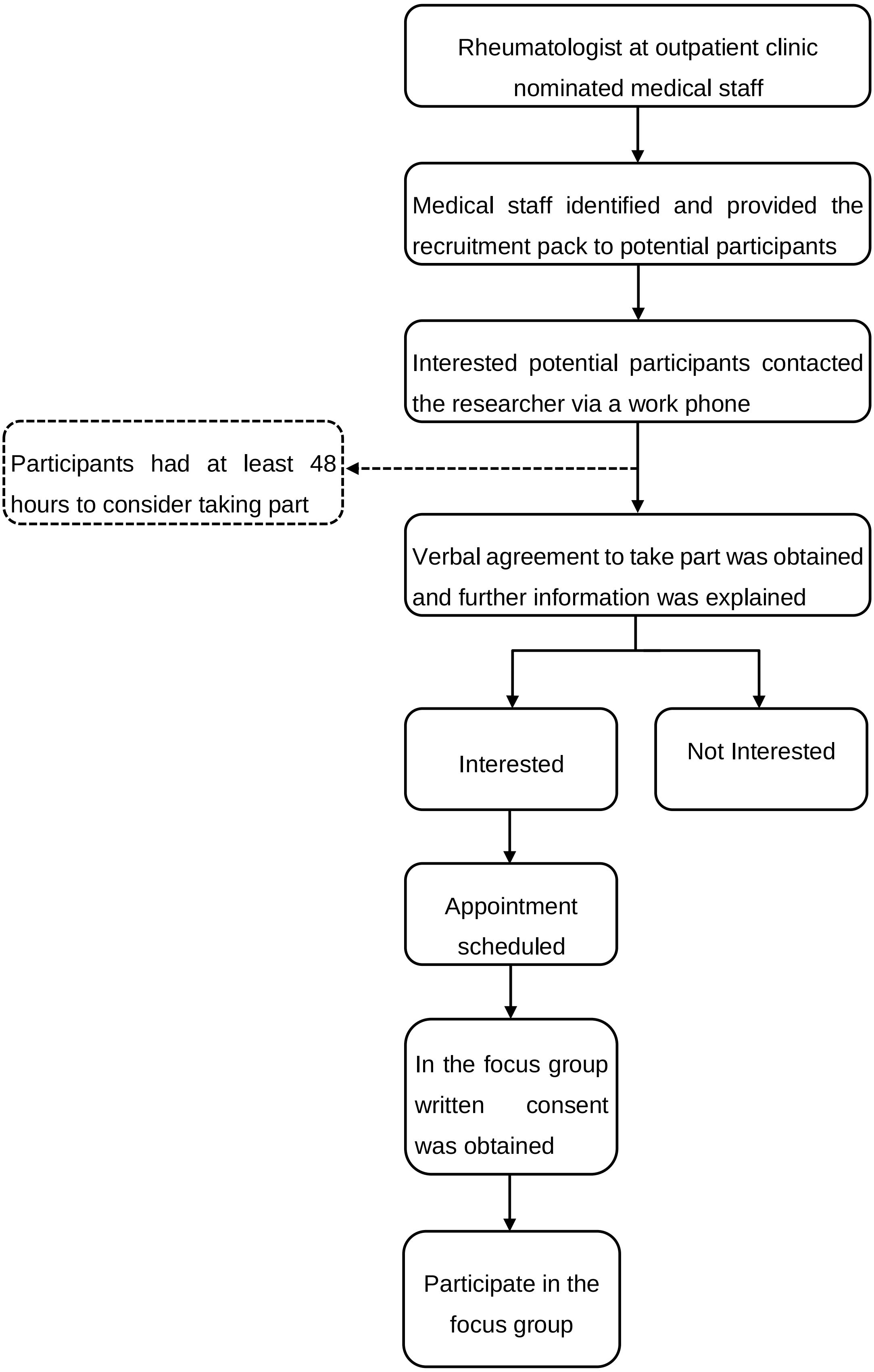


Figure 5-3 Flowchart for the recruitment process

5.5.9.2 Procedure for conducting focus groups

The focus group sessions were conducted at the Faculty of Health Sciences, AAUP. A consistent data collection method was followed to collect the main study data (see section 5.5.3.3). For each focus group session, the researcher made brief notes during the session to highlight anything emphasised by the participants, as well as any analytical thoughts and impressions. After each focus group session, the researcher reflected on the session regarding the characteristics of the participants, their comments during the focus group sessions and the flow of the discussion. A debriefing meeting (15-20 minutes) between the researcher and note-taker was held immediately after each focus group. These assisted in evaluating the quality of the session and checking the responses, thus improving the researcher's skills in facilitating discussions. The researcher also listened to the focus group recording prior to conducting the next focus group and critically reflected on each one to improve his technique. This helped to identify whether there was a need to get more information on a particular question and to identify where the group did not fully answer a question, so the researcher was alert to that during the next group interview (Krueger and Casey 2009). The researcher's UK supervisory team were contacted after each focus group session to give an update on the progress and discuss any issues that may have arisen during the data collection process.

5.5.10 Data Analysis

5.5.10.1 Transcription

Individual experiences were captured using digital recordings and were transcribed verbatim in Arabic and verified by the researcher prior to analysis. To ensure no meaning was lost, the researcher transcribed all of the data from the recordings. The researcher then applied a naturalised standardised approach, where every utterance was captured, since it might add to the meaning. This included slang, grammatical errors, non-verbal sounds and background noise (McLellan et al. 2003). The names of individuals, places and organisations were replaced with substitution phrases to maintain contextual information without breaching confidentiality. The process of transcribing was a time-consuming process, however, revising the transcripts for obvious errors such as spelling, enhanced the validity and reliability of the data and increased the researcher's familiarity with the data.

5.5.10.2 Use of computer software for data management and analysis

Microsoft Word 2016 was utilised for writing up the field notes and transcribing the data. Participants' actual names and codes including sociodemographic data were entered onto password-protected Word documents. Although the researcher had planned to use NVivo 11™ (QSR International Pty Ltd, 2015) to support the researcher during the data analysis process, several challenges hindered the ability to use that particular software. Importantly, in the analysis procedure employed in the current study (i.e. meaning condensation procedure), there was a need for specific meaning units to be broken down into more specific sub-concepts and this was not possible using NVivo 11™ (Davis and Meyer 2009). For instance, a meaning unit "*I can't grip, therefore I can't tear bread to eat when my hands are bad"* contains two sub-concepts which are problem gripping and difficulty tearing bread. Additionally, NVivo 11™ was found to be incompatible with Arabic, which is written from right to left. Thus, functions such as the "search" and "query" do not work appropriately. Despite the researcher's efforts to solve this problem with help from the NVivo software support team, no solution was found. Many researchers continue to advocate the use of manual analysis techniques, especially for novice researchers, since using qualitative data analysis software may affect the creativity of analysis and the researchers may unintentionally distance themselves from the data (Davis and Meyer 2009). The analysis of the current study data was therefore carried out manually using the Microsoft Word software package 2016 (Microsoft Corporation, 2015) as a management tool.

5.5.10.3 Data analysis procedure: Meaning condensation procedure

- **Rationale for the analysis method**

Focus group data were analysed using a meaning condensation procedure. This is a modified form of content analysis, which includes the abridgment of the meanings expressed by the interviewees into shorter formulations (Kvale and Brinkmann 2009). This method of analysis was chosen because of its systematic and clearly defined approach, which complements the next quantitative component of this thesis. This method of analysing qualitative data has also been successfully used in previous similar qualitative rheumatology research aiming to identify concepts of function important for patients with RA (Coenen et al. 2006; Stamm et al. 2007; Stamm et al. 2014).

Translation is of principal importance when conducting cross-language qualitative research, because if it is not completed in a transparent and systematic way, the credibility of the data is compromised (Twinn 1998; Al-Amer et al. 2015). However, there are no standardised translation procedures in qualitative healthcare research with non-English speaking participants (Al-Amer et al. 2015). This is coupled with fact that translating Arabic is challenging because of its linguistic structure. In a qualitative cross-language study, Al-Amer et al. (2016) underlined several difficulties translating Arabic qualitative data to English in terms of managing data with regard to metaphors, the connotation of the text, medical terminology and essentially preserving the meaning between the original and translated data. These challenges are exaggerated when the research is conducted with participants who are not using Modern-Standard Arabic (MSA) in daily conversation. In Palestine, MSA is generally used in academic institutions, whereas the use of colloquial Arabic dialects, “al-Ammiyya”, are typically used in daily conversation and in informal communications. These spoken dialects are usually oral rather than written and vary based on geographical location and the social status of its speakers (i.e. urban, village and Bedouin) (Al-Amer et al. 2016).

Studies that explore the lived experiences of people are challenging to conduct using a cross language design. The exact word usage is paramount and translation may negatively influence the integrity of data, since understanding of lived experiences and perspectives of participants is the foundation to maintaining the truthfulness of the data (Twinn 1998; Squires 2009). Therefore, a translation of the transcribed Arabic data may alter the original meaning and subsequently not allow the researcher to deeply capture the essence of the phenomenon in the translated language. For that reason, several scholars have recommended that qualitative studies exploring the lived experiences of participants should be undertaken in the language of the interview (source language) (Twinn 1998; Squires 2009). Therefore, the analysis of the present study was undertaken in Arabic.

- **Stages of the meaning condensation process**

The focus group data were analysed inductively, as there was insufficient former knowledge to inform the analysis of these phenomenon (Elo and Kyngas 2008). The meaning condensation procedure, derived from Kvale and Brinkmann (2009) was adapted for this study, as detailed in Table 5-5. Four steps were used to guide the analysis, which included familiarisation, dividing up the text into meaning units, identifying sub-concepts contained in the meaning units, and grouping the sub-concepts to yield comprehensive concepts. These steps are illustrated with a representative example from the focus groups data in Figure 5-4. The process of analysing was a continuous reflective and iterative process involving identifying meaning units, extraction of sub-concepts and concepts, then returning to the raw data to reflect on the initial analysis. Therefore, adjustments were needed after the initial analysis. For instance, a meaning unit might need to be further split into two meaning units to capture an additional core meaning. A sub-concept might need to be modified to more closely match the meaning unit, or a concept name tweaked to more accurately describe the included sub-concepts.

The analysis of the present study was completed entirely by the researcher and independently verified by his Palestinian Arabic speaking colleague and PhD (JD) student who was involved in the data collection process as the note taker. A preliminary pilot two-page data analysis exercise was conducted where both the researcher and JD independently extracted meaning units, sub-concepts and concepts contained in a sample consisting of two pages of the Arabic transcript. The results of this two-page exercise were discussed together to explore and obtain a mutual understanding about the meaning units and the depth of the concepts until a consensus was achieved. Following the exercise, the researcher independently analysed all of the focus groups data and the result were then verified by JD. Several debriefing meetings with the supervisory team were conducted afterwards to refine the concepts and, where necessary, amendments were made after reaching a consensus. The findings (i.e. concepts and quotations) of this study were then translated into English by the researcher. The translation process focussed on transferring the meaning of the words rather than re-writing them; aiming to consider the content equivalence in translation, while maintaining semantic equivalence (Lopez et al. 2008). The translation was independently verified for accuracy by a professional translator as recommended (Twinn 1998; Lopez et al. 2008). Following that, the supervisory team independently reviewed and verified the findings presented.

Table 5-5 Meaning condensation procedure (Kvale and Brinkmann 2009)

Step	Description
Familiarisation	▪ The initial step of the meaning condensation procedure involved familiarisation with the data to gain a general sense of the text as a whole. Familiarity with the content of the focus group discussions was attained by listening and re-listening to the audio-recording in addition to reading and re-reading the transcripts. This was coupled with reviewing the notes taken during focus group sessions. During this stage the researcher made brief notes to highlight the participants' emphases and any initial analytical thoughts and impressions. These were noted on the right margin of the transcripts during this stage. This allowed any important contextual issues to be noted.
Dividing up the text into meaning units	▪ In the second step of analysis, data were separated into units of meaning. A meaning unit was defined as a specific unit of text containing either a few words or a few sentences with a common theme relevant to the study questions. Therefore, a meaningful unit did not follow grammatical rules, but the text was divided where the researcher perceived a shift in meaning. This process was completed by systematically reviewing the transcript line by line to identify meaning units.
Identifying sub-concepts contained in the meaning units	▪ In the third step, sub-concepts contained in the meaningful units were identified. A meaningful unit could contain more than one sub-concept. A sub-concept in the analysis was defined as a unique meaningful entity distinctive from other sub-concepts. During this stage of extracting sub-concepts the researcher wrote notes on impressions and reactions to the text.
Grouping the sub-concepts to yield comprehensive concepts	▪ In the fourth step, sub-concepts were organised and grouped together according to their meaning to yield concepts that are more comprehensive. This was completed by comparing sub-concepts and appraising them to determine which sub-concepts seem to belong together, thereby forming a concept.

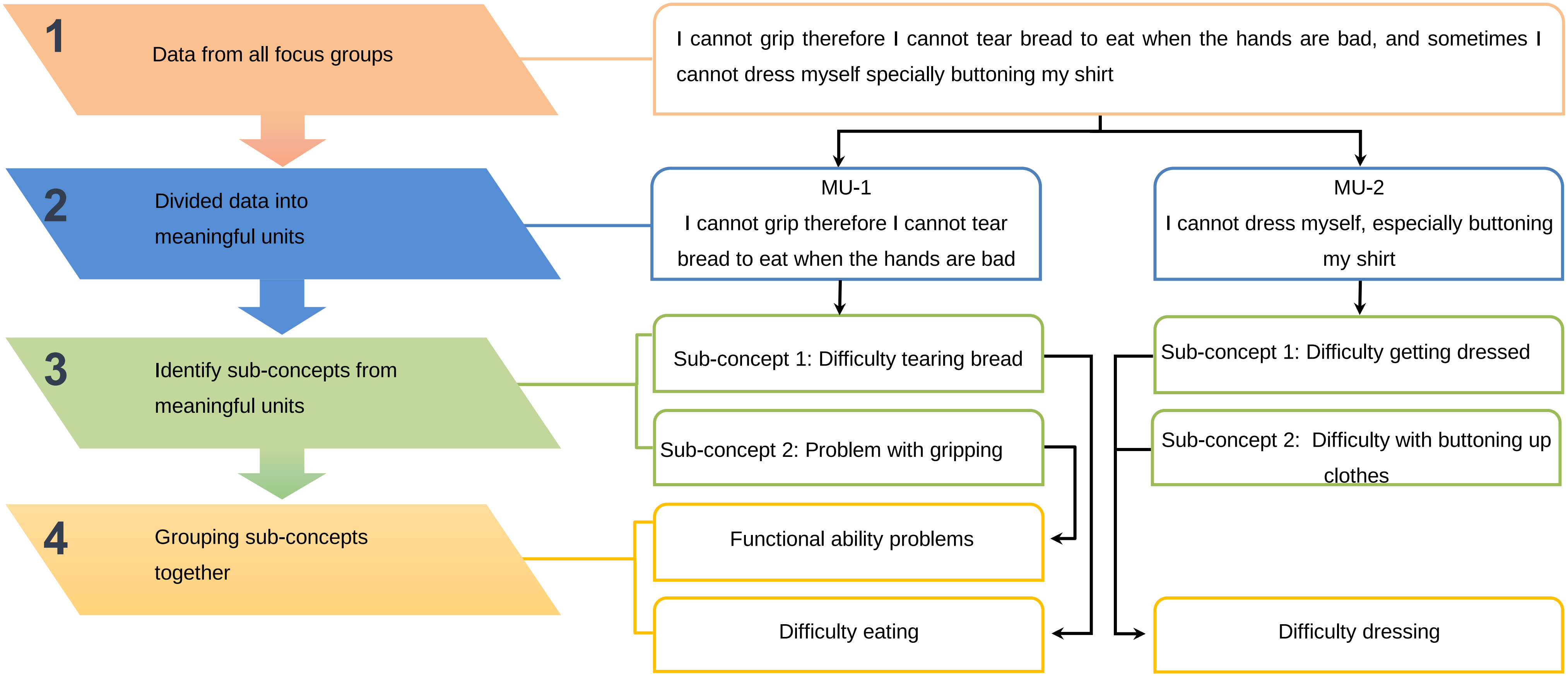


Figure 5-4 Data analysis steps using meaning condensation procedure with an example (Kvale and Brinkmann 2009)

5.6 Enhancing trustworthiness in qualitative research

Qualitative research is fundamentally subjective and open to interpretation and different perceptions. However, qualitative research in general and qualitative content analysis, in particular, must be open to scrutiny at every point, from the data collection stage to the reporting of the results (Elo et al. 2014). Quantitative research evaluation criteria are mainly rooted in a positivist research paradigm, which focuses majorly on validity, reliability, and generalisability. However, qualitative research differs from conventional positivist in its research purposes and inferences process, making the traditional criteria unacceptable for qualitative researchers (Finlay 2006; Finlay and Ballinger 2006; Tracy 2010; Korstjens and Moser 2018). Given the diverse forms of qualitative research, there are no globally accepted criteria to assess qualitative research (Leung 2015). However, trustworthiness criteria, introduced by Lincoln and Guba (1985), are commonly used with qualitative content analysis studies (Elo et al. 2014). Lincoln and Guba (1985) redefined the qualitative criteria as credibility, dependability, conformability, and transferability. Finlay and Ballinger (2006) argued that there is a need to link the choice of evaluation criteria of qualitative research with the researcher’s ontological position. Therefore, in this focus group study, as a result of the researcher’s subtle realist position, the proposed criteria of Lincoln and Guba (1985) were considered appropriate to ensure that this study is carried out thoroughly and carefully (Finlay and Ballinger 2006; Elo et al. 2014). Furthermore, to enhance confidence in the quality of this study, the COREQ checklist (Tong et al. 2007) was used as a guideline for reporting this study (Appendix G). The next sections provide a detailed overview of how each trustworthiness criterion was addressed in the study.

5.6.1 Credibility

Credibility is one of the most important criteria for establishing trustworthiness and has replaced the idea of internal validity in quantitative research (Lincoln and Guba 1985). Credibility criterion assesses the confidence in the truth of the findings (Shenton 2004; Finlay 2006). To enhance the credibility of this study, strategies recommended by Shenton (2004) and Elo et al. (2014) for qualitative research were used. These are detailed below.

Firstly, the selection of the most appropriate method for collecting qualitative content analysis data is essential for establishing credibility (Elo et al. 2014). Therefore, it was recommended that the method for data collection and analysis are derived from evidence, which has been successfully utilised in previous comparable research projects (Shenton 2004). In this study, the data collection method, sampling strategy, and the selection of the analysis method were derived from similar rheumatology projects, as outlined earlier. Importantly, the sampling strategy employed in this study warranted that patients with diverse clinical variations were represented in the study sample, thus the findings are constructed based on the contribution of a range of people with RA (Shenton 2004). Additionally, this study underwent a rigorous peer review process before ethical approval was sought; consequently, it has been refined and developed based on the different perspectives of those who reviewed the research.

Considering credibility, it is important to reflect on the researcher's background, qualifications and expertise, as the researcher is the primary instrument of data collection and analysis (Shenton 2004). Therefore, detailed Information about the researcher's skills, qualifications and training are included in section 5.5.3.1 and Chapter 7 (section 7.7). Enhancing the researcher's interviewing skills through training and a pilot focus group study supported the researcher to raise self-awareness when interviewing the participants. Self-awareness is an essential component for establishing credibility (Koch 2006), as the researcher aims not to influence the direction of the interview. As recommended by Shenton (2004) and Koch (2006) a reflective diary was kept to raise the researcher's self-awareness and enhance the credibility of the qualitative study (Shenton 2004; Koch 2006). This diary was used to document the researcher's observations, impressions, and thoughts. The reflective diary was divided into three main sections: preliminary visits to the rheumatology clinic, data collection, and on-going reflection about the analysis. During visits to the rheumatology clinic, the reflective process involved a description of the medical care provided for Palestinians with RA, as well as describing the situation in the clinic in detail. Furthermore, the reflective diary entries that were undertaken after each focus group session included describing the participants' characteristics and other details about them during the focus groups sessions. Furthermore, notes were taken during the focus groups discussions, as well as were during the process of analysis, in order to allow the researcher to reflect on the analysis as the concepts and grouping of sub-concepts were generated. Although the participants' raw data from the group sessions was the focus of the analysis, the reflective diary and notes were useful to raise the researcher's awareness of his own beliefs and predisposition, which may influence the analysis (Wall et al. 2004). To further enhance the reflective process, regular supervisory meetings were used as an opportunity to highlight any practical issues and raise awareness about the analytical process, as recommended by Shenton (2004). Elo et al. (2014) recommended that the recorded data should also be examined throughout the data collection process as a strategy to support the researcher's ability to critically assess his/her actions and raise self-awareness. Accordingly, the first recorded focus group data were listened to prior to conducting the next focus group interview, with each one being critically reflected upon to identify key points.

The researcher developed a familiarity with the culture of the participating rheumatology clinic involved in participant recruitment early on, before the data collection took place. This was due to the fact that the preliminary visits to the rheumatology clinic had contributed to developing a relationship of trust between the researcher and staff (Shenton 2004). Furthermore, it helped the researcher to understand the process of care offered to the Palestinian people with RA. This engagement process confirmed the researcher's commitment to reflecting the participants' reality, because it supported the researcher to challenge his personal assumptions.

Researchers are encouraged to employ different tactics to ensure participants are truthful and authentic when sharing their experiences and views (Shenton 2004). Participants could have been worried that their views and identity would be shared with their healthcare provider. Therefore, participants' honesty was encouraged by explaining and reaffirming their rights to confidentiality, anonymity, and the fact they had the freedom to take part or to withdraw. The researcher was aware that his position could influence the participants' responses and carefully considered how to introduce himself to the participants. For instance, the researcher introduced himself as a postgraduate student rather than as a clinical academic, aiming to reduce any potential barriers relating to possible perceptions around hierarchy and expertise. Subsequently, participants may have felt reluctant to share their experiences, as they may have felt that their views or experiences were wrong. Therefore, to enhance their honesty, the researcher explained to the participants of each focus groups that there were no right or wrong answers to the questions asked and that the researcher was simply interested in hearing about their personal views and experiences.

Involving the research participants in confirming and checking the results is referred to as respondent validation or member checking, and is a method used to minimise the researcher bias and enhance credibility (Shenton 2004; Birt et al. 2016). This was not achievable in this study because of limited resources, that is to say, the researcher was not able to travel back to Palestine to check and confirm the results personally with the participants. However, the researcher did check whether his understanding of the participants' accounts was accurate during and at the end of the focus groups. This was attained by summarising the participants' responses, asking if they had been described accurately, whether they have anything further to add and whether they felt there was anything the researcher had failed to mention. This helped to confirm the data and ensure that the researcher did not control the direction of the focus groups. Furthermore, frequent debriefing sessions with the supervisory team were vital to discuss the research process and findings. Debriefing is based on the same principle as member checking, but involves the researcher discussing the research and findings with the supervisory team who have experience applying qualitative methods (Shenton 2004).

Finally, a triangulation procedure in which two investigators perform the analysis independently and then discuss their findings to reach consensus has been recommended to enhance the credibility and conformability of the qualitative analysis research (Finlay 2006; Elo et al. 2014). However, for inductive content analysis, there are no published recommendations on how this triangulation procedure should be performed. Therefore, it has been suggested that one researcher should perform the analysis and another researcher should be responsible for checking the whole analysis (Elo et al. 2014). Therefore, the procedure of triangulation used in similar rheumatology projects conducted by Stamm and her colleagues (Stamm et al. 2009; Stamm et al. 2011) was employed in this study, as described in the data analysis procedure section.

5.6.2 Transferability

Generalisability of the findings from the study sample to the larger population is a major concern in positivist quantitative research. However, since qualitative research is often conducted with small samples in a naturalistic setting with few control variables, then the generalisability of findings is not seen as relevant (Krefting 1991; Leung 2015). Despite the unique contexts in qualitative research, readers of the research may consider the situation comparable to their own (Lincoln and Guba 1985; Shenton 2004; Tracy 2010). To enhance transferability, the responsibility lies with the researcher to ensure that readers are provided with sufficient and rich contextual information (Shenton 2004). For this study, a detailed description of the setting has been provided in the method section (section 5.5.4), which is in line with recommendations from Shenton (2004) regarding enhancing transferability information, including the participating organisation, the total number of participants, the data collection method, the number and length of data collection sessions, and the time period over which the data were collected, have been detailed in this study (see section 5.7.1 and 5.5.4).

5.6.3 Dependability

In quantitative research, reliability is the quality criterion that refers to the extent the research findings can be replicated if using the same process and participants (Leung 2015). However, in qualitative research, the situations cannot be replicated due to the iterative nature of the research, thus making the reliability criterion redundant (Finlay 2006). Therefore, Lincoln and Guba (1985) introduced dependability as the equivalent criterion in qualitative research. They suggested that the researcher should provide sufficient detail to allow others to repeat their research without necessarily obtaining the same results. To enhance dependability in this study, as recommended by Shenton (2004), the researcher provided an account of all of the research activities and a detailed description of the processes within this study in the materials and methods subsections. Additionally, any deviation from the processes were documented and the impact reflected on accordingly. Finally, the transcription documents have been checked for errors several times by the researcher to enhance the dependability of the study findings.

5.6.4 Conformability

Conformability in qualitative research is the equivalent concept to objectivity in quantitative research. Conformability indicates that the findings should reflect the experiences of the participants, as opposed to the individual views and perspectives of the researcher (Shenton 2004). It has been suggested by Guba and Lincoln (1989) that conformability is achieved when credibility, transferability, and dependability are fulfilled. This indicates that research decisions and influences should be delineated clearly throughout the research (Koch 2006). To enhance the conformability of this study, the researcher acknowledged his predispositions and beliefs by reflecting on his ontological and epistemological stance. The reasons for favouring the approach used in this study have been articulated, and alternative methodology and methods have been discussed. Additionally, the weaknesses and limitations of the approach employed are demonstrated in a subsequent section of this chapter. Furthermore, having a second Arabic speaking research collaborator able to independently verify the researcher’s analysis and independently cross-check the findings enhanced the conformability of these results (Elo et al. 2014). Finally, to demonstrate an audit trail, as recommended by (Shenton 2004), the steps taken to collect, manage and analyse the study data are clearly described, and research documentation is included in the appendices.

5.7 Results

This section describes the focus group study's findings, which are organised as follows. The first section presents the characteristics of the participants and focus groups, as well as a reflection on the focus groups' dynamics. Following this, the description of the concepts obtained in the qualitative content analyses, alongside data saturation, are outlined. The last four sections present the concepts related to hand function assigned to the ICF components.

This study was not intended to compare women and men, however, for some concepts, a comparative analysis was introduced to permit a greater breadth of understanding of the context of the findings. The illustrative participants' quotes are provided with some additional, contextually relevant information. These quotes have been carefully translated, and minimally edited to maintain the flavour of what the participants said. To provide context/perspective for each quote provided, the researcher identified which focus group the quote derived from (e.g. FG1: focus group 1) and the participant number within the focus group (e.g. P1: participant 1).

5.7.1 Description of participants and focus groups

In total, 48 individuals with RA were invited to participate in this qualitative study. Twenty-three individuals with RA agreed to participate (48% recruitment rate). Three male participants cancelled their appointment prior to the focus groups. Despite their initial enthusiasm to participate, one participant was unable to rearrange the appointment around his busy full-time work schedule and another declined to participate because of time commitments for a social event. As is common with focus groups, one male individual did not attend on the day (Happell 2007). In total, 20 individuals with RA participated, 12 women (60%) and eight men (40%). The age range of the participants was 42-69 years, and the disease duration between one and 35 years. Three participants (15%) were retired, and 11 (50%) were unemployed. This study population reflects the high rate of unemployment (85.6%) reported among Palestinian people with disabilities in the West Bank (Kaur et al. 2016). All of the women who participated in this study had a primary or at most secondary educational level (equivalent to the General Certificate of Secondary Education (GCSE) in the UK). In contrast, three male participants had completed an undergraduate education and two of those had completed postgraduate education.

Table 5-6 details the overall participant characteristics for all of the focus groups and Table 5-7 shows the participant characteristics by focus group. Details of individual participants are included in Table 5-8. Five focus groups (three for women and two for men) were conducted, including participants with a range of ages and disease duration (Table 5-6). The duration of the focus groups ranged between 51 minutes and 63 minutes, with a mean of 55 minutes (SD 4.5 minutes).

Table 5-6 Participant characteristics in all focus groups

	***n* (%)**	**Age (yrs)**		**Disease duration (yrs)**	
		Range	Mean (SD)	Range	Mean (SD)
Women	12 (60)	42-69	53.3 (6.9)	1-35	9.8 (10.1)
Men	8 (40)	44-65	57.1 (7.1)	3-25	10.1 (3.9)
All participants	20 (100)	42-69	54.9 (7.1)	1-35	9.9 (8.0)

SD: Standard Deviation; Yrs: Years

Table 5-7 Participant demographics by focus group

FG	**FG composition**	**Employment status**	**Age (yrs)**	**Disease duration (yrs)**	**Educational level**
1	3 F	3 unemployed	Range:52-59 Mean: 55.0 SD: 3.6	Range:1-11 Mean: 7.0 SD: 5.3	3 secondary
2	4 F	1 employed 3 unemployed	Range:45-54 Mean: 50.0 SD: 4.2	Range:1-6 Mean: 3.0 SD: 2.2	2 primary 2 secondary
3	5 F	4 unemployed 1 retired	Range:42-69 Mean: 55.0 SD: 9.8	Range:4-35 Mean: 16.8 SD: 12.3	2 primary 3 secondary
4	4 M	3 employed 1 unemployed	Range:44-65 Mean: 53.8 SD: 8.8	Range:8-13 Mean: 11.3 SD: 2.2	1 undergraduate 1 postgraduate 2 primary
5	4 M	2 employed 2 retired	Range:57-65 Mean: 60.5 SD: 3.3	Range:3-15 Mean: 9.0 SD: 5.2	2 primary 1 secondary 1 postgraduate

FG: Focus group; F: Female; M:Male, Yrs: Years, SD: Standard Deviations

Table 5-8 Individual participant demographic information

FG	Participant	Employment status	Age (yrs)	Disease duration (yrs)	Educational level
1	P1	Unemployed	54	11	Secondary
	P2	Unemployed	59	1	Secondary
	P3	Unemployed	52	9	Secondary
2	P1	Unemployed	53	3	Primary
	P2	Unemployed	48	2	Secondary
	P3	Employed	45	6	Primary
	P4	Unemployed	54	1	Secondary
3	P1	Retired	69	12	Primary
	P2	Unemployed	51	4	Secondary
	P3	Unemployed	57	10	Secondary
	P4	Unemployed	42	23	Secondary
	P5	Unemployed	56	35	Primary
4	P1	Employed	51	12	Undergraduate
	P2	Unemployed	44	12	Primary
	P3	Employed	55	13	Postgraduate
	P4	Employed	65	8	Primary
5	P1	Retired	65	15	Secondary
	P2	Employed	60	11	Primary
	P3	Employed	57	3	Postgraduate
	P4	Retired	60	7	Primary

FG: Focus group; P: Participant; Yrs: Years

- **Reflection of the focus group dynamics**

Participants in all of the focus group were relaxed and easy to engage. They listened to, related to and discussed the questions effectively with each other, which made it easy for the researcher to encourage pertinent discussions. However, the level of engagement and interaction of the participants differed between focus groups. For instance, the women in focus group three actively interacted with each other, that is to say, they clearly expressed their consensus and/or disagreement in relation to the others' experiences, and they asked questions among themselves. In contrast, the researcher did not feel that the participants in the second focus group engaged as effectively as the other groups. All of the participants, however, were friendly and seemed comfortable within their group, and therefore shared their information and experiences freely.

When reviewing the focus groups conducted with women compared to those conducted with men, it was apparent that the women were more emotionally expressive. For example, in focus group three, one participant started to cry, this emotional expression was not present in the male only group. Furthermore, all of the participants in this female only focus group showed empathy with the participant and the level of active interaction increased afterwards.

Overall, discussions were polite, and participants tended to wait for their turn to speak to each other and to the researcher. On occasions, the discussions strayed off topic, but this was monitored by the researcher, and sometimes by the group members, who brought the discussion back to the original question asked. However, a participant in the fourth focus group session occasionally did not wait for his turn to speak and sometimes coerced the others into agreeing with his views. The researcher curbed this dominant participant, by addressing questions to group members who were reluctant to talk, to balance out their participation. This was accomplished by politely telling him that the researcher appreciated his feedback, but also liked to hear from other focus group participants.

5.7.2 Concepts obtained in the qualitative content analyses

The number of concepts and sub-concepts identified and aligned to each ICF component is presented in Table 5-9. The transcribed Arabic data resulted in 4,731 lines of text. In the transcribed data of the focus groups, 666 meaningful units were first identified. From these, 224 sub-concepts were identified, which were then organised and grouped into 32 concepts. Activity and participation comprised the largest number of concepts (16 concepts), followed by body function and structure (7 concepts), personal factors (5 concepts), and finally environmental factors (4 concepts).

Table 5-9 Number of concepts and sub-concepts related to the ICF components

ICF components	Number of concepts	Number of sub-concepts
Body function and structure	7	41
Activity and participation	16	105
Environmental factors	4	29
Personal factors	5	49
Total	32	224

A preliminary evaluation of the raw focus group transcripts showed saturation after the fourth focus group session (i.e. no new concepts were identified in the fifth focus group). Saturation has been defined as the point during the data analysis in which two consecutive focus groups reveal no additional concepts that have not already been obtained (Coenen et al. 2012). However, after in-depth qualitative data analysis, one concept, which was not derived from the initial focus groups, was identified in the last focus group transcript. The number of new concepts from each successive focus group developed from 22; to 4; to 3; to 2; to 1.

5.7.3 Concepts in the body function and structure component

Before asking the in-depth questions, the first question in the topic guide (Table 5-1) was about what participants felt was the most affected structure of their hand(s). There was a wide variety of responses across and within all of the focus groups, however, generally, it was reported that the PIP joints and wrist joints were thought to be the most affected hand structures, followed by the MCP joints, and the least affected being the thumb joints. Several participants recognised that when the wrist joint was involved, the hand movements or activities were severely affected. For example, one participant stated that the involvement of his wrist joint reduced the ability to move and use the hand:

> *‘When the wrist area swells, it is so excruciatingly painful that it becomes impossible to move my hand [...] it’s so debilitating, because all my hand movement comes from the wrist’ (FG4, P3)*

Participants in the focus groups revealed that they felt there was a variation in the impact of the disease on their right and left hand (i.e. dominant vs non-dominant hand). They also identified that involvement of their dominant hand was very important in how successfully they felt they could carry out their daily tasks. It seemed that the participants' ability to accomplish ADLs is heavily dependent on the participants' feelings that they have a functional dominant hand. The participant in the example given below described how the fact her right (dominant) hand was less affected helped her to accomplish her ADLs, but she also highlighted that both hands are required for her to complete her activities.

> *'I feel very fortunate because my right hand is not too bad […] most people use the right hand more. However, my left hand is the problem for me and requires help' (FG2, P4)*

The second question in the guide was an in-depth question to identify hand abilities and impairments considered important for Palestinian people with RA. The seven concepts shown in Figure 5-5 related to the body function and structure component of the ICF were identified as being important by participants. The next sections will present these seven concepts in more detail.

5.7.3.1 Disease symptoms and body structure of hand and fingers

This concept is related to the disease symptoms which have been experienced by the participants, and which are described by participants as influencing their hand function. Participants often recounted typical RA symptoms of pain, stiffness, and swelling in their hands. The qualitative analysis revealed a detailed description of pain identified as important to them, including a description of pain sensation, night pain, pain at rest, pain intensity, pain in specific hand parts, activity-related pain and pain affecting sleep. Illustrative quotations of pain description are presented in Table 5-10. Hand pain was perceived as a barrier for performing activities or making continued activity impossible. Participants revealed that during periods of severe hand pain, their ADLs were adversely affected.

> *'For me, on the days when the disease comes to me and the pain increases, I just have to stay in bed. I cannot move and use my hands' (FG5, P4)*

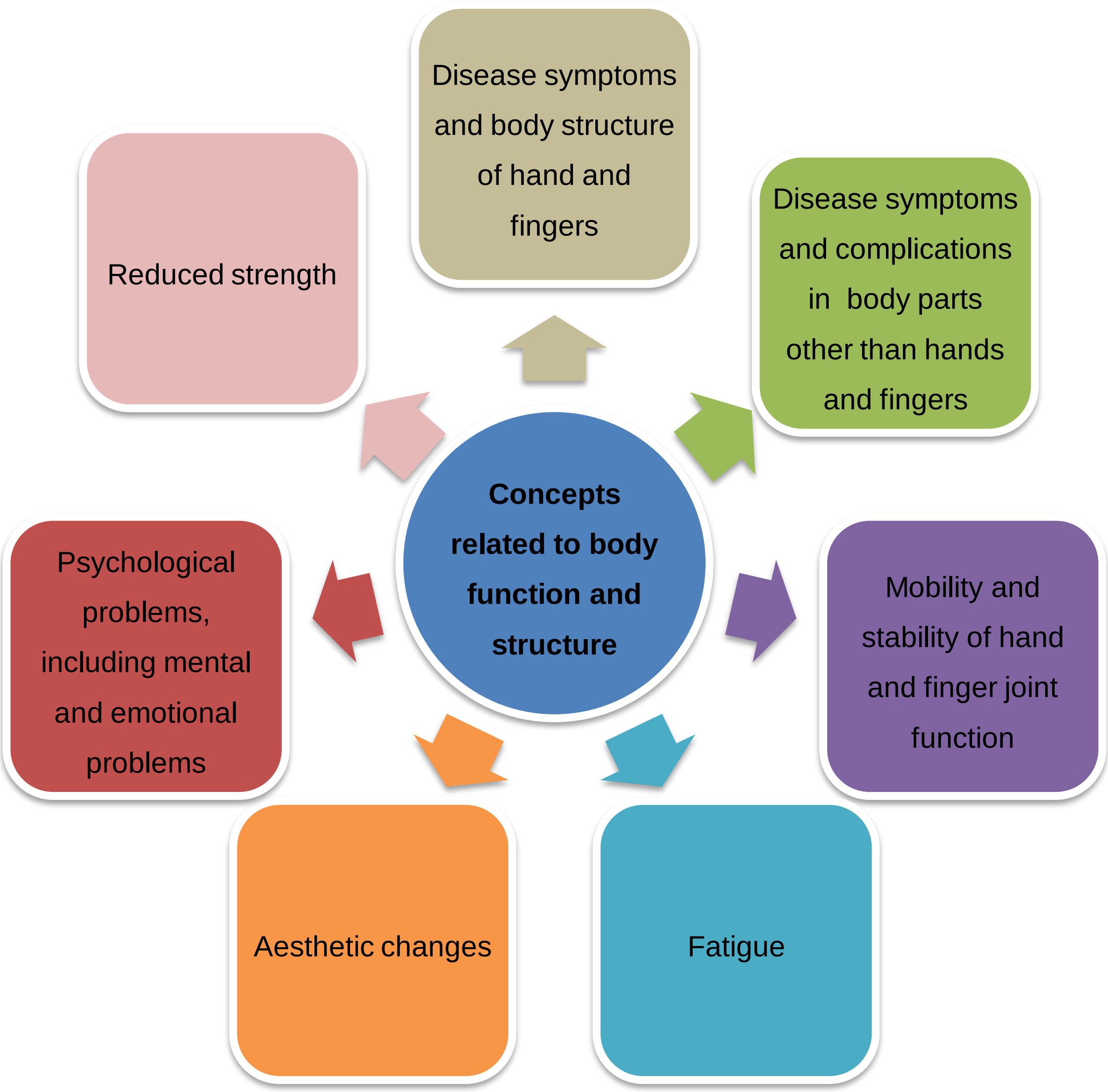


Figure 5-5 Concepts related to body function and structure components

Table 5-10 Supporting quotations for the participants' description of their hand pain

Pain description	Illustrative quotations
Night pain	*During the night I experienced such excruciating pain in my hand, that when they [my family] took me to the hospital, I said to them [medical staff] just chop it off, I don't want my hand. I can't take the pain anymore! (FG1, P3)* *…in the night I put it [my hand] beside me, like the one who is putting a baby to sleep beside him, because of pain (FG2, P4)*
Pain in specific hand parts	*Exactly, yes, the middle joint [the PIP joint] is the most painful joint (FG1, P1)* *So far, my thumb is still hurting me, I mean, the pain in my hand and fingers is less, but this finger [thumb] is still agonising (FG3, P3)* *Believe me, when you are weeding the herbs, you feel like the herbs have defeated you, and the pain starts in the joint making it impossible to continue (FG4, P3)*
Description of pain intensity	*Too much pain (FG1, P2); Very, very severe pain (FG5, P1); Excruciating pain (FG5, P3)*
Description of specific pain sensations	*I feel the pain like burning in my bones (FG1, P3); The pain is like a knife or saw cutting (FG1, P1); The pain is like an awl digging into my hand joints (FG5, P4)*
Activity related pain	*When I, for example, want to wash dishes, and I want to apply pressure onto the dishes, I cannot, I feel too much pain, and [it is] too difficult (FG2, P3)* *If I want to clap hands [in a wedding] like this [participant clap hands], to let my group [relatives or friends] feel I'm good and participating, when I go home, I cannot sleep because of the extreme pain in my hands (FG3, P1)* *So far, when I carry a bucket, of course, there is pain going on in my hand (FG4, P2)* *If I want to do hoeing under a tree […], I will stay two nights unable to sleep because of the pain in my hand (FG5, P1)*
Pain at rest	*Right now that I'm sitting with you, I feel pain here [participant pointed to his wrist] (FG5, P1)* *Pain exists for twenty-four hours a day (FG4, P2)*
Pain affect sleep	*Sometimes I could not sleep at night, because of my hand pain (FG2, P1)*

The hand pain itself, or together with poorly adapted environments, prevented the participants from engaging in their valued daily activities. Activities were described by participants as a mediator of hand pain and having both a positive and negative impact on the level of pain perceived. Participants recounted that being involved in activities, especially social activities, helped their wellbeing, as it allowed them to shift their focus away from thinking about their hand pain.

> *'…I feel that doing nothing and sitting at home is the cause of idleness […] for instance when I have houseguests, I feel more active and forget my hand pain, but when I'm doing nothing, I feel tired and psychologically affected' (FG2, P3)*

Participants also identified and named specific activities that they felt would induce their hand pain, subsequently making continued daily functional activities impossible (e.g. clapping hands, wringing out clothes and garden work). Most participants also felt that if they overused their hand, it would ultimately lead to an increase in their level of hand pain. In many instances, participants were able to specifically locate their pain to particular hand parts such as the wrist joint, PIP joints and palm. However, participants described different hand pain presentations, that is to say, there did not seem to be a typical hand pain presentation between participants.

Similarly, the participants understood that swelling was another important hand symptom, due to its negative impact on their movement and daily activity. Participants provided different descriptions of how they identified their swelling using both visual descriptors of the signs, as well as symptomatic explanations about how it felt to have hand swelling, using words such as *"very swollen" (FG1, P3), "very red and blue" (FG3, P3)*, and *"spongy" (FG5, P1)* to describe this symptom. They reported transient periods of joint swelling and noted that the swelling would appear in one hand location and then move to another joint.

> *'…swelling, for example, my supervisor comes to me, and I have to tell him that I am unable to grip a pen or chalk to write on the board, the hand swelling paralyses your ability to move your hand' (FG5, P3)*

> *'… you wake up in the morning and your hand is swollen in the joints, not all of them, this finger in the middle is the most [swollen], but the next day you find it [swelling] has moved to another joint' (FG1, P3)*

Joint stiffness was another commonly reported symptom. Most participants described classic morning stiffness, while others described stiffness that lasts all day. However, in all of the focus groups, participants recognised stiffness as another important symptom, due to its negative impact on movement and activity, rather than in terms of its duration or severity.

> *‘In the morning, when you wake up, you feel like your joints are rigid [stiff], and you cannot move your hand at all’ (FG5, P3)*

> *‘…in the morning I wake up, and I find my hands are rigid […] when I try to work, they [the hands] cannot help me’ (FG2, P3)*

In many instances, the participants talked about their symptoms in relation to how active their rheumatoid disease was and described this as an increase or decrease in disease symptoms using terms pertaining to disease activity such as “*disease is high*” (FG3, P4) and “*rheumatism is low*” (FG3, P5). Generally, the participants also identified that their symptoms were fluid and varied daily.

> *‘There are some days when I am more active, not all days, some days, I wake up in the morning, and the rheumatism is low, and I feel active and then I do all the housework’ (FG3, P5)*

Some participants reported a worsening of symptoms, particularly during cold weather. One participant used the word ‘*enemy*’ (FG5, P1) to describe the cold and its pervasive effect on their level of pain. Many participants mentioned worsening symptoms in association with an activity, whereas few participants reported worsening symptoms in association with mood.

> *‘…when there is extreme cold, you cannot move your body and hands, even with medication, there is still such extreme pain in my hands’ (FG5, P2)*

> *‘…if I work a bit and get slightly tired, my fingers swell immediately’ (FG4, P1)*

> *‘…I mean, if I just get angry or sad, the pain increase in my hands, yes, it immediately increases to high’ (FG3, P5)*

5.7.3.2 Disease symptoms and complications in body parts other than hands and fingers

This concept emerged from disease symptoms and complications in body parts other than hands and fingers, which influence the ability to use the hand in day-to-day activities. On many occasions, participants described how their RA symptoms and the subsequent consequences on other body parts, particularly upper limb joints, have a negative impact on their daily activities. Furthermore, a few of them stressed that hand and upper limb problems are interrelated and should not be separated.

> *'In general, the problems are in the hands, and the problems develop to involve the elbow and shoulder […] you cannot separate the hand problems from the upper limb problems' (FG3, P1)*

> *'For example, I used to cut Molokhia* [Jute mallow] *with my hands, but I had to stop, then I had to use the mezzaluna knife, but it caused shoulder and hand pain, so I had to stop, and now I use the Moulinex* [blender] *to cut it' (FG3, P4)*

The quotes above demonstrate participants' difficulties in isolating the hand from the rest of the body, particularly from the upper limb with regard to their experiences of activity limitation.

5.7.3.3 Mobility and stability of hand and finger joint function

This concept comprises participants' accounts of the problems related to the mobility and stability of the hand and finger joint function. Participants described several activities that they have faced difficulties doing, due to an inability to move (open or close) their hand and finger joints actively. Participants with a longer disease duration often recognised the limitations they face in terms of moving their hand(s) freely and reported this as a problem for them.

> *'… look [the participant showed his hands], I can't close my hands as well as I want […] I was working, but, as I said, this happened to me, and so I'm not able to work anymore' (FG4, P2)*

Similarly, the participants reported examples in which the stability of their hand(s) and fingers influenced their ability to use their hands.

> *'…If it happened, for example, and I sit on the floor, not on the chair and I want to stand up, my hand snaps and I cannot stand up' (FG3, P2)*

5.7.3.4 Reduced strength

Participants in all of the five focus groups reported that they recognised that their hand strength had been reduced. One participant provided an estimate of his current hand strength *'you can say it [hand strength] is sixty percent' (FG5, P3)* compared to the strength before having the disease. Furthermore, participants provided examples of daily life activities (e.g. carrying and lifting activities) they have experienced difficulty with, as a result of reduced hand strength.

> *'…I don't have [hand] strength; I used to wring the clothes out, right now I just move them from the washing machine to the dryer' (FG2, P1)*

5.7.3.5 Fatigue

The concept of fatigue was described by the participants as physical exhaustion and tiredness, having consequences for hand use in everyday activities and requiring rest after carrying out normal daily tasks. Furthermore, participants described that the fatigue impeded their ability to continuously carry out hand-related activities.

> *'This year I cut Molokhia* [Jute mallow] *for my daughter […] I picked and cut nineteen kilograms, truly my hand got tired, I would have to stop and rest my hand for a bit, then I would grip the knife again and cut, till I finished them' (FG3, P1)*

For the majority of the participants, fatigue restricted their ability to fulfil normal social roles that require hand use, causing them to reduce their activities, particularly social activities. However, functional roles and work were given a higher priority than social activities, consequently participants described their efforts to plan, pace, prioritise and relax/rest in response to their hand-related fatigue.

5.7.3.6 Aesthetic changes

The concept of aesthetic changes included problems of appearance (if the appearance of the hand and fingers was bothering the participants) and the wearing, or not, of jewellery. Aesthetic concern was a salient factor related to the participants' psychological status, particularly for the younger female participants. They expressed their concern and embarrassment about their deformed hands. Quite a few female participants raised worries about developing fingers deformities or the progression of deformities to other fingers. The quote below describes how a young female participant felt embarrassed by the appearance of her fingers, and consequently, how she tries to hide her hands in public.

> *'My fingers were thin, but they became plump. I really feel embarrassed because of this…a person who's ninety years old is not like me. I hide my right hand, especially when it became like this, because I don't like to show it to others' (FG3, P4)*

Another female participant described how she struggled to remove a ring and ended up not wearing rings.

> *'…when I went to a social event, I put on my ring, but when I came back, I could not remove it until I used oil to pull it off. For this reason, I have thrown them [my rings] away' (FG3, P5)*

5.7.3.7 Psychological problems, including mental and emotional problems

This concept was related to psychological distress caused by an inability to use their hands effectively in everyday activities or due to RA hand symptoms/physical appearance. Participants described having emotions such as anxiety, fear, frustration, sadness, a sense of oppression, a sense of guilt and embarrassment when detailing the impact of having RA in their hand(s) on them. The participants specifically identified that these psychological problems were linked with the functional constraints of their hands, as well as the disease symptoms, particularly due to pain, swelling and the change in appearance. However, in some circumstances, what affected the psychological status of participants and subsequently affected their hand function, was not only the RA hand complications, but also environmental factors such as having a poor socioeconomic status and their family's attitude (i.e. not feeling understood by family members).

> *'My psychological status is affected so much, especially when my fingers are swollen' (FG3, P4)*

The most frequently expressed emotional response reported by the majority of the participants was frustration and embarrassment, which in turn had the potential to cause to depression or anxiety. This was often reported when the participants were not able to complete or carry out tasks or when alternative methods of doing tasks failed. In addition, hand functional constraints and an inability to conform to social norms made the participants feel uncomfortable in certain settings, as the quotation below illustrates.

> *'…the food was slipping from my spoon and people were looking at me. I became too embarrassed to eat in front of others' (FG1, P3)*

The excerpt above illustrates how difficulties with hand function may impact on social activities and relationships. The embarrassment of not being able to use the spoon in a proper way in public and the subsequent outcome of the food slipping had had an adverse impact in terms of social restriction, but even more importantly, it may lead to possible stigmatisation. For the participants, this example indicates that maintaining their dignity and independence are considered as higher order values. Overall, the issue relating to embarrassment was more evident in the accounts from the female participants and was especially notable among the younger women. Thus, it seemed that for the younger Palestinian females with RA, their social persona was affected by the visibility of their hand deformity or functional inability.

5.7.4 Concepts in the component activity and participation

The data showed that hand-related activities are interlinked within the overall ability to complete tasks in everyday life. Some individuals experienced functional limitations of the hand as a common feature of everyday life, whereas for others, they were related to specific tasks such as chopping food. Furthermore, the data revealed that participants experienced a wide range of hand-related activity problems, depending on their personal circumstances, life stage and roles. However, the variations that occurred largely depended on gender and related social roles. Men were primarily concerned about the loss of their role as breadwinners and commented on difficulties performing manual work such as stone carving. In contrast, women were more concerned about their loss of roles involved with taking care of their family and homemaking such as preparing food. Hand functional limitations often resulted in a loss or change of role and a perceived shift in their sense of identity when they could no longer perform the activities they had previously been able to perform. The major concern for the participants regarding identity was about distinguishing themselves before and after the onset of their disease symptoms and hand problems, and the subsequent loss or fear of losing their social or financial roles. Few participants identified themselves as being “disabled” because of their inability to use their hands effectively in daily life activities. Notably, independence in performing activities associated with their principal productive social roles was seen as a crucial factor in identifying as being “disabled” or not. For others, particularly young women, disability was viewed as a physical, observable, hand structure deformation.

> *‘It is almost a complete disability to perform any work’ (FG4, P3)*

The importance of maintaining independence and autonomy were reiterated throughout the focus groups due to the loss, or fear of losing hand function abilities. If individuals were no longer able to do activities related to daily living or those related to their social roles, then they were more likely to perceive themselves as being dependent. Many participants revealed that needing to depend on others was causing them to become frustrated, as they felt a loss of control. Other participants expressed their fears of losing their independence in the future and maintaining their level of control.

> *‘…if I had, for instance, cancer then it would be fine, because with cancer you know you will die, but having this disease and then disability, this is what I am afraid of, because I have seen my mother’s deterioration - she is unable to help herself and I do not want to be like her’ (FG3, P3)*

However, the participants appeared to be pro-active in their attempts to stay independent, and provided examples of how they had found new ways or changed their habits of doing activities, and changed their activities.

Concepts of hand function pertaining to the activity and participation component of the ICF were grouped into six domains including self-care, productivity, religious practices and rituals, social participation and interaction, leisure, and mobility and functional ability. Figure 5-6 shows all of the concepts within each of these domains. The next sections present the major concepts within each domain.

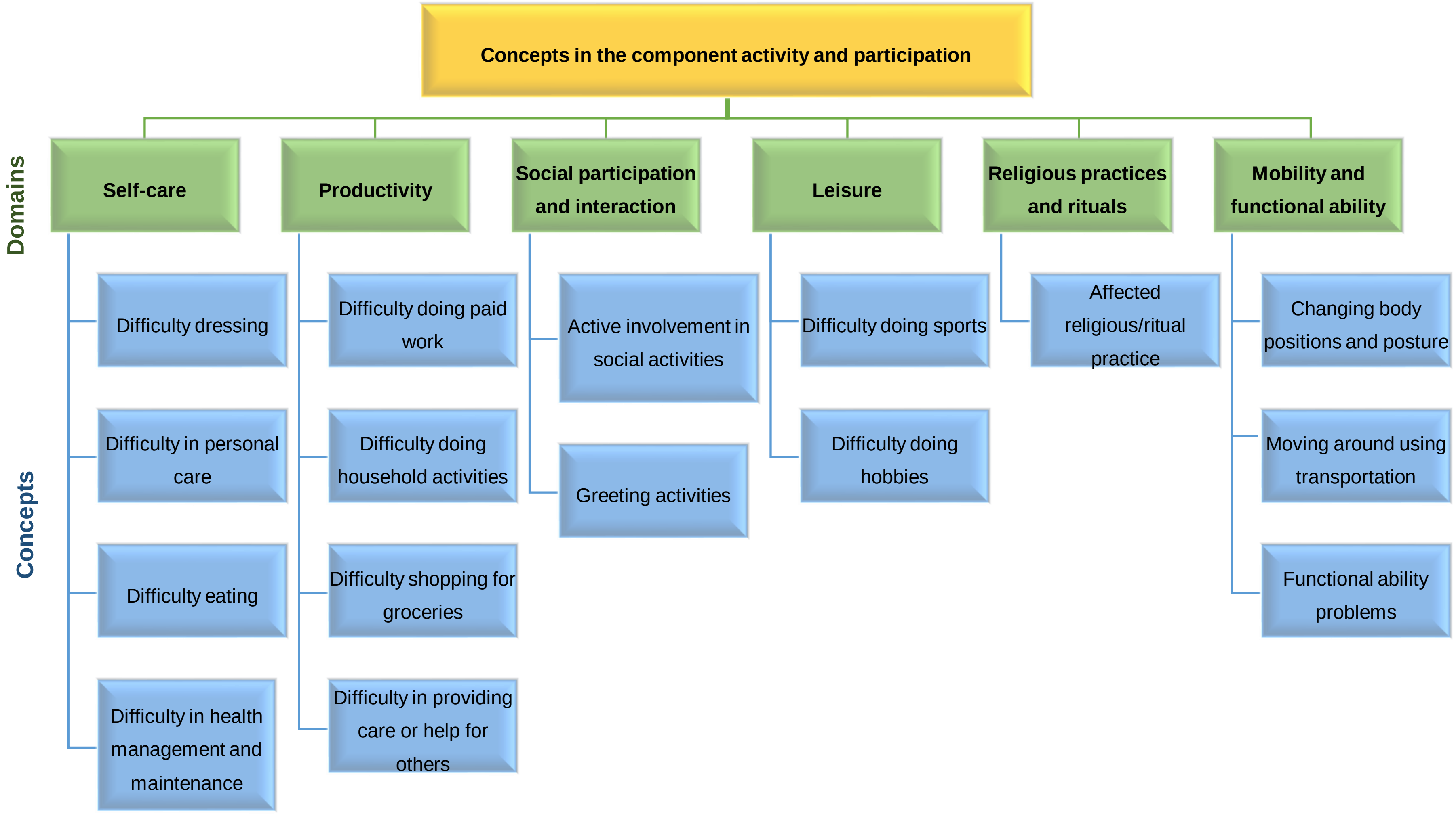


Figure 5-6 Concepts related to the activity and participation component

5.7.4.1 Mobility and functional ability

The mobility and functional ability domain included “changing body positions and posture”, “moving around using transportation”, and “functional ability problems” concepts. The participants reported a few activities related to changing body positions and posture that were difficult or impossible to perform such as pushing up to stand from the floor and getting out of or turning in bed. These activities posed a lot of challenges, particularly pushing up to stand from the floor, because this is an important activity performed many times a day by Palestinians, either when pushing up to stand from sitting on the floor (the traditional way of sitting for Palestinians) or during Muslim prayers (performed five times each day). Quite a few participants reported that the fact they have difficulty in pushing themselves up from the floor had considerably affected their safety, reporting that they had previously fallen trying to stand up from the floor.

> *‘…I went on a trip with my children and there were no chairs to sit on, and I sat on the floor near the edge of the swimming pool, I tried to stand up but I could not and I fell in the swimming pool’ (FG3, P1)*

Problems related to transportation were reported by the participants. These included problems related to getting into and out of public transportation and driving a car. Opening doors and using grab rails to assist in getting into and out of public transportation were reported as very difficult by many of the participants. Some participants avoided traveling alone and reported that they usually arrange to have a family member assist with transportation. The male participants reported difficulties when driving a car, due to problems handling the shift and holding on to the steering wheel. Those with a long disease duration reported that they are currently unable to drive a car, mainly due to the loss of mobility and function in their hands and fingers. However, others reported that hand pain was the major cause of them not driving.

> *‘I used to be a bus driver. These days, I cannot grip the wheel of a car, and I cannot drive at all’ (FG5, P4)*

Problems with functional skills or tasks described by the participants to be basic and fundamental to performing complex daily living activities were considered as functional ability problems. These included problems with fine hand use and control (e.g. problems with gripping), performing small day-to-day tasks (e.g. turning a key) and carrying/pushing/lifting things. Many participants reported several incidents of not being able to grip and pinch objects with their hands. They frequently spoke of difficulties carrying out activities that required hand dexterity and motor control skills such as picking up or handling small objects, writing, typing on computers, using scissors, and pressing with the fingertips when using (mobile) phones or TV remote controls. These functional activities were important to perform daily living activities particularly for those who needed them for their jobs.

> *'…I cannot pick up a needle, pin, or nail' (FG5, P2)*
>
> *'It is difficult for me to grip a pen and write' (FG1, P2)*

Furthermore, participants reported many incidents of sudden grip release which occurred unexpectedly and resulted in objects being dropped. This often led to objects breaking, which in turn infuriated the participants, leading them not to continue the activity. The problem of dropping things was exclusively revealed in the female focus groups.

> *'…like serving food, you may try to serve something, and it suddenly falls from your hands' (FG3, P1)*

Hand problems affected the performance of small tasks in the day-to-day living of the participants. They frequently spoke of difficulties in "turning a key", "turning door handles", "turning a tap on/off", "opening a new or tight jar lid", "opening a bottle" and "opening a can using a can opener". Female participants reported more difficulty doing these small tasks than men. This is possibly related to the fact that in their role of housekeeping, women usually perform these activities and that they require hand strength, which may be lacking, compared to the roles and tasks the male participants typically carry out.

> *'…it's difficult to turn a doorknob' (FG5, P2)*
>
> *'I cannot open a bottle with a tight lid; I gave it to my children to open it' (FG2, P3)*

Nearly all of the participants reported problems with activities that involved carrying, lifting and pushing objects, however, for a few participants even carrying or lifting light weight objects was a problem. The inability to hold and carry grandchildren was a difficult task, frequently reported by female middle-aged participants, which also had emotional well-being consequences (i.e. feeling sad).

> *‘When my daughter gave birth, I was not able to carry the baby. This made me feel very heavy-hearted’ (FG1, P3)*

5.7.4.2 Self-care

The participants reported difficulty with a range of self-care activities. As shown in Table 5-11, four concepts have been identified with regard to the self-care domain.

Table 5-11 A summary of self-care concepts and activities which participants reported having difficulty with

Self-care concepts	Activities	
Dressing	Putting on and tying a Hijab Putting on/taking off a dress Getting dressed Buttoning up clothes	Wearing socks Tying shoelaces Putting on shoes Putting on trousers
Personal care including personal hygiene, grooming, toileting and bathing	Combing and tying hair Toileting difficulties Having a bath	Cutting nails Rubbing the body Washing body parts
Eating	Pinching and holding the food to take it to the mouth	Tearing bread Use a spoon
Health management and maintenance	Opening medication containers	Taking medication

Compared to other self-care difficulties, dressing difficulties were the most frequently identified as important. These were described by the participants in all of the focus groups, particularly the tasks of putting on a dress and buttoning up clothes. A possible explanation for the participants frequently reporting dressing difficulties may be related to the fact that getting dressed without help from others has a strong personal meaning linked to independence. For instance, in focus group four, one participant said that getting dressed by himself gives him a sense that he is still alive.

> *'…If it took me two hours to dress or button up my shirt, I would not ask my wife or children to do it for me, because when I do it myself, I feel alive' (FG4, P3)*

Another important self-care concept is eating. This is because eating using one's hands (i.e. not using cutlery) is customary for Palestinians. The participants reported difficulties tearing bread by hand, and pinching and holding food to put it in their mouth.

> *'…sometimes I could not tear bread; If my wife did not tear it for me, then I was not able to eat' (FG4, P1)*

5.7.4.3 Productivity

The participants reported a number of problems in the productivity domain. These were problems related to identified concepts related to the difficulty of "doing paid work", "doing household activities", "shopping for groceries", and "providing care or help for others". Hand problems caused by RA can have a significant impact on the ability to work, and participants identified how difficult it was to keep on working or fulfilling their job roles. The participants also reported several specific problems related to doing their paid work, including those that were difficult or impossible to do such as typing on a computer, writing, handling small objects and holding tools such as knives. However, physically demanding work was reported by the men to be extremely difficult.

> *'Manual work and any physical and heavy work are impossible to do […] almost all of us are not working. I used to work in manufacturing stones. These days, it is impossible to do this work, it is impossible' (FG5, P2)*

Another participant, who had worked as a teacher, described how he was unable to fulfil the tasks required for his job.

> *'When it comes to me, I was unable to write my teaching portfolio; my colleagues were doing it for me' (FG4, P3)*

In addition to the difficulty of doing paid work, a considerable number of male and female participants reported difficulty harvesting their olive crops. In Palestine, picking olives is not only a source of income, but also part of the culture and heritage. Many participants highlighted that this work was difficult for them.

> *'...although I'm a teacher, you know I have olive trees […] for me I can't pick olives, I had been producing around one hundred to one hundred twenty gallons of olive oil, but unfortunately I can't do this anymore' (FG4, P1)*

One participant, who was a housewife. predicted that the impact her RA would have on her ability to take part in olive picking would be disastrous.

> *'The olive picking season is coming. This will be a disaster for me' (FG3, P4)*

Many problems were reported for activities related to household activities. These activities were grouped into: (1) home establishment and management, and (2) meal preparation and cleaning up, as presented in Table 5-12.

There was a gender specific reporting of household activities. Almost all household activities were reported within the female focus groups, excluding 'gardening or doing yard work', 'fixing a wall outlet or light switch' and 'changing a light bulb', which were exclusively reported in the male focus groups. This is in line with Palestinian culture and provides some indication of how the participants viewed themselves as performers of activities in specific gender roles. In the Palestinian context, which is a male-dominated society, women have multiple roles, primarily a housekeeping and child caring role, while home maintenance activities such as gardening activities are considered a male role. However, exceptions were reported regarding this, as Palestinian men may perform these activities in special circumstances (e.g. if the wife is sick) or as a personal preference.

> *'Who told you that one could not do the household activities? When your wife is sick, or she had surgery, who is going to take responsibility? For me, I have been preparing Suhur* [pre-dawn meal] *during Ramadan, and when I was going to work, I made my lunch food and every morning I made the breakfast for my children' (FG4, P3)*

Table 5-12 A summary of household activities which participants reported having difficulty with

Household categories	**Activities**	
Home establishment and management	Turning off/on a gas cylinder	Doing laundry
	Opening the refrigerator door	Cleaning the house
	Hanging out the laundry	Shaking the rugs
	Fixing a wall outlet or light switch	Changing a light bulb
	Attaching/detaching a gas cylinder	Wiping surfaces
	Lifting a bucket out of a well	Using a clothes peg
	Squeezing a hand cloth	Folding linen
	Opening a washing machine door	Sweeping a floor
	Wringing out cloths/clothes	Mopping the floor
	Gardening or doing yard work	Making a bed
Meal preparation and cleaning up	Using a knife	Digging courgettes
	Washing dishes, cups and cooking pans	Making Eid Cookies
	Opening/closing kitchen cabinets	Flipping a pot
	Stirring food in a pan	Cutting Molokhia leaves
	Cooking	Rolling grape leaves
	Serving drinks and food	Making pastries
	Kneading and rolling out dough	Chopping food
	Making a pot of coffee or tea	Purification of lentils
	Putting in/lifting out a tray from the oven	Squeezing fruits
	Peeling fruits and vegetables	Lifting pots and pans

Other male participants reported value in performing some household activities, because it was linked with their sense of independence. This was reflected by a male participant who described that he had been preparing his drinks (i.e. coffee and tea) without asking for help from his family, as he prefers to do it by himself.

> *'…I love to drink coffee and tea in the morning. I do all these activities [making coffee or tea] by myself without letting the family feel I need help' (FG4, P4)*

The participants frequently reported difficulties with shopping, due to an inability to carry shopping bags. This problem was thus explained by the embedded activity of carrying objects, reflecting how activities are interlinked within the overall ability to complete tasks in everyday life.

> *'I was responsible for buying the household groceries; I used to buy the vegetables […] now I avoid going to the markets […] carrying vegetable bags is just too difficult' (FG1, P1)*

The participants had varying responsibilities regarding their family that they identified had being negatively affected by their hand RA, including taking care of ageing parents, children, and grandchildren. Caring for their grandchildren and children was highlighted as both an important but challenging issue for the female middle-aged participants. Due to the fact they highly valued bathing, feeding, dressing and carrying their grandchildren, as well as providing help for their children, they expressed deep sadness at being unable to fulfil this role.

> *'When I went to the hospital with my daughter when she was giving birth, the women were helping her and I was sitting [there] useless' (FG1, P1)*

For the male participants too, caring for their children and helping others with work that required strength were also indicated to be valued activities that mattered to them, but also presented difficulties.

> *'…any work that requires the use of your hands, you cannot help with […] suppose someone asked you for help lifting bags, you cannot help' (FG5, P3)*

5.7.4.4 Social participation and interaction

Two concepts have been identified in the social participation and interaction domain including "active involvement in social activities is difficult" and "greeting activities are difficult". The concept "active involvement in social activities" reflected the participants' problems in participating and contributing to social activities, such as having houseguests and participating in weddings. Difficulty participating in social activities was reported to be secondarily affected by the experienced hand-related activity limitations particularly related to Palestinian culture such as hand clapping, making Henna, and serving guests at weddings. For many participants, a reduction of ability in activities that required the use of their hands had forced them to withdraw from social activities that they had previously valued. Furthermore, contributing to certain social gatherings was deemed to be very important in the social well-being of participants. The impact of what other people thought about the participants' ability to contribute to social events was particularly important and had a big impact on individuals.

> *'People who are unsatisfied with me are more than the people who are satisfied, because I cannot go [to weddings]. I mean, if I go, I need to participate, and if I didn't, they would wonder why I haven't participated, and this will bother them, the best is not to go…for instance, there are very close people to me, and I want to contribute and help them serve food and drinks to guests […], but I cannot carry anything' (FG3, P2)*

However, there were also examples of different levels of tolerance towards the impact of hand limitations on social participation. Some participants reported they were still satisfied with their social participation, even though they were now incapable of performing the same hand-related activities. For example, one participant described that he could continue to participate in weddings by pretending to clap his hands, which was sufficient for him to experience these important events.

> *'…sometimes they insist you participate [clapping hands at weddings], but I have been pretending that I am clapping my hands, like this [showed how he was clapping his hands], it was not done with high emotion, but it was okay' (FG4, P3)*

In the example above, the participant described his personal experience of participation, as well as the influence of the social context. It appeared that the experience of participation for some participants is not coupled with the capacity to perform hand-related activities.

In social interactions, participants reported difficulty doing activities that require the use of a hand to greet people, particularly including shaking hands and having the hands kissed by children. Many participants reported having difficulty shaking hands, mainly with what they called "warm handshaking" (i.e. hand shaking with more grip strength to convey emotion). However, a few women reported that handshaking was not a problem, as they did not shake hands with men. This indicates that performing hand-related activities is related to the individuals' life circumstances.

> *‘Shaking hands is difficult, they warmly shake your hand, and it is too painful’ (FG3, P1)*

A few participants reported having difficulty with their hand(s) when it was being kissed by their children. This is an important cultural greeting activity, which is usually done on specific occasions such as when celebrating Eid (religious holiday celebrated by Muslims), to show respect to one’s father or mother.

> *‘My son came to kiss my hands; I did not allow him to do this, because I cannot, it is too painful’ (FG3, P3)*

5.7.4.5 Leisure

The majority of the participants’ reported that their leisure time, spent doing sedentary and passive activities such as watching TV and informal gatherings with relatives or neighbours, had not been affected by the problems with their hands. However, a few participants experienced problems participating in recreational leisure activities that required hand use. For recreational leisure activities two concepts have been identified, which included “difficulty doing sports” and “difficulty doing hobbies”. The majority of the male participants reported a lack of opportunity to allocate time for recreational leisure activities during their everyday lives, however, a few of them reported that their sporting activities, which mainly depend on hand use such as table tennis and volleyball, had become difficult. Although sports activities were reported exclusively by men to be difficult, they were practiced occasionally and in specific contexts. For instance, one participant, who stated he was a teacher, reported playing volleyball when there was free time at school.

> *‘Playing volleyball at school is difficult […] how can I hit the ball with my hands?’ (FG4, P3)*

The concept ‘difficulty doing hobbies’ was identified in the female focus groups exclusively. Involvement in hobbies such as making pastries and sweets was reported by a few women to be difficult, although these activities are also part of a woman’s role preparing meals.

> *‘My hobby was making pastries […] currently it is very difficult to do it’ (FG1, P3)*

Possibly, leisure activities are easy to relinquish if time is limited, in favour of other important or essential activities such as work. This is because both male and female participants' who have reported difficulties with recreational leisure activities have also reported that they have had completely given up these activities.

5.7.4.6 Religious practices and rituals

The impact that hand problems had on daily religious and rituals practice, particularly with Salah (the Islamic praying activity), was evident across all of the focus groups. When praying, the participants described the difficulty they had in prayer practice, with their hands being painful and not strong enough to push themselves up from the floor from the prostration position used in prayer.

> *'…it is difficult to stand up from Sujud* [prostration during prayer]*, I cannot push myself up while my hands are open – it is far too painful. I have been making a fist to be able to push myself up' (FG3, P4)*

Participants also described experiencing difficulties with Islamic ritual practices, including doing Wudu (ritual washing which is performed in preparation for prayer) and Dua (a prayer of supplication or request).

> *'I was not able to do Wudu* [ablution before prayer]*. I was trying to collect the water with my hands to wash my face, but I could not do it' (FG2, P2)*

Whilst hand problems have affected the religious practices and ritual of Muslim participants, a Christian female participant reported that her hand problems have not affected her religious and ritual practices. It appeared that the difference in religious ceremonies may have an impact on the experienced hand-related activity limitations. This could suggest that individuals' life circumstances may influence the performed hand-related activities.

5.7.5 Concepts relating to environmental factors

Four major concepts related to the environmental factors have been identified (Figure 5-7) and are presented in the subsequent sections.

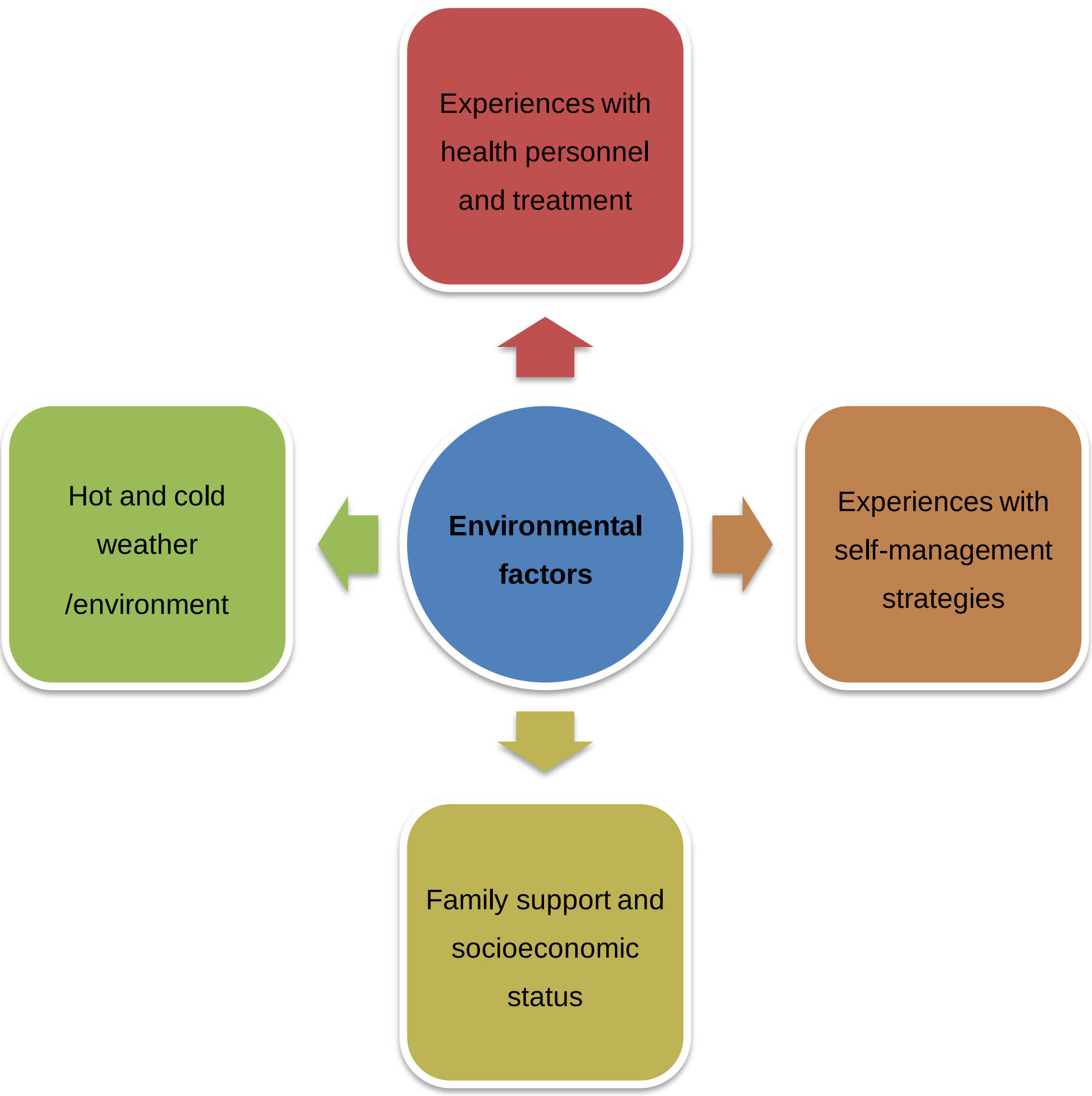


Figure 5-7 Concepts related to environmental factors

5.7.5.1 Experiences with health personnel and treatment

The participants in all of the focus groups talked about their experiences in relation to RA medical management and the potential impact on their hand function. These experiences were mainly about diagnosis difficulties, the treatment applied by health personnel and their relationships with health personnel. The participants had experienced long delays before they were diagnosed and for some it took them many years before they were even able to obtain a diagnosis. The participants recounted, on several occasions, that they had been unable to receive appropriate medical care, and provided examples of Palestinian healthcare workers not being well trained enough to recognise RA. They also reported that general practitioners and orthopaedic specialists initially treated them, and they had perceived these treatments to be useless and ineffective. This meant that early diagnosis and treatment of RA was not routinely the case and participants did not offer positive examples of early referral for evaluation and development of a management plan by specialists.

> *'…initially, I did not know that it is rheumatism […] at that time I was being treated by a general doctor [general practitioner] and I asked him for medication to treat my joints […] I took the medication that he prescribed to me and the pain in my hands decreased for one or two days, but then it came back' (FG2, P1)*

Although diagnoses delays were mainly discussed by the participants in relation to inadequate recognition of RA by the medical team, a few participants reported delays in seeking medical advice, because they thought that their RA hand symptoms were related to the fact their lifestyle involved hard work. It seemed that participant-related factors may also have contributed to the reported diagnosis delay.

> *'When I had my hand pain, I did not visit a doctor, I thought the pain was because I had exhausted myself cleaning the house' (FG2, P3)*

After being diagnosed and receiving the appropriate medication, most of the participants reported a significant improvement in their hand function, attributing this to their regular attendance at a rheumatology clinic. Participants were generally positive about the effects of the medication in minimising the impact of RA on hand function. However, they emphasised that their hand problems had not resolved completely with the medication. Furthermore, many participants reported increasing their medication dose, without consulting their rheumatologists, or taking over the counter analgesics.

> *'…it is true that our hands improved with the medications […], but medications do not completely remove the pain from our hands' (FG2, P1)*

> *'Sometimes, I wake up in the morning and one of my fingers is swollen like I have hit it against a wall. I can't move it, so I increase my corticosteroid*

> *[medication]. He [the rheumatologist] prescribed five [tablets] a day, but I take ten [tablets]' (FG2, P2)*

Their experiences with hand surgery treatment were discussed by two participants in two different focus groups, who stated they had found it helpful for improving hand function. In contrast to medical treatments (i.e. medication and surgery), the majority of the participants had no previous experience of rehabilitation interventions. Indeed, many participants reported that they were not aware of rehabilitation interventions and had not been referred to rehabilitation by their rheumatologist or physicians. A few participants reported self-referral to rehabilitation services, which were reported to improve hand function by some, but not others. Interestingly one participant reported having been recently taught by an occupational therapist how to do her prescribed hand exercises, which in turn had improved her hand function.

> *'…I had two surgeries in my hands […] following the surgeries, the rigidity [stiffness] in my hands decreased' (FG3, P4)*

> *'…she [occupational therapist] taught me hand movements [exercises] […] I have practiced these movements at home, and then I was able to push myself up from the floor when praying' (FG3, P4)*

Most of the participants commented on their experiences of rheumatology care, highlighting that they had had negative experience with regards to the professional skills of medical staff, specifically in terms of poor communication and the attitudes of the doctors. The main communication problems included doctors' poor listening skills and lack of provision of appropriate information at the appropriate time. In terms of negative attitudes, the participants mainly commented on not being examined by doctors. When reflecting on their experiences with rheumatologists, as well as medical doctors, the participants appeared not to trust the medical staff. This was openly stated by one participant, as shown in the excerpt below.

> *'…they [the doctors] didn't explain anything to us at all, even on that day when I did my tests, I asked him [the doctor], and he didn't talk' (FG2, P4)*

> *'In the West Bank we don't have competent rheumatologists or doctors, all of them are useless' (FG4, P3)*

The analysis of this study data revealed that most of the participants expressed a lack of knowledge about the disease and treatments. Participants linked their lack of knowledge with poor information provision from the medical staff. It appeared that poor information provision is a barrier to improving hand function, as the participants expressed that greater information would improve their self-care knowledge, which in turn would allow them to take precautions to mitigate the disease symptoms in their hands.

> *'Of course, when you know more, you will not do things that will harm you and worsen the disease in your hands' (FG2, P2)*

Others reported that their prior knowledge helped them to tolerate the pain, adhere to the medication regimen and alleviate tension. This meant that health knowledge could inform the participants' understanding, thereby improving their health literacy and self-management skills.

> *'…my knowledge about the disease has helped me. I know when you have pain, it will not last for a long period, it will only be for a short period and with medication, it will decrease. This helps you to relax and tolerate the pain. Because, if you do not know, then you will be anxious and start thinking, is it the end of the world?' (FG5, P3)*

These data highlighted some gender differences regarding the ability to seek health information and treatments. Compared to women, men showed a greater tendency to seek information and treatments using different sources (e.g. the internet and books) to manage their hand problems, while women were more dependent on information obtained from their personal community. Therefore, female participants approached friends, relatives and neighbours for personal and on-going support. It seemed that personal social networks were important for the engagement with self-care management and may buffer the negative impact of poor health information provision by health personnel, thereby improving health literacy.

> *'…where can we know from? Unless you have someone in your family or a relative who has rheumatism, then you may know' (FG2, P2)*

5.7.5.2 Experiences with self-management strategies

This concept presents strategies identified and reported as supportive by the participants in relation to hand function. The participants reported using various individual and self-invented management strategies such as using herbal remedies, stabilising hand joints (using off-the-shelf and cultural bracelets), using technical devices and changing home appliances. One of the most important strategies reported in all of the focus groups was seeking out and using herbal remedies to relieve disease symptoms, which had varying results. For many, these herbal remedies were often recommended by people in the participants' personal community such as their relatives, friends and neighbours. It seemed that personal social networks were important in providing the basis for greater engagement with self-care management among Palestinians with RA.

> *'…I had so much pain in my fingers […] they [relatives] told me about Tahina [sesame oil] and I have used it to rub my fingers and the pain disappeared, Tahina has helped me a lot' (FG1, P1)*

Another commonly reported self-management strategy was using a culturally well-known bracelet that is usually made from red wool thread to support the wrist joint, as illustrated below on a healthy individual (Figure 5-8). Many participants reported that the bracelet was helpful in decreasing their hand pain.

> *'Look! [the participant showed her hand] I have this wool thread specially for the pain, I have never removed it, it decreases my hand pain' (FG1, P1)*

Figure 5-8 Traditional wrist brace worn in Palestine (Image: authors own)

A few participants reported varying results thanks to the use of available off-the-shelf hand splints to reduce hand pain, which were not felt to be helpful overall. They had either been recommended by a doctor or used through personal choice. Their experience of using hand splints was, therefore, considered as a separate sub-concept related to the self-management concept.

> *'…the doctor said to me that I have to wear a splint for my hand. I bought it from the pharmacy. I have used it, but I felt it was putting so much pressure on my hand and fingers, then I threw it away because the pain just came back in my hand' (FG1, P3)*

The use of technical devices was also a very important self-management strategy to facilitate performing activities. Often the participants had themselves arranged to have well-designed tools made for cooking, dressing, cleaning and gardening to facilitate their activities within the home environment. These included electric citrus juicers, large handled tools, lighter cutlery, shoes without laces, and lightweight gardening tools. Furthermore, many participants reported that changing their home appliances had facilitated the performing of activities. Therefore, they described the changes they had made to their home appliances as being appropriate to their situations, as they enabled them to keep performing their activities. Notably, no participant had accessed these through rehabilitation services.

> *'Squeezing an orange or a lemon [using the manual citrus juicer] is difficult, because rotating the hand is difficult, so I have bought an electrical [citrus juicier]; it has made squeezing easier' (FG3, P4)*

> *'…I have changed the taps of the washbasin and kitchen sink to gear taps; they are easy to use now' (FG3, P4)*

Generally, the participants emphasised that the above self-management strategies were helpful to reduce and control disease symptoms in their hands and facilitated the use of their hands in daily living activities.

5.7.5.3 Family support and socioeconomic status

Physical and emotional support from the family, as well as the family's attitude and socioeconomic status were recognised by the participants as facilitators or barriers in relation to hand function. The participants stressed the importance of physical help from the family as a facilitator to performing activities such as self-care, household activities and transportation. Furthermore, they also emphasised that emotional support in the form of encouragement and reinforcement is an integral part of family support.

> *'Without help from my family, I couldn't do anything, I used to push the furniture when mopping the floor, but if my children are not at home to help me, then I cannot do it anymore' (FG3, P5).*

> *'It is not only physical help, but also encouragement from my husband and children' (FG3, P5)*

Generally, women reported receiving less physical help from a spouse and, depending on their children, particularly daughters, to get activities done. In contrast, men depended heavily on their wives and children to help them perform their daily living activities. Therefore, some women living only with their spouses, and with no children at home, expressed how they felt as if they were living alone, or what is termed here as functionally living alone.

> *'…I do not like anybody to visit us, because I'm living alone and I don't have anybody to help me make and serve drinks, I can't make a pot of tea or coffee and serve them' (FG1, P3)*

Although the majority of the participants in all of the focus groups expressed an increase in comfort by relying on family members to help with daily tasks, many of the participants expressed that physical help from people outside their family context is not convenient for them. They provided reasons for not accepting help from other people such as not liking other people to feel sorry for them. It seemed that this attitude (not accepting help form others) corresponds to the personal resilience which appears to emerge from the Palestinian culture of not seeking physical support from others outside the family. For example, anyone seeking physical help from outside the family could be seen as being weak and bringing shame on the family.

> *'…when I want to get on the bus or get off, I refuse to let anybody help me' (FG4, P1)*

The attitudes of the close family played a significant role in determining participants' experiences. A negative family attitude was reported as a barrier to being able to manage and live, which in turn impacted hand function directly or indirectly. In particular, female participants felt their needs were not understood by their families who made too many demands on them and identified this as an important barrier linked with their hand functional problems and psychological well-being. Other female participants described, in many instances, being criticised by their husbands, because they were sick, taking so much medication and having to visit a rheumatology clinic on a regular basis.

> *'Everything is requested from me when my husband and children come home. They start asking, "What have you cooked?" and "What are we going to eat?" […] I feel like I am a servant for them, they do not have mercy on me' (FG3, P4)*

> *'…I avoid showing him [husband] I am taking medication, because he keeps blaming me […] what can I do? I need to take medication to enable me to move' (FG2, P2)*

Finally, the participants described a complex relationship between their poor family socioeconomic status and their hand function. For example, the inability to buy medication due to lack of money and subsequent deterioration of hand function is an example of the direct influence of poverty on hand function. Other participants reflected that their family's poor economic status prevented them from buying technical devices or changing their home appliances. There were examples in which the participants described their poor economic status as being a significant factor related to their psychological status, which in turn could result in hand problems.

> *'…it happened to me, I no longer had the medication, and I was not able to buy it […] then I was not able to move' (FG2, P1)*

> *'Our financial status is not good […], because of this I am always stressed, and the pain has increased, especially in my hands' (FG2, P2)*

5.7.5.4 Hot and cold weather/environment

The impact of the weather and temperature on increasing the disease symptoms in their hands was discussed by all of the focus groups. Many patients reported a worsening of disease symptoms, particularly on cold days or due to the use of an air conditioner or fan. However, a few participants experienced worsening symptoms with hot weather or extreme ambient temperatures.

> *'I have pain in my hands, especially in cold weather, so much pain' (FG4, P4)*

5.7.6 Concepts in the component personal factors

The final objective of this study was to identify personal factors that influence hand function. Five personal factors were identified as being important (Figure 5-9). In the following sections these factors are explained.

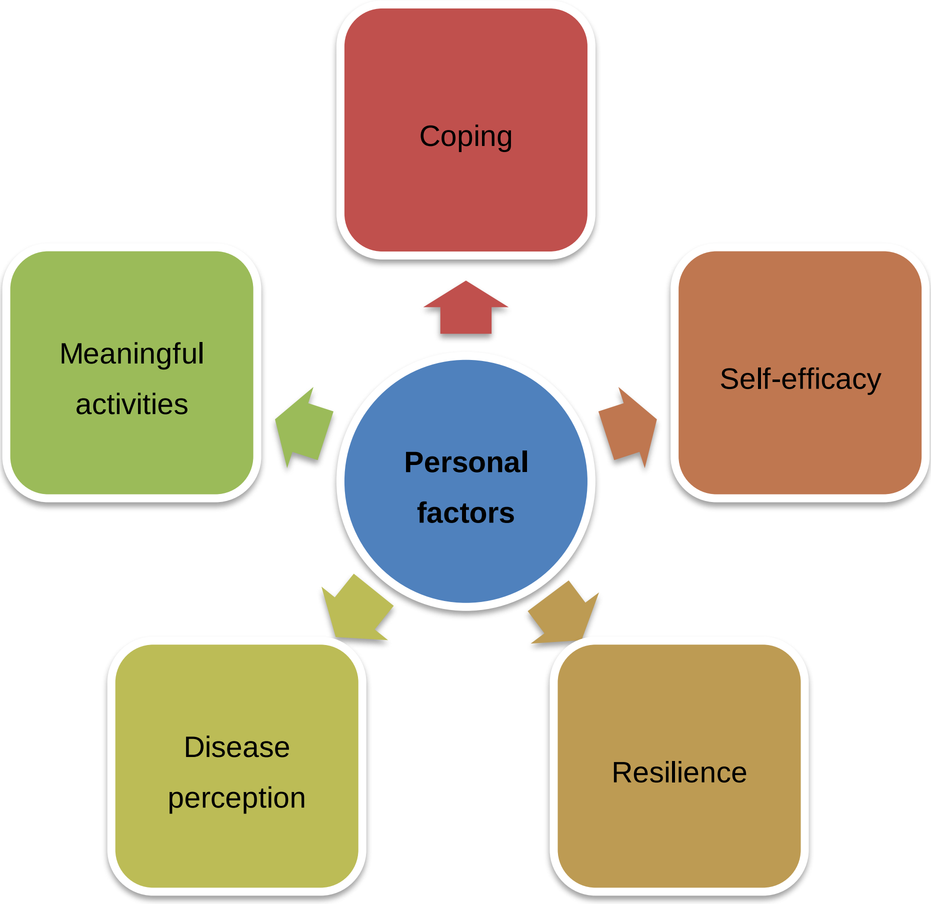


Figure 5-9 Important personal factors for hand functioning

5.7.6.1 Coping

Hand problems posed different challenges and limitations to the participants' lives. As a result, participants described employing various coping strategies in their efforts to manage these challenges. The participants generally appeared active in their attempts to cope, and their ability to remain independent was determined by strategies that involved problem-based mechanisms and, where possible, the use of technical devices or adaption. For example, individuals' spoke of employing coping strategies such as pacing/planning, compensatory strategies, and modifying or changing tools and objects in their attempts to continue performing daily living activities. However, for situations where they did not find a solution to their difficulty they seemed to give up/avoid doing it/them, hiring others or delegating activities/tasks to others in an attempt to conceal their hand function constraints. These strategies were employed when problem-based mechanisms failed or when they perceived themselves as unable to conform to normal or conventional standards. Illustrative quotations regarding problem-based coping strategies are presented in Table 5-13.

Table 5-13 Coping strategies with illustrative quotations

Coping strategy	**Illustrative quotations**
Giving up or avoiding activities	*I used to make pastries, sweets, and cake, I no longer make them (FG1, P1)* *I avoid warm handshaking, it is just too difficult (FG1, P3)*
Hiring others	*…I used to cut the grass on my land, but when I had these problems in my hands, I had to hire someone to do it (FG4, P3)*
Delegating activities or tasks to others	*Hard vegetables, like potatoes, I have to give it to my daughter or my husband to peel it, because it is too difficult for me to do (FG2, P2)*
Planning and pacing	*I have started subdividing the housework, like one day for arranging the wardrobe, one day for cleaning the carpets, one day for laundry. I have subdivided the work to make it more manageable; otherwise I wouldn't be able to do it (FG3, P2)*
Utilising a compensatory strategy	*…when a lemon is too hard, I can't squeeze it […] what I have been doing is putting it under my legs and press on it to soften it, then squeezing will be easy (FG3, P3)*
Modifying or changing tools and objects	*I made a small tear in my socks, which make it easy for me to dress them and pull them up (FG4, P4)*

Besides employing the above behavioural coping strategies, the analysis of the focus group discussions also clearly showed that the participants described cognitive coping strategies. These strategies were mainly in the form of social comparisons (creating downward comparisons), acceptance, avoiding thinking, and finding help in religious beliefs. It appeared that participants have used these coping strategies to feel better about their hand function difficulties. Importantly, the data highlights the frequent use of downward comparisons by giving examples of others who had more difficult hand problems and minimising the severity of their own hand problems.

> *'I met a woman who needs her daughters-in-law to feed her. Her hand cannot reach her head. She cannot even comb her hair' (FG2, P1)*

In the same vein, a few participants compared their previous hand function abilities with present ones and, in most of the cases, this elicited sadness. This was evident in focus group three, in which a female participant started to cry when she compared her past functional capabilities with her current ones. It appeared that this form of self-temporal comparison did not offer a facilitative coping strategy.

5.7.6.2 Self-efficacy

Participants in all of the focus groups provided examples that illustrated their capacity to organise and execute a range of courses of action required to manage the challenges posed by their hand problems. These examples of life events (sub-concepts) were mainly about the capacity to manage and solve difficult problems encountered in participants' daily lives if effort was invested, they took an active involvement in their disease management, stuck to their aims and accomplished their personal goals. The concept of self-efficacy was considered a comprehensive concept that incorporated these sub-concepts.

> *'…I was not able to hold the rug and shake it. I used to ask my children to do it. I felt that I had paralysed myself by my own actions, because I was depending on others too much. So now I am starting to rely on myself more […] I have started to shake the rug by myself over and over again, I mean I tried until I could do it' (FG3, P4)*

Despite the difficulties experienced, the participant in the above example demonstrated that she was able to manage difficult hand-related activities when she invested effort. As such, participants with high self-efficacy approached difficult hand-related activities and did not avoid them. On the other hand, participants who were unable to approach these activities, regarded themselves as being helpless, which indicates that a low sense of self-efficacy is associated with emotional problems.

> *'When I went to the hospital with my daughter when she was giving birth, the women were helping her and I was sitting [there] useless' (FG1, P1)*

Self-confidence as a sub-concept was included as a sub theme within the self-efficacy concept. Some participants reported having lost their sense of confidence, due to an inability to perform activities that required hand use.

> *'I do not trust myself, for instance, my son has twins […] I cannot carry them or give them a shower, I am afraid of dropping them' (FG2, P1)*

5.7.6.3 Disease perception

Disease perception contained sub-concepts that referred to the person's beliefs about the disease and treatment (pharmacological and non-pharmacological). The participants felt that their hand problems had negatively affected their lives and some of them described this as a disability. Some participants expressed severe consequences in relation to the impact of their hand problems on their emotional states, social roles, work, and productivity, even though the severity of the disease symptoms in their hands had decreased. It appeared that some participants may report more hand disability compared to others, depending on their perception of the consequences, and not merely because of the disease symptoms in their hands.

> *'This disease [RA] has paralysed me […] Our life is confined to one place, and we are disabled […] If you lose your hands, you lose your life' (FG1, P3)*

The potential causes of RA were discussed by several participants, who suggested that their RA had been caused by the cold, stress, tonsillitis or was a hereditary condition, giving examples from their own family history. These perceived causes were mainly based on the participants' personal experiences (e.g. working in a very cold environment) or information gathered from people in their social networks (e.g. relatives and friends). Surprisingly, few participants who had been diagnosed with RA several years before had questioned the cause of their disease. However, there were a few examples where the participants correctly recognised RA as an autoimmune disease. Besides discussing the potential causes of RA, many participants reflected that they believed the disease would be life-long, and that their hand problems would inevitably continue until their death. It seemed that perception of the disease causes and timelines can influence hand function, since it can affect the individual's ability to cope, which in turn can influence their hand function, as illustrated by the participant below:

> *'Rheumatism [RA]…everyone has an immune system to attack the diseases […] the immune system becomes blind and starts attacking the joints…As long as you have an immune system, it will continue to attack the joints in your body and hands, so you have to cope' (FG4, P3)*

Although most participants reported that their RA medications were beneficial and important, they expressed their fears and concerns about the side effects of these medications. Therefore, some of them showed strong beliefs in herbal remedies and mentioned several positive aspects and beliefs they associated with using herbal remedies such as being natural, healthier, and with no side-effects. They also recognised that RA itself could not be cured and the medications prescribed to them were analgesics. It appeared that participants' beliefs and concerns about medication for RA and its curability may influence their decisions whether to take medication, since a few raised questions regarding the point of taking the medication if the disease is not curable. Furthermore, some participants felt that their hand problems would progress over time, regardless of any medical intervention. These negative attitudes toward medication influenced their adherence to taking their medication, as they revealed that they sometimes stopped taking their medication, and others reported being non-adherent to their therapeutic regimen and instead using herbal remedies. However, there were other examples where participants showed a strong belief in the benefits of their medication and reported their adherence to their medication regimen.

> *'I have searched the internet; all of them [medications] are analgesics' (FG4, P1)*

> *'…if it is not curable, why do I have to come back for treatment' (FG4, P3)*

> *'I am afraid of the medication, sometimes I feel cured, and then I quit the medication for two weeks or sometimes three weeks […] The medications have side effects on the kidney and liver, so I try to clean my body then I come back to the medication. I do not know if this has harmed or benefited me' (FG5, P2)*

Generally, the participants' perceptions of RA and their treatment varied. Disease perceptions and attitudes toward treatment seemed to affect hand function outcomes, as it influenced disease-specific behaviours such as adherence to medication, and coping.

5.7.6.4 Resilience

Resilience was another important concept, which was associated with hand function outcomes. Analysis of the focus groups revealed numerous factors that represented resilience in response to hand problems. These factors can be grouped into individual personal strengths and weaknesses. When the participants were directly asked about their personal factors that they consider as facilitators and barriers to their hand function outcomes, the majority started by describing their individual strengths – the personal resources they bring with them to their RA journey. Factors that could be considered as individual strengths included tolerance to the disease symptoms (i.e. pain and stiffness), not giving in to the pain, strength derived from past experiences, and having a strong personality, willpower, and determination. Furthermore, their attitudes towards accepting help from others were recognised as a resilience resource. The participant in the quote below is also a cancer survivor, and she described how her past experiences with pain have helped her to tolerate hand pain.

> *'I feel my personality is strong, as I have experienced very difficult circumstances […] I can tolerate my hands' pain, because I have experienced too much pain in my life' (FG1, P3)*

However, only a few participants described their personal factors that they considered to negatively influence their hand function outcomes. These factors included giving in to the pain and having a weak personality. A participant with multiple hand deformities described that her attribute of giving in to the pain led to the development of her hands' deformities.

> *'…I succumbed to the pain […] this has made my hands as they are now' (FG3, P5)*

Participants in this study recognised their personal strengths and weaknesses in helping to overcome their hand problems. They predominantly emphasised their positive personal attributes offering them the strength to deal with the day-to-day challenges of living with RA. These were identified as positive personal resources that people with RA brought to their disease journey.

5.7.6.5 Meaningful activities for the individual and/or the social context

Meaningful activities another essential concept identified in the data that has the potential to promote hand function. The participants emphasised the importance of doing what they believed to be meaningful in life. Doing meaningful activities was regarded as so important that some of the participants rejected the option of engaging a family member or other people to do it for them. Many participants revealed that maintaining committed activities (i.e. activity related roles), associated with their principal productive social roles (e.g. household responsibilities, paid work), or as they called them 'responsibilities', is highly valued and being able to perform the same activities as they did prior to their disease was important. The participants stated they continue doing these activities despite their hand problems. Some participants revealed that performing valued activities were perceived to enhance their wellbeing by shifting the focus away from the pain.

> *'Today I could not get out of the house until I did the laundry, washed the dishes, cleaned the house, the cooker and kitchen, although my hands are tired' (FG1, P1)*

> *'…when I work [doing household activities] I feel psychologically relaxed and forget the pain in my hands' (FG3, P4)*

Meaningful social activities (e.g. shaking or clapping hands) were considered important for some participants and they performed these activities despite knowing that they were very difficult for them and that there would be consequences (e.g. severe pain during the activity or afterwards). One participant provided an example of a valued individual and cultural activity, specifically making Eid Maamoul (cookies made especially for Eid), which is an important cultural activity.

> *'You could not avoid shaking hands; it is difficult not to shake hands. I do shake hands with people, but I hide the pain in me' (FG1, P3)*
>
> *'Eid Maamoul, I love it so much, and I have to make it even when I am so sick' (FG1, P1)*

However, when individuals' hand abilities were insufficient to overcome the challenges of doing valued activities, the meaning and value of such an activity seemed to be downgraded, thus minimising its perceived importance or value. Many participants reflected on this, as they demonstrated that this issue left them with no other choice than to quit an activity.

> *'If you want to participate in Dahiya* [hand clapping in weddings] *and you cannot, then it is not important' (FG4, P3)*

5.8 Discussion

This focus group study aimed to explore and identify the concepts related to hand function important for Palestinian people with RA. The concepts of hand function identified in this study cover a wide spectrum of impairments (7 concepts), activities of daily living (16 concepts), as well as correspond to personal (5 concepts) and environmental (4 concepts). Understanding the participants' perspectives of hand functioning through qualitative enquiry has provided useful insights into determining what to measure in the clinical and research field. As such, the identified concepts facilitated discussion, leading to recommendations on the most appropriate hand function outcome measure(s) to use with the Palestinian RA population. The concepts of this study may also be used to consider the validity of widely used international hand function self-reported instruments for Palestinian people with RA. Furthermore, the current study has allowed the researcher to recognise the important environmental and personal concepts to consider in relation to hand function.

To the researcher's knowledge, this is the first study that has explored the lived experiences of Palestinian people with hand RA. Although previous European studies have highlighted the concepts of functioning in daily life important for individuals with RA, they had their primary focus on general functioning and did not specifically aim to explore concepts of functioning in relation to hand problems (Meesters et al. 2014; Stamm et al. 2014). An overview of the findings suggests that the participants' lived experiences related to hand function in daily life were impacted upon by the interaction of their health condition and contextual (personal and social) factors. These findings reflect similar findings in the qualitative rheumatology literature concerning individuals' experiences living with RA (Hwang et al. 2004; Schneider et al. 2008; Stamm et al. 2010). In the current study, the descriptions provided by the participants support the multidimensional and complex nature of the impact of hand functional disability in RA, as conceptualised by the ICF framework (Chung et al. 2011; Andrade et al. 2016). As such, these findings support the ICF framework as a useful tool to offer a comprehensive description and understanding of the experiences of those living with a hand disability (Stamm et al. 2009), and are also relevant for Palestinian people living with hand RA. For example, difficulties in performing hand-related activities were considered a barrier to individuals contributing to social events, which led to some participants not wanting to attend these activities, and therefore feeling socially isolated and often depressed.

This discussion is subdivided into five sections, discussing the findings in relation to previous research findings.

5.8.1 Overview of the concepts

The findings from this study demonstrated that the emphasis on hand function problem-related concepts identified by the participants related to the ICF component “activities and participation”. While the majority of these concepts are similar to those identified in previous RA focus group studies (Meesters et al. 2014; Stamm et al. 2014), new emerging concepts have also been identified. For example, “greeting activities are difficult” and “affected religious/ritual practice” were unique concepts in the current study. The “greeting activities are difficult” concept which emerged from the focus groups in the present study involved a “shaking hands” concept reported by Stamm et al. (2014) in their focus group study with RA patients. However, the “greeting activities are difficult” concept in the current study is more comprehensive, since it includes cultural activities such as “having their hand kissed by their children”. This is coupled with the fact that although the concepts in this study may appear to be similar to those identified in previous RA studies (Meesters et al. 2014; Stamm et al. 2014) or hand OA studies (Stamm et al. 2009), the content of a concept may differ between socio-cultural contexts. This is because concepts in the component “activity and participation” are largely underpinned by culturally related activities. For instance, the concept “difficulty eating” was mainly related to problems tearing bread or eating with their hands in the current study, and not using a knife and fork as in Western countries. Thumboo et al. (2017) reported that there are differences in the hand function perspective between Asian and European people with hand OA. Stamm et al. (2014) reported that problems of general functioning in daily life in six rheumatic conditions (including RA) within eight European countries were found to be similar, but the experiences were different. These findings suggest that the concepts of hand function important for patients with RA are not inevitably transferable between different socio-cultural contexts and they should be interpreted in term of their content.

Apart from the ICF component “activities and participations”, several personal and environmental factors were found to be important, as they have the potential to influence hand function. The importance of these factors was apparent in the present study when the participants described how they managed their hand problems and impairments. Whilst the concepts around activity and participation related only to the negative aspects of hand dysfunction, positive and negative aspects were described by the participants in personal and environmental factors. This is in line with the qualitative evidence showing that both personal and environmental factors have both positive and negative aspects and are important for functioning in general (Schneider et al. 2008; Stamm et al. 2010), and specifically hand function in RA patients (Nicklasson and Jonsson 2012).

Although previous research has identified environmental factors important for functioning among RA patients (Meesters et al. 2014; Stamm et al. 2014), the findings of the present study suggest that other environmental factors such as poverty and diagnostic difficulties may also influence hand function outcomes. Similarly, some of the personal factors identified in this study are similar to those identified in studies which aimed to validate the RA ICF core set (Kirchberger et al. 2007b; Kirchberger et al. 2008; Gebhardt et al. 2010) and explore the coverage of patient-reported outcome measures of the personal factors in RA (Dur et al. 2015). For instance, concepts such as “coping” and “self-efficacy” have been frequently identified in the studies above. However, the concept “disease perception” is an emerging concept, which was not addressed by these studies.

Overall, the concepts of hand functioning identified in the current study are broadly similar to studies concerning concepts of functioning in RA (Meesters et al. 2014; Stamm et al. 2014) and concepts of functioning important for people with hand OA (Stamm et al. 2009). However, the findings of this study suggest that the content and meaning of concepts may differ across socio-cultural contexts. In addition, new emerging concepts were identified which have not been addressed in Western studies. Importantly, this study reflected that hand-related activity and participation concepts among Palestinian RA people are largely underpinned by culturally related activities. These findings are important and have potential implications for clinical practice and research. Firstly, they confirm that RA affects hand function in Palestinian people generally, as in other socio-cultural contexts, but highlight that individuals’ experiences may differ. Therefore, hand functioning concepts are not necessarily transferable between different socio-cultural contexts. Secondly, they support the idea that to gain in-depth information and to establish a client centred treatment programme within Palestinian clinical practice, it is vital that open-ended interviews should be used to understand hand function limitations. Finally, they extend existing knowledge of hand function in RA by providing in-depth information, which may not have been revealed from quantitative methods alone.

The main findings are discussed in further depth in the next sections.

5.8.2 Concepts related to body function and structure of the International Classification of Functioning, Disability and Health (ICF)

The finding that participants in the present study identified several impairments as an important part of hand functioning is in line with previous focus group studies among RA patients (Meesters et al. 2014; Stamm et al. 2014). Problems with physical symptoms, pain, mobility, strength, fatigue, psychological distress, as well as appearance were described by the participants in the present study as having a negative influence on hand function. In particular, the participants reported that hand impairments including pain, strength and mobility are major problems in relation to performing hand-related daily life activities. These findings are consistent with recent reviews that have indicated that pain and grip strength are the main determinants of hand function in RA (Arab Alkabeya et al. 2019a) and are among the important outcomes of treatment for RA patients (Hulen et al. 2017). However, in the present study, hand mobility problems were particularly important in the account of participants with longer disease duration compared to those with shorter disease duration, which suggests that hand mobility problems may reflect disease progression.

Disease symptoms, particularly pain, were the main concept of hand impairments that affected hand functioning in this focus group study. Hand pain as an impairment was linked to hand-related activity limitations and participation restrictions, as well as contextual factors, suggesting that hand pain in RA is complex and multifactorial. For instance, the participants described a complex relationship between hand pain and emotional states, which in turn influenced their hand function in daily life. The complexity of pain in RA has been described in previous research, which advised considering pain within a biopsychosocial context (Björk et al. 2008; Ahlstrand et al.

2012). A well-established fact in rheumatology literature is that pain affects all aspects of life for people with RA (Ahlstrand et al. 2012). This is also reflected in this study's findings, as the participants reported that pain had a widespread impact on their ability to perform hand-related activities and was perceived as a barrier for performing activities or making continued activity impossible. Importantly, the participants described activities as a mediator of hand pain and related the pain they experienced when performing activities to their hand activity limitations and participation restrictions. This finding supports the conclusion of Thyberg et al. (2016) that hand pain during activity may have the potential to explain an on-going hand functional disability in people with RA.

Participants perceived fatigue as a dominant problem and described its physical and social impact in relation to hand function. These findings are not new, but reinforce the findings of qualitative studies from the UK and European countries, which were synthesised in a recent qualitative meta-synthesis study concerning the experiences of those living with RA-related fatigue (Primdahl et al. 2019). Previous studies among individuals with RA has shown that fatigue is one of the most important treatment goals for patients (Carr et al. 2003; Hewlett et al. 2005), and has been considered as a critical outcome by the OMERACT group in RA (Kirwan et al. 2003). Therefore, it is important for health professionals to acknowledge the impact of fatigue on the ability to use one's hands in everyday life. However, the impact of fatigue on hand function is poorly addressed in the literature and the available evidence provided inconclusive results regarding the association between fatigue and hand function (Arab Alkabeya et al. 2019a).

Psychological distress was evident in participants' responses to their hand function limitations, as well as in relation to their hand disease symptoms or physical appearance. Participants often reported being frustrated when they lacked the ability to be in control or when their efforts to solve problems failed. Evidence from previous studies into individuals with RA has also demonstrated a relationship between personal control and depression (Murphy et al. 1999; Groarke et al. 2004; Graves et al. 2009). Furthermore, hand function problems have been linked with mental and psychological problems in individuals with RA (Aktekin et al. 2011; Durmus et al. 2013). These findings are reflected in the present study, as several participants commented that their hand function problems had resulted in psychological problems. However, the participants also recognised that contextual factors may also negatively affect their psychological well-being, which in turn could adversely affect their hand function. These findings indicate that psychological problems are multifactorial and could negatively influence hand function.

One interesting finding in the current study is that younger women reported being embarrassed because of their visible hand functional problems or hand deformities. This possibly contributed to them experiencing low self-esteem, as these participants mentioned trying to hide their deformed hands in public or not to perform activities in front of others. Importantly, participants in the present study did not explicitly provide examples of being publicly stigmatised because of their RA hand appearance or functional problems. Therefore, it appeared that the reported feelings of embarrassment originated from the participants' personal perceived stigmatisation rather than evidence of real public stigma, which in turn may result in low self-esteem and emotional problems. However, personal perceived stigmatisation could originate from low self-esteem. Although previous research among individuals with RA has demonstrated that younger individuals with RA reported feeling publicly stigmatised because of their hand deformities or physical capacity (Lempp et al. 2006), a recent study showed that 74% of RA patients reported personal perceived stigmatisation (internalised stigma) at different levels, which was associated with self-esteem (Corker et al. 2016). It seemed that embarrassment in relation to hand functioning resulted from the deficiencies in one's presented self, which also often resulted in psychological distress and low self-esteem.

5.8.3 Hand-related activity and participation

The findings indicate that hand-related activities were performed within the structures of social and cultural practice. Also, the results showed that activities are interwoven and influenced by personal and environmental factors, within the ability to complete tasks in everyday life. The participants prioritised some activities based on person-specific meanings and gendered roles. For example, women prioritised cooking as part of their role in home management. The strain of experienced activity problems was dependent upon individual's living conditions such as housing environments or family support. For example, if the participants had physical help from a family member, they reported fewer problems in hand-related activity, thus the tension of experienced hand-related activity problems was minimised. Despite sharing the common diagnosis of RA, variances existed in how participants reported their lives had been affected due to their hand problems. Some participants stated that had experienced hand-related activity problems as a common feature of their everyday lives, while others mentioned they were related to specific activities. These findings are consistent with previous studies on activity and participation in everyday life among RA (Stamm et al. 2010; Ahlstrand et al. 2012; Nicklasson and Jonsson 2012) and hand OA patients (Bukhave and Huniche 2014).

The value placed on identity by the participants as an “independent person” in their private lives and also in their productive social roles in the present study was in line with previous studies. For example, Lempp et al. (2006) showed that the current or potential loss of independence was a concern for the majority of RA patients. Other studies showed that for RA patients, the most important treatment outcome was to “stay independent”, particularly during the later disease stage (Carr et al. 2003; Hewlett et al. 2005). Patients’ general functionality is a core outcome domain of disease status in RA (Felson et al. 1993), but not hand functional disability. It has been argued that the assessment of hand functional disability should be included as distinct entity in the global assessment of RA patients (Eberhardt et al. 2008). Reflecting on this study, hand functional disability is an important outcome in RA, because it appeared to have a substantial impact on the individual’s sense of identity and independence.

Having paid employment represents a major life responsibility for most adults, and the European RA population qualitative evidence showed that hand function in relation to ability to do paid work is an important domain to consider (Stamm et al. 2008). Reflecting on this study, hand function problems in relation to ability to do paid work were also shown to be a major consideration for the participants, particularly men. However, the unemployment rate in the present study was high, particularly among women. This can be explained by the high rate of unemployment (85.6%) reported among Palestinians with disabilities in the West Bank (Kaur et al. 2016), and among Palestinian women in general (82%) (Palestinian Central Bureau of Statistics 2017). Many factors may contribute to the high rate of unemployment in the Palestinian context, which are mainly related to the political situation. However, the high rate of unemployment among Palestinian women may be related to Palestinian cultural norms, which restrict women to remaining in a traditional female role of taking care of their family and not allowing them to work in paid employment.

The ability to contribute to social activities was seen as an important aspect of experiencing participation by the majority of the study participants. The contribution aspect of participation highlighted by the participants demonstrated that participants could experience satisfactory participation in the same social events, even though they were unable to perform the same activities as before. This is an interesting finding of the current study, as it indicates that participation is an individual experience that is connected to the social context. Accordingly, the capacity to perform hand-related activities is not necessarily related to the experience of participation, a finding that has also been reported in a qualitative study recruiting RA patients with hand deformities (Nicklasson and Jonsson 2012). These findings are not in accordance with the ICF in the interpretation of the concept of experienced participation and the reasons for a restriction in experienced participation. The ICF recognise the separate assessment of activity and participation but underlines the strong link between them. This is coupled with the fact that activity and participation are classified within a single list that involves the full range of life areas in the ICF. As a result, there is an on-going debate in the literature about the domains of participation and activities, coupled with the lack of distinction between the definitions of each (Piskur et al. 2014). Furthermore, the ICF definition of participation has been criticised for excluding subjective experience or satisfaction (Hemmingsson and Jonsson 2005). According to this study's findings, open-ended interviews could be a useful approach to assess participation restrictions, due to hand-use difficulties, rather than using an objective measure.

5.8.4 Environmental factors

In the context of this study, the environmental factors included social, physical, and healthcare system-related factors that are present in the living environment of people with RA. Most of the participants reported family as a facilitating or hindering factor which could directly or indirectly influence hand function. This might be expected, given that Palestine has a culture that is family-oriented like other Arabic countries. From the participants' point of view, a lack of physical and emotional support from their immediate family, as well as negative family attitudes, were barriers for hand function. Participants who had easy access to help from their families were more relaxed and reported fewer hand functional problems, as their families organised difficult activities for them. Nevertheless, the negative attitudes and perspectives of family members were among the most important environmental factors found to hinder them, in terms of having the potential to adversely influence hand function. These findings are in accordance with the concepts “support of others” and “attitudes of others” identified by Stamm et al. (2014) among her RA patients. However, in the present study, support and attitudes were related to the immediate family, with the spouse and children making unique individual contributions when hand function was recognised as challenging. Importantly, it appeared that there is a gender difference regarding the support received in performing daily living activities, as the female participants generally reported receiving less help from their family members, especially from their spouse. This was reflected in the fact some women described themselves as living alone, despite living with the spouse. Although the gender differences in relation to the help received from family members and the unique contributions of the spouse and children are rarely examined in arthritis studies (Hung et al. 2017), the findings of this study suggest that, for Palestinian people with RA, immediate family support should be considered in relation to hand function, and that the involvement of patients’ family members into the rehabilitation process is important.

Participants reported that the experiences of living with and managing RA hand problems was mitigated through their relationships with others in their personal social networks. Relatives, friends and neighbours were mentioned as being important to the participants in supporting them to manage their hand problems and gather information about their disease. Therefore, it appeared that social networks not only influenced how the participants managed their hand problems, but also their disease perception. This resonates with other recent research that indicated that personal social networks including friends, family and neighbours provide a greater opportunity for the involvement of self-management support among people with musculoskeletal conditions (Adams et al. 2019). The findings of this study suggest that it may be reasonable to consider how to provide self-management support for Palestinian people with RA outside clinical settings based on a social support approach.

Some participants also recognised that their poor economic status could directly, or indirectly, negatively influence hand function. The inability to buy medication or technical devices and change home appliances due to poverty had an important impact on some participants. While Western studies have addressed “loss of income” as an environmental factor that could affect functioning in RA people (Stamm et al. 2014), they have not considered poverty, although a qualitative study conducted in a low-middle resource context (South Africa) concluded that poverty has negative functional consequences among RA patients (Schneider et al. 2008). Furthermore, data from a low-income Arab country (Morocco) showed that 91% of RA patients had financial difficulties, which resulted in inadequate treatment compliance (61%) (Rkain et al. 2006). In the Palestinian context, therefore, it is advisable that health professionals consider the contributing effect of the patients’ economic status on RA individuals’ hand function.

The healthcare-system-related factors pertained mainly to diagnostic difficulties and the patient-healthcare-provider relationship. Diagnosis difficulty was raised by many participants, highlighting that healthcare physicians were not trained in recognising RA, which meant that some participants waited years for a diagnosis. Data from the Middle East region has shown that patients with RA are often diagnosed late (Halabi et al. 2015; Barhamain et al. 2017). Since some participants reported a delay in seeking medical help, it seemed that diagnosis difficulty is probably a combination of patient-related and physician-related factors, a finding that has also been reported in a recent review study of diagnosis delay in RA (Barhamain et al. 2017). This could potentially be improved by raising awareness of RA symptoms among the wider population, educating general practitioners regarding early symptoms of RA and improving the referral system.

In addition to diagnosis difficulty, the majority of Palestinian RA participants stated that they felt that their needs are neglected by medical staff. They were largely dissatisfied about their medical staff’s attitudes and placed a strong emphasis on the need for effective physician-patient communication in terms of providing timely information to adopt self-management behaviours. It seemed that the participants’ negative experiences with medical staff resulted in a lack of trust and may have limited their confidence in the treatment they were receiving. This was illustrated in this study, as a few participants explicitly stated that they do not trust medical staff. Evidence from the rheumatology literature has demonstrated that higher levels of trust in the physician and active patient involvement in healthcare decisions were found to be linked to favourable health outcomes such as greater treatment satisfaction, more positive beliefs about their control over the disease and better medication adherence, with fewer side effects from medication (Georgopoulou et al. 2018). It could be assumed that poor physician-patient relationships would emerge from the Palestinian healthcare system, since it is based on a traditional biomedical approach. Within such healthcare systems, the hierarchy, or the elevated societal position of physicians may impose passivity on patients or the patients may voluntary adopt passive roles in the patient-healthcare provider relationship (Williams et al. 2000). Recent evidence from Palestine has shown that a considerable percentage of Palestinian physicians (55%) are unfamiliar with patient-centred care and did not perceived it as important (Sultan et al. 2018). These findings together suggest that further exploration is needed to evaluate how healthcare information is provided in rheumatology clinics. Further work is also needed to change the attitudes of Palestinian physicians towards patient-centred care. For this purpose, the theory of organisational readiness for change could be used as a framework to explore and assess the readiness for change at the individual, group, department or organisational level of the Palestinian healthcare system (Weiner 2009).

The data highlighted that Palestinians with RA were not routinely referred to rehabilitation services by their rheumatologists or general practitioners. This observation may be due to different reasons, including doctors’ ignorance of the rehabilitation services, a lack of awareness of the benefits of rehabilitation services, an underestimation of the impact on daily living with a long-term condition such as RA, a lack of money to refer patients on to further services, and a lack of integrated care pathways for RA management. Another possible explanation could be that rehabilitation departments are not adequately advertising their services. Therefore, more emphasis on an interdisciplinary model of healthcare may enable Palestinian care providers to address the challenges that people with RA face in achieving their daily living activities. It would also be very worthwhile raising Palestinian healthcare providers’, especially rheumatologists, awareness of the importance of rehabilitation for people with RA.

5.8.5 Personal factors

The findings of the present focus group study showed that the influence of personal factors in relation to hand functional ability is complex and multidimensional and can impact hand function both positively and negatively. For instance, the study participants offered examples as to how their personal resources related to the identified concepts of “resilience” or “self-efficacy” allowed them to approach and accomplish activities despite their hand problems. A review of the scientific literature on the conceptualisation of the ICF personal factors suggested that it is important to understand personal factors as determinants, outcomes and mediators in relation to functioning and disability (Geyh et al. 2011). The evidence from the RA literature demonstrated the complexity of personal factors in relation to performing valued life activities. For example, it was reported that personal factors (i.e. self-efficacy and pain acceptance) were associated with the performance of valued life activities and partially mediated the relationship between RA related pain and the performance of valued life activities (Ahlstrand et al. 2016). Furthermore, various studies and systematic reviews have supported the positive effects of interventions targeting personal factors in people with RA (Riemsma et al. 2003; Savelkoul et al. 2003; Carandang et al. 2016). The findings of the present study suggest that interventions targeting personal factors such as coping or self-efficacy could support RA individuals to achieve their full hand function potential and reduce the impact of RA on their hands.

Furthermore, the analysis showed that the participants have employed a range of behavioural and cognitive coping strategies in relation to their hand function problems. While strategies that belong to the cognitive component were mostly positive, the behavioural component contained both negative and positive strategies. Importantly, the participants appeared to be pro-active in their attempts to cope, by implementing behavioural strategies in the form of problem-solving approaches. However, they tended to give up or avoid activities when they were unable to conform to a normal standard, which often resulted in social restrictions for some participants. The findings of this study regarding coping strategies fit with the framework of Lazarus and Folkman (1984) that coping comprises both behavioural and cognitive efforts to manage challenges caused by illness. In terms of RA, there is considerable knowledge about coping and the changes that RA patients undergo, which are reflected in the present study’s findings (Sinclair and Blackburn 2008; Stamm et al. 2008; Gronning et al. 2011).

This study has provided examples of cognitive coping in the form of social comparison, with frequent use of downward comparison and no evidence of upward comparison. The participants also used temporal comparison (Albert 1977), which was associated with negative emotions. This mainly involved comparison with an earlier time prior to the disease. It has previously been suggested that downward comparison is employed when the means to change a situation are not achievable (Wills 1981), which could be the situation in people with RA in their hand(s). Social comparison in the form of downward comparisons were recognised as an adaptive coping strategy frequently used by RA patients in their efforts to reframe and accept their situation (Sinclair and Blackburn 2008). Studies which investigated the role of social comparisons in RA reported that patients who made comparisons with those in a worse state had better levels of satisfaction with their functional abilities and psychological adjustment (Arigo et al. 2014). It may be suggested that those using a self-temporal comparison in the current study were less satisfied with their hand function abilities and less well-adjusted than those using downward comparison. This may well have implications for future hand function interventions in RA.

Although functional roles, work and social activities were described as challenging by the participants, some of them continue to actively perform activities related to these domains, despite their experienced or consequential hand pain and problems. The motivation to stay active and do these activities was described by the participants as important for promoting their well-being. Therefore, it seemed that meaningful activities may have motivated participants to approach activities, which in turn may have promoted hand function. These findings are in agreement with other findings (Ahlstrand et al. 2012; Nicklasson and Jonsson 2012) and suggest that hand pain relief strategies can be used based on the individual's meaningful and important activities. However, it appears that this study's participants struggled to find the right balance between activity and rest, since most of them reported that hand overuse is followed by subsequent increased hand pain or complications. Indeed, difficulty in finding activity or occupational balance has been reported by woman with RA elsewhere (Stamm et al. 2004a).

The present study suggested that the participants' perception about their disease has the potential to influence hand function. This is in line with the illness perceptions model, which describes how beliefs about illness enable the patients to make sense of their disease and guides any coping actions (Leventhal et al. 1997). This is illustrated in the findings, which indicated that the participants' beliefs about their RA may influence the way in which they then cope. For instance, the participants described how their perceptions of the cause and timeline (i.e. a life-long condition) of RA allowed them to cope. Similarly, beliefs about RA medications and non-pharmacological treatments (i.e. herbal remedies) may also influence hand function directly. Many of the comments made by the participants indicated that they strongly believed in the beneficial effects of herbal remedies, whereas their beliefs about RA medications were generally negative. These beliefs may have influenced the participants' adherence to medications and their self-management behaviour. However, the findings of the study also pointed out that the participants were in a state of dilemma about medication. On the one hand they believed that RA medications have serious side effects, and on the other hand many of them expressed an intention to self-manage hand problems by increasing their medication dose or using over-the-counter analgesics. This may reflect the lack of knowledge about RA and medication, as reported by the participants in the present study. It is likely that the correction of any misconceptions about RA and specific medical treatments will be important for supporting Palestinian patients through their journey with RA. This could potentially be improved by providing Palestinian RA individuals with clear and straightforward educational materials and adopting an approach that supports the building of health literacy. This could facilitate their coping and adherence to necessary medications, and ultimately improve their hand function.

5.9 Clinical implications and recommendations

Insights from analysing the implications of the data led to the formulation of recommendations for clinical practice, which are considered and presented in the following sections.

5.9.1 Assessment of hand function

One of the major objectives of this study was to consider which hand function outcomes are useful to measure among Palestinian individuals with RA. The findings of this study suggest that disease symptoms (particularly the pain), and hand impairments (mainly hand strength) were related to hand function and had an important association with difficulties in performing hand-related activities. Therefore, the assessment of these outcomes is recommended in routine clinical assessments of hand function for Palestine people with RA.

The findings of this study also suggest that for Palestinian people with RA, it is useful to use hand functional measure(s) involving multiple joints of the upper limb and to assess their ability to perform activities using both hands, as opposed to focussing on the abilities of each individual hand. These suggestions are based on the following findings within the study:

- Participants revealed difficulties in performing numerous Palestinian culturally specific hand activities, such as “flip a pot upside down”, “purification of lentils” and so forth. These activities carry a great deal of importance, as described by the participants. However, many of the currently used hand function outcome measures do not address these kinds of cultural activities (Oksuz et al. 2017). Since many hand-related cultural activities were identified in this study, it would be difficult to establish a hand function questionnaire that incorporates all of them.

- Several participants commented that disease symptoms and consequences in other parts of the body, especially the upper limb, were a barrier to their ability to perform hand-related activities, and a few of them emphasised that the hand and upper limb should be treated as one functional unit. In agreement, a qualitative study by Nicklasson and Jonsson (2012), which recruited RA patients with hand deformities, reported that participants faced difficulty in considering the hand in isolation from the rest of the body when considering hand functioning. Therefore, it would be suggested that with the Palestinian RA population, hand function outcome measures involving multiple joints of the upper limb such as the DASH (Hudak et al. 1996) would offer more versatility for research and clinical practice.

- Participants in the current study suggested that accomplishing daily life activities was facilitated by less RA involvement of the dominant hand. This finding supports previous research results in concluding that hand dominance has a considerable effect on hand function (Hodges and Adams 2007). People with RA with a less affected dominant hand may report better hand function compared to those with a more affected dominant hand. However, the majority (>90%) of hand-related activities identified in the study required the use of both hands. Additionally, for patients and clinicians, the focus is on their ability to function with both hands, and not merely on assessing hand function in the dominant and non-dominant hand or left and right hand separately. Therefore, for people with RA, it is advisable to use hand functional disability measures that assess the ability to perform activities using both hands.

Although standardised hand functional (dis)ability measure(s) are necessary to establish evidence-based practice, these instruments may not reflect the complex nature of hand-related activity problems and the influence of contexts illustrated within this study. Therefore, standardised hand function (dis)ability measure(s) should be supplemented with an open-ended interview to gain better insight into this.

5.9.2 Management of hand problems

The findings of this study suggest the following recommendations for managing hand function problems among Palestinian individuals with RA:

- Develop management strategies for hand pain relief based on the individual's activities considered meaningful and important to that particular person.
- Analyse and treat hand pain during activities requiring hand function considering the context of the individual's perspective and needs of people with RA.
- Implement a client-centred rehabilitation approach to treat hand function problems.
- Involve family members of Palestinians with RA in the process of rehabilitation.
- Provide multidimensional rehabilitation care for Palestinian people with hand function problems, with specific consideration of personal factors when planning interventions to facilitate performing daily life activities.
- Targeted educational programmes for Palestinian physicians, to improve the early identification of RA and facilitate referral, so that treatment can be initiated on time. It is also advisable that changing Palestinian physicians' attitudes towards patient-centred care is timely and warranted.

- The Palestinian Ministry of Health's policy should put in place a policy that raises public awareness about RA.

- Design, develop and provide accessible clear and straightforward educational materials and resources for Palestinian RA individuals, alongside supporting an approach that facilitates the building of health literacy.

5.10 Implications for further research

- This study used the ICF as a framework to explore and describe the concepts of hand function, including impairments, activity limitations and participation restrictions, personal factors and environmental factors, but further studies are needed to examine the relationship between these components in the ICF.
- Participants located pain in specific parts of the hand. This aspect of pain should be explored further in future research in connection with hand functional disability.
- Further epidemiological research is warranted with the aim of examining the frequency and importance of problematic hand functioning in Palestinian people with RA.

5.11 Strengths and potential limitations of this study

Encouraging people to discuss and reveal information about limitations related to their ability to complete tasks in everyday life is a methodological challenge, since details about daily living are frequently thought of as mundane (Bukhave and Huniche 2014). However, the qualitative methodology used to generate the data provided adequate flexibility and was well suited to exploring the individuals' perspectives on everyday life when living with hand problems due to RA. As such, qualitatively exploring the experiences of Palestinians with RA in terms of their hand function has provided in-depth and insightful data, which a quantitative method may not have generated. To the best of the author's knowledge, this is the first qualitative study which provides in-depth data about hand function among Palestinian individuals with RA. The use of a rigorous qualitative method was a major strength of this qualitative study. The choice of inductive content analysis, which involved the discovery of concepts of hand functioning without predetermined assumptions, was suitable for exploring the experiences of people with RA regarding hand function. The strengths of the study were the involvement of patient partners and the use of a pilot focus group study to inform the main study design and data collection.

Nevertheless, this study had several limitations. Hand problems reported by the participants were treated as equally important and no attempt to quantify these using frequencies or ranking the importance of the reported hand problems was made. This is because this study aimed to reveal knowledge of a phenomenon, which has not been addressed before; thus, quantitative analysis was thought not to be relevant for the context of this study. This study recruited a convenience sample that was in line with other qualitative studies but was not designed a priori to achieve saturation. However, the number of new concepts developed from each successive focus group reduced (from 22 to 4 to 3 to 2 to 1). Therefore, the possibility that further extra information would be revealed from an additional focus group session is low. The participants in this focus group study were recruited from one rheumatology outpatient unit, therefore the results may not be generalisable to all Palestinian people with RA receiving healthcare in the private sector or from non-governmental organisations. In addition, the number of younger women (*n*=2) and working participants (*n*=6) was low in the present study. Therefore, the findings may not reflect the experiences of younger women and working individuals with RA.

Although measures were taken to enhance trustworthiness within this study, there are inherent complexities of language within cross-language qualitative studies. This is particularly important, since a specific concept in one language may not have the same meaning in another (Twinn 1998). Therefore, the analysis of the present study was undertaken in Arabic and several debriefing meetings with the supervisory team were conducted afterwards to refine the concepts. Afterwards, all of the concepts presented in this study were independently verified by the supervisory team. It is pertinent to acknowledge that this procedure minimised discrepancies and reflects accurate insights into the participants' experiences.

The published work has shown that contextual factors may influence the experiences of those living with RA (Schneider et al. 2008). Although the capacity for hand use depends on the musculoskeletal structure and physiology, the choice and meaning of hand usage are unique and influenced by sociocultural values and beliefs (Black 2011). Therefore, further studies among RA patients from other cultures and contexts that use the same methodology as the present study are warranted. Although the study sample included male and female participants of different ages and with varying disease durations, there were more female participants, and therefore more female focus groups. However, this study population reflects the global RA population (Symmons et al. 2002; Helmick et al. 2008; Neovius et al. 2011).

5.12 Chapter summary

This study identified 32 concepts related to hand functioning considered to be important for Palestinian people with RA. The participants' description of their hand-related difficulties due to RA provided evidence of the complex interaction of an individual with a health condition and the context in which they live. Hand function concepts generated in this study cannot be directly compared with the findings of the European studies concerning general functioning in RA. There are some similarities between the concepts highlighted by Palestinians and Europeans with RA, which reveal the common effect of this condition on people’s lives. However, there are also important differences between the two contexts; Palestinians with RA seem to experience the additional burdens of poor living conditions (i.e. low family income), low levels of health literacy and the consequences of the biomedical model of Palestinian healthcare system, with noticeable impacts due to the lack of integrated interdisciplinary rehabilitation services.

For patients with RA, this study has highlighted the paramount need to assess hand impairments; particularly hand pain. In addition, it is also clear that some measures are required to reduce environmental barriers and increase facilitators such as the provision of rehabilitation services, improving societal and healthcare providers’ education regarding RA and raising awareness of the potential benefits of family involvement in the process of care. In addition, personal factors are an integral part of this study findings. Mindful consideration of personal factors when planning interventions to facilitate hand functioning is also warranted. A further study on the relationship between the components of the ICF identified in this study is required and addressed in a subsequent study in this thesis (Chapter 6).

Chapter 6 Hand function and related variables in Palestinian people with RA: A cross-sectional study

6.1 Chapter overview

This chapter presents a cross-sectional study that investigated hand function and factors contributing to hand function in ADL among Palestinian individuals with RA. This chapter is organised as follows. The first two sections outline the background, purpose and objectives of the study. The study methods are then presented including the design, setting, participant recruitment, data collection and analysis and ethical considerations. The following five sections present the study results, interpret the major findings, identify the study limitations, assess the clinical implications alongside the future research directions and present the conclusion.

6.2 Introduction

As has been described in the literature review in Chapter 2, the functional consequences of RA on the hands of Palestinian people was unknown to date. This is coupled with a lack of studies exploring the contribution of personal and environmental factors to hand function among individuals with RA, as demonstrated by the systematic review study (Arab Alkabeya et al. 2019a). It is important to investigate the hand function of people living with RA, due to the prevalence of hand involvement, and because hand function is an essential component in performing ADL. In addition, some evidence suggests that hand function tests are appropriate assessments to monitor change in functional status, as they are sensitive to clinically significant treatment responses (Eberhardt et al. 2008; Bremander et al. 2019). Therefore, it is important to measure the progression of hand functional impairment in RA, to understand the impact of the disease, determine treatment strategies and evaluate interventions used in hand RA management. Furthermore, exploring the contribution of environmental and personal factors to hand function will facilitate the establishment of a bespoke multidimensional treatment plan for Palestinian people living with hand RA.

The second aim of this thesis is to evaluate the impact of RA on hand function and investigate the factors that contribute to hand function in ADLs among Palestinian people living with RA. This aim could not be fully achieved by using a quantitative approach alone. This is because both an uncertainty regarding the appropriate hand function outcome measures to be used in the Palestinian context, and the lack of evidence identifying the important personal and environmental factors in relation to hand function for this population. Therefore, it was decided that a sequential mixed method approach starting with a qualitative enquiry (focus group study), which subsequently informed the design of the present cross-sectional study, would be adopted. In view of the focus group study findings, it was suggested that for Palestinian participants living with hand RA, hand function outcome measures involving multiple joints of the upper limb such as the DASH (Disabilities of the Arm, Shoulder and Hand questionnaire) (Hudak et al. 1996) or QuickDASH (Beaton et al. 2005) were more relevant, versatile and appropriate for Palestinian research and clinical practice. This is because Palestinian people with hand RA found it difficult to differentiate upper limb joint problems from hand problems. In addition, self-reported questionnaires are suitable to be used in low-income contexts, such as Palestine, because they do not require specific equipment and are less time-consuming. Important environmental and personal factors experienced by Palestinians with RA as facilitators and barriers in relation to their hand function in daily living tasks were identified in the focus group study. Therefore, the assessment and evaluation of these factors in relation to hand function is now warranted.

6.3 Aim and objectives

This study aimed to examine hand function and the related variables among Palestinian people with RA. The specific objectives of this study were to:

1) Describe the demographic and clinical characteristics of Palestinians with RA.
2) Describe and measure the functional consequences of RA with regards to hand impairment in Palestinians with RA.
3) Describe and measure the functional consequences of RA with regards to hand-related activity limitations and participation restrictions in Palestinian people with RA.
4) Analyse the associations between hand-related activity limitations and participation restrictions (hand functional impairment), and disease variables,

hand impairments, and personal, environmental and health-related factors in Palestinian people with RA.

6.4 Methods

6.4.1 Study design

This was a multicentre cross-sectional observational study conducted to describe and measure the consequences of RA on hand function outcomes, as well as analyse the associations between hand functional ability and factors from the entire scope of the ICF. A cross-sectional design was chosen, because it is appropriate to measure risk factors and outcomes, describe their characteristics and explore the association between them (Mann 2003; Sainani and Popat 2011). The advantages of this design is that data are collected at a single point time and multiple outcomes can be studied, thus this type of study allows the identification of relationships that can then be more rigorously studied using a longitudinal or randomised control study (Mann 2003). However, this type of study design cannot differentiate the cause and effect from simple relationships (Mann 2003).

The STROBE statement checklist (von Elm et al. 2007) was used to guide the reporting of this cross-sectional study and the completed checklist is provided in Appendix L. Support was provided by a medical statistician (SE) from the School of Health Sciences, University of Southampton, who assisted in planning and analysing data.

6.4.2 Study setting

Potential participants were recruited from three rheumatology outpatients' clinics situated within governmental hospitals in the northern region of Palestine from March - July 2019. Adults with RA who met the eligibility criteria (section 6.4.3) and consented to take part were invited to attend a single session for data collection in the rehabilitation department within the hospitals they were recruited from.

6.4.3 Participants

1) Inclusion Criteria

Participants were eligible to participate if they:

- had a confirmed diagnosis of RA as defined by the American College of Rheumatology (ACR) criteria (Arnett et al. 1988)
- were aged 18 years or above
- presented at one of three participating sites (between March - June 2019)
- cooperated and had sufficient language skills to complete assessments

2) Exclusion Criteria

Participants were excluded from the study if they:

- had a history of major hand trauma or neurological disorders affecting their upper limbs (e.g. stroke, hemiparesis), as these conditions have the potential to influence hand function
- were unable to complete the questionnaires due to cognitive impairments, mental health conditions, or who were unable to read or write Arabic
- took part in the focus group study, as recommended by Creswell and Plano Clark (2018)

6.4.4 Sampling method and sample size

This study recruited a convenience sample of Palestinian people with RA. A convenience sampling design is a widely used method to enrol participants according to their availability and accessibility (Elfil and Negida 2017), particularly when the number of patients cannot be individually identified (Kumar 2014). There are no data stratified by Palestinian regions in terms of the number of people with RA and rheumatology services available. Therefore, recruiting participants from three major rheumatology services in the northern region of Palestine had the potential to provide a representative sample of Palestinians with RA.

The mean and standard deviation of the QuickDASH (the main hand function outcome used in this study) in people with RA has been reported to be 38.33 (SD 19.78) (Palamar et al. 2017). A sample size calculation identified that a sample of 62 participants was sufficient to estimate the mean score with a 95% confidence interval of ± 5%. To compensate for anticipated dropouts, the calculated sample size was increased by 10%, resulting in 69 participants.

6.4.5 Participant recruitment procedure

Participants were recruited through a collaborative effort by the rheumatology medical staff (e.g. nurses, physicians) at each rheumatology unit. The medical staff were provided with detailed information about the study aims, process, and inclusion and exclusion criteria by the researcher. Furthermore, they were given an opportunity to ask questions. The medical staff were asked to give the recruitment pack (Appendix M), which included the invitation letter and PIS, to the patients who met the inclusion criteria. Potential participants were given at least 48 hours to read and understand the PIS and to discuss it with their families or relatives.

Participants contacted the researcher if they were interested in taking part in the study via a work phone at the AAUP and were given further details about the study. During the phone call, the researcher assessed the eligibility of potential participants using the inclusion and exclusion criteria as a checklist. Participants had the opportunity to ask any questions about the study during the phone call. Verbal agreement to take part was initially obtained from the eligible participants at the end of the phone call. Eligible participants were then invited to one data collection session that was conducted in the rehabilitation units located within their rheumatology clinics.

6.4.6 Data collection

6.4.6.1 Sociodemographic and clinical characteristics

Sociodemographic and clinical information were collected from the participants and their health records, and recorded using a sociodemographic questionnaire (see clinical research questionnaires-Appendix N) and medical data sheet (Appendix O). The first section of the sociodemographic questionnaire included basic information pertaining to the participants such as age, gender, marital status, educational level and employment status. This section also included sociodemographic questions such as living arrangements, living area, personal responsibilities and economic status. The second section of the questionnaire was focussed on the disease-related characteristics and therapeutic data such as disease duration, length of time taken to obtain a diagnosis of RA, use of hand splints, previous rehabilitation treatment, and any previous hand surgery within the past six months. In addition, participants were asked to indicate if they had experienced hand pain within the past six months.

Details of all prescribed RA medications were also collected from the hospital prescription records. The serum rheumatoid factor level (RF) was obtained from the hospital patients' records, as this is routinely assessed for all patients every time they have a follow-up appointment at one of the rheumatology clinics. Information about comorbidity was obtained from the hospital patients' medical records and documented using a binary response (Yes/No) to the six European League Against Rheumatism (EULAR) comorbidity domains (cardiovascular, malignancies, infections, gastrointestinal disease, osteoporosis, depression) (Radner et al. 2018).

6.4.6.2 Measures

A summary of the main measures assigned to the ICF model are showed in Table 6-1. Appendix N contains the clinical research questionnaires. In-depth details about the measures are presented in the following subsections.

Table 6-1 Summary of the main outcome measures collected for each participant

ICF	Domain	Data source	Measures – Instrument
Activity & participation	Function	Research Clinic Questionnaire (participant reported)	Quick Disabilities of the Arm, Shoulder and Hand (QuickDASH) questionnaire- Overall score (a scale score ranging from 0 (no disability) to 100 (most severe disability).
Body function and structure	Impairments	Research Clinic Examination (performed by outcome assessor)	Wrist (flexion/extension) ROM- Goniometer
			Thumb functional mobility - Kapandji (1986)
			Power grip strength- Jamar Dynamometer
	Disease activity	Medical Records	Erythrocyte sedimentation rate (ESR-mm/h) and/or C-Reactive protein (CRP mg/l) blood test
	Pain	Research Clinic Questionnaire	Hand pain during activity- Pain NRS during test of grip strength
			Hand pain at rest- Pain NRS
	Psychological distress	Research Clinic Questionnaire	Depression and anxiety - Patient Health Questionnaire (PHQ-4)
	Fatigue	Research Clinic Questionnaire	Vitality subscale of the SF-36
	Aesthetic changes	Research Clinic Questionnaire	bMHQ aesthetic changes item
Environmental	Family support	Research Clinic Questionnaire	Family support subscale- MSPSS
Personal	Coping	Research Clinic Questionnaire	Brief COPE Inventory (BCI)
	Resilience	Research Clinic Questionnaire	The Brief Resilience Scale (BRS)
	Disease perception	Research Clinic Questionnaire	Brief Illness Perception Questionnaire (IPQ)
	Self-efficacy	Research Clinic Questionnaire	Arthritis Self-efficacy Scale (ASES)- 8-items
	Personal attitudes	Research Clinic Questionnaire	Beliefs about Medicines Questionnaire (BMQ)
	Health literacy	Research Clinic Questionnaire	Single-item health literacy screening (SILS) questionnaire

bMHQ: Brief Michigan Hand Outcomes Questionnaire; MSPSS: Multidimensional Scale of Perceived Social Support; NRS: Numeric Rating Scale; ROM: Range of Motion

▪ Hand-related activity limitations and participation restrictions (QuickDASH)

Hand-related activity limitations and participation restrictions were evaluated using the QuickDASH questionnaire (Beaton et al. 2005). The QuickDASH is a shortened version of the DASH instrument, which is designed to assess generalised upper limb functional ability across a wide variety of upper limb disorders. It uses 11 of the original 30 items to assess impairments (3 items) and activity limitations and participation restrictions (8 items) of the upper extremity. Each item is scored on a five-point Likert scale, and the scores for all of the items are used to calculate a scale score ranging from zero (no disability) to 100 (most severe disability). A content validation analysis study of the 30 DASH items according to the ICF taxonomy demonstrated that 15 items were identified as uniquely related to activity limitations, two items were classed as pure measures of participation restrictions, and five items were related to both activity limitations and participation restrictions (Dixon et al. 2008). As reported by Dixon et al. (2008), the QuickDASH has five items purely related to activity limitations, one item uniquely related to participation restrictions and two items related to both activity limitations and participation restrictions.

The QuickDASH is the best tool to use with patients who cannot differentiate upper limb joint problems from hand problems, as evident in RA populations (Angst et al. 2011). It should be used in preference to the full DASH, as it gives the same information (Aasheim and Finsen 2014), but with a lower burden for both participants when completing and clinicians in scoring the test (Ochi et al. 2015). The QuickDASH is possible to use with no cost for non-commercial and research applications, making it suitable for the Palestinian context. The QuickDASH is now available in several languages, including Arabic, and reported to have good construct validity, test-retest reliability and responsiveness to change in people with RA (Ochi et al. 2015; Salaffi et al. 2019). Furthermore, the cut-off values for the QuickDASH have been recently established for RA patients, allowing clinicians to better distinguish between functional categories and interpreting the QuickDASH score in clinical practice (Salaffi et al. 2019). To make the results more accessible for clinical and healthcare policy purposes, the QuickDASH scores were converted into a dichotomous variable based on the published data related to QuickDASH scores: no impairment ≤ 13, 13 < low impairment ≤ 18.5, 18.5 < moderate impairment ≤ 31.5, and high impairment > 31.5 (Salaffi et al. 2019). Additionally, the QuickDASH scores were compared to expected age- and sex-specific reference values published by Aasheim and Finsen

(2014). These were based on a random sample of 444 volunteers recruited from a wide variety of settings in Norway.

- **Body function and structure variables**

1) Hand impairments

A protocol for the comprehensive assessment of hand impairments in RA populations was unavailable and previous studies concerning hand function in RA had used different methods to evaluate and report hand impairments (Arab Alkabeya et al. 2019a). The following subsections provide details about the selected hand impairment measures included in this study.

a) Range of motion and functional mobility measures

RA has a significant negative impact on hand and finger joint ROM, which can influence the ability to use the hand in everyday life (Erol et al. 2016). The focus group study findings identified that wrist joint and thumb ROM are important components of hand functioning. Accordingly, active ROM of the wrist flexion and extension for both hands were assessed by the researcher from a neutral position using a goniometer (Norkin and White 2009). The goniometer measures articular angles, which are considered to be the gold standard in ROM measurement (Santos et al. 2012). Several studies have been performed to establish the interrater and intrarater reliability of using a goniometer for measuring joints of the upper extremity, including wrist ROM (Horger 1990; LaStayo and Wheeler 1994). Excellent intrarater reliability (ICC>.90) and good interrater reliability (ICC>.77) was reported for active wrist flexion and extension ROM measured using the goniometer in people with hand musculoskeletal problems (Horger 1990). In the present study, active wrist flexion and extension ROM were evaluated following the standardised operating procedure employed in the Strengthening and Stretching for Rheumatoid Arthritis of the Hand (SARAH) randomised controlled trial conducted in the UK (Williams et al. 2015). Detailed information about the procedures and data collection instructions for assessing wrist ROM are presented in Appendix P. In the present study wrist mobility was considered to be impaired if the active measurement was ≥15° less than normative values (Horsten et al. 2010).

The thumb is very important for comprehensive hand function; its function accounts for ~50% of total hand use (Tsai et al. 2017). Therefore, assessment of the thumb's functional mobility is essential to fully understand the fundamental functional consequences of the pathological processes. In the present study, the thumb's functional mobility for both hands was evaluated using the Kapandji (1986) index. The Kapandji (1986) index is considered as a functional evaluation of the thumb using anatomic landmarks of the hand as a reference, with the clinician giving a score from zero (impossible to do) to 10 (completely accomplished). The validity, reliability and responsiveness to change of the Kapandji (1986) has been established in people with RA (Lefevre-Colau et al. 2003). The interrater reliability of the Kapandji (1986) index was excellent (ICC=.90) and convergent and divergent validity results suggested good construct validity (Lefevre-Colau et al. 2003). The data collection instructions for assessing the thumb's functional mobility using the Kapandji (1986) index are presented in Appendix P.

b) Power grip strength

Hand strength is an impairment of the hand that can be objectively measured and is frequently assessed in RA. The findings of the initial systematic review suggested that hand strength is a reliable indicator of hand function in the RA population (Arab Alkabeya et al. 2019a). This was corroborated by the results from the focus group study, which identified that hand strength was considered an essential component related to hand functioning. Therefore, measuring hand strength as a separate impairment variable is crucial to provide more understanding of the impact of RA on hand function. A lack of consistency for measuring handgrip strength, with no consensus regarding an optimal test protocol in RA, has been identified (Higgins et al. 2018). However, Mathiowetz (1991) grip strength protocol, which uses standardised positioning and verbal prompting, and which records the best result of three trials, has been considered to work well with the RA population (Adams et al. 2008). A subsequent study found that a single trial was sufficient, so this approach was adopted in the present study to measure the participants' bilateral power grip strength (Kennedy et al. 2010). Despite the lack of consensus as to which instrument is the best to use when measuring grip strength, practical issues such as cost and availability need to be considered (Higgins et al. 2018). Therefore, the Jamar Dynamometer, considered as standardised for the measurement of grip strength in rheumatology patients (Blenkiron 2005) and available to the researcher at the AAUP university, was used to measure power grip strength. The standardised operating procedure and data collection instructions for measuring power grip strength according to Mathiowetz (1991) are shown in Appendix P. The Jamar Dynamometer (J. A. Preston Corporation, Clifton, NJ, US) used in this study was new and calibrated by the manufacturer before purchase.

Power grip strength values for both hands were compared to the expected age- and sex-specific consolidated reference values from the literature (Bohannon et al. 2006). These were based on 12 publications presenting normative values for grip strength obtained with the Jamar dynamometer. Consolidated grip strength reference values provide a better standard for comparison than using one source for normative data (Bohannon et al. 2006). Accordingly, the average grip strength was compared to the corresponding expected value. In addition, individual participants whose power grip strength was less than the lower limit of the confidence interval of the corresponding normative value was considered to have impaired power grip strength (Bohannon et al. 2006).

c) Pain

The participants in the focus group study identified hand pain as the predominant health status impairment, and as one of the most important symptoms for them to treat and alleviate. In addition, hand pain has been found to be an important factor that influences hand function in people with RA (Arab Alkabeya et al. 2019a). Numerous outcome measures and scales are available for measuring pain in RA. A systematic review of pain measures in RA recommended the use of the visual analogue scale (VAS), the numerical rating scale (NRS) and the verbal rating scale, since their psychometric information (i.e. validity, reliability, and responsiveness) were found to be good (Englbrecht et al. 2012). Alghadir et al. (2016) reported that the Arabic NRS is valid, reliable and easily understood by an Arabic patient population. For the present study, two types of pain intensity in hands were reported on the Arabic NRS for both hands. First, participants were asked to report their pain while resting (i.e. hand pain at rest) over the past week. Thereafter, participants' hand power grip strength was tested using the Jamar Dynamometer, as detailed previously. After measuring their power grip strength, participants were asked to report their hand pain experienced during this grip strength test (hand pain during test) on the Arabic NRS. This procedure has also been employed in a Swedish cohort study exploring intensity of hand pain and activity limitation in people with RA (Thyberg et al. 2016).

2) Disease activity

Different levels of RA disease activity can result in a variation in the ability to use the hands to perform daily life activities. Therefore, assessing disease activity is crucial to understanding hand function in people with RA. The core set of variables that are used to assess disease activity have been endorsed by the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR) (Felson et al. 1993; Karonitsch et al. 2008). The core set includes swollen and tender joint counts; a physician assessment of disease activity; a patient assessment of disease activity, pain and physical function; and levels of an acute phase reactant, specifically either the C-reactive protein (CRP) level or the erythrocyte sedimentation rate (ESR). In the current study, disease activity variables included documenting the acute phase reactant (CRP and ESR). Therefore, blood test results that contain data about the CRP, and ESR, as well as RF, were obtained from the rheumatology clinics on the same day as the evaluation session.

Regarding disease activity, Carroll (2016) suggested that the QuickDASH could be used as a viable surrogate disease activity index in RA, as changes in the QuickDASH correlated closely with changes in disease activity established by the RAPID3 (The Routine Assessment of Patient Index Data 3) (Pincus et al. 2006). As well as using the QuickDASH to assess hand-related activity limitations and participation restrictions, the proposed disease activity ranges of the QuickDASH (Carroll 2016) were used to explore the participants' disease activity status in the present study.

3) Psychological distress

Psychological consequences may be an important aspect to consider in relation to impaired hand function, and have been identified as an important aspect of functioning in RA (Stamm et al. 2005; Coenen et al. 2006; Meesters et al. 2014). Cumulative evidence from the rheumatology literature has shown that psychological problems are an important modifiable parameter, which significantly contribute to functional disability in people with RA (Benka et al. 2012; Benka et al. 2014; Ji et al. 2017; Karpouzas et al. 2017). The analysis of the focus group study identified a complex relationship between psychological problems and hand function. For instance, participants revealed that they had experienced emotional problems because of their inability to use their hands effectively in daily life activities. However, the systematic review showed that psychological consequences are not routinely considered as being related to hand function in people with RA (Arab Alkabeya et al. 2019a). Therefore, exploring the role of psychological problems in relation to hand function in RA is warranted. For this reason, it was felt to be important to explore the role of psychological problems in relation to hand function in RA.

The ICF based assessment of hand injuries and disorders (Kus et al. 2017) recommends using two brief self-reported questionnaires including the patient health questionnaire (PHQ-2) depression scale and generalised anxiety disorder (GAD-2) for screening psychological problems (Kroenke et al. 2003; Kroenke et al. 2007). The PHQ-2 comprises the first two items of the PHQ-9 scale (Spitzer et al. 1999). The primary question is, "Over the last two weeks, how often have you been bothered by any of the following problems?”. The two items are “little interest or pleasure in doing things” and “feeling, down, depressed, or hopeless”. The response options for each item range from zero “not at all” to three “nearly every day” and the total score ranges from zero to six (a high score indicates that there is an underlying depressive disorder). The recommended cut-off point is a score of three or higher (Kroenke et al. 2003). Similarly, the GAD-2 consists of the first two items of the GAD-7 (Spitzer et al. 2006), with response options identical to the PHQ-2, therefore it can be scored as continuous variables from zero to six, with a cut-off point of three or higher indicating that there is an underlying anxiety disorder. Kroenke et al. (2009) combined the PHQ-2 and GAD-2 into a composite four-item scale, called the PHQ–4, to serve as a general marker of psychological distress, with the total score on this composite measure ranging from zero to 12. The advantages of using the PHQ-4 include the ability to measure both depression and anxiety and provide a summary score for each, as well as measuring psychological distress reflected as a total score of both scales. All of the scales (PHQ-2, GAD-2 and PHQ-4) are freely available in the public domain, do not require permission for use, and have well established psychometric properties to support their use with primary care patients and the general population (Kroenke et al. 2010; Pettersson et al. 2015; Plummer et al. 2016). The PHQ-9 and GAD-7 have been cross-culturally validated in the Arabic language and are reported to be valid and reliable (AlHadi et al. 2017). In the present study, the PHQ-4 was used to assess the patients’ psychological distress.

4) Fatigue

Fatigue was another disease outcome considered important in relation to hand function by the participants in the focus group study. There has been no consensus on the most appropriate fatigue scale to be used with RA populations, with the majority of the available scales having limited evidence of validity (Hewlett et al. 2007). However, the vitality subscale of the Short Form 36 (SF-36) was reported to have some reasonable validity in measuring fatigue in RA (Hewlett et al. 2007). This scale consists of four items asking, “How much of the time during the past 4 weeks did you have a lot of energy?” “…have you felt full of life?” “…did you feel worn out?” and “…did you feel tired?”, with six responses from “all of the time” to “none of the time”. Standardised scores range from zero to 100, with lower scores indicating greater fatigue (Ware et al. 1993). The results from several studies including RA patients have demonstrated the reliability and construct validity of the SF-36 (Ruta et al. 1998; Kosinski et al. 1999). Similarly, results from studies conducted in Arab countries have shown that the Arabic SF-36 has satisfactory validity and reliability in a variety of population samples (Coons et al. 1997; Khader et al. 2011; Sheikh et al. 2013). Therefore, the Arabic SF-36 vitality subscale was used in the present study. The SF-36 is available to the public, and no written permission is required for its use (RAND Corporation 2018).

5) Aesthetic changes

The aesthetic status of the hand was reported to have a clear importance in relation to hand functioning by some participants in the focus group study. This domain is often overlooked in patients with hand disorders, as the majority of hand function outcome measures do not evaluate aesthetic changes (Badalamente et al. 2013), except for the Michigan Hand Outcomes Questionnaire (MHQ) (Chung et al. 1998) and the brief MHQ (Waljee et al. 2011). The MHQ has four items which focus on aesthetic hand appearance for the right and left hand separately, whereas the brief MHQ has only two items focussing on hand appearance. For this study, one item from the brief MHQ focussing on aesthetic hand appearance was used to explore the participants' satisfaction regarding the appearance of their hand(s). This one item asks the participants to indicate if they are satisfied with the appearance of their hand, with response options ranging from "strongly agree" (=1) to "strongly disagree" (=5). The brief MHQ has a well-established validity and reliability in RA (Waljee et al. 2011), but has not yet been cross culturally validated in Arabic. Therefore, the brief MHQ aesthetic item was cross-culturally adapted following the recommended guidelines for the cross-cultural adaption of health status measures (Beaton et al. 2000; Wild et al. 2005). Initially, the permission to translate the brief MHQ aesthetic hand appearance item was obtained from the developers (Appendix Q). The researcher and a colleague from the Health Sciences department at the AAUP, who are both bilingual, then translated the brief MHQ aesthetic hand appearance item into Arabic. Two independent bilingual colleagues from the English Linguistic department at the AUUP, who were blinded to the original brief MHQ, then performed a back translation of the generated Arabic version of the item. All experts involved in the process of forward and backward translation then met and resolved any inconsistencies to produce the pre-final version of the item. Finally, face validity was assessed by seeking feedback from the RA patient partner collaborators. Cognitive debriefing interviews with at least five patients is a recommended step to establish face validity in the process of translation and cultural adaption of PROMs (Wild et al. 2005). Cognitive interviewing is a formal research methodology, which aims to understand how participants perceive and interpret questions and to identify potential problems when completing PROMs or questionnaires

(Drennan 2003). Therefore, cognitive debriefing interviews were conducted with five Palestinian RA patient partner collaborators (2 men and 3 women) who had a range of educational levels, ages and disease duration, in order to evaluate the ease of completion, relevance and clarity of the brief MHQ aesthetic item. Modifications were made according to the patients' feedback and understanding. After reaching an agreement in term of the Arabic aesthetic item's wording, clarity and cultural equivalence, it was utilised in the present study.

▪ Environmental factors

1) Family support

Most of the participants in the focus groups study reported family as a facilitating or hindering factor in relation to hand function. A lack of immediate family physical support, as well as negative attitudes from family members, were experienced by participants as barriers for hand function. Previous research has shown that social support can affect long term functional disability (Evers et al. 2003) and emotional support moderates the influence of functional disability on feelings of depression in people with RA (Benka et al. 2014). However, previous RA studies have not addressed the role of family support or social support in relation to hand function (Arab Alkabeya et al. 2019a). Therefore, family support in relation to hand function in people with RA was explored in the present study.

The Multidimensional Scale of Perceived Social Support (MSPSS) is one of the most widely used measures in research to assess the perceived social support from different resources including family support. For this study, the family support subscale of the MSPSS was utilised to measure perceived family support (Zimet et al. 1988). The MSPSS family support subscale is a self-administered measure that has four items, and each item is scored on a 7-point Likert scale ranging from “very strongly disagree” (=1) to “very strongly agree” (=7). The cumulative score ranges from four to 28, with a higher score indicating higher family support. The mean score of the subscale can be calculated based on considered support levels; scores ranging from 1 to 2.9 (low support), 3 to 5 (moderate support), and 5.1 to 7 (high support) (Zimet; 2018). The MSPSS is free to use and has been widely used with different patient populations, including RA (Liu et al. 2017a; Xu et al. 2017). The validity and reliability of the MSPSS have been confirmed by several publications (Zimet et al. 1988; Zimet et al. 1990). In addition, the MSPSS has been cross-culturally validated for use in Arabic countries, and the Arabic family support subscale of the MSPSS has an acceptable internal consistency (Cronbach's alpha =.82) (Merhi and Kazarian 2012). The MSPSS is also freely available in the public domain and does not require permission for its use.

- **Personal factors**

1) Coping

The focus groups study identified that hand problems posed different challenges to and limitations in the participants' lives. As a result, Palestinians with RA have described employing various coping strategies in their efforts to manage these challenges. The coping strategies employed by Palestinian people with RA have the potential to influence hand function, either negatively or positively. For instance, negative coping strategies such as giving up and avoiding activities may lead to undesirable consequences such as weaker hand strength. Alternatively, positive coping strategies, such as planning, may lead to improved hand function, as patients approach and engage with activities rather than withdraw from them. The influence of coping strategies in relation to hand function is poorly addressed in people with RA (Arab Alkabeya et al. 2019a). Therefore, in the current study, the influence of adaptive and mal-adaptive coping strategies was deemed important and explored in relation to hand function.

There is no "gold standard" outcome measure to evaluate coping in RA. Dur et al. (2015) identified 14 PROMs commonly used with patients with RA, which included items that measured coping. For the present study, the Brief Coping Inventory (BCI) (Carver 1997) was used to evaluate the coping strategies employed by Palestinian individuals with RA. The BCI is a widely used coping measure which identifies the nature of coping strategies implemented by individuals in many health-relevant situations (Krägeloh 2011) and has been used with the RA population (Rzeszutek et al. 2017). It comprises 14 subscales that can be grouped into two main scales: (a) the adaptive coping scale, which includes active coping, planning, instrumental support, acceptance, emotional support, religion, humour, and a positive reframing subscale, and (b) the maladaptive coping scale, which includes denial, behavioural disengagement, self-distraction, self-blame, venting and a substance use subscale (Meyer 2001). Each subscale of the BCI contains two items (i.e. 28 items in total) and each item is scored on a Likert scale from one "I haven't been doing this at all" to four "I have been doing this a lot". The total score for each subscale of the brief BCI is calculated by summing the appropriate items for each subscale. Similarly, the score for the adaptive or maladaptive scale is calculated by summing the relevant subscales scores.

The subscales of the brief BCI have reported reliability (Cronbach's alpha) ranging from .50 to .90 (Carver 1997). The brief BCI Arabic version has reported an internal consistency (Cronbach's alpha) ranging from .63 to .94, and divergent validity results suggest good construct validity (Nawel and Elisabeth 2015). The substance use scale of the BCI may introduce cultural bias, since the statements on this scale enquire about alcohol or drug use (recreational), which are not culturally acceptable in Palestine. Therefore, the substance use subscale of the BCI was not included in the measure of coping for this study's Palestinian sample population. The BCI can be used freely and written permission for its use is not required (Carver 2018).

2) Resilience

Resilience is an important personal factor identified in the focus group study which plays a significant role in people overcoming hand problems caused by RA. However, resilience is seldom studied in RA (Liu et al. 2017b), and little is known about its influence on hand function in people with RA (Arab Alkabeya et al. 2019a). Therefore, self-reported resilience capacity was assessed and explored in terms of its association with hand function in the present study.

A review study of resilience outcome measures conducted by the Resilience and Healthy Ageing Network in the UK concluded that a "gold standard" for measuring reliance was unavailable and the majority of the measures currently used lack psychometric evidence (Windle et al. 2011). However, for the current study, resilience was assessed utilising the Brief Resilience Scale (BRS) (Smith et al. 2008), which was found to be among the measures that have the best psychometric ratings (Windle et al. 2011). The BRS was developed with a specific focus on bouncing back from stress; thus, making it suitable to be used with people who are already dealing with stressful life events such as health-related problems. The BRS is a self-reported scale that contains three positive valence items (items 1, 3 and 5) and three negative valence items (items, 2,4 and 6) rated on a 5-point response scale, ranging from "strongly disagree" (=1) to "strongly agree" (=5). Sample items are, "I tend to bounce back quickly after hard times," and "I have a hard time making it through stressful events". To calculate the BRS score, the negative valence items are reverse scored, then the six items are summed and an average score is then calculated, so that a higher score indicates a higher degree of resilience. Smith et al. (2013) suggested that the BRS scores can be interpreted as low (1.00-2.99), normal (3.00-4.30) and high resilience (4.31-5.00). The internal consistency (Cronbach's alpha) of the BRS was reported to range from .80 to .91, and the test-retest reliability (ICC) of the scale was reported to range from .62 to .69 (Smith et al. 2008). The BRS has been cross-culturally validated for use in Arabic countries and the Arabic BRS scale has shown acceptable internal consistency (Cronbach's alpha =.78) (Younes and Massoud 2017; Younes and Alzahrani 2018). Lastly, the BRS can be used freely in research and education (Smith et al. 2008).

3) Disease perception

Data analysis from the focus group study suggested that disease perception seemed to affect hand function outcomes, as it could influence disease-specific behaviours such as adherence to treatment, and coping strategies. Previous research has shown that better disease perception is associated with favourable health outcomes in RA patients (Graves et al. 2009; Løchting et al. 2013). However, disease perception has not been explored in relation to hand function in RA (Arab Alkabeya et al. 2019a). Since disease perception is a modifiable parameter, which may play an important role in relation to hand function, assessing and exploring its relationship with hand function is considered essential in the present study.

There are a few outcome measures that assess disease perception in rheumatology. Maas et al. (2009) reviewed the disease perception outcome measures in rheumatology and reported that only five outcome measures could be used, of which only two had been extensively validated. The Illness Perception Questionnaire (IPQ) (Weinman et al. 1996; Moss-Morris et al. 2002) is among the self-reported outcome measures that have been extensively validated in rheumatology and recommended for use in the clinical and research field (Maas et al. 2009). However, the IPQ contains many items making its suitability for clinical and research use limited, especially when disease perception is only part of a large set of measures being explored, as is the case in the present study. Accordingly, a shorter version of the IPQ has been developed (Broadbent et al. 2006). The brief IPQ comprises nine items that assess cognitive illness representation (five items including consequences, timeline, personal control, treatment control, and identity), emotional representation (two items including concern and emotional response), and illness comprehensibility (one item of understanding). An assessment of the causal representation is through an open-ended response item. Responses are scored on a scale ranging from zero to 10, excluding the causal representation domain, which asks the client to list three important causal factors to their disease. The brief IPQ uses a single-item scale approach, in which a score of zero for items 1,2,5,6 and 8 indicates good disease perception and a score of 10 indicates poor disease perception. For items 3, 4, and 7, a score of zero indicates poor disease perception, and 10 indicates a good disease perception. Responses to the causal item can be grouped into categories such as hereditary, and categorical analysis can then be performed (Broadbent et al. 2006). Like the IPQ, the general version of brief IPQ uses the word “illness”, but it is possible to replace this with the name of a particular disease such rheumatoid arthritis. The brief IPQ is feasible to use for research purposes and is available in several languages, including a standardised Arabic version that has been used for cardiac diseases, with good validity and reliability (Saarti et al. 2016). This scale has demonstrated good test-retest reliability (ICC >.78) and internal consistency (Cronbach’s alpha=.72) (Saarti et al. 2016).

4) Self-efficacy

The role of self-efficacy in relation to performing valued activities has been previously addressed in the rheumatology literature. It was concluded that high self-efficacy facilitates participation in valued life activities in people with RA (Ahlstrand et al. 2016). However, little is known about the role of self-efficacy in relation to hand function in people with RA (Arab Alkabeya et al. 2019a). In the context of the focus group study, it was evident that high self-efficacy can influence hand function positively by allowing the participants to approach and solve difficult hand-related activities rather than withdraw from them. Therefore, it is evident that self-efficacy is an important variable to be explored in the present study.

A recent review of instruments assessing self-efficacy in RA failed to provide recommendations on the most appropriate self-efficacy instrument to use in the clinical and research field (Garratt et al. 2014). This study also concluded that the testing of self-efficacy instruments was generally of poor quality. However, compared with other self-efficacy measures, the Arthritis Self-efficacy Scale (ASES) (Lorig et al. 1989) is the most common scale used to measure self-efficacy for managing arthritis and has been extensively examined for validity and reliability (Brady 2011; Garratt et al. 2014). The ASES comprised 20 items (which may preclude its use in both clinical and research fields), however, an 8-item version (ASES-8) has since been developed to reduce participants’ burden in research studies (Gonzalez et al. 1995). The ASES-8 contains two items from the ASES pain subscale, four items from the ASES other symptoms subscale, and two new items which relate to preventing pain and fatigue from interfering with things the patients want to do. These items measure the patients’ confidence on a scale of 1 (very uncertain) to 10 (very certain). Responses are averaged to yield a score ranging from 1-10, with a higher score indicating greater self-efficacy. The validity and reliability of the ASES-8 are well established in different languages, including Spanish (Gonzalez et al. 1995), German (Mueller et al. 2003), English (Wilcox et al. 2014) and Chinese (Gao et al. 2016; Gao et al. 2017). The ASES-8 was chosen to be used in the current study to assess self-efficacy. However, a cross-cultural adaption of the ASES-8 Arabic version had yet to be established. Therefore, permission to translate the ASES was obtained via email from Dr. Kate Lorig (Appendix R). The recommended method for the cross-cultural adaption of the health status measures previously documented (section 6.4.6.2) was followed to translate and establish the face validity of the Arabic ASES-8. Secondary data analysis of the present study demonstrated that the Arabic ASES-8 was valid and reliable for evaluating self-efficacy in patients with RA (Arab Alkabeya et al. 2020). The published content of this analysis is provided in Appendix S.

5) Personal attitudes towards medications

Many participants in the focus group expressed strong beliefs and concerns about their medications, especially with regards to potential side effects. As a result, some of them revealed that they had preferred to stop taking their prescribed medications. Indeed, a previous study reported that a higher level of concern over medication was associated with non-adherence to RA medications (Neame and Hammond 2005). Therefore, investigating beliefs related to medication is especially important in people with RA, as there be a link with hand function. Medication beliefs were assessed in this study using the Beliefs about Medicines Questionnaire (BMQ) after obtaining permission from the developer (Horne et al. 1999). The BMQ is a patient self-reported questionnaire which was developed to assess patients' beliefs and concerns about taking medication for their disease. It comprises two scales: the BMQ-Specific, which assesses representations of medication prescribed for personal use, and the BMQ-General, which assesses beliefs about medicines in general. For this study, the BMQ-Specific was used. The BMQ-Specific is a 10-item questionnaire that incorporates two subscales:

a) The Specific-Necessity subscale assessing the clients' beliefs about the necessity of prescribed medications (e.g. “My medicines protect me from becoming worse”),
b) The Specific-Concern subscale assesses the clients' concern regarding the potential adverse outcomes from using medications (e.g. “I sometimes worry about the long-term effects of my medicines”).

Each item in both subscales of the BMQ-specific is scored on a five-point Likert scale ranging from “strongly disagree” (=1) to “strongly agree” (=5). Scores obtained for the individual items are summed to give a total score for each subscale (range 5-25), with a higher score indicating a strong belief and concern in the concepts represented by the subscale (Horne et al. 1999). The BMQ is a well-established instrument for assessing individuals' perceptions and expectations about medications that has been used with the RA population (Neame and Hammond 2005; Kumar et al. 2008; Nestoriuc et al. 2010; Horne et al. 2018) and has been translated into many languages (Granas et al. 2014). Furthermore, the BMQ has been cross-culturally adapted and validated for use in Arab countries. The Arabic version of the BMQ-specific Arabic version has demonstrated good test-retest reliability (person’s correlation coefficients was ≥.78 for both subscales) and acceptable internal consistency for the specific-necessity subscale (α=.55) and the specific-concern subscale (α=.65) (Alhalaiqa et al. 2015). Permission was granted for the BMQ to be used in the current study and the license agreement is included in Appendix T.

6) Health literacy

Preliminary studies have reported that low health literacy (HL) is associated with more functional disability in people with RA (Hirsh et al. 2010; Hirsh et al. 2011; Kuipers et al. 2018). Furthermore, the findings of the focus group study showed that health literacy has the potential to influence hand function. Therefore, investigating the health literacy level of patients is important in RA, as it may have a relationship with hand functional impairment.

Health literacy is not a straightforward concept and has been defined broadly and in different ways in the literature. Therefore, the available instruments designed to assess health literacy differ in their scope, with the majority of them focussed on functional health literacy (Altin et al. 2014) using medical terms found in the medical setting (Mancuso 2009). In RA, there is no clear consensus on health literacy measurements. However, when selecting a test to assess health literacy, special consideration should be given to the cost of the test, the time required to administer it, the validity and reliability of the test, and its appropriateness for the target population (Mancuso 2009). Because the majority of health literacy assessment tools are either too long or potentially embarrassing for individuals and require further validation before being used in the clinical setting (Chew et al. 2004), many researchers in RA have attempted to evaluate health literacy with simple screening questions (Caplan et al. 2014; Grose-Hodge et al. 2018). Chew et al. (2004) and her colleagues evaluated 16 single screening questions to identify inadequate health literacy. They found three screening questions to be predictive of limited health literacy in a sample of male Veterans Administration patients. Wallace et al. (2006) tested the three screening questions created by Chew et al. (2004) with different patient populations and reported that only one of the questions was effective in detecting limited and marginal health literacy (How confident are you filling out medical forms by yourself?). Quinzanos et al. (2015)

reported that Wallace et al.'s (2006) Single-item health literacy screening (SILS) questionnaire has construct validity in the RA patient population. The SILS question asks the patient "How confident are you filling out medical forms by yourself?" with response options of "extremely", "quite a bit", "somewhat", "a little bit" or "not at all" (Wallace et al. 2006). For testing sensitivity, and specificity values of the SILS, Wallace et al. (2006) utilised the Receiver Operating Characteristic Curves (AUROC), in order to compare the performance of the screening question in relation to other health literacy measures. They recommended the cut-off point to be the "somewhat" response. The AUROC was reasonable for detecting limited or marginal health literacy (.82 to .79, respectively), sensitivity (83% and 77%, respectively) and specificity (65% and 74%, respectively) (Wallace et al. 2006). The SILS is available in the public domain, has been validated for use in Arabic countries and is reported to be associated with educational level, self-efficacy and the Short Test of Functional Health Literacy for Adults (S-TOFHLA) (Fadda et al. 2018). In the present study, the SILS was utilised to evaluate the health literacy of Palestinians with RA. The participants were characterised as having "inadequate" health literacy if they responded "not at all/a little/somewhat", and "adequate" health literacy if they replied "quite a bit/extremely confident".

6.4.7 Data collection procedure

Data collection sessions were conducted on the same day the potential participants (who were recruited) attended the rheumatology clinic for their medical follow up. This ensured that all the outcome measures, including disease variables collected via blood tests, were collected at the same time to minimise patient burden and expenses. Upon arrival at the rehabilitation unit, the researcher provided all of the participants with information about the aims of the research and the procedure. Participants were then invited to ask any questions regarding the procedure or voice any concerns. Following informed consent, assessments were carried out in a convenient quiet and private room within the rehabilitation units. First, the researcher administered the research clinic questionnaires and assisted the participants, if necessary (Appendix N). The researcher was present to answer any questions regarding the measures, but was careful to answer objectively, so as not to influence the participant's responses. It took the participants approximately 56 minutes to complete the clinical questionnaires. Participants were given breaks during this stage.

Following the completion of the clinical research questionnaires, the assessments of hand impairments were performed in a standardised order (wrist ROM, thumb functional mobility, and power grip strength, respectively), and using standardised positions. The primary investigator, a qualified rehabilitation specialist registered with the Palestinian Ministry of Health who has substantial experience in assessing hand function, collected all of the hand outcome study data. Standardised data collection instructions were followed when performing the assessments (Appendix P). These measurements took approximately 20 minutes to be recorded. Although the included hand examinations have not been shown to cause fatigue, the participants were given a break (2 minutes) between each assessment test. Hand pain at rest was reported prior to the grip strength and hand pain during the activity was reported after the participants completed the power grip strength measurement, as detailed earlier. Data were documented using the data-recording sheet shown in Appendix U.

6.4.8 Patient public involvement and a pilot study

The perspectives of PPI representatives and the results/findings from the pilot study were considered important in informing the present study. Preliminary PPI representatives (five Palestinian people with RA) were consulted to inform the format of the clinical questionnaires (i.e. fonts and layout) and to establish the face validity of the brief MHQ aesthetic item and the ASES-8 scale. Those representatives were approached through a collaborative personal effort from a Health Sciences colleague at the AAUP in Palestine, and they collaborated with the researcher as contributors to the research (i.e. they were not recruited as research participants). To improve the format of the clinical research questionnaires, the PPI representatives completed the questionnaires and afterwards were asked if they had any comments or suggestions regarding how the questionnaire booklet could be improved (e.g. instruction, appearance or design). Regarding the face validity of the Arabic brief MHQ aesthetic item and ASES-8 scale, the PPI representatives were asked to complete these questionnaires, and then asked if the items and questions of these scales were well-defined and easily understood. Feedback from the PPI representatives improved the format and clarity of the research clinic questionnaires and established the face validity of the brief MHQ aesthetic item and ASES-8 scales. Feedback from the PPI representatives indicated the need to increase the font size of the clinical questionnaires and the space between the items on the questionnaires. These changes were made prior to using the clinical questionnaires in the present study. Modifications to the original brief MHQ aesthetic item and ASES-8 scale were not required, since no conceptual or cultural difference was found. Based on the comments from the PPI group, the Arabic brief MHQ aesthetic item and ASES-8 were found to be clear and easy to understand.

In general, a pilot study is conducted to evaluate the feasibility of the procedure that is intended to be used in a large-scale study. It can help to identify potential problems in the research instruments and procedure, and improve the researcher’s skills in terms of conducting the main study with precision and accuracy (Leon et al. 2011). Therefore, a pilot study enhances the probability of success in a larger subsequent study. For this study, data collected using the above stated procedure from the first five participants were considered as a pilot study. The pilot study did not indicate that substantial changes were required for the study procedure. Therefore, data obtained from this pilot phase were incorporated into the main study data analysis. Figure 6-1 shows the output and links of the PPI and pilot study in informing this study design.

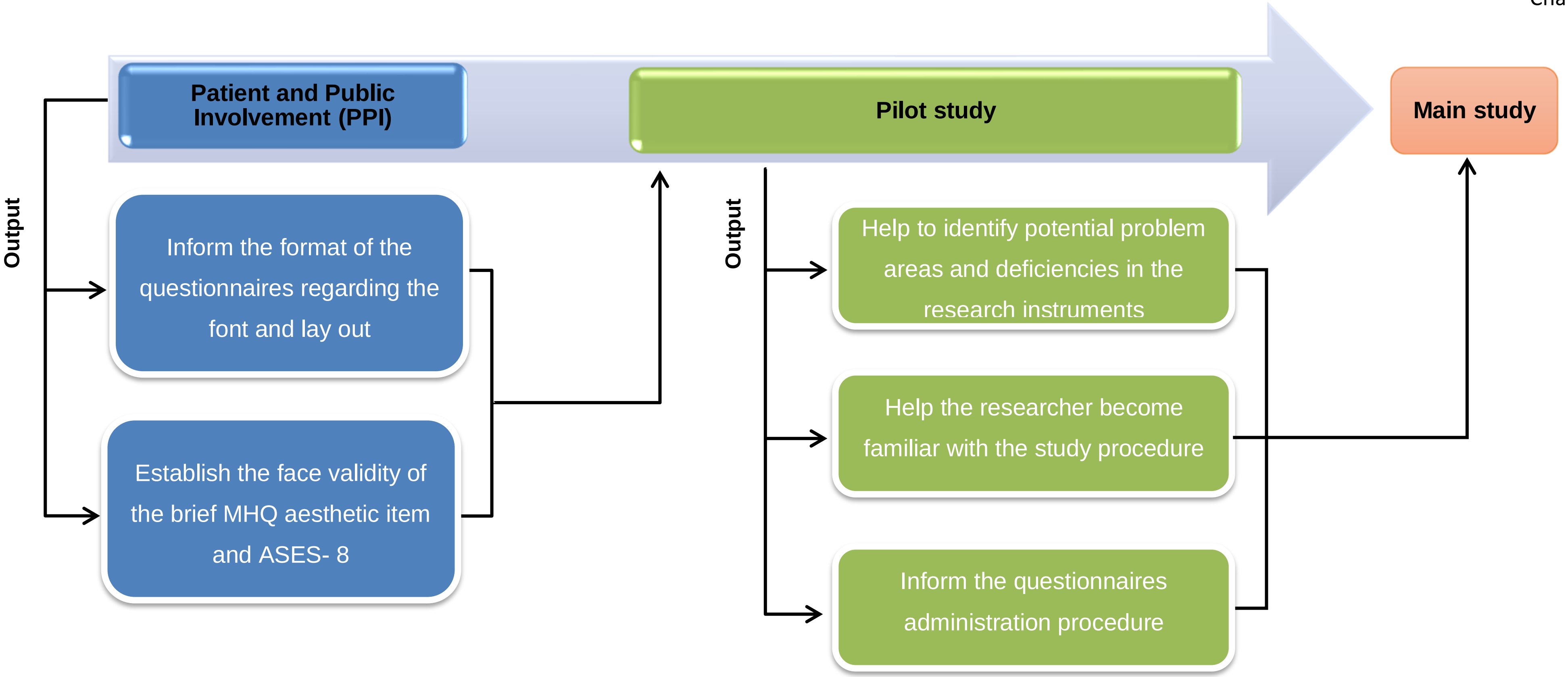


Figure 6-1 Patient and Public Involvement (PPI) and pilot activity output and links with the main study

6.4.1 Statistical analysis

All of the statistical analysis was completed by the lead researcher (HA) in consultation with a senior statistician (SE) from the School of Health Sciences, at the University of Southampton. Data were stored in a Microsoft Excel database and processed with SPSS version 25 (IBM Corp, Armonk, NY, US).

6.4.1.1 Checking for assumption of a normal distribution

Prior to statistical analysis, the data distribution was checked for normality using a combination of visual inspection (histograms), checking skewness and kurtosis, and the formal normality test: the Shapiro-Wilks test. Since visual inspection and formal normality tests may show incompatible results for the same data, the use of the above-mentioned three approaches to check the normality assumption was deemed necessary enhance the accuracy of decision regarding data distribution (Ghasemi and Zahediasl 2012; Kim 2013). Furthermore, parametric tests were applied when data were normally distributed, otherwise, non-parametric tests were used.

6.4.1.2 Descriptive statistics

The demographic and clinical characteristics of the participants were presented as means and standard deviations (mean ± SD) when the data were normally distributed. However, when the data were not normally distributed, the value of the median and interquartile range (median, IQR) were presented. Frequencies and percentages were presented for categorical data.

6.4.1.3 Relationships between QuickDASH and study variables

To explore the associations between the hand-related activity limitations and the participation restrictions, as measured by the QuickDASH, and the factors from the entire scope of the ICF, different statistical methods were utilised depending on the data distribution. The independent t-test or one-way ANOVA (parametric test) were used with normally distributed data, whereas the Mann-Whitney test or Kruskal-Wallis test (non-parametric test) were used with data which were not normally distributed. One of these tests was used to examine the differences between subgroups in relation to the QuickDASH scores. To examine the association between two continuous variables (e.g. QuickDASH score and disease duration)

Spearman's correlation coefficient (non-parametric test) or Pearson's correlation coefficient (parametric test) were used to determine the magnitude, direction and the significance of correlations between the variables. The strength of correlation was classified as the following: (.00-.30) negligible, (.31-.50) low, (.51-.70) moderate, (.71-.90) high, and (.91-1.00) very high (Mukaka 2012). A p value of <.05 was considered statistically significant.

6.4.2 Ethical considerations

This study was approved by both the ethical committees of Southampton University School of Health Sciences (Ethics no. 47047) and the Palestinian Ministry of Health (Ethics no. 162/126/2019, Appendix V). Participants' written consent was obtained. The purpose and requirements of this study were explained to each participant and participants were aware of their right to withdraw from the study at any time, without the need to give any reason. It was emphasised to all of the participants that taking part in this study would not influence any potential treatment or care that they might receive. Participants were given the opportunity to ask any questions regarding the study procedures or any concerns they might have.

This study took place in Palestine. All of the documentation and data were anonymised, and securely stored in a locked cabinet in the researcher's office at the AAUP. Personal and medical data were kept separately in a locked cabinet. All of the documents, including consent forms, demographic data, questionnaire data and physical examination data were transported to the University of Southampton securely (i.e. kept in a locked handbag) and stored in a locked cabinet in the researcher's office. An individual code was allocated for each participant's data to ensure anonymity and data protection. Accordingly, all of the data were anonymised and stored in a password-protected computer, which was accessible only to the researcher. The data obtained were used for the purposes of this study, and only shared between the researcher and the supervisory team. Finally, the data collected in the study were kept confidential, thus conforming to the Data Protection Act (1998). Accordingly, any identifiable personal data was kept secured until the data analysis was complete, at which point it were deleted. However, all of the other data will be stored for at least 10 years, according to the University of Southampton research data management policy.

6.5 Results

6.5.1 Recruitment

Participant recruitment began at the end of February 2019 and finished in mid-June 2019. During this time, 121 Palestinian individuals with RA were invited to participate in the study, and 71 (59%) responded (56 women and 15 men). Four respondents were excluded, due to either previous participation in the focus group study (*n*=2) or having had recent major traumatic hand injury (*n*=2). Figure 6-2 shows the numbers of patients recruited for the study.

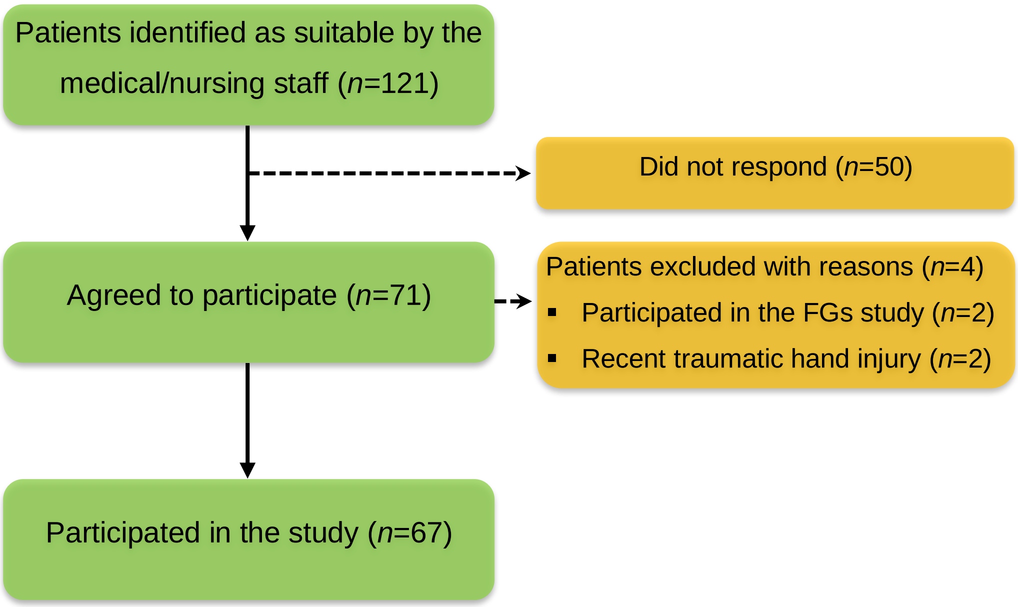


Figure 6-2 Numbers of patients recruited to the study

6.5.2 Data completeness and normality

There were no missing data, except for the CRB values, which were available for only 55 participants. Therefore, the available case analysis method was used for the analysis of CRB values (Kwak and Kim 2017). The statistical tests and visual inspection of the data showed that the majority of the data were normally distributed, excluding the disease variables (ESR, CRP), functional mobility of the thumb(s), and the MSPSS family support subscale, IPQ subscales and BCI subscales. Hence, appropriate parametric and non-parametric tests were used for further analysis based on the normality of the data distribution.

6.5.3 Sociodemographic and clinical characteristics

The main sociodemographic and clinical characteristics are summarised in Table 6-2. This study included sixty-seven participants with an age range between 29 to 77 years (53.39 ± SD 11.42). The majority of the participants were female (*n*=53, 79%), married (*n*=59, 88%), not working at the time of the interview (*n*=54, 81%), and had completed their study up to post-secondary level (*n*=47, 70%). Regarding living arrangements, the majority of the patients were from villages (*n*=35, 52%), living with others (*n*=57, 85%), providing care for children (*n*=37, 55%), not providing care for others (*n*=46, 69%) and had less than or equal to 2,400 NIS (New Israeli Shekel) net income per month (*n*=43, 64%). Regarding the disease-related characteristics, the median disease duration was 7 (IQR 2.0-15.0) years, and approximately half of the participants (49%) had waited 12 months or more to obtain a RA diagnosis. About half of the participants presented with a positive rheumatoid factor (RF) (51%). Most of the participants (*n*=62, 93%) reported hand pain and problems during the past six months. Regarding therapeutic data, the majority of the patients had not receive rehabilitation treatment (physiotherapy or occupational therapy, *n*=59, 88%, *n*=66, 99% respectively) nor had used hand splints (*n*=54, 81%) in the previous six months.

6.5.3.1 Comorbidities

Approximately half of the participants had one or more comorbid diseases (*n*=31, 46%), including cardiovascular (*n*=23, 34%), gastrointestinal (*n*=13, 19%), osteoporosis (*n*=7, 10%), depression (*n*=2, 3%) and infections (*n*=1, 1%).

6.5.3.2 Prescribed medications

A total of 76% of the participants were taking non-biological DMARDs at the time of the study, with methotrexate the most commonly used drug (*n*= 34, 51%), either combined with other DMARDs or utilised as a monotherapy. Approximately 24% of the study population was on biologicals. In addition, 36% of the participants were taking prednisolone (range: 2.5-5 mg a day). The prescribed medications are shown in Table 6-3.

Table 6-2 Sociodemographic and clinical characteristics of the participants (*n*=67)

Variable	*n* (%)
Age (years)†	53.39 (11.42)
Gender	
Women	53 (79%)
Men	14 (21%)
Disease duration (years)‡	7.0 (2.0-15.0)
Rheumatoid Factor (RF) positive	34 (51%)
Marital status	
Married	59 (88%)
Other (single, divorced, widow)	8 (12%)
Education	
≤ post-secondary	47 (70%)
> post-secondary	20 (30%)
Net income per month	
≤ 2400 NIS per month	43 (64%)
> 2400 NIS per month	24 (36%)
Living arrangement	
Living alone	10 (15%)
Living with others	57 (85%)
Employment status	
Working (full-time, self-employed)	13 (19%)
Not working (retired, unable to work, looking after home)	54 (81%)
Received physiotherapy treatment within the past six months	
Yes	8 (12%)
No	59 (88%)
Received occupational therapy treatment within the past six months	
Yes	1 (1%)
No	66 (99%)
Had hand surgery within the past six months	
Yes	2 (3%)
No	65 (97%)

†: Values shown are mean and standard deviation; ‡: Values shown are median and interquartile range

Table 6-2 (Continued)

Variable	***n* (%)**
Hand splints use in within the past six months	
Yes	13 (19%)
No	54 (81%)
Providing care for children	
Yes	37 (55%)
No	30 (45%)
Providing care for others	
Yes	21 (31%)
No	46 (69%)
Time from symptoms onset to diagnosis	
< 12 months	34 (51%)
≥ 12 months	33 (49%)
Geographic region	
City	26 (39%)
Village	35 (52%)
Camp	6 (9%)

Table 6-3 Prescribed medications

Prescribed current medication	***n* (%)**
Diclofenac	5 (7%)
Other non-steroidal anti-inflammatory	7 (10%)
Sulfasalazine	2 (3%)
Hydroxychloroquine	11 (16%)
Methotrexate	34 (51%)
Leflunomide	17 (25%)
Prednisolone	24 (36%)
Etanercept (Enbrel)	20 (30%)
Adalimumab (Humira	2 (3%)
Rituximab (Mabthera)	1 (1%)

6.5.3.3 Disease activity

The median ESR value for all of the participants was 31.0 (IQR 17.0-50.0) mm/hour with more than half of the participants (*n*=38, 57 %) having an ESR value of >25 mm/hour which indicates an elevated (abnormal) ESR level (Keenan et al. 2008). Similarly, about half of the participants (*n*=27, 49%) (CRP values were recorded for only 55 of the study sample) had a CRP value of >5mg/L, which indicates an elevated (abnormal) CRP level (Orr et al. 2018). However, the median value of CRP was acceptable (4.70, IQR 1.62-12.0 mg/L). The median values of ESR and CRP among women were higher and elevated in comparison with men (Table 6-4). With reference to the recently proposed disease activity levels based on the QuickDASH score (Carroll 2016), 64% of these study participants had a high level of disease activity (Table 6-5).

Table 6-4 Disease activity variables. Data are presented as the median (IQR)

Variable	Women	Men	All
ESR (mm/hour)	33.00 (20.00-57.00)	19.0 (14.25-33.25)	31.00 (17.00-50.00)
CRP (mg/L)	5.71 (1.78-12.00)	2.44 (0.74-15.75)	4.70 (1.62-12.00)

CRP: C-reactive protein; ESR: Erythrocyte sedimentation rate

Table 6-5 Frequency of disease activity levels based on QuickDASH score

level	QuickDASH score	Women n (%)	Men n (%)	All n (%)
Remission	0-12.0	6 (11%)	4 (29%)	10 (15%)
Low	12.1-20.0	1 (2%)	1 (7%)	2 (3%)
Moderate	20.1-37.1	10 (19%)	2 (14%)	12 (18%)
High	≥37.2	36 (68%)	7 (50%)	43 (64%)

6.5.4 Hand-related activity limitations and participation restrictions (QuickDASH)

There were no missing data nor outlier scores for the QuickDASH. The QuickDASH discriminated well between all levels of ability, and the participants reported functional (dis)ability throughout the full score range (Figure 6-3). The mean score on the QuickDASH using the standardised scoring system (range 0–100) was 45.73 (*SD* 24.66), which was higher than the corresponding expected value of 14.66 (*SD* 3.89) for the total study population (Figure 6-4). Responses on the QuickDASH ranged from a score of 2.30 (low self-report functional disability), to a score of 90.90 (high self-report functional disability). Furthermore, the QuickDASH scores were higher in women compared to men (Women: 48.16 ± SD 23.27; Men: 36.54 ± SD 28.37).

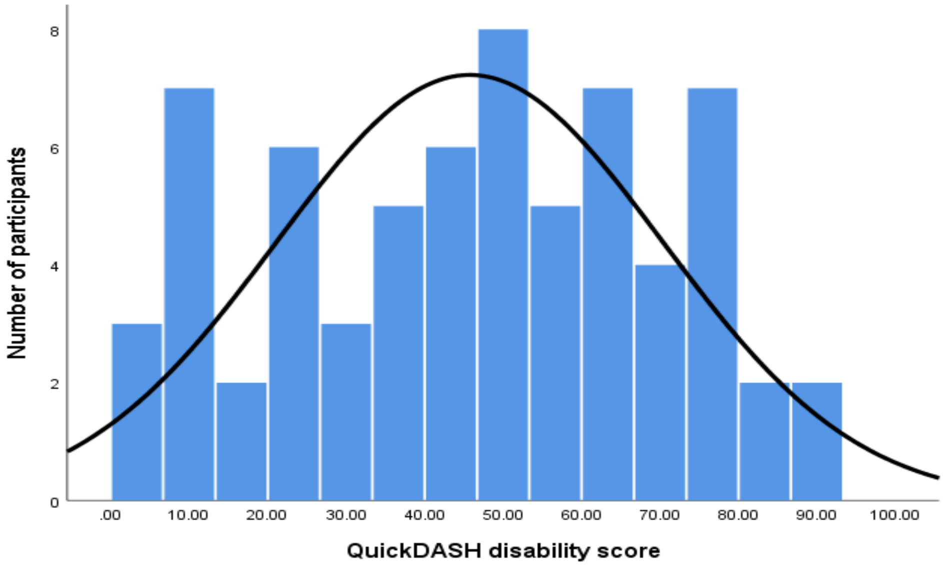


Figure 6-3 A histogram to show the distribution of the QuickDASH disability score

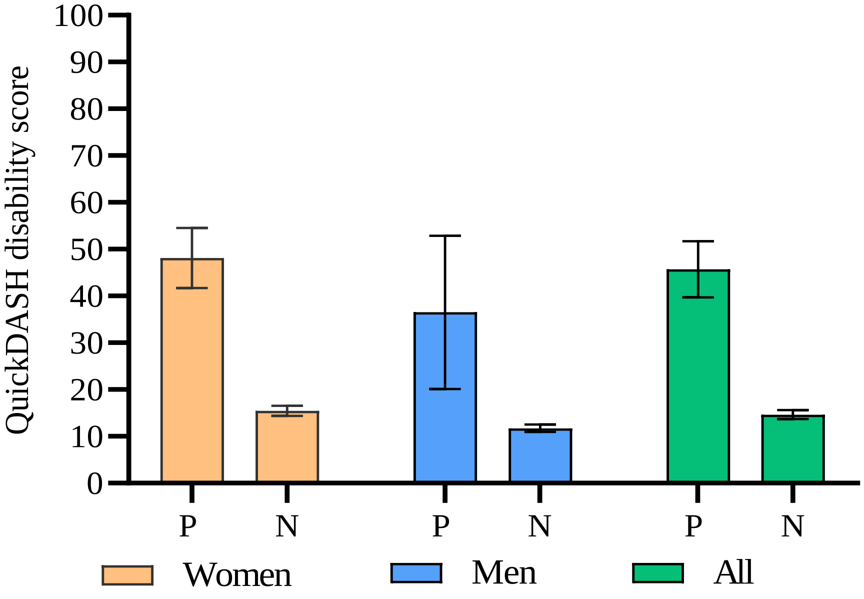


Figure 6-4 QuickDASH score by gender for the patients (P), normative values (N), and for the total study population. Values are means with 95% confidence intervals

The specific question score of activities as part of daily living showed that the mean activity QuickDASH score was highest in question two (do heavy household chores), and lowest in question five (use a knife to cut food), with 3.34 and 2.46, respectively, as shown in Figure 6-5. In general, women reported more pronounced difficulties than men on all of the QuickDASH items. The results of the specific item score are reported in Table 6-6.

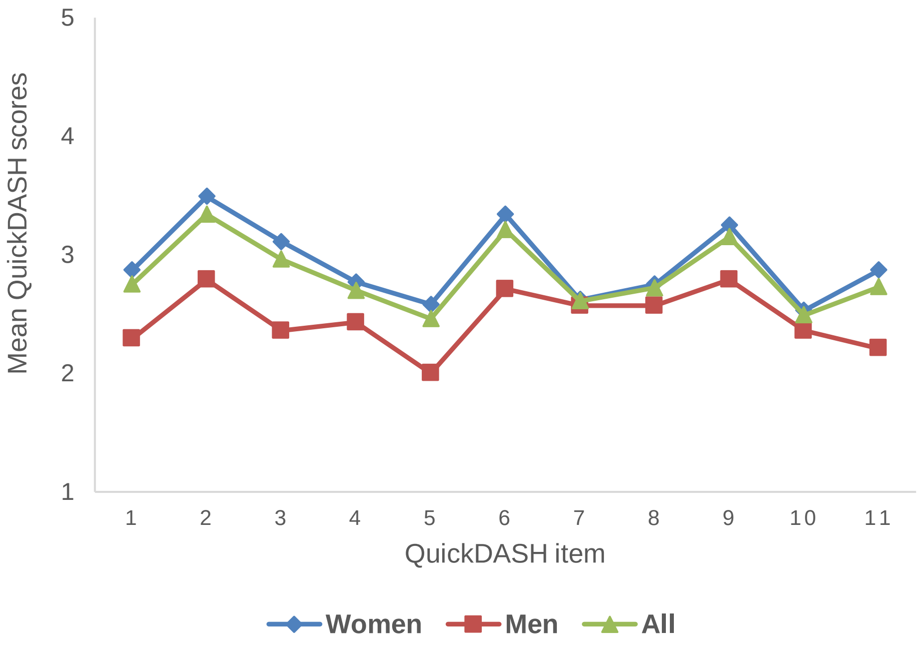


Figure 6-5 Mean QuickDASH scores for each question item

Table 6-6 Mean and standard deviations for responses on each QuickDASH question

Item no	Item	Women	Men	All
1	Open a tight or new jar	2.87 (1.26)	2.29 (1.38)	2.75 (1.30)
2	Do heavy household chores	3.49 (1.19)	2.79 (1.53)	3.34 (1.29)
3	Carry a shopping bag or briefcase	3.11 (1.17)	2.36 (1.34)	2.96 (1.24)
4	Wash your back	2.77 (1.35)	2.43 (1.55)	2.70 (1.39)
5	Use a knife to cut food	2.58 (1.13)	2.00 (1.36)	2.46 (1.20)
6	Recreational activities	3.34 (1.30)	2.71 (1.44)	3.21 (1.34)
7	Social activities	2.62 (1.18)	2.57 (1.45)	2.61 (1.23)
8	Work or other regular daily activities	2.75 (1.04)	2.57 (1.09)	2.72 (1.04)
9	Arm, shoulder or hand pain	3.25 (1.07)	2.79 (1.19)	3.15 (1.10)
10	Tingling	2.53 (1.28)	2.36 (1.15)	2.49 (1.25)
11	Sleeping difficulty	2.87 (1.14)	2.21 (1.31)	2.73 (1.20)

For presentation purposes, the categories were collapsed into three sections of the QuickDASH severity ratings for activity and participation items (Table 6-7 and Table 6-8). Up to 51% reported that they were unable to perform, or had severe difficulties in performing, gross motor activities that required some degree of force (e.g. do heavy household chores, or recreational activities taking force through the arm). In addition, social and work activities (items 7 and 8) were most likely to be moderately or slightly difficult for this sample (52% and 69%, respectively).

Table 6-7 Frequency of reported difficulty for the QuickDASH items (one to six)

Severity rating	**QuickDASH item**	**Women** *n* **(%)**	**Men** *n* **(%)**	**All** *n* **(%)**
Unable to do or severe difficulty	Open a tight or new jar	18 (34%)	3 (21%)	21 (31%)
	Do heavy household chores	28 (53%)	6 (43%)	34 (51%)
	Carry a shopping bag or briefcase	22 (42%)	3 (21%)	25 (37%)
	Wash your back	21 (40%)	3 (21%)	24 (36%)
	Use knife to cut food	12 (23%)	2 (14%)	14 (21%)
	Recreational activities	25 (47%)	4 (29%)	29 (43%)
Moderate or mild difficulty	Open a tight or new jar	25 (47%)	5 (36%)	30 (45%)
	Do heavy household chores	21 (40%)	4 (29%)	25 (37%)
	Carry a shopping bag or briefcase	24 (45%)	6 (43%)	30 (45%)
	Wash your back	20 (38%)	6 (43%)	26 (39%)
	Use knife to cut food	28 (53%)	4 (29%)	32 (48%)
	Recreational activities	23 (43%)	6 (43%)	29 (43%)
No difficulty	Open a tight or new jar	10 (19%)	6 (43%)	16 (24%)
	Do heavy household chores	4 (8%)	4 (29%)	8 (12%)
	Carry a shopping bag or briefcase	7 (13%)	5 (36%)	12 (18%)
	Wash your back	12 (23%)	5 (36%)	17 (25%)
	Use knife to cut food	13 (25%)	8 (57%)	21 (31%)
	Recreational activities	5 (9%)	4 (29%)	9 (13%)

Table 6-8 Frequency of reported difficulty for the QuickDASH items (seven and eight)

QuickDASH item	Severity rating	Women *n* (%)	Men *n* (%)	All *n* (%)
Social activities (item 7)	Not at all	12 (23%)	4 (29%)	16 (24%)
	Moderately or slightly	29 (55%)	6 (43%)	35 (52%)
	Extremely or quite a bit	12 (23%)	4 (29%)	16 (24%)
Work or other regular activities (item 8)	Not limited at all	7 (13%)	2 (14%)	9 (13%)
	Moderately or slightly	36 (68%)	10 (71%)	46 (69%)
	Unable or very limited	10 (19%)	2 (14%)	12 (18%)

Severity ratings for QuickDASH symptoms items were collapsed for presentation purposes, as shown in Table 6-9. The severity of symptoms (pain, tingling and difficulty sleeping) were most likely to be moderate or mild (55% , 51%, and 51% respectively). Overall, more women compared to men reported more pain and difficulty sleeping (Figure 6-6).

Table 6-9 Frequency of reported severity for the QuickDASH symptoms items (9,10, and 11)

Severity rating	QuickDASH item	Women *n* (%)	Men *n* (%)	All *n* (%)
Extreme/so much or severe	Pain	21 (40%)	3 (21%)	24 (36%)
	Tingling	13 (25%)	2 (14%)	15 (22%)
	Difficulty sleeping	16 (30%)	3 (21%)	19 (28%)
Moderate or mild	Pain	27 (51%)	10 (71%)	37 (55%)
	Tingling	25 (47%)	9 (64%)	34 (51%)
	Difficulty sleeping	28 (53%)	6 (43%)	34 (51%)
None	Pain	5 (9%)	1 (7%)	6 (9%)
	Tingling	15 (28%)	3 (21%)	18 (27%)
	Difficulty sleeping	9 (17%)	5 (36%)	14 (21%)

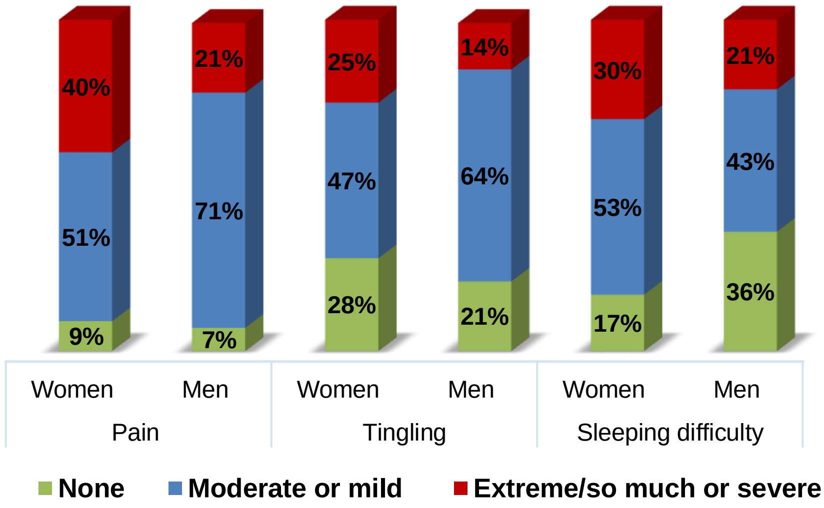


Figure 6-6 Frequency of responses per each collapsed Likert point on the QuickDASH symptom items for women and men

Based on the QuickDASH cut-off values, hand functional impairment at various levels was present in 85% of the participants, with the majority (70%) scoring >31.5 on the QuickDASH, which corresponds to "high impairment" (Salaffi et al. 2019). The percentage of women categorised as having "high impairment" was greater than men (75% and 50%, respectively) (Figure 6-7).

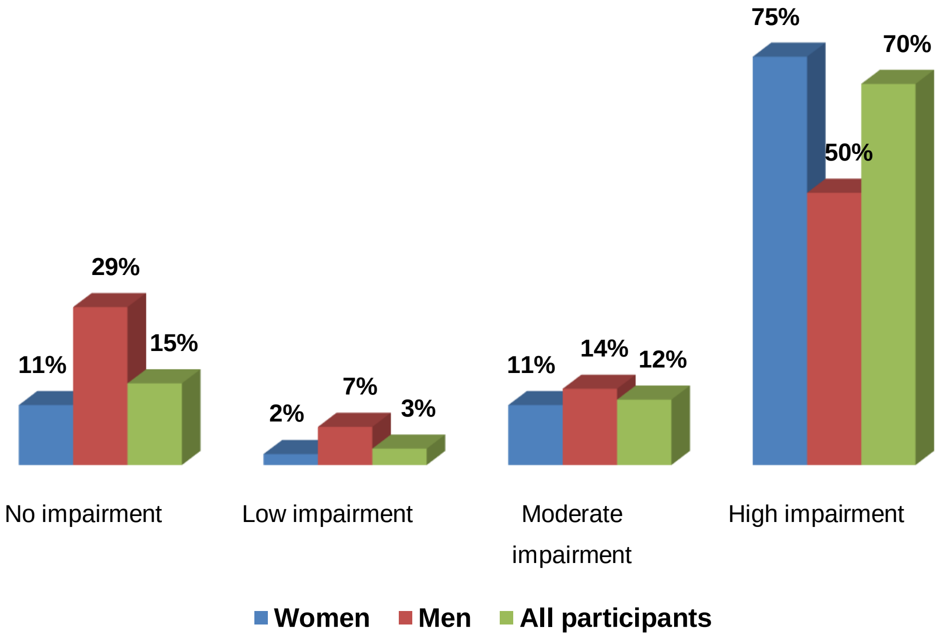


Figure 6-7 Prevalence of hand functional disability according to the QuickDASH cut-off values

6.5.5 Measures of body function and structure variables

Descriptive statistics for the measures of body function and structure factors are presented in Table 6-10.

Table 6-10 Descriptive statistics for the measures of body function and structure variables. Data are presented as mean (SD) unless otherwise indicated

Measurement	Women	Men	All
Wrist flexion ROM (degrees)			
Right hand	44.19 (15.58)	35.57 (17.64)	42.39 (16.28)
Left hand	44.51 (15.91)	37.79 (12.43)	43.10 (15.41)
Wrist extension ROM (degrees)			
Right hand	46.51 (14.27)	40.86 (15.04)	45.33 (14.50)
Left hand	46.08 (13.81)	42.36 (15.54)	45.30 (14.15)
Kapandji Index (score range 0-10)			
Right thumb	9.0 (9.0-10.0)†	9.0 (7.6-9.0)†	9.0 (9.0-10.0)†
Left Thumb	9.0 (9.0-10.0)†	9.0 (8.8-10.0)†	9.0 (9.0-10.0)†
Power grip strength (Kg)			
Right hand	19.61 (8.65)	28.50 (9.79)	21.47 (9.54)
Left hand	19.19 (8.39)	26.66 (8.33)	20.74 (8.86)
Hand pain at rest (score range, 0-10)			
Right hand	2.64 (2.18)	2.57 (1.99)	2.63 (2.12)
Left hand	2.40 (2.29)	2.86 (1.92)	2.49 (2.21)
Hand pain during test (score range, 0-10)			
Right hand	4.77 (2.88)	4.14 (2.71)	4.64 (2.84)
Left hand	4.25 (2.80)	4.43 (2.24)	4.28 (2.68)
Psychological distress			
PHQ-4 (score range, 0-12)	5.55 (3.23)	4.57 (4.52)	5.34 (3.52)
PHQ-2 (score range, 0-6)	2.77 (1.76)	2.43 (2.62)	2.70 (1.95)
GAD-2 (score range, 0-6)	2.77 (1.74)	2.14 (2.11)	2.64 (1.82)
Fatigue (score range, 0-100)	43.21 (19.52)	42.50 (22.93)	43.06 (20.09)

†: Data are presented as the median (IQR); GAD-2: Generalised anxiety disorder (GAD-2); PHQ-2: The patient health questionnaire-2 (depression scale); PHQ-4: The patient health questionnaire-4; ROM: Range of motion

6.5.5.1 Range of motion and functional mobility measures

As depicted in Table 6-10 hand mobility in relation to wrist flexion/extension was restricted, with the wrist flexion ROM being restricted more than extension according to norm values (flexion=80°, and extension=70°) (Clarkson and Clarkson 2013). Compared to maximal wrist mobility values, wrist flexion and extension ROM were reduced to approximately 48% and 36%, respectively. Almost all of the participants in this study had impaired (i.e. active measurement was ≥15 degrees less than the maximal range of wrist motion) wrist joint flexion mobility (right hand 97%, left hand 99%). Impaired wrist joint extension mobility was found in 72% and 73% of the participants' right and left hands, respectively. Furthermore, there was a gender difference in relation to wrist flexion/extension ROM, with women having better ROM scores. Regarding thumb functional mobility, the results showed that a considerable proportion (66% right thumb, 61% left thumb) of the participants had scores of less than 10 (best score) on the Kapandji Index.

6.5.5.2 Pain

The mean values of hand pain intensity at rest and during tests (power grip) for both hands were ≤5 (pain NRS) which corresponds to mild pain severity (Boonstra et al. 2016). For both hands, pain intensity during activity was twice as high as that at rest in this sample. The hand pain intensity level at rest or during tests was almost the same across genders and between the right and left hand (Figure 6-8).

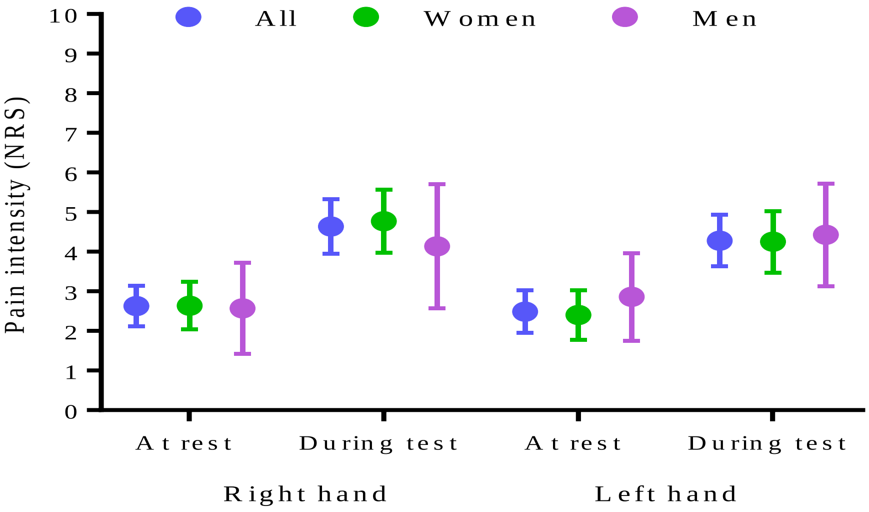


Figure 6-8 Hand pain intensity at rest and during tests, for all patients and by sex (right and left hand). Values are means with 95% confidence intervals

6.5.5.3 Hand grip strength

The observed mean grip strength for the right (21.47 ± SD 9.54) and left (20.74 ± SD 8.86) hand were reduced compared to the expected values (right hand: 32.63 ± SD 6.54; left hand: 30.00 ± SD 6.15) (Table 6-11). Grip strength reductions in the right and left hands were 34% and 31%, respectively (Figure 6-9). Regarding gender differences, women showed a greater reduction in the right and left-hand grip strength (42% and 37%, respectively), compared to men (30% and 31% for the right and left-hand grip strength, respectively). The data for grip strength in both sexes demonstrated that the right hand was stronger than the left hand, with men having greater hand strength compared to women in both hands. Approximately 72% (*n*=48) and 69% (*n*=46) of the participants were found to have impaired right and left-hand strength, respectively (i.e. grip strength less than the lower limit of their corresponding normative data). These participants had lost on average 11.96 kg (SD 7.16) and 9.32 kg (SD 6.85) of their right- and left-hand grip strengths, respectively.

Table 6-11 Grip strength of the right and left hand compared to age- and sex-specific reference values. Data are presented as mean (SD)

	Right hand		**Left hand**	
	Observed	Expected	Observed	Expected
All participants	21.47 (9.54)	32.63 (6.54)	20.74 (8.86)	30.00 (6.15)
Women	19.61 (8.65)	33.90 (3.12)	19.19 (8.39)	30.53 (3.11)
Men	28.50 (9.79)	40.59 (9.60)	26.66 (8.33)	38.54 (7.35)

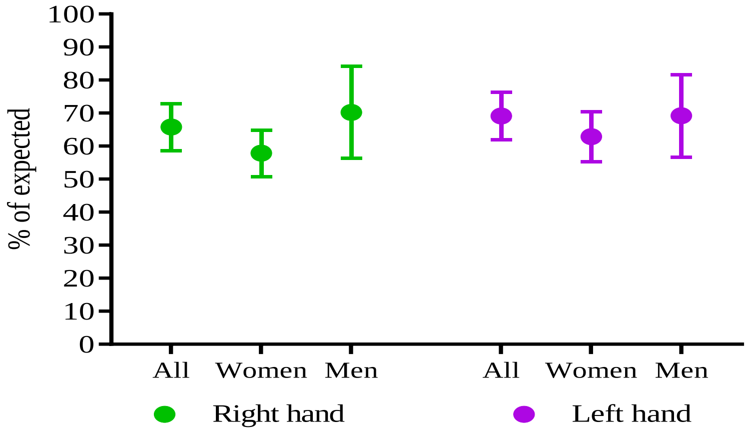


Figure 6-9 Grip strength with the percentage of expected values, for all patients and by sex (right and left hand). Values are means with 95% confidence intervals

6.5.5.4 Psychological distress

The mean score of the PHQ-4 was 5.34 (SD 3.52), corresponding to a symptom severity of mild psychological distress (Kroenke et al. 2009). The proportion of participants with depression (PHQ-2 scale) or anxiety (GAD-2 scale) symptoms (defined as a score of ≥3 on either scale) was 49% and 48%, respectively. There were six (9%) participants with only anxiety, seven (10%) with only depression, and 26 (39%) with both anxiety and depression. More than half of the women (51%) presented with clinically significant depression and anxiety symptoms, whereas 43% and 36% of men presented with depression and anxiety symptoms, respectively.

6.5.5.5 Aesthetic changes

As shown in Figure 6-10, the majority of the participants (70%) responded as “agree” or “strongly agree” to the bMHQ aesthetic item, indicating that they were satisfied with the appearance of their hands. However, more women (28%) compared to men (14%) were not satisfied with the appearance of their hands (i.e. responded as “disagree” or “strongly disagree”).

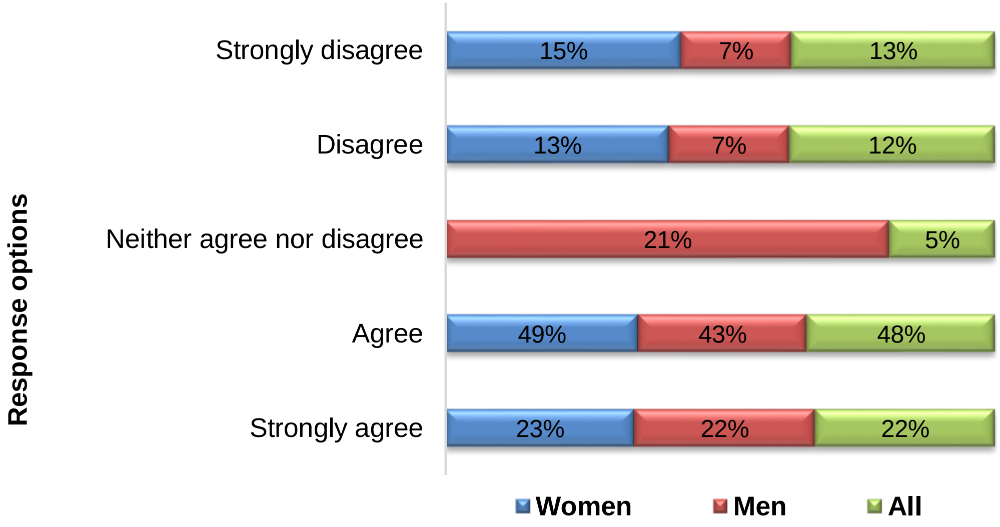


Figure 6-10 Frequency of responses per each Likert point on the bMHQ aesthetic item

6.5.6 Measures of environmental variables

6.5.6.1 Family support

The median value on the MSPSS family support subscale average scores was 5.50 (IQR 4.50-6.50), illustrating that study participants perceived themselves as receiving high levels of family support. With reference to the scale cut-off values (Zimet; 2018), the majority of the study participants were categorised as having high family support (*n*=41, 61%), followed by moderate (*n*=23, 34%) and low support (*n*=3, 5%). The data regarding family support for women and men separately, demonstrated that both groups perceived themselves as having high family support (women: 5.75, IQR 4.63-6.50; men: 5.25, IQR 4.00-6.18).

6.5.7 Measures of personal variables

6.5.7.1 Coping

A description of the sample-specific response patterns for the Brief Coping Inventory (BCI) adaptive and maladaptive scale, alongside the subscales, are displayed in Table 6-12. Approximately 73% of the participants had scores greater than the midpoint on the adaptive coping scale, suggesting that the participants showed a broad tendency to exert adaptive coping effort. However, a considerable proportion of the participants (39%) endorsed a relatively high level of maladaptive coping effort (i.e. had scores greater than the midpoint on the maladaptive coping scale). Comparisons between women and men showed that both were highly engaged in adaptive coping (women 75% and men 65% had scores greater than the midpoint on the adaptive coping scale). However, more women compared to men showed a tendency towards maladaptive coping strategies (47% of females and 7% of males had scores greater than the midpoint on the maladaptive coping scale). On the subscale level, the results demonstrated that the participants were broadly engaged with adaptive coping strategies related to religion and acceptance, whereas for maladaptive coping strategies they showed higher engagement with venting, self-blame and self-distraction coping strategies. For all of the BCI subscales, women scored higher than men in almost all cases.

Table 6-12 Descriptive statistics for the Brief Coping Inventory (BCI) adaptive and maladaptive coping scale along with subscales. The data are presented as median (IQR), unless otherwise indicated.

Coping strategies	Women	Men	All
Adaptive coping scale	46.11 (7.03)†	41.86 (7.44)†	45.22 (7.28)†
Active coping	5.0 (3.0-5.0)	5.0 (4.0-6.5)	6.0 (4.0-7.0)
Planning	6.0 (4.5-7.0)	5.5 (5.0-6.0)	6.0 (5.0-7.0)
Instrumental support	6.0 (4.0-7.0)	5.0 (2.0-6.3)	6.0 (4.0-7.0)
Acceptance	8.0 (6.0-8.0)	7 (5.5-8.0)	7.0 (6.0-8.0)
Emotional support	6.0 (4.0-7.0)	5.0 (2.8-6.5)	6.0 (4.0-7.0)
Religion	8.0 (7.0-8.0)	7 (6.8-8.0)	8.0 (7.0-8.0)
Humour	3.0 (2.0-4.0)	3.0 (2.0-4.3)	3.0 (2.0-4.0)
Positive reframing	6.0 (5.0-7.0)	5.0 (3.8-6.0)	5.0 (4.0-7.0)
Maladaptive coping scale	20.85 (5.44)†	16.26 (5.40)†	19.90 (5.71)†
Denial	4.0 (2.0-5.0)	3.0 (2.0-4.3)	3.0 (2.0-5.0)
Behavioural disengagement	3.0 (2.0-4.5)	3.0 (2.0-4.3)	3.0 (2.0-4.0)
Self-distraction	5.0 (3.0-5.0)	3.0 (2.0-4.0)	4.0 (3.0-5.0)
Self-blame	4.0 (2.0-5.0)	2.0 (2.0-4.3)	4.0 (2.0-5.0)
Venting	4.0 (3.0-6.0)	3.0 (2.0-5.0)	4.0 (3.0-6.0)

†: Data are presented as mean (SD)

Note: Score range for adaptive coining scale 16-64; Score range for maladaptive coping scale is 10-40; Score range for subscales is 2-8

6.5.7.2 Resilience

The participants' average BRS score was 3.19 (SD .69, range=1.33 to 4.67) suggesting a normal resiliency level (Smith et al. 2013). Men's BRS average score was relatively similar to women (men: 3.33 ± SD .85; women: 3.19 ± SD .66). According to Smith et al. (2013), the cut-off values of the BRS for the proportion of participants with low, normal and high resilience was 30%, 64% and 6%, respectively.

6.5.7.3 Disease perception

Descriptive statistics pertinent to eight items comprised by the brief IPQ questionnaire are shown in Table 6-13. Among the eight items of the brief IPQ, understanding and timeline had the highest score, suggesting that the participants tended to view their RA as a chronic disease that would last a long time, and they understood the disease very well. The identity and treatment control items were also scored high, indicating that the participants have experienced many RA-related symptoms, which can be well controlled with the appropriate treatment. To some extent, they were convinced that they could control their disease on their own (personal control); however, they were worried that RA would have an adverse effect on their life (concern). They mostly perceived RA as a disease that has no serious consequences (consequences), so they were quite emotionally detached (emotional response). The individual results related to each item were distributed throughout a full-scale range (0-10). Considering the negative illness perceptions, it is noteworthy that the female participants were more concerned about their illness, had experienced more RA-related symptoms and were more emotionally distressed compared to men.

For the open-ended question of the brief IPQ (item 9) regarding patients' opinion on the possible causes of their illness, sixty-two participants (93%) gave at least one written response (Table 6-14). According to the participants' beliefs, the main causes of RA were “cold or humidity” (*n*=19, 31%), “fatigue” (*n*=18, 29%), “emotional state” (*n*=16, 26%), “inflammation or other conditions” (*n*=14, 23%), and “overwork or work conditions” (*n*=12, 19%). It is worth noting that 5% of the participants, despite living with their diagnosis >2 years, wrote, “don't know” when asked for the cause of their RA disease.

Table 6-13 Descriptive statistics for the Brief Illness Perception Questionnaire (bIPQ) items. Data are presented as median (IQR)

Item	Women	Men	All
Consequences	5.0 (3.0-7.0)	5.50 (1.8-7.3)	5.0 (3.0-7.0)
Timeline	9.0 (5.0-10.0)	7.5 (4.3-10.0)	9.0 (5.0-10.0)
Personal control	6.0 (5.0-8.0)	5.0 (5.0-7.8)	6.0 (5.0-8.0)
Treatment control	7.0 (5.0-8.0)	7.5 (5.8-10.0)	7.0 (5.0-9.0)
Identity	7.0 (5.0-9.0)	5.0 (4.0-8.5)	7.0 (5.0-9.0)
Concern	6.0 (4.0-8.5)	3.5 (0.8-7.3)	6.0 (3.0-8.0)
Emotional response	5.0 (3.5-8.0)	3.5 (0.0-6.0)	5.0 (3.0-7.0)
Understanding	9.0 (6.5-10.0)	10.0 (9.0-10.0)	9.0 (7.0-10.0)

Table 6-14 Frequency of responses of possible causes of participant's illness

Item	*n* (%)
Cold or humidity	19 (31%)
Fatigue	18 (29%)
My emotional state (e.g. stress, anxiety, sadness)	16 (26%)
Inflammation or other conditions (e.g. tonsillitis, diabetes)	14 (23%)
Overwork or work conditions	12 (19%)
Hereditary	8 (13%)
Poor medical care in my past	6 (10%)
Frequent pregnancies	3 (5%)
Don't know	3 (5%)
The will of God	2 (3%)
Aging	1 (2%)
Altered immunity	1 (2%)

6.5.7.4 Health literacy

More than one-third of the participants (*n*= 23, 34%) were characterised as having inadequate health literacy according to the SILS cut-off value. The proportion of females characterised as having inadequate health literacy was higher than males (females: *n*=20, 38%; males: *n*=3, 21%).

6.5.7.5 Self-efficacy

The mean self-efficacy score on the Arabic ASES-8 was 5.51 (SD 1.70), with a range of 1.88 to 8.50. The results on the self-efficacy scale for women and men were approximately the same (women: 5.52 ± SD 1.67; men: 5.48 ± SD 1.85).

6.5.7.6 Personal attitudes towards medications

The majority of the participants (*n*=58, 87%) had scores greater than the midpoint on the BMQ specific-necessity subscale, demonstrating that they believed in the necessity of their medication to maintain both their current and future health (Table 6-15). On the other hand, a considerable proportion of the participants (*n*=44, 66%) reported concerns about the potential adverse consequences of taking their medication (i.e. had scores greater than the midpoint on the BMQ specific concern subscale). The participants were also concerned about the potential long-term adverse effects of their medications (*n*=46, 69%), becoming dependent upon medications (*n*=45, 67%) and not having adequate information about their medications (*n*=40, 60%). There was much less concern about the disruption to their routines associated with taking medications (*n*=17, 25%). In general, women compared to men reported more medication necessity and concerns. Importantly, a considerable proportion of women were concerned about having insufficient information about their medication (*n*=36, 68%).

The results of the BMQ subscales are presented in Table 6-16. The mean necessity score of 19.58 (SD 3.53) was greater than the mean concerns score of 17.24 (SD 3.75). This was similar across genders, with women's necessity and concerns scores greater than those of the men. The mean necessity–concerns differential was +2.34 (SD 3.13). For ten participants (15%) their necessity score was lower than their concerns score (i.e. a negative necessity–concerns differential). For eight participants (12%) their necessity and concerns scores were equal.

Table 6-15 Percentage of participants agreeing/strongly agreeing with Beliefs about Medicines Questionnaire (BMQ) statements

	Statement	**Women**	**Men**	**All**
		***n* (%)**	***n* (%)**	***n* (%)**
Necessity subscale	▪ My health, at present, depends on my medicines	44 (83%)	11 (79%)	55 (82%)
	▪ My life would be impossible without my medicines	35 (66%)	7 (50%)	42 (63%)
	▪ Without my medicines I would be very ill	44 (83%)	9 (64%)	53 (79%)
	▪ My health in the future will depends on my medicines	36 (68%)	7 (50%)	43 (64%)
	▪ My medicines protect me from becoming worse	44 (83%)	11 (79%)	55 (82%)
Concerns subscale	▪ Having to take medicines worries me	39 (74%)	6 (43%)	42 (63%)
	▪ I sometimes worry about long-term effects of my medicines	37 (70%)	9 (64%)	46 (69%)
	▪ My medicines are a mystery to me	36 (68%)	4 (29%)	40 (60%)
	▪ My medicines disrupt my life	15 (28%)	2 (14%)	17 (25%)
	▪ I sometimes worry about becoming too dependent on my medicines	38 (72%)	7 (50%)	45 (67%)

Table 6-16 Mean and standard deviation for Beliefs about Medicines Questionnaire (BMQ) subscales

BMQ-subscale	Women		Men		All	
	Mean(SD)	Min-Max	Mean(SD)	Min-Max	Mean(SD)	Min-Max
Necessity	19.81(3.55)	11-25	18.71(3.45)	12-25	19.58(3.53)	11-25
Concern	17.74(3.44)	10-25	15.36(4.38)	9-23	17.24(3.75)	9-25

6.5.8 Association between hand-related activity limitation and participation restriction and study variables

Study variables were systematically mapped to the most appropriate ICF components (Figure 6-11). The results for the associations between hand-related activity limitation and participation restriction, as measured with QuickDASH, and the study variables are presented in the subsequent sections.

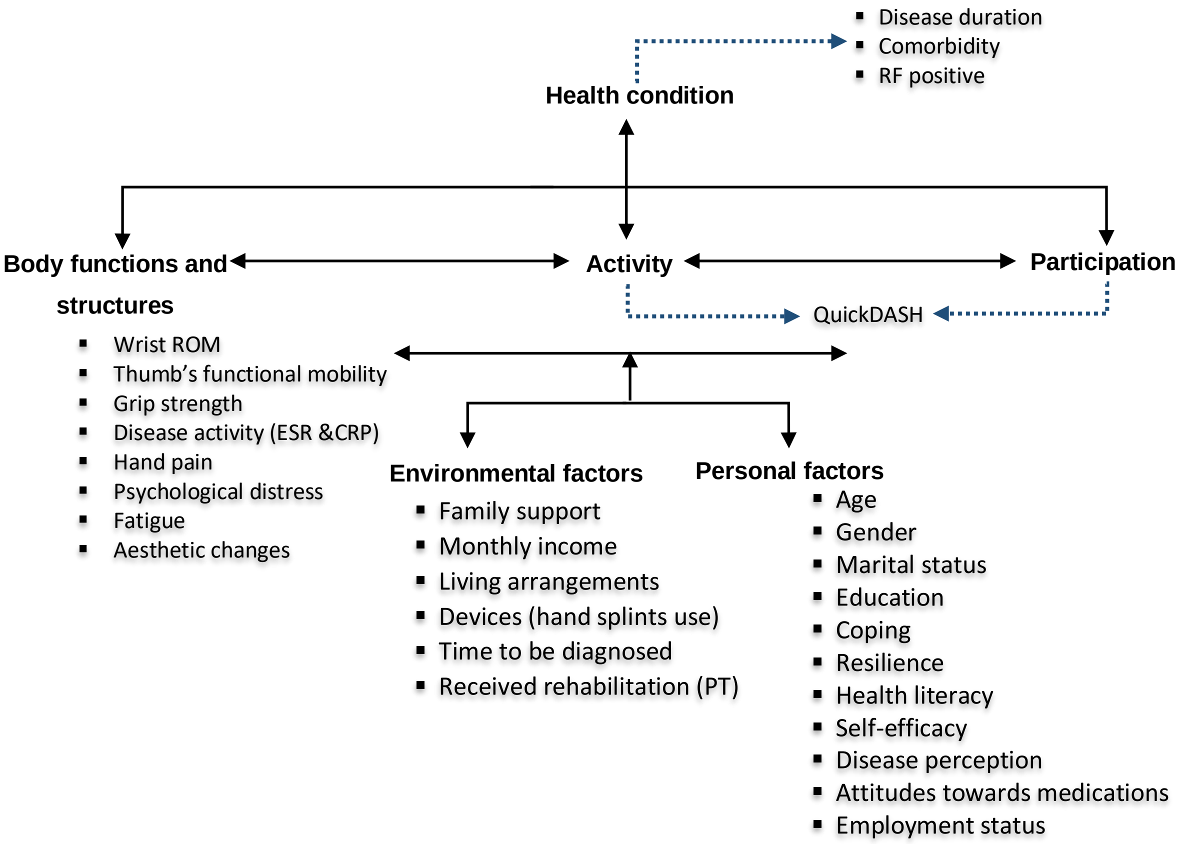


Figure 6-11 Variables assigned to the components of the International Classification of Functioning, Disability and Health (ICF)

6.5.8.1 Associations between the QuickDASH and the variables related to the body function and structure component of the International Classification of Functioning, Disability and Health (ICF)

Table 6-17 displays the correlations between QuickDASH and body function and structure variables. Almost all of the body function and structure variables were significantly associated (except CRP and right-hand wrist extension ROM) in the anticipated directions, with the QuickDASH score correlation coefficients ranging from negligible to high (range: r=.15 to r=.76). Hand pain intensity measures showed significant low to moderate positive associations with the QuickDASH (range: r=.42 to r=.52, all p_s<.001). Wrist ROM measures of flexion and extension were found to be negatively and significantly (except right hand wrist extension ROM) associated with QuickDASH scores, with correlations ranging from negligible to low (range: r=−.15 to r=−.34). The associations between thumb functional mobility and QuickDASH were significant low inverse associations (right thumb: r=−.27, p=.03; left thumb: r=−.29, p=.02). There were statistically significant inverse correlations between grip strengths and QuickDASH, which were moderate. Regarding disease activity variables, there was a low significant association between the QuickDASH and ESR (r=.34, p=.01), whereas the association with CRP was very small and insignificant (r=.13, p=.34). The psychological distress scores using the PHQ-4 were highly associated with the QuickDASH (r=.72, p<.001), with the anxiety subscale showing the strongest association (r=.76, p<.001). An increased level of dissatisfaction regarding hand appearance was significantly associated with a high QuickDASH score (r=.43, p<.001). Lastly, perceived fatigue, as measured with the SF-36 vitality scale (high score means low fatigue), showed an inverse high association with the QuickDASH scores (r=−.73, p<.001).

6.5.8.2 Associations between the QuickDASH and the variables related to the environmental factors component of the International Classification of Functioning, Disability and Health (ICF)

A lower level of family support was associated with greater hand functional impairment. However, the association was negligible and did not reach statistical significance (r=−.05, p=.68). An independent sample t-test indicated that the mean difference of the QuickDASH scores between individuals who had physiotherapy treatment (61.94 ± SD 18.79) and those who did not (43.53 ± SD 24.66) was statistically significant (*p*=.05) (Table 6-18). Although there was no statistically significant difference in the QuickDASH scores in terms of the length of delay in diagnosis, participants who had had a delay of one year or more showed greater hand functional impairment. There were no differences in QuickDASH mean scores in relation to splint use, monthly income and living arrangements (Table 6-18).

Table 6-17 Correlations between QuickDASH and variables related to the ICF body function and structure component. Correlation coefficients are Pearson's correlation coefficients, unless otherwise indicated.

Measure	**95% confidence interval**		**Correlation coefficient**	***P*-value**
	Lower limit	Upper limit		
Pain (NRS)				
Rt. hand pain at rest	.33	.67	.52	<.001
Lt. hand pain at rest	.29	.65	.48	<.001
Rt. hand pain during activity	.24	.57	.42	<.001
Lt. hand pain during activity	.29	.67	.49	<.001
Wrist ROM				
Flexion – Rt. hand	−.09	−.50	−.30	.014
Flexion – Lt. hand	−.15	−.53	−.34	.005
Extension – Rt. hand	.09	−.36	−.15	.24
Extension – Lt. hand	−.07	−.47	−.28	.02
Thumb functional mobility (Kapandji index)				
Rt. thumb	−.03	−.49	−.27†	.03
Lt. thumb	−.06	−.50	−.29†	.02
Grip strength				
Right hand	−.32	−.65	−.51	<.001
Left hand	−.30	−.67	−.50	<.001
Disease activity variables				
ESR	.11	.56	.34†	.01
CRP	−.16	.42	.13†	.34
Psychological distress (PHQ-4)	.56	.84	.72	<.001
Depression symptoms (PHQ-2)	.37	.76	.58	<.001
Anxiety symptoms (GAD-2)	.62	.85	.76	.001
Aesthetic changes (bMHQ)	.21	.62	.43†	<.001
Fatigue (SF-36 vitality scale)	−.61	-.83	−.73	<.001

†: Spearman's rank correlation coefficient; bMHQ: Brief Michigan Hand Outcomes Questionnaire; CRP: C-reactive protein; ESR: GAD-2: Generalised anxiety disorder (GAD-2); Lt.:Left; NRS: Numerical Rating Scale; PHQ-2: The Patient Health Questionnaire-2 (depression scale); PHQ-4: The Patient Health Questionnaire-4; Rt.: Right

Table 6-18 Results of independent t-test and descriptive statistics for QuickDASH by monthly income, time to diagnosis, splint use, living arrangement and physiotherapy treatment

Variable	Groups	Mean (SD)	Mean difference (95% CI)	*t*-statistic (df)	*P*-value
Monthly income	≤ 2400 NIS (*n*=43)	46.25 (24.08)	1.45 (−11.19,14.09)	.23 (65)	.82
	> 2400 NIS (*n*=24)	44.80 (26.15)			
Time from symptoms onset to diagnosis	< 12 months (*n*=34)	41.38 (23.31)	−8.83 (−20.76,3.09)	−1.48 (65)	.14
	≥ 12 months (*n*=33)	50.21 (25.55)			
Splint use	Yes (*n*=13)	46.16 (24.48)	.53 (−14.79,15.86)	0.07 (65)	.94
	No (*n*=54)	45.63 (24.93)			
Living arrangement	Alone (*n*= 10)	45.91 (26.23)	.21 (−16.80,17.22)	0.02 (65)	.98
	With others (*n*=57)	45.70 (26.61)			
Physiotherapy treatment	Yes (*n*=8)	61.94 (18.79)	18.40 (.27,36.53)	2.03 (65)	.05
	No (*n*=59)	43.53 (24.66)			

NIS: New Israeli Shekel

6.5.8.3 Associations between the QuickDASH and the variables related to the personal factors component of the International Classification of Functioning, Disability and Health (ICF)

Several statistically significant associations between the QuickDASH and personal factors were identified (Table 6-19), and the directionality of the relationships was found to be as predicted. There was no significant association between QuickDASH scores and age. The results showed that higher involvement in dysfunctional coping strategies (maladaptive coping) was positively and significantly associated with greater hand functional impairment (i.e. higher QuickDASH scores; *r*=.45, *p*<.001). However, adaptive coping showed a positive, but not a statistically significant association with the QuickDASH (*r*=.03, *p*=.80). Further exploratory analyses were carried out using the subscales of the BCI. The analyses showed that worse hand function was only significantly associated with greater use of denial, behavioural disengagement and self-blame coping strategies (*r*=.24, *p*=.05; *r*=.35, *p*<.001; *r*=.57, *p*<.001, respectively). A lower arthritis self-efficacy scale score (ASES-8) was moderately and significantly associated with greater hand functional impairment (*r*=−.57 (*p*<.001). Similarly, a lower level of resilience was associated with higher hand functional impairment (*r*=−.47, *p*<.001). Almost all of the disease perception dimensions were significantly associated in a logical way with the QuickDASH score, with correlation coefficients ranging from −.31 to −.53 and .51 to .59. However, the dimension “timeline” correlated positively, but not significantly, with the QuickDASH score, indicating that participants who perceive their disease as chronic have higher hand functional impairment. Overall, a lower level of perceived personal control, treatment control and understanding of RA were associated with a higher QuickDASH score. In the same vein, a greater perception of negative disease consequences, symptoms (identity), concerns, and emotional responses were related to a higher hand functional impairment score. Regarding personal attitudes towards medication, a higher level of concern about medications was associated with greater hand functional impairment (*r*=.36, *p*=.003). Furthermore, greater beliefs in the necessity of medication were positively associated with the QuickDASH scores but did not reach statistical significance (*r*=.19, *p*=.13).

Independent t-tests were performed to examine potential differences within groups related to gender, educational level, marital status, employment status, and health literacy (Table 6-20). An independent sample t-test demonstrated that the mean

QuickDASH score was significantly higher for people with inadequate health literacy (64.33 ± SD 19.09) than for individuals with adequate health literacy (36.01, ± SD 21.56). Women had greater QuickDASH mean scores (48.16 ± SD 23.27) compared to men (36.54 ± SD 28.37); however, the difference was not statistically significant. There were no significant differences related to marital status, employment status and educational level in the QuickDASH scores (Table 6-20).

Table 6-19 Correlations between QuickDASH and variables related to the ICF personal factors component. Correlation coefficients are Spearman's rank correlation coefficients, unless otherwise indicated.

Variables	**95% confidence interval**		**Correlation coefficient**	***P*-value**
	Lower limit	Upper limit		
Age (years)	.06	−.38	−.16†	.18
Coping (BCI)				
Maladaptive coping	.24	.62	.45†	<.001
Adaptive coping	−.18	.26	.03†	.80
Resilience (BRS)	−.24	−.65	−.47†	<.001
Illness perception (bIPQ)				
Consequences	.32	.67	.52	<.001
Timeline	−.04	.47	.20	.10
Personal control	−.33	−.65	−.46	<.001
Treatment control	−.34	-.69	−.53	<.001
Identity	.37	.74	.59	<.001
Concern	.38	.70	.56	<.001
Emotional response	.34	.66	.51	<.001
Understanding	−.01	−.53	−.31	.01
Self-efficacy (ASES-8)	−.38	−.73	−.57†	<.001
Personal attitudes towards medications (BMQ)				
Necessity	−.06	.41	.19†	.13
Concern	.07	.58	.36†	.003

†: Pearson's product moment correlation; ASES-8: Arthritis Self-efficacy Scale-8 items ; BCI: Brief Coping Inventory ; bIPQ: brief Illness Perception Questionnaire; BMQ: Beliefs about Medicines Questionnaire; BRS: Brief Resilience Scale

Table 6-20 Results of independent t-test and descriptive statistics for QuickDASH by gender, educational level, employment status, marital status and health literacy

Variable	Groups	Mean (SD)	Mean difference (95% CI)	*t*-statistic (df)	*P*-value
Gender	Women (*n*=53)	48.16 (23.27)	11.62 (−3.01, 26.25)	1.59 (65)	.12
	Men (*n*=14)	36.54 (28.37)			
Education	≤ post-secondary (*n*=47)	44.15 (26.73)	−5.29 (−18.47,7.89)	−0.80 (65)	.43
	> post-secondary (*n*=20)	49.44 (18.99)			
Employment	Working (*n*=13)	49.66 (20.51)	4.88 (−10.40, 20.16)	0.64 (65)	.53
	Not working (*n*=54)	44.78 (25.63)			
Marital	Married (*n*=59)	45.53 (25.01)	1.63 (−17.06, 20.32)	0.17 (65)	.86
	Other (*n*=8)	47.16 (23.32)			
Health literacy	Adequate (*n*=44)	36.01 (21.56)	−28.98 (-38.98, −17.65)	−5.30 (65)	<.001
	Inadequate (*n*=23)	64.33 (19.09)			

6.5.8.4 Associations between the QuickDASH and health condition variables

A Spearman's correlation was run to determine the relationship between disease duration and QuickDASH scores. There was a positive, but not a significant correlation, between disease duration and QuickDASH scores (*r*=.22, *p*=.08). An independent samples t-test was performed comparing the mean QuickDASH scores of individuals with a positive and negative RF. Participants with a positive RF (62.17 ± SD 16.54) had greater hand functional disability than RF negative participants (28.79 ± SD 19.72), *t* (65) =−7.52, *p*<.001 two-tailed. On average, participants with comorbidities (47.44 ± SD 25.91) had more hand functional impairment than those without comorbidities (44.26 ± SD 23.80). This difference of −0.52, BCa 95% CI (-15.13, 8.95) was not significant (*p*=.60).

6.5.9 Summary of the results

The key findings of this study are summarised in the following subsections.

6.5.9.1 Clinical characteristics

- Forty-six percent of the participants had one or more comorbid diseases, 34% had cardiovascular disease.
- More than three quarters (76%) of the participants were currently taking non-biological DMARDs, and the rest (24%) were on biologicals.
- More than half (51%) of the participants presented with positive RF.
- Ninety-three percent of the participants reported having had hand pain and problems in the six months before the study.
- Approximately half of the participants showed clinically significant depression (49%) and anxiety (48%) symptoms.
- The majority (82%) of the participants had high or moderate disease activity.

6.5.9.2 Impact of RA on hand function

- Almost all of participants had impaired wrist joint flexion mobility (right hand 97%, left hand 99%). Impaired wrist joint extension mobility was found in 72% and 73% for the participants' right and left hand, respectively.

- Grip strength reduction was 34% and 31% in the right and left hand, respectively.

- More than 60% of the participants had limited right and left thumb functional mobility.

- Hand pain intensity during activity was twice as high as that at rest. However, pain intensity (at rest and during activity) was mild in severity.

- Hand functional impairment at various levels was present in 85% of the participants, with the majority (70%) having a high impairment.

6.5.9.3 Factors associated with hand functional disability

- Body function and structure factors with the strongest contribution to hand functional impairment were hand pain, grip strength, psychological distress (depression and anxiety), and fatigue perception.

- Hand functional impairment was significantly associated with modifiable personal factors, including self-efficacy, maladaptive coping, resilience, disease perception, concern about medications and health literacy.

- Personal factors including age, gender, marital status, employment status and educational level were not significantly associated with hand functional impairment.

- Environmental factors including family support, hand splint use, living arrangements, and the length of delay in diagnosis were not significantly associated with hand functional impairment.

- Health condition variables including the presence of comorbidity and disease duration were not associated with hand functional impairment. However, individuals with a positive RF had greater hand functional impairment than RF negative participants.

6.6 Discussion

The present study aimed to describe and assess the functional consequences of RA with regards to hand impairment and hand-related activity limitations and participation restrictions. Furthermore, it aimed to analyse the associations between hand-related activity limitations and participation restrictions, disease variables, hand impairments, and personal, environmental, and health-related factors within the ICF framework. This study has also provided detailed information about the demographic and clinical characteristics of Palestinian individuals with RA. Therefore, the results of this study can be used to inform the clinical practice and decision making in Palestine regarding the optimal care provided for people with RA. In particular, this study has considered the factors associated with hand functional impairment from the entire scope of the ICF. As a result, several modifiable factors which could influence hand functional impairment have been determined. This discussion is subdivided into five sections that discuss the results in relation to the previously published research findings.

6.6.1 Patient characteristics and disease activity

This is the first cross-sectional study providing information about the clinical characteristics of Palestinian people with RA. The data about comorbidity, type of treatment and disease activity provide an insight into the effectiveness of therapy and are required to ensure an appropriate management approach for RA patients (Boonen and Severens 2011). Comorbidities were common in this study sample, with about half of the patients having one or comorbidity disease. Importantly, the prevalence of cardiovascular disease was high (34%) among this study sample. A previous cross-sectional international study that included data from Arab countries indicated a high prevalence of comorbidities in general, and specifically cardiovascular ones, among RA patients, which varied widely among countries (Dougados et al. 2014). However, the prevalence of cardiovascular diseases reported in this study is greater than those reported in previous international studies (range: 6% to 18.6%) (Dougados et al. 2014; Pappas et al. 2018) and regional data from five Arab countries (3.7%) (Dargham et al. 2018). Screening and management of cardiovascular disease is needed in Palestinian people with RA, because active inflammatory arthritis is an independent risk factor, and RA medications contribute to the development of cardiovascular diseases (Gabriel and Crowson 2012). For that reason, the EULAR proposed specific recommendations for cardiovascular risk management in patients with RA (Peters et al. 2010), which can be implemented in the Palestinian healthcare system.

Another important issue which should be considered is that almost half (49%) of the study participants had experienced a delay of more than 12 months before receiving their RA diagnosis and starting treatment. The data from Middle East region has shown that patients with RA are often diagnosed late (Barhamain et al. 2017). For instance, in Saudi Arabia, the average verified time of RA diagnosis is approximately 30 months (Hussain et al. 2016). Empirical evidence demonstrates that RA patients in the earliest stages (<3 months of symptom onset) respond better to treatment compared to patients with established disease (van der Linden et al. 2010). Indeed, a recent systematic review and meta-analysis reported strong evidence supporting the beneficial effect of an earlier initiation of therapy in RA (van Nies et al. 2014). Given this evidence, the high rate of delay in RA diagnosis reported in this study signposts the need to explore the reason behind this phenomenon. Previous evidence has shown that a combination of factors related to the patients (e.g. ignoring early symptoms) and healthcare system (e.g. referring patients to non-rheumatologists) contribute to a delay in RA diagnosis (Barhamain et al. 2017; Raciborski et al. 2017). These factors were raised by the Palestinians with RA in the focus group presented earlier in this thesis.

In this study, 76% of the patients were prescribed non-biological DMARDs, whereas 24% were treated with biological DMARDs. When compared with other regional data, a study that recruited 895 RA patients from five Arab countries reported similar percentages of average non-biological DMARDs (67%) and biological DMARDs (33%) use in the five countries (Dargham et al. 2018). Methotrexate was the most frequently prescribed DMARD (51%), consistent with what has been described in other RA populations in the Middle East and Europe (Lapadula et al. 2011; Alawneh et al. 2014; Bal 2015; Dargham et al. 2018) and in agreement with the European and American guidelines, which suggest Methotrexate as the first line treatment (Singh et al. 2016; Smolen et al. 2017). However, most countries in the Middle East, particularly Arab countries do not have guidelines for RA management (Halabi et al. 2015; Dargham et al. 2018) and Palestine is no exception. The management of RA in Palestine is based on a clinician’s preferences, with no clearly defined target.

Despite the patients in the study being actively treated with biological and non-biological DAMRDS, a considerable proportion had elevated disease activity markers (ESR 57% and CRP 49%), as well as the presence of RF (51%). However, people with RA show unique clinical presentations; no single disease activity marker can accurately mirror every patient's disease activity at any given point in time (Salomon-Escoto et al. 2011). Ochi et al. (2015) proposed the use of the QuickDASH as a disease control measure, demonstrating a strong correlation with DAS-28 in patients with a disease duration of more than five years. Subsequently, disease activity benchmarks based on the QuickDASH score were introduced by Carroll (2016) and used in the current study. The results showed that RA in Palestine is a rather severe disease, with the majority (82%) of patients having high or moderate disease activity; only 15% were in remission. Although the severity of RA varies greatly across Middle Eastern countries (Halabi et al. 2015), regional data from Jordan and the United Arab Emirates reported similar findings to those in this study finding (Badsha et al. 2008; Alawneh et al. 2014). For example, in Jordan, Alawneh et al. (2014) reported that 88% of patients with established RA (with a mean disease duration of 6 years) had high or moderate disease activity, with only 5% in remission. Similarly, in the United Arab Emirates, Badsha et al. (2008) found that 12% of their RA patients (mean disease duration 5.1 years) were in the low disease activity or remission categories. In contrast, another regional study conducted in Qatar reported that almost half (49%) of the RA patients were in remission (Lutf et al. 2014). In a multinational cross-sectional study, remission rates based on the DAS-28 definition were high among western populations with RA, reaching up to 41% among RA patients from the Netherlands (Sokka et al. 2008). These seemingly paradoxical results may be explained by the difference in the management practices of RA across countries, which can be influenced by healthcare infrastructure and socioeconomic status of patients. In addition, different definitions of remission yield different remission rates (Sokka et al. 2008).

In conclusion, this study's results showed that despite the high use of DMARDs, many of the Palestinian people with RA had high or moderate disease activity. This finding suggests that RA is poorly controlled in Palestine. Further analysis is warranted to explore the reasons behind this study finding. However, the results of this study have highlighted some possible factors that may have contributed to the high rate of disease severity. For instance, high comorbidities, which were found to be common among this study sample, may limit treatment options and subsequently preclude the possibility to control the disease activity. Another possible reason includes the delay in disease presentation to rheumatology clinics. Furthermore, the absence of any Palestinian guidelines related to managing RA leave Palestinian rheumatologists to manage RA based on their own personal preferences, with no clearly defined treatment targets for remission or low disease state.

6.6.2 Hand impairments

The second objective of this study was to describe and measure the functional consequences of RA regarding hand impairment. The most important clinical characteristics of RA are pain, reduced joint mobility, and grip strength. These measures were selected to reflect hand function at the impairment level.

6.6.2.1 Pain

The present study indicated that the prevalence of hand pain was high (93%) among the participants, although pain intensity was stated as being mild. In accordance, Horsten et al. (2010) reported a high prevalence of hand pain in individuals with early and long-standing RA (range= 87% to 93%), despite low disease activity. Previous reports have shown that general pain and hand pain remain a problem in people with early and established RA, despite good clinical responses to pharmacological treatment (Roche et al. 2003; Taylor et al. 2010; Altawil et al. 2016; Thyberg et al. 2016). The findings of these studies, including the present one, confirm that more effective pain management is needed for patients with RA. In addition, these studies indicate that pain in RA may not be directly related to inflammation, suggesting that non-inflammatory factors such as central and peripheral pain mechanisms may contribute to the expression of pain in RA (Boyden et al. 2016; McWilliams and Walsh 2017). Thus, the high prevalence of hand pain in the present study may be partly related to non-inflammatory factors. However, this conclusion is certainly tentative, since the majority (82%) of this study sample were categorised as having high or moderate disease activity. Future research with a specific focus on the pattern of hand pain in relation to the treatment response would provide an insight into whether hand pain is inflammatory mediated or not. A systematic review by Nicholls et al. (2012) reported that multiple factors such as disease history, age, being female, and weak hand strength were associated with hand pain in adults aged 50 years and over. This evidence may provide another potential explanation for the high prevalence of hand pain reported in this study, since most of this study sample were aged 50 years or more (64%), female, had comorbidities and impaired grip strength.

The results of this study have also shown that hand pain during active grip testing was higher than hand pain during rest, which was the lowest in both sexes. This confirms and extends other studies that have reported similar findings (Durmus et al. 2013; Thyberg et al. 2016). In a recent cohort study of patients with early RA, Thyberg et al. (2016) found that hand pain during active grip testing was higher than hand pain during rest in both sexes, and 22% of the patients reported high levels of hand pain (≥40mm VAS) on hand grip testing at the 12-month follow-up. In people with established RA, Durmus et al. (2013) reported that hand pain was 42.0 mm (VAS) and 30.6 mm (VAS) during grip testing and at rest, respectively. In this study, the mean hand pain for both hands were 4.46 (NRS) and 2.56 (NRS) during grip testing and at rest, respectively. However, a direct comparison of the current results with previous investigations is not possible, because of differences in patients' characteristics and the pain outcome measures used.

6.6.2.2 Range of motion and functional mobility

This study provided evidence that Palestinian people with RA experience substantial reduced wrist and thumb mobility. Indeed, there was about a 48% reduction in wrist ROM with respect to normative data. Similar comparative results were reported in a recent study, which showed that Chinese RA patients with a mean disease duration of 8.4 (*SD* 8.7) had up to a 50% reduction in active wrist flexion/extension (Zhang et al. 2018). A decrease in wrist joint ROM as the RA progresses was reported by several studies (Goodson et al. 2007; Yayama et al. 2007; Erol et al. 2016; Kinikli et al. 2016), although comparability is limited due to differences in patients' characteristics, reporting methods, and ROM measurement procedures.

A considerable proportion of this study sample (range:72% to 99%) were categorised as having impaired wrist ROM. Similarly, Horsten et al. (2010) reported a high prevalence of wrist ROM impairment in both hands among patients with early and long-standing RA. One possible explanation of these results, is that the involvement of the wrist is common in people with RA, and affects up to 50% of patients within the first two years after the onset of the disease, increasing to 90%

after ten years (Trieb and Hofstatter 2009). Another reason is perhaps related to the fact that percentages of impaired wrist mobility were dependent on the selected cut-off point (i.e. active measurement was ≥ 15 degrees less than the maximal range of wrist motion). In terms of RA, clinically relevant cut-off points for wrist ROM that indicate the absence of hand functional impairment are currently unavailable. Recently, Kojima et al. (2018) reported that a cut-off value of 70-89 degrees for wrist flexion-extension indicates the absence of functional disability based on the HAQ score for patients with long-standing RA. Given that ROM results in RA can be influenced by multiple factors (.e.g. pain and disease activity) (Zhang et al. 2018), establishing cut-off points for the hand joint ROM that indicate the absence of hand functional impairment may be difficult and unfeasible. Indeed, evidence has shown that alteration in the mobility of hand joints have different implications in relation to hand related activity limitations in people with RA (Hakkinen et al. 2005). Moreover, in clinical practice, the wrist functional ROM required to perform daily living activities can be more important than normal ROM, since only 70% of maximal wrist motion is required to carry out daily living activities (Ryu et al. 1991). However, while the selected cut-off point in the current study may lack face validity, it holds the advantage of being objective and reproducible between and within studies.

As in the case of wrist ROM, limited right and left thumb function mobility was found in 66% and 61% of all patients, respectively. Horsten et al. (2010) cross-sectional study reported that the thumb was affected in 18% of patients at an early stage (2-4 years) of RA, increasing to 30% in patients with a disease duration of ≥ 8 years. They also pointed out that thumb Z-deformity in the dominant and non-dominant hand significantly increased with disease duration. Toyama et al. (2014) longitudinal study documented that 62% of patients with established RA developed thumb deformities over five years, and thumb function mobility (measured with the Kapandji Index) significantly decreased over time. The high percentage of limited right and left thumb functional mobility reported in the present study is partly explained by the fact that 46% of this study sample had a disease duration of ≥ 8 years, suggesting that the current sample may have considerable thumb deformities. In addition, in the present analysis, participants were considered to have impaired thumb function mobility if they did not score10 (best score) in the Kapandji Index. Therefore, the selected cut-off value may have contributed to this finding.

6.6.2.3 Grip strength

Sufficient grip strength is essential for performing many ADL and for maintaining functional independence (Fiebert et al. 1996). In the present study, grip strength scores among RA patients were lower than the corresponding expected values, suggesting that inflammatory pathology reduced grip strength. Furthermore, these results indicate that lower grip strength observed among the participants is independent of the aging process and occurs at a greater rate of decline than natural aging. This is supported by the previous evidence showing that patients with RA had significantly lower grip strength compared to healthy referents (Bjork et al. 2007; Erol et al. 2016; Kinikli et al. 2016; Packer et al. 2016; Sferra da Silva et al. 2018) and normative data (Bjork et al. 2006; Rydholm et al. 2018).

In people with early RA, Bjork et al. (2006) found that patients had about 70% grip strength reduction at diagnosis and about 50% after receiving RA treatment, compared to the normative data. Similarly, Packer et al. (2016) reported that grip strength was 50% lower in the patients with established RA compared with healthy age- and gender-matched controls. A recent longitudinal study recruiting early RA patients reported a high reduction in dominant handgrip strength at inclusion (60%) and about 43% after five years compared to expected normal reference values (Rydholm et al. 2018). Recently, Sferra da Silva et al. (2018) reported that patients with long-standing RA (mean age=57.50 years, median disease duration=10 years) had a 30% and 31% reduced right and left hand grip strength respectively, compared to healthy referents. In the present study, the corresponding reduction was up to 34% when compared to the same normative data. The data described above show that there is wide variability among studies regarding hand strength reduction in RA. This variability may be related to different reasons, including, but not limited to, the methods used to quantify grip strength reduction (i.e. use of control group or normative values), patient’s characteristics, the grip strength measurement procedure and the tools used for measuring grip strength. Apart from age and sex, grip strength can be influenced by anthropometric measurements like the size of the hand, weight and height (Fraser et al. 1999), which are not usually considered when the grip strength data of RA patients are compared with a healthy control group or the normative data. In addition, grip strength results may be influenced by other clinical states such as frailty and cardiovascular disease, which frequently overlap with RA. The impact of these conditions on the interpretation of grip strength results in RA has not yet been explored (Higgins et al. 2018). Overall, recent studies tend to report a lesser degree of grip strength reduction, which is probably explained by earlier aggressive interventions to manage disease activity.

Particularly low grip strength levels have been reported in healthy women (Bjork et al. 2007) and RA patients (Bjork et al. 2006; Bjork et al. 2007; Rydholm et al. 2018). Evidence from the RA literature suggested that reduced grip strength to a level of functional significance is more common in women; therefore, the overall impact of grip strength reduction is greater in women than men (Thyberg et al. 2005). In agreement with this, hand functional disability measured using the QuickDASH was worse in females compared to males in the current study. This is consistent with the previous rheumatology reports (Hallert et al. 2012; Krishnan et al. 2012; Hekmat et al. 2014; Rydholm et al. 2018). However, the grip strength values of men were also considerably reduced compared to the expected values, indicating a major relative consequence of RA on hand strength in both sexes. In the present study, attention should be given to the high proportion of participants recognised as having impaired hand strength (range 69% to 72%). This is coupled with the fact that the majority of them (87%) had not received rehabilitation services. These results, alongside the evidence for hand exercises being beneficial for RA patients (Hammond and Prior 2016; Williams et al. 2018), underline the importance of evaluating grip strength in clinical settings and providing rehabilitation interventions for Palestinian people with RA.

6.6.3 Hand-related activity limitation and participation restriction

The third objective of this study was to describe and measure the functional consequences of RA regarding hand-related activity limitations and participation restrictions. Conventional measures of hand impairments discussed before such as ROM and grip strength only explain part of the limitations in performing activities in daily life. Therefore, the QuickDASH was used for evaluating hand-related activity limitation and participation restrictions. In this sample population of individuals with RA, their self-reported hand function disability varies throughout the entire QuickDASH questionnaire. The mean disability score (45.7 ± SD 24.66) on the QuickDASH was triple the expected value of the normative data, confirming that hand function of Palestinian people with RA was negatively affected. In a recent cross-sectional study among women with established RA (mean disease duration=7years), the mean QuickDASH score was 38.33 (SD 19.78), which is comparable with the mean score reported in this study (Palamar et al. 2017).

The QuickDASH scores mean value for women and men in this study were much higher than the normal values found across all age groups reported in a study by Aasheim and Finsen (2014). Furthermore, the QuickDASH scores were higher in women compared to men. This is not surprising, given that gender difference in QuickDASH scores was also reported in the normative data (women had worse scores) (Aasheim and Finsen 2014), and women with RA reported more pronounced hand-related activity limitations compared to men (Thyberg et al. 2005). However, the reasons behind the gender discrepancy in disability are not entirely understood in RA, although it has been argued that higher pain perception, lower muscle strength, and more emotion-focused pain coping strategies could contribute to this difference (Affleck et al. 1999; Thyberg et al. 2005; Leeb et al. 2007). In this study, higher hand functional disability scores in women could be related to somewhat higher disease activity variables and lower grip strength. Furthermore, the results of this study showed that women had worse scores compared to men based on the psychological measures (i.e. depression and anxiety) and personal factors measures such as disease perception, which could provide another possible explanation for the gender difference in hand functional impairment scores. These observed differences are of major clinical relevance and should be further studied.

Specific hand-related activities in daily living affected by RA are mainly heavy activities that require some degree of force such as household chores and carrying bags. Prehensile tasks such as using a knife and activities that tend to require more ROM, such as washing one’s back, were stated as being moderately or mildly difficult for this sample. These findings are consistent with a study by Adams et al. (2005b), which was conducted among people with early RA using the DASH questionnaire. The fact that more pain was experienced during activity (grips strength test) alongside reports that activities that require some hand strength are difficult support the hypothesis that on-going hand related-activity limitation and participation restriction are influenced by hand pain during activity (Thyberg et al. 2016).

The recently established cut-off values of the QuickDASH in RA were used in the present study to reflect hand functional impairment severity (Salaffi et al. 2019). This is an advantage in the present study, making the QuickDASH score meaningful for both clinical and research settings. Hand functional impairment at various levels was present in 85% of the participants, with the majority (70%) of them recognised as having high functional impairment. These results are in line with a Turkish study which showed that 81% of RA patients with mean disease duration of 7.6 (*SD* 6.1) had hand functional impairment at various levels according to the HAQ hand disability index (Bodur et al. 2006). In contrast, a study conducted by Horsten et al. (2010) in the Netherlands reported that only 30% of patients with early and established RA had severe functional impairments based on the DASH score (i.e. DASH score was above the normative mean DASH score plus twice the standard deviation).

It has previously been reported that functional ability is predominantly influenced by disease activity in early RA, while in patients with established RA, functional ability is influenced by joint destruction (Welsing et al. 2001). Since this study largely included participants with established RA, a high prevalence of hand functional impairment is possibly related to articular damage. However, this conclusion should be treated with caution, since articular damage was not evaluated. Furthermore, it has previously been reported that functional disability in RA is influenced primarily by disease activity, pain and psychological status (Karpouzas et al. 2017). In the present study, a considerable percentage of the participants reported hand pain (93%) and approximately half of the participants were found to have clinically significant depression and anxiety symptoms, as well as abnormal disease activity variables. As such, the QuickDASH data may be influenced by these variables, and so this resulted in the high prevalence of hand functional impairment reported in this study.

6.6.4 Factors associated with hand-related activity limitations and participation restrictions

The final objective of this study was to analyse associations between hand-related activity limitation and participation restrictions (measured with the QuickDASH) and disease variables, hand impairments, and personal, environmental and health-related factors. When all of the factors were mapped according to the ICF framework components, all of the components were found to have at least one factor that is significantly associated with hand functional disability. This finding supports the view that components in the ICF framework are interrelated and contribute to hand functional disability in the RA population. This provides further support for the argument that hand functional disability in RA is multifactorial in aetiology (Chung et al. 2011; Andrade et al. 2016). However, interventions targeting hand function in RA have focused on one domain instead of using a multifactorial approach. Therefore, future research should focus on the effectiveness of multifactorial interventions, with a specific focus on personal and environmental factors that are found to contribute to hand function in RA.

For the factors associated with hand functional impairment, the results will be discussed selectively in the subsequent sections.

6.6.4.1 Body function and structure variables

Among the different components of the ICF, "body function and structure" contains the largest number of factors associated with hand functional disability (QuickDASH). In the present study, body function and structure factors with the strongest contribution to hand functional disability were found to be hand pain, grip strength, psychological distress (depression and anxiety), and fatigue perception. Similarly to this study, several previous studies analysing hand function in RA reported strong associations between the QuickDASH and grip strength and pain (Ochi et al. 2015; Palamar et al. 2017). Evidence from the RA literature has also demonstrated that grip strength and pain are among the most effective factors for determining hand function in individuals with RA (Arab Alkabeya et al. 2019a).

The current study reported that approximately half of the participants showed clinically significant depression and anxiety symptoms. Prevalence estimates for anxiety and depression among RA patients differ across the studies (Isik et al. 2007; Covic et al. 2012) and vary considerably across countries (Dougados et al. 2014). However, a recent study from China reported a high prevalence of anxiety (60%) and depression (62%) among RA patients (Pu et al. 2018). In this study anxiety and depression strongly correlated with hand functional disability (range: *r*=.58 to 76). Although a direct comparison of these results with the previous data is not appropriate, previous evidence has reported a significant association between hand function and mental health (SF-36) (Aktekin et al. 2011; Durmus et al. 2013). Similarly, strong evidence of a relationship between functional disability and mental and psychological problems in individuals with RA has been reported (Benka et al.

2012; Benka et al. 2014; Ji et al. 2017; Karpouzas et al. 2017). Taken together, the findings of this study, alongside previous evidence, suggest that psychological distress (depression and anxiety) is an important factor to consider in relation to hand function. However, to explore this further, longitudinal studies are needed to provide further information, to determine if changes in psychological distress would independently yield clinically meaningful changes in hand functional status.

It is a well-established fact that fatigue in people with RA is highly prevalent, as reported by 42%–80% of the patients, and is perceived as being a dominant problem that has a substantial impact on everyday life (Repping-Wuts et al. 2009; Nikolaus et al. 2013; Primdahl et al. 2019). A high fatigue perception level was common among this study sample (66%) and highly correlated (r=−.73) with hand functional impairment. However, there is conflicting evidence for the association between fatigue perception and hand function in individuals with RA (Arab Alkabeya et al. 2019a). It is noted, that in terms of magnitude, the strength of association reported in the current study between fatigue perception and hand functional impairment is higher than that reported in previous studies (range: r=.36 to .54) (Aktekin et al. 2011; Durmus et al. 2013). Although a combination of variables might be the underlying mechanism for RA fatigue (Nikolaus et al. 2013; Matcham et al. 2015), systematic reviews examining variables related to fatigue in RA have reported that fatigue was consistently associated with pain, depression and anxiety (Nikolaus et al. 2013; Matcham et al. 2015). Therefore, the high association between fatigue perception and hand functional impairment found in the present study may be arbitrated by pain, depression, and anxiety, which were also common among this study sample.

Finally, negligible to low significant correlations were found between the QuickDASH and wrist joint ROM (except right wrist extension ROM). Studies evaluating the association between wrist joint ROM and hand functional impairment provided controversial results. For instance, van Lankveld et al. (1998) and (Özeri et al. 2008) reported a statistically significant low relationship (range: r=.30 to .46) between hand function and wrist flexion and extension in people with established RA. In contrast, Goodson et al. (2007) reported that the association between wrist flexion-extension and hand function was not significant. The differences between studies concerning ROM measurement methods, patients' characteristics, and measures of hand function may be the reasons behind these contradictory results. In the present study, the correlation between the right wrist extension ROM and the QuickDASH was negligible and did not reach statistical significance. This may be due to relatively small sample size of the present study. Another possible explanation is related to the fact that an alteration in the mobility of hand and upper limb joints have different implications in relation to hand and upper limb related activity limitations. For instance, wrist flexion ROM limitations were related to griping activities on the HAQ, whereas wrist extension ROM limitations were related to dressing and grooming activities (Hakkinen et al. 2005). Studies analysing the association between hand disability and thumb function mobility are rare. A validation study of the Kapandji index reported a negligible association ($r=-.24$) between thumb function mobility and the Cochin rheumatoid hand disability scale (Lefevre-Colau et al. 2003), which is comparable with this study ($r=-.27$ to $-.29$). Overall, the magnitude of correlations between the QuickDASH and wrist ROM or thumb function mobility were, at most, low. This indicates that ROM measures may reflect RA disease progression and not merely the hand functional status.

6.6.4.2 Personal factors

The principal and original element introduced by this study was to explore the contribution of modifiable personal factors in relation to hand function. These factors included self-efficacy, coping, resilience, disease perception, attitudes towards medications and health literacy. Self-efficacy was shown to have the strongest relationship with hand functional impairment, that is to say, the participants who reported low self-efficacy were more likely to have greater hand functional impairment. Previous reports have shown that hand functional impairment has a considerable impact on general functional disability (BİRcan et al. 2014; Salaffi et al. 2019) and self-efficacy measured with the ASES was consistently identified as a factor strongly associated with functional disability in people with RA in a recent systematic review and meta-analysis study (Jackson et al. 2019). Therefore, interventions targeting self-efficacy in people with RA may have beneficial effects on hand function among people with RA. However, there is a lack of literature addressing this issue in individuals with RA.

Participants who reported more involvement in maladaptive coping strategies had significantly higher hand functional impairment ($r=.45$, $p<.001$). However, involvement in adaptive coping strategies was not related to hand function in this study sample. Similar results were reported by van Lankveld et al. (1999). Beside the small sample size of this study, the structural validity of the BCI (the scale used to evaluate coping) may have influenced this study's result. This is because the structural validity of the BCI differs across cultures and populations (Su et al. 2015; Baumstarck et al. 2017). However, the structural validity of the Arabic BCI in the RA population has not yet been established; thus, verifying the structural validity of the Arabic BCI is warranted in people with RA. Overall, the result of this study showed that consideration of coping strategies as a component of hand therapy and rehabilitation in RA may be important in achieving the desired outcomes.

Resilience is another important personal variable that has shown to make a significant contribution to hand function in this study sample. It has been previously confirmed that resilience involves maintaining a favourable functioning level following adversity, and that it is a dynamic process rather than a personal trait (Johnston et al. 2015). Studies of resilience in RA are scarce; however, recent evidence has suggested that resilience may benefit RA patients, leading to lower fatigue (Xu et al. 2017) and disease activity and higher mental health-related quality of life (Liu et al. 2017b). Notwithstanding this issue, Liu et al. (2017b) documented that resilience was not associated with physical health-related quality of life in individuals with RA. On reflection of the present study results, it could be that resilience attenuates the impact of RA disease on hand function by positively moderating the relationship between hand function and psychological distress, disease activity and fatigue. This explanation would be consistent with the previous literature, but it is not supported by this study results, since resilience was directly associated with hand function. An alternative and straightforward explanation for the link between resilience and hand function is that poor resilience results in greater hand disability, psychological distress, and fatigue perception. A recent qualitative study concerning resilience in RA indicated that resilience is shaped through a dynamic process, which can be improved through behavioural interventions and social support (Shaw et al. 2019). Considering this study results, as well as recent evidence, it can be concluded that resilience is a valuable resource and interventions targeting it may offer a promising approach to improved functioning and, ultimately, hand function in patients with RA.

This study also showed that there was a strong relationship between disease perceptions and hand functional impairment. One possible explanation for the strong relationship between disease perception and hand functional impairment is that disease perceptions are a true reflection of the status of the disease. Accordingly, it would be expected that patients with more disease activity and pain would report a greater negative illness perception. However, several RA studies have indicated that the link between disease perception and functional disability is not explained by disease status (Carlisle et al. 2005; Graves et al. 2009). Another possible explanation for the relationship between disease perceptions and hand functional disability, is that positive disease perception triggers and influences the selection of adaptive coping strategies, which in turn influence hand function. This explanation would be consistent with the illness perceptions model (Leventhal et al. 1997), but is not supported by the findings of this study, which showed a negligible relationship between adaptive coping and hand functional disability. Similarly, Carlisle et al. (2005) reported that the associations between adaptive coping strategies and illness representation were negligible and not statistically significant in the RA population. It seems that illness perception may be associated with hand functional disability, independent of coping strategies used. However, this conclusion should be treated cautiously, as coping reactions could influence disease perception, which may then feedback to influence the choice of coping strategy (Hale et al. 2007). Alternative possible explanations for the association between disease perceptions and hand functional disability is that negative disease perceptions directly result in greater hand functional impairment or lead to medication non-adherence, which in turn influence hand function. However, the relationship between adherence and disease perception was not evaluated in the present study, therefore the explanation stated above needs to be treated with caution. Although this study results showed that disease perceptions could be of importance as a potential modifiable factor that could serve as a treatment target in patients with RA, longitudinal studies of illness perception in relation to hand functional status would provide a clearer insight into whether disease perceptions are a valuable treatment target to consider.

Although most people in the present study had strong beliefs about the necessity of their medication (87%), levels of concern were high (66%). These results are in agreement with a recent systematic review demonstrating that most RA patients believed that their medications were necessary, but expressed high levels of concerns about the side effects of the medications they were taking (Palominos et al. 2018). In the present study, patients' belief in the necessity of their medication outweighed their concern, suggesting that participants were adherent to their pharmacological treatment. This is because the positive necessity-concerns differential was reported to be associated with better adherence in RA population (Neame and Hammond 2005). In comparison with previous RA studies, the average BMQ specific necessity (mean=19.58) and concern score (mean=17.24) were similar to those reported by Neame and Hammond (2005) (necessity: mean=19.92, concern: mean=15.84). Previous studies have predominantly focused on medication beliefs in relation to adherence, which is understandable since medication adherence has been shown to have a strong association with favourable outcomes in RA (Nakagawa et al. 2018). In scoping the rheumatology literature, only one study was found to explore the association between beliefs about medication and functional disability (Neame and Hammond 2005). This study reported positive significant associations between the HAQ and the BMQ specific necessity (r=.36, p<001) and concern scores (r=.22, p<001). In the current study, only the concern score was significantly associated with hand functional disability (r=.36, p=.003). These results, taken together with the significant association found between the concern subscale of the IPQ and hand functional impairment, imply the importance of RA patients' concern beliefs in relation to hand function.

Although the single-item health literacy screening (SILS) used in the present study can be considered a self-reported confidence measure for health literacy, the evidence has shown that it is effective in detecting people with limited and marginal health literacy (Wallace et al. 2006). Therefore, the result of the SILS can be considered as an accurate measure of health literacy rather than a confidence measure of health literacy. Accordingly, this study showed that a considerably substantial number (34%) of Palestinian people with RA had inadequate health literacy. This rate is greatly higher than those reported in samples of patients of RA in the UK (8%) (Grose-Hodge et al. 2018), and Canada (18.6%) (Gong et al. 2015) measured using SILS. Despite the fact that health literacy is poorly studied in Arab countries (Fadda et al. 2018), the estimate of 34% of this study sample having inadequate health literacy is consistent with other population estimates recently published from Arabic countries. For instance, a high prevalence of inadequate health literacy was documented among the Iraqi (30.3%) (Al-Jumaili et al. 2015) and Saudi populations (46%) (Almubark et al. 2019) evaluated with SILS. Western studies among RA patients have identified different risk factors in relation to low health literacy (Buchbinder et al. 2006; Hirsh et al. 2010; Gong et al. 2015). However, in the present study, a high prevalence of inadequate health literacy may be related to fact that this sample consisted of older participants who had both low levels of education and income. These factors have been reported to be associated with low health literacy among the Arabic population (Almubark et al. 2019).

The analysis of this study also showed that participants with inadequate health literacy significantly reported high hand functional impairment compared to those with adequate health literacy. Interestingly, their educational level was not found to be associated with hand functional impairment. These finding are consistent with those in the RA literature, demonstrating that the association between hand function and educational level is not significant (Belghali et al. 2017) and health literacy is strongly associated with functional status (Hirsh et al. 2010; Caplan et al. 2014; Kuipers et al. 2017). Taken together, these findings suggest that depending on education attainment as a proxy for health literacy should be avoided. Furthermore, when addressing low health literacy in Palestinian people with RA, the next step should involve empowering them by adopting an approach that supports the building of health literacy. This could be initially addressed by providing accessible, clear, and straightforward educational materials and resources for Palestinian individuals with RA.

6.6.4.3 Environmental factors

The results reported in this study showed that RA patients who reported receiving more social support from their family have a better functional status in their hand(s) than those who do not. However, the strength of association between family support and hand functional impairment was very low and did not reach a statistical significance (r=−.05, p=.68). Various reasons could explain why family support was found not to significantly contribute to hand functional impairment. Firstly, the sample size of this study was relatively small and could be underpowered to detect statistically significant associations. Secondly, it was suggested that social support could affect health positively by buffering the effects of potential stressors, known as the “stress-buffering hypothesis” (Cohen and Wills 1985). In the context of this study, it could be assumed that family support may buffer the relationship between pain (stressor) and functional impairment in the hand(s) (outcome). However, there has been a long-lasting debate, which remains unsolved, as to whether social support has a direct effect on health outcomes or whether it operates as a buffer against the unfavourable health outcome (Uchino et al. 2012). Recent and prior empirical evidence has shown that the stress-buffering hypothesis is not supported among the RA population (Doeglas et al. 2004; Brandstetter et al. 2017). On the other hand, the existing RA studies yield inconsistent results regarding the cross-sectional association between social support and functional status, and these studies have also collectively reported that the longitudinal association has diminished (Demange et al. 2004; Strating et al. 2007). Therefore, it is possible that patients with a long disease duration, as the case in the present study, have coped with their illness for so long that the family support might be of little importance. Finally, it should be noted that the participants in the current study reported high levels of family support. Therefore, it may be questioned whether this result reflected the actual high levels of perceived family support or a tendency for the instrument (MSPSS family subscale) to elicit socially desirable responses. A previous psychometric study showed that the MSPSS did not elicit socially desirable responses (Dahlem et al. 1991). Therefore, the high scores obtained in the present study may reflect the actual level of family support. This is because Palestine is a family-oriented society and failing to provide care for a family member is considered culturally shameful and unacceptable.

Contradictory to the expectation, people who reported receiving physiotherapy treatment had worse hand functional impairment compared to those who did not. This is despite the fact that many systematic reviews have shown the beneficial effect of rehabilitation interventions in reducing pain and improving function among patients with RA (Al-Qubaeissy et al. 2013; Hammond and Prior 2016; Park and Chang 2016; Siegel et al. 2017; Williams et al. 2018). However, given the sample size limitation of the present study, and the fact the data about the physiotherapy treatment received by the participants were not recorded, it precludes the possibility of judging if evidence-based physiotherapy was provided to the patients or not. Furthermore, given that Palestinian people with RA are not formally referred to rehabilitation services, it could be that those who reported receiving physiotherapy had self-referred, as they had not benefited from pharmacological treatment. This would provide another possible explanation for the unexpected results regarding physiotherapy treatment.

6.6.5 Practicalities and usefulness of using the QuickDASH

For clinicians in routine clinical care, as well as in research, it is important to have easily administrated outcome measures which are quick to complete. Importantly, the outcome measures should be valid, reliable and reflect the problems that the patient is experiencing. In low-income countries such as Palestine, the resources for the healthcare sector are often particularly limited. In these settings, it is crucial to use outcomes which are feasible and free to use. The QuickDASH questionnaire fulfils these criteria, making it suitable for the Palestinian context. In the present study, the QuickDASH was well-liked by the patients, based on the feedback from the PPI contributors and study participants, as they stated that they found it easy to understand, simple to complete and not too time-consuming.

The results of the present study showed that the QuickDASH discriminated well between the most able and least able participants. In addition, the QuickDASH strongly correlated with the hand impairment measures, as well as the psychosocial variables. This confirms that the QuickDASH is a valid and viable tool which can evaluate hand functional impairment and mirror psychosocial aspects of illness behaviour. Previous studies have revealed that the QuickDASH demonstrated a strong correlation with disease activity (DAS-28), was sensitive to change in RA disease activity, and was strongly associated with functional disability (HAQ) and hand grip strength (Ochi et al. 2015; Carroll 2016; Palamar et al. 2017; Salaffi et al. 2019). Although concerns have previously been raised regarding the viability of the summated score of the QuickDASH (Fayad et al. 2009; Gabel and Cuesta 2016), a recent study among RA patients employing a modern test theory perspective (Rash analysis) demonstrated the unidimensionality of the scale (Prodinger et al. 2019). Furthermore, secondary data analysis of the present study was carried out (data are not presented) to explore the factor structure of the QuickDASH using exploratory factor analysis (EFA). The factor analysis indicated that the QuickDASH comprised a one-factor structure, with all of the items loading heavily on this factor. These results supported the construct validity of the QuickDASH and indicate the suitability for a single summated score.

6.7 Clinical implications and future research directions

The results of this study have the following implications for clinicians working in the management of Palestinian people with RA who have hand function problems:

- At the hand impairment level, high hand pain intensity, particularly hand pain during activity, as well as weak grip strength, could be the main determinants of hand functional impairment in individuals with RA. Although hand ROM and functional mobility measures were associated with hand functional impairment, these measures may reflect disease progression rather than hand functional status in people with RA.
- Factors associated with hand functional impairment in people with RA are complex and varied, encompassing the dimensions of health condition, body functions and structures, and contextual factors of the ICF.
- Clinicians' evaluations of people with RA should take into consideration all of the factors discussed in this study, however, a sole focus on hand-related activity limitations and participation restrictions should be avoided.
- Multidimensional and multidisciplinary interventions may be valuable in assisting in the management of hand function problems for people with RA.
- In RA, the QuickDASH is a valid and viable PROM to evaluate hand functional impairment and can reflect psychosocial aspects of illness behaviour.

As an extension of the current study, there are some recommendations for future research:

- Longitudinal studies on modifiable factors in relation to (change in) hand functional status in patients with RA are warranted. This will provide a better understanding of which factors could be relevant when targeting treatment.
- Future research studies may also consider investigating the role of psychosocial factors in explaining gender differences regarding self-reported hand functional impairment.

- Although the results from this study suggest that treatment programmes for hand function problems in RA should be multidisciplinary and multidimensional, future studies should focus on the optimal content and mix of rehabilitation intervention components.

6.8 Strengths and potential limitations of this study

This is the first study to assess and report the impact of RA on hand function among Palestinian patients and to provide an overview of the factors associated with hand functional impairment for this population. An important contribution of the present study is the use of a specific theoretical framework (i.e. ICF) to understand hand functional impairment in RA. This conceptual framework places the various factors that could influence hand function in a focussed context, rather than simply examining whether any of the numerous variables available were associated with hand functional impairment. Also, the novelty of this study lies in the fact it explored the contribution of personal and environmental factors in relation to hand function. Therefore, the results of this study provide a more specific and comprehensive understanding of the nature of the variables that could influence hand function in RA, and thus can guide decision making in management of rheumatic hand function problems. Furthermore, the results of the study can serve as a foundation for future research in developing a conceptual model of functional disability in the hands of those with RA, which in turn will facilitate approaching hand rehabilitation in clinical practice from a multidimensional perspective.

This study has some limitations that need to be acknowledged. For this study, 121 Palestinian people with RA from three rheumatology outpatient units were invited to take part and 60% of them agreed to participate. The data about non-respondents were not available, and this might have led to an over-estimation of the prevalence of clinical characteristics (e.g. comorbidities), and hand related variables (e.g. symptoms and impairment) in this study population. However, recruiting participants from three major rheumatology services in the northern region of Palestine had the potential to provide a representative sample. In addition, this study sample was considered by the Palestinian medical staff to be a true reflection of real-life patients receiving medical care in rheumatology units.

It is worth mentioning that the cross-sectional design of this present study prevents an inference of cause and effect relationships, although significant associations between variables were found. Therefore, future longitudinal studies are recommended to be able to draw firmer conclusions on cause and effect relations. Another limitation of this study is that the sample size was small. Small sample sizes increase the risk of reporting type II errors and not detecting small effects. In addition, the majority of the participants were not working and were categorised with high disease activity. This indicates that some groups of the Palestinian RA population may have been underrepresented in the sample, and the generalisability of the findings beyond the sample is limited.

The analysis aimed to consider the relative contribution of multiple factors to hand functional impairment in a relatively small sample. These different types of factors are unlikely to operate independently, but rather are likely to interact with other characteristics in a given patient. For instance, a patient may experience less pain or fatigue if he/she has a favourable resilience or self-efficacy profile, leading them to report less hand functional impairment. In contrast, another patient with high psychological distress may magnify pain or fatigue, thus exaggerating hand functional impairment. The analyses presented in this study did not consider any of these complex interactions in relation to hand functional impairment in RA. In addition, the analysis was not adjusted for the potentially confounding effects of variables such as medical therapies or delay in diagnosis. This may have had distorted the associations observed in the present study. Ideally, future studies would account for these confounding variables, either through the study design (e.g. randomisation), or by using statistical methods (e.g. regression analysis).

Although this study included patients with early RA, the majority had longstanding RA disease; thus, the generalisation of this study’s results can only be tentative. Furthermore, the results may not be generalisable to males, since their number was small, although their relative proportion (21%) was very close to the prevalence of RA in men in the population (women to men ratio=3:1) (Poole 2019).

Testing and measuring hand structural impairment (i.e. ROM) and functional capacity (i.e. grip strength) are susceptible to measurement error, assessor bias and performance bias. In the present study, the intrarater reliability for the objective assessments of hand impairments was not tested, due to the difficult political situation in Palestine, making repeat hospital visits impossible. However, attempts were made to minimise measurement bias and enhance reliability by ensuring that all of the assessments were carried out only by the author using a calibrated instrument (i.e. Jamar dynamometer) and following standardised test protocols. Although the time of the day for the measurement was not standardised, all of the assessments were carried out after 9:30 am to minimise the impact of any possible morning stiffness.

Finally, another limitation of the present study includes the lack of a control group of people without RA. Therefore, age- and sex-specific reference values for grip strength (Bohannon et al. 2006) and the QuickDASH (Aasheim and Finsen 2014) were obtained from the literature and used for comparison. However, grip strength normative values were standardised for age and sex, but not for other factors such as anthropometric measurements (e.g. hand size), work status/occupation, body mass index or comorbidities. It is not possible to exclude that residual confounding by these factors may have affected the results of this study. Despite this limitation, normative grip strength values were consolidated from 12 resources, which provide a better standard for comparison than using one source for normative data. Similarly, the QuickDASH scores were compared with age- and sex-specific normative values from Norway (Aasheim and Finsen 2014). Given that the QuickDASH scores could be influenced by socioeconomic factors including education and income (Finsen 2015) and dominant hand involvement (Kachooei et al. 2015), it cannot be precluded that these factors may have influenced the results of the present study.

6.9 Chapter summary

This study showed that Palestinian people with RA have severe RA disease and a low remission rate, coupled with a high prevalence of comorbidities and diagnosis delay. The findings demonstrated that Palestinian people with RA have an overall lower hand performance across all functionality dimensions, which comprise measurement of both objective and patient-reported outcomes. Regarding the impairment level, the patients were found to have reduced grip strength, and limited hand mobility and hand pain remained a problem. Furthermore, hand functional impairment (i.e. hand-related activity limitation and participation restriction) were detected in 85% of the patients at various levels. The bivariate analyses revealed that hand related-activity limitation and participation restriction were associated with different aspects of functional dimensions, indicating that hand functional impairment in RA is complex. Overall, RA has considerable functional consequences in terms of pain, mobility limitation, strength reduction, and generates problems in many areas of activity and participation. The analyses also showed that hand functional impairment is associated with different functionality dimensions. Consequently, rehabilitation interventions should be multidisciplinary and multifaceted, and aim to alleviate hand impairment, improve occupational performance and enhance modifiable personal and environmental factors.

Chapter 7 General discussion and conclusions

7.1 Chapter overview

This thesis was developed in response to the lack of information regarding hand function among Palestinian individuals with RA. The overall aim of this thesis, was to explore hand function and the factors contributing to hand function in ADL among Palestinian individuals with RA. To achieve this, a mixed methods approach was employed to sequentially gather data from different sources, with the intention of both strengthening the context of the research and widening its application. Initially, a qualitative method was adopted to explore the concepts of hand functioning important for Palestinian people with RA and guide and inform the development of the subsequent quantitative study. A further quantitative cross-sectional research grounded in the views of participants in the focus group study allowed the examination of hand function and its related variables among Palestinian people with RA.

This chapter summarises and draws together the main findings from the investigative phases conducted within this thesis. The advancement in knowledge and unique contribution towards clinical practice made by this research are discussed, along with recommendations for future research. A discussion of the strengths and limitations of the research as a whole is also presented. A personal reflection of the researcher's experience conducting this work is discussed. Finally, a summary of the thesis is presented.

7.2 Summary and integration

This PhD thesis used a combination of qualitative and quantitative approaches, and the integration of these results is presented below. Integrating data sources helps to improve the validity and reliability of the research, provide comprehensive information about the research phenomena, and minimise the inadequacies of the qualitative and quantitative data collection methods (Fetters et al. 2013; Creswell and Plano Clark 2018).

7.2.1 Hand function in Palestinian people with rheumatoid arthritis

This thesis was the first to use a mixed exploratory approach to investigate hand function in Palestinian People with RA. First, a focus group study (Chapter 5) was conducted to explore the perspectives of Palestinian people with RA regarding important hand abilities and impairments. In addition, this study explored and identified hand-related activity limitations and participation restrictions that cause Palestinian people to experience difficulties with ADL due to RA affecting their hands. The findings of this study showed that impairments were considered by the Palestinian people with RA in this study as important limitations to hand functioning. The participants reported that hand impairments, including pain that impacts on strength and mobility, are major problems in relation to hand functioning. Based on the results of the quantitative study (Chapter 6), the majority of the Palestinian people with RA in this study had reduced grip strength and limited hand mobility, and hand pain remains a problem.

With regard to hand-related activity limitations and participation restrictions, the qualitative focus group study revealed that the participants experienced a wide range of hand-related activity and participation problems. Based on the quantitative analysis, it is evident that RA has considerable consequences on the ability for those with RA to perform and participate in a wide range of activities. Hand functional impairment, at various levels, was present in 85% of the participants. Furthermore, the specific hand-related activities that form part of daily living that were found to be affected by RA mainly include heavy duty activities, which require some degree of force. These findings confirm the accounts of the participants in the qualitative investigation, which revealed that the participants experienced substantial difficulty with activities that require muscle strength. The findings from this study regarding the activities frequently reported as difficult to perform by Palestinians are largely consistent with previous reports (Adams et al. 2005b). Overall, the qualitative focus group study revealed a broader range of hand-related activity limitations and participation restrictions that Palestinian people with RA experience difficulty with than was revealed by the quantitative investigation. As a result, the cross-sectional study did not provide the same level of detail and full range of hand-related activity and participation problems, therefore the interpretation of these results in comparison with the qualitative findings needs to be treated with caution.

7.2.2 Factors associated with hand functional disability

This research also focused on the factors associated with hand functional disability among Palestinian people with RA. The qualitative study revealed a wide range of body function and structure, as well as personal and environmental factors influencing hand function in ADL. At the body function and structure level, problems with physical symptoms, pain, mobility, strength, fatigue, psychological distress, as well as appearance, were described by the participants in the qualitative study as influencing hand function (section 5.7.3). From the participants' accounts, and based on the results of the quantitative study, it was evident that these factors were associated with hand functional disability among Palestinian individuals with RA (section 6.5.8.1). In particular, the findings of the cross-sectional study regarding the association between hand functional disability and hand pain and strength are in line with the systematic review study results (Chapter 3). This research was the first to explore the association between psychological distress and hand functional disability, which was reported in the cross-sectional study to be high and statistically significant (r=.72, p<.001) (section 6.5.8.1). Although the evidence regarding the association of perceived fatigue (vitality) and hand functional disability is conflicting (Chapter 3), the quantitative analysis showed a strong and statistically significant association (r=−.73, p<.001) between fatigue perception and hand functional disability (section 6.5.8.1). Overall, the results reported in the cross-sectional study regarding the association between hand functional disability and body function and structure variables reinforced the accounts of the participants in the qualitative investigation for the huge impact of these variables on hand function.

Unlike prior studies, which have paid little attention to exploring the influence of personal and environmental factors on hand function (as detailed in Chapter 3), this research has identified potentially modifiable personal and environmental factors influencing hand function among Palestinian people with RA (Chapter 5). Through bivariate analyses, a number of these variables that can influence hand function were explored (Chapter 6). Although the analysis showed significant associations between hand functional disability and these variables, care should be exercised when interpreting the results, as findings from a cross-sectional study do not prove causal relationships.

The findings of the focus group study showed that the influence of personal factors in relation to hand functional ability is complex and multidimensional and can impact hand functioning positively or negatively. This has largely been corroborated in the subsequent quantitative cross-sectional study which showed that hand functional ability was statistically significantly associated with maladaptive coping, resilience, self-efficacy, illness perception, personal attitudes towards medications (concern) and health literacy level (section 6.5.8.3). However, personal factors such as adaptive coping and medication necessity showed negligible and non-statistically significant associations with hand functional disability (section 6.5.8.3). This may be related to the small sample size of the cross-sectional study, and not merely because of differences between the qualitative and quantitative findings.

From the participants' accounts in the qualitative focus group study, social, physical, and healthcare system-related factors were among the environmental factors influencing hand function. Some of these factors include diagnosis difficulties, negative health professional skills, lack of knowledge provision, family physical and emotional support, and self-invented management strategies. Based on the results of the quantitative analysis, environmental factors including family support, living arrangements, monthly income, and time required for diagnosis, have the potential to influence hand function among Palestinian people with RA (section 6.5.8.2). Although these results substantiate the accounts of the participants in the qualitative investigation, the strength of the associations between these variables and hand functional impairment were very weak and did not reach statistical significance. Although this research examined as many environmental factors as possible, given the multiple environmental factors influencing hand function, this research might not have been positioned to capture all of the key factors involved. Therefore, future investigations might help to identify additional environmental factors influencing hand function in RA and to inform more comprehensive interventions.

7.3 Contribution of the thesis to the advancement of knowledge

This thesis provides evidence, for the first time, on hand function and the factors influencing hand functional disability among Palestinian individuals with RA. This thesis involved a comprehensive examination of hand functioning and influencing factors, and the findings will add to the growing literature concerning hand function in RA. The advances in knowledge made by the research studies forming this thesis have been discussed within each of the corresponding chapters. The key advances in knowledge made through this programme of research are summarised below:

- Identification of a lack of consistency, due to the variation in measures used, in reporting hand impairments in RA.
- Confirming that power grip strength, disease activity and pain are the main modifiable factors that may have a considerable effect on hand function in people with RA.
- Summarising that current evidence is insufficient to advise on which environmental and personal factors might influence hand function in RA.
- Distinguishing 32 concepts of hand functioning considered to be important for Palestinian people with RA including body function and structure (7 concepts), activity and participation (16 concepts), environmental factors (4 concepts) and personal factors (5 concepts).
- Indicating that Palestinian people with RA have poorer control of disease, as well as a high prevalence of comorbidities and diagnosis delay.
- Demonstrating that Palestinian people with RA have, overall, a lower level of hand performance across all functionality dimensions, which comprise the measurement of both objective and patient-reported outcomes.
- Establishing that hand functional impairment (i.e. hand-related activity limitation and participation restriction) was detectable in 85% of the sample of Palestinian people with RA at various levels.
- Determining that hand related-activity limitations and participation restrictions are associated with different aspects of functional dimensions among Palestinian people with RA.

7.4 Clinical implications and recommendations

Clinical implications and recommendations relevant to the individual studies included in this thesis have been addressed within each of the respective chapters. The following sections outline the important clinical implications and recommendations from this overall body of work.

7.4.1 Assessment of hand function

This work has highlighted that hand functional problems are a prevalent and important part of the patients' experience of RA, and have a significant impact on the daily life of Palestinian individuals with RA. This reinforces the need for Palestinian health professionals to be aware of the importance of assessing hand function during routine clinical practice. The clinical relevance of assessing hand function in RA has been emphasised in a recently published longitudinal study (Bremander et al. 2019).

This programme of research has provided a descriptive experience of Palestinian people with RA, in terms of what they identify as important concepts of hand functioning. The findings of the qualitative phase indicated that hand-related activities were performed within the structures of social and cultural practice. Notably, concepts identified in the domain of "activity and participation" on the ICF were largely underpinned by culturally related activities. In addition, the results showed that activities are interwoven and influenced by personal and environmental factors when completing tasks during everyday life. These findings suggest that in order to establish a client centred and tailored treatment programme targeting hand function for Palestinian individuals with RA, it is advisable to use open-ended interviews.

While an open-ended interview approach is recommended to assess hand function among Palestinian individuals with RA, standardised hand functional (dis)ability measure(s) are necessary to establish evidence-based practice. Based on the findings from the focus group study, it was evident from the patients' accounts that there was a strong conviction that the hand and upper limb should be treated as one functional unit. This is coupled with the fact that the majority (>90%) of hand-related activities identified in the qualitative investigation required the use of both hands. These findings suggest that for Palestinian participants living with hand RA, hand function outcome measures involving multiple joints of the upper limb, such as the DASH (Hudak et al. 1996) or the QuickDASH (Beaton et al. 2005), offer versatility for research and clinical practice in Palestine. Accordingly, the QuickDASH has been utilised in the cross-sectional study (Chapter 6). The QuickDASH was well liked by the patients, discriminated well between the most able and least able participants, and was strongly correlated with hand impairment measures, as well as psychosocial variables. These findings provide evidence for the QuickDASH as a valid and viable tool that can evaluate hand functional impairment and mirror psychosocial aspects of illness behaviour among the Palestinian RA population.

The findings of the focus group study (Chapter 5) also suggest that disease symptoms (particularly pain), and hand impairments (mainly hand strength), were related to hand function and had an important association with difficulties in performing hand-related activities. The results of the quantitative phase showed that these hand impairment outcomes could be the main determinants of hand functional impairment in Palestinian individuals with RA. This is in line with the systematic review study results. Therefore, the assessment of these outcomes is recommended in routine clinical assessments of hand function among Palestine people with RA. The participants, mainly those with a long disease duration in the focus group study, identified hand mobility as an important component of hand function. However, hand mobility measures showed negligible to weak associations with hand functional disability in the cross-sectional study. This indicates that hand mobility measures may reflect disease progression rather than hand functional status among Palestinian people with RA.

7.4.2 Management of hand problems

The findings of this thesis also have clinical relevance for the rehabilitation management of hand function problems among Palestinian people with RA. The thesis results are in line with previous research findings, specifically that hand functional disability is associated with different aspects of functional dimensions (Chung et al. 2011; Andrade et al. 2016). This suggests that rehabilitation interventions should be multidisciplinary and multifaceted, and aim to alleviate hand impairment, improve occupational performance and enhance modifiable personal and environmental factors. Although the findings do not provide evidence to recommend the optimal content of rehabilitation interventions, they provide the basis and possible structure required for approaching therapeutic intervention research that targets hand function. In addition, the factors identified as influencing hand function in this thesis may form a helpful reference for Palestinian clinicians to consider when planning interventions for Palestinian people living with hand RA.

From the findings presented in this thesis, it is evident that family members can influence the hand function of Palestinian people with RA. It would therefore be beneficial for clinicians to involve family members of Palestinian people with RA in the process of rehabilitation. Gender difference emerged regarding hand-related activity limitations, participation restrictions, and activities causing difficulties, confirming the importance of client-centred rehabilitation interventions in clinical practice. Lastly, the finding that activities were used to distract from hand pain indicates that management strategies for hand pain relief can be used based on the individual's meaningful and important activities.

7.4.3 Other advice

Multiple sources of data allowed the researcher to understand the needs of Palestinian people with RA and to make general suggestions. Participants in both the focus group and cross-sectional studies reported delays in their RA diagnosis and treatment initiation, so efforts should be directed towards reducing this problem. Such efforts would include raising awareness of what RA is among the wider population, educating general practitioners regarding early symptoms of RA and improving the referral system in Palestine.

As presented in the cross-sectional study, Palestinians with RA experience poor control of disease coupled with a high prevalence of comorbidities. These findings are combined with the fact there is a lack of RA management pathways or guidelines in Palestine, and patients with RA are not referred to rehabilitation services. These observations highlight the need to develop RA management guidelines tailored to the Palestinian patient population and the healthcare system. The introduction of treatment recommendations that are specific to people with RA in the Palestinian practice setting should therefore help to influence practice on effective management and minimise unnecessary care (Mian et al. 2019). This would also provide a formal process for screening and treating patients at risk of chronic diseases. The findings from this work are beginning to have a wider influence on Palestinian clinical practice; discussions between the author and the PSR are underway on the development of treatment recommendations for Palestinian people with RA.

This research is the first to report the sociodemographic, clinical, and pharmacological variables of Palestinian people with RA (section 6.5.3). Since there are no population databases or registries in Palestine, the findings provide important information regarding the understanding of RA in the region. However, the findings of the present thesis are based on cross-sectional data from a small convenience sample. Considering this, it is recommended that a national registry for people with RA in Palestine be established. The registration of Palestinian RA would provide a comprehensive understanding of patient characteristics, treatment use, disease prevalence, and health-related outcomes including quality of life and clinical effectiveness (Carpenter et al. 2013). Importantly, this would raise the visibility of the condition, allowing changes over time to be monitored and to timely allocate required resources, as this would ultimately improve the quality of care.

7.5 Future research

There are several important areas identified in the included studies of this thesis that deserve further exploration. The main areas suggested for further research are discussed here. Firstly, there is a lack of consistency in reporting hand function and impairments, due to the variety in outcome measures used, which makes comparison between studies difficult and limits the translation of research findings into clinical practice. Therefore, developing and adhering to protocols during hand function and impairment assessments in the RA population is now warranted. This could be achieved by building a consensus among experts in the field of rheumatology using a Delphi method.

The findings from both the qualitative (Chapter 5) and quantitative (Chapter 6) studies identified modifiable factors influencing hand function. Additional longitudinal research on these factors in relation to change in hand function status, would provide a better understanding of the factors that could be relevant when considering treatment. This, in turn, may then facilitate appropriate descriptions of the optimal content and mix of rehabilitation intervention components.

Finally, social networks were found to be important in supporting Palestinian people with RA to manage their hand problems and gather information about their disease. It may be reasonable to consider how to provide self-management support for patients with RA outside clinical settings based on a social support approach in future research. The other issue highlighted by the patients is the need to obtain timely information to adopt self-management behaviours. This may require the development of clear and simple educational materials for patients, which should be developed in collaboration with patient advisors and be tested for accessibility with different patient groups before being utilised in a clinical setting.

7.6 Strengths and limitations

The specific strengths and limitations of the individual studies included in this thesis were discussed within each chapter. In the following sections, a summary of the key strengths and limitations are discussed.

7.6.1 Strengths

One of the strengths of this programme of research is that it employed a sequential, exploratory mixed methods design to provide a comprehensive understanding of hand functioning and the factors contributing to hand function in ADL among Palestinian people with RA. The main strength of the qualitative phase was the depth of information obtained from analysing the experience of patients regarding important concepts of hand functioning, which led to the development of the quantitative follow-up phase features. The quantitative phase helped to assess the extent of hand functional problems and to identify the factors associated with hand functional disability. Integrating qualitative and quantitative data improved the validity, credibility, and applicability of the research findings. Furthermore, integrating the data provides a broader insight and perspective that are beyond the scope of any single method of data collection methods (Fetters et al. 2013; Creswell and Plano Clark 2018).

The sequential, exploratory design method led to the uncovering of concepts and information that would not have otherwise been discovered, such as the importance of personal and environmental factors. This design also guided the selection of the hand function outcome measures, as well as the variables examined for the association with hand functional disability, hence reducing the uncertainty surrounding the selection of hand function outcome measures and variables for quantitative research.

Previous examinations of the factors associated with hand functional disability have typically been limited to body function and structure factors, and the relationships between other variables, particularly personal and environmental, had not been fully explored (Chapter 3). This thesis has expanded the knowledge in relation to personal and environmental factors influencing hand functional disability in RA, by identifying these factors through the qualitative work and subsequent quantitative analyses. Apart from identifying previously unreported personal and environmental factors such as “resilience” (personal factor) and “family support” (environmental factor), this thesis also re-evaluated previously identified body function and structure factors associated with hand functional disability.

Peer-reviewed protocols and analysis plans were used as the foundation for all the studies included in this thesis, which enabled the research to benefit from different research perspectives and enhanced transparency. In addition, the analysis of the qualitative data from the focus group study was completed entirely by the researcher and independently verified by a Palestinian Arabic speaking PhD student (JD), who was involved in data collection as the note taker. Furthermore, several debriefing meetings with the supervisory team were conducted to refine the concepts that emerged from the qualitative analysis. This allowed the researcher to lead all of the aspects of the research and reduced the risk of bias or errors being introduced, which may have occurred if all of the analysis had been conducted by only one individual.

The involvement of a patient advisory group throughout this programme of research is another important strength of the present thesis. This informed the design and data collection of the included studies within this thesis and ensured that the research tools and procedures were culturally relevant and meaningful to the Palestinian context.

Finally, another strength of the study is that three articles within this research have already been published in relevant international peer-reviewed journals. In addition, parts of this thesis have been presented at national conferences in the UK, which enabled feedback from interested researchers and clinicians.

7.6.2 Limitations

The studies forming this thesis have several limitations. The limitations related to each study were explained in the preceding chapters, however, the key limitations of the research are discussed again in this section.

The samples for the studies in this thesis had a great representation of female participants. Twelve of the 20 patient focus group participants (60%) and 79% of the cross-sectional participants were females, which could affect the generalisability of findings to males. However, the relative proportion of males was very close to the prevalence of RA in men in the population (women to men ratio=3:1) (Poole 2019).

The research participants were recruited using purposive and convenience sampling methods. As a result, some groups of the Palestinian RA population may have been under- or over-represented in the samples, and the generalisability of the findings beyond the samples is limited. The focus group study was not designed a priori to achieve saturation, however, the number of new concepts developed from each successive focus group reduced (from 22 to 4 to 3 to 2 to 1). Therefore, the possibility that further extra information would be revealed from an additional focus group session is low. Furthermore, the sample size of the cross-sectional study was relatively small and may have been underpowered to detect statistically significant associations. However, the cross-sectional study was larger than many previous studies that have addressed hand function in RA (Chapter 3), and had the strength that the data was collected across multiple clinical settings. Most of the data in the cross-sectional study were collected using self-report methods and the reliance on these data is a limitation. This is because some participants might have provided responses that may not reflect their actual status or genuine attitudes. To minimise the reporting bias, it was explained to the participants that there were no right or wrong answers. Furthermore, the researcher was present to answer any questions regarding the measures, but was careful to answer objectively, so as not to influence the participant's responses.

Finally, this research was undertaken in a developing country setting and may not be transferable to other settings, as differences in healthcare systems, access to medication, the economy and culture could all affect the transferability of findings. Nevertheless, the research findings may have relevance to other countries with similar healthcare systems and sociocultural contexts. Future research could improve transferability by including larger and more representative samples.

7.7 Personal reflection

The adoption of a reflective stance is considered an important element to enhance confidence in qualitative research and establish the researcher's credibility by making the researcher's position transparent (Shenton 2004). Although reflecting is a necessary element of quality applied solely to the qualitative studies, the following reflections address all of the aspects of this research work. The following section (written in my own words) includes a summary of the researcher's background, steps taken to underline any preconceptions that might have influenced the data collection and/or interpretation of the qualitative component, and the challenges faced conducting research in a conflict-affected area.

I am a male physiotherapist who had more than 5 years' experience in the field of rehabilitation before entering into academia in 2011. I had voluntarily continued to work clinically for a non-government rehabilitation organisation throughout my life as an academic. I believe that maintaining a clinical role was important, as it allowed me to help many Palestinian patients who had limited access to rehabilitation services. Furthermore, I found voluntary clinical work to be a rewarding area which allowed me to focus on all aspects of patient care, and importantly, inspired the development of this doctoral research.

In recent years, I have had the opportunity to treat patients with RA. Most of whom often presented with severe hand function problems. From this clinical observation and also through collaborative discussions with Palestinian colleagues in the rehabilitation setting, the ideas within this thesis were developed and shaped into a researchable and scientific question, thanks also to continuous and valuable discussions with my PhD supervisors (JA & AMH).

Before embarking on this programme of research, I had experience of quantitative, but not qualitative research. Although I was familiar with clinical interviews in which a direct line of questioning is used, research-based interviews are different. Therefore, prior to conducting the qualitative component of this thesis, I completed general academic and practical qualitative research training at the University of Southampton. However, I was not an established qualitative researcher, and a desired output of the qualitative study was to enable me to further develop my skills in qualitative research.

The reflection on my personal background, as well as using a reflective diary to raise my self-awareness and take it into account during the qualitative study, were important while performing this work. As a rehabilitation specialist, I am aware that I am personally responsible for evaluating and treating the hand function problems of Palestinian people with RA. I therefore made a conscious effort not to let my previous knowledge, experience, and views of this to either influence the direction of the focus group discussions or interpretation of the data. This was minimised by the lack of existing evidence on this topic. I also attempted to approach each focus group session with a deliberate naiveté. Before conducting the qualitative study, I was familiar with much of the published literature surrounding functioning in RA. This facilitated the development of the discussion guide along with the input of the patient advisory and supervisory team. However, the data analysis was conducted inductively and was not restricted to pre-identified concepts.

In terms of the patients who participated in the included studies of this thesis, none of them were known to me and I did not work (either paid or voluntary) in any of the participants' healthcare settings. I was aware that my position could influence the participants' responses and carefully considered how to introduce myself to the participants. For that reason, I introduced myself as a postgraduate student rather than as a physiotherapist or clinical academic, aiming to reduce any potential barriers relating to possible perceptions around hierarchy and expertise.

Undertaking this research project in a conflict-affected geographical area has been a challenging journey. The main challenges I faced during this study were related to the Israeli checkpoints and roadblocks, which on many occasions did not allow me to reach the research venues. This encouraged me to take precautions and find workable solutions. For instance, rather than using public transportation, I sometimes organised transport to and from research venues using ambulances which belonged to the Palestinian Ministry of Health, as these were not subject to the same restrictions as public transport. This strategy was employed a few times when Israeli checkpoints restricted public transportation between the West Bank cities.

Finally, doing this research was an exciting journey, which has improved my research and communication skills. Given the importance of disseminating results and sharing knowledge in research, an important area of my personal development *during this process was that three articles were published in well-known international peer reviewed journals such as Arthritis Care & Research and Disability and Rehabilitation. I hope to continue to publish other work from this thesis and to continue to develop my skills as a researcher.*

7.8 Thesis summary

Hand function problems are common among people with RA and are relevant in both clinical and research contexts. Despite this, hand function and the factors that contribute to hand function in the performance of ADLs among Palestinian people with RA are under studied. The results from the systematic review (Chapter 3) suggested that the evidence from the existing literature was insufficient to advise on the environmental and personal factors that might influence hand function in RA. Therefore, this project was designed to provide an in-depth exploration of hand function and the factors influencing hand functional disability among Palestinian people with RA. For that reason, a combination of a qualitative (focus group study) and quantitative (cross-sectional study) approach was used. The research findings from the focus group study (Chapter 5) facilitated the researcher's discussion and recommendations on the most appropriate hand function outcome measure(s) for the Palestinian RA population. Furthermore, it allowed the important environmental and personal factors in relation to hand function to be explored and identified. This has informed the design of the subsequent cross-sectional study (Chapter 6), which aimed to examine hand function and the related variables among Palestinian people with RA.

The research findings suggested that it is suitable to use open ended interviews to gain better insight about hand functioning in Palestinian people with RA. In addition, the findings suggested that for Palestinian participants living with hand RA, hand function outcome measures involving multiple joints of the upper limb offer versatility for research and clinical practice. The findings from this research have demonstrated that Palestinian people with RA have an overall lower hand performance across all functionality dimensions, as measured by both the patient-reported and objective outcomes.

This research has identified factors influencing hand function among Palestinian individuals with RA, which included personal and environmental factors, as well as hand impairment variables. The relative importance of these factors in relation to hand function in ADL performance have been investigated. The results of this also investigation revealed that hand functional disability is associated with different aspects of functional dimensions, indicating that hand functional impairment in RA is complex.

The research findings inform the best clinical and research practice regarding hand functional assessment and management for people with RA in Palestine. However, future longitudinal research is needed to shed light on hand functional abilities over time, and to look beyond epidemiological patterns, in order to identify causal factors amenable to change.

Thesis outputs

Publications

Arab Alkabeya H, Hughes A-M and Adams J (2019) Factors associated with hand and upper arm functional disability in people with rheumatoid arthritis: A systematic review. Arthritis Care Res 71(11): 1473-1481

Arab Alkabeya H, Sankah BEA, Hughes A-M and Adams J (2019) Measurement properties of patient-reported hand function measures in rheumatoid arthritis: a systematic review protocol. Phys Ther Rev 24(3-4): 60-65

Arab Alkabeya H, Daibes J, Hughes A-M and Adams J (2020) The Arabic Arthritis Self-Efficacy Scale-8 (ASES-8): A valid and reliable measure of evaluating self-efficacy in Palestinian patients with rheumatoid arthritis. Disabil Rehabil, 1-7

Conferences

Arab Alkabeya, H, Hughes, A-M, & Adams, J Factors Associated with Hand Functional Disability in People with Rheumatoid Arthritis: A Systematic Review and Best-Evidence Synthesis. Oral Presentation. 20th International Conference on Rheumatology (ICR) 2018, London

Arab Alkabeya, H, Hughes, A-M, & Adams, J Factors Associated with Hand Functional Disability in People with Rheumatoid Arthritis: A Systematic Review. Poster Presentation. Southampton Medical and Health Research Conference 2018, Southampton

Arab Alkabeya, H, Hughes, A-M, & Adams, J A systematic review of the factors associated with hand functional disability in people with Rheumatoid Arthritis. Oral Presentation. British Association of Hand Therapists Annual conference 2018, Birmingham; doi.org/10.1177/1758998319833544

Presentations

Arab Alkabeya H Demystifying hand function in rheumatoid arthritis: uncover the influence of personal and environmental factors. Musculoskeletal State of the Art Colloquium, University of Southampton 2018

Appendices A to V

Appendix A Main terms and search strategy: RA in Palestine

1. Embase search through OvidSP

		Results	
#	Search terms	January 2017	March 2020
1	rheumatoid arthritis/ or RA.ti,ab.	205,585	229,981
2	Palestin* or Gaza or “west bank”	3476	4489
3	1 AND 2	3	4

2. CINAHL search through EbscoHos

		Results	
#	Search terms	January 2017	March 2020
S1	(MH "Arthritis, Rheumatoid") or (TI RA) or (AB RA)	20,153	24,949
S2	Palestin* or Gaza or “west bank”	995	1,581
S3	S1 AND S2	0	0

3. MEDLINE search through EbscoHos

		Results	
#	Search terms	January 2017	March 2020
S1	(MH "Arthritis, Rheumatoid") or (TI RA) or (AB RA)	133,673	134,632
S2	Palestin* or Gaza or “west bank”	4,455	5,984
S3	S1 AND S2	2	5

4. PsycINFO search through EbscoHos

		Results	
#	Search terms	January 2017	March 2020
S1	DE "Rheumatoid Arthritis" or (TI RA) or (AB RA)	2,891	3,803
S2	Palestin* or Gaza or “west bank”	2,669	3,186
S3	S1 AND S2	0	0

5. AMED search through EbscoHos

		Results	
#	Search terms	January 2017	March 2020
S1	"Rheumatoid Arthritis" or (TI RA) or (AB RA)	1,728	1,934
S2	Palestin* or Gaza or “west bank”	40	58
S3	S1 AND S3	0	0

6. Web of Sciences

		Results	
#	Search terms	January 2017	March 2020
1	Ts="Rheumatoid Arthritis" OR TI=RA	160,013	178,818
2	Ts=(Palestin* or Gaza or “west bank”)	16,752	19,658
3	1 AND 2	10	11

Appendix B Published systematic review protocol

PHYSICAL THERAPY REVIEWS
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Measurement properties of patient-reported hand function measures in rheumatoid arthritis: a systematic review protocol

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ABSTRACT

Background: Patient-reported outcome measures (PROMs) are commonly used to evaluate hand function in people with rheumatoid arthritis (RA). A decision will always need to be made about which appropriate PROMs to use. The present review therefore aims to describe the available hand function PROMs for use in people with RA by appraising their methodological quality and psychometric properties using a contemporaneous method.

Methods/design: The proposed systematic review will include published studies written in English, which report evidence for psychometric properties and/or practical properties of hand function PROMs in RA. Four major databases (MEDLINE, Embase, PsycINFO, and CINAHL) will be searched from inception to May 2019. A three-staged search strategy will be applied: (1) electronic bibliographic databases for published studies, (2) 'named measures' searching approach, and (3) reference lists of studies with included PROMs. The proposed systematic review will be conducted in compliance with the consensus-based standards for the selection of health measurement instruments (COSMIN) guideline for systematic review of PROMs. Accordingly, the methodological quality of the included studies will be assessed against the updated COSMIN risk of bias checklist, and each study's results will be assessed for their psychometric quality.

Conclusion: The proposed systematic review seeks to provide rigour, and transparent evaluation of PROMs used to evaluate hand function in the RA population. The findings will provide clarity for healthcare professionals and researchers on the appropriate PROMs for hand function assessment. It will also provide a summary of hand function PROM recommendations for RA.

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Hand function; rheumatoid arthritis; systematic review; patient reported; measurement properties

Introduction

Rheumatoid arthritis (RA) is the most prevalent form of inflammatory arthritis and affects ~1% of the world's population [1]. Hand involvement is typically present in about 80%–90% of the people with RA [2]. Some common impairments associated with hand RA are pain, stiffness, deformities, limited range of motion (ROM) and functional limitations which often present in symmetrical patterns [3]. The importance of hand function in RA is underlined by the fact that RA has a particular predilection for the hands and hand function is an essential component in performing activities of daily living (ADLs). Furthermore, hand function domain is included in the International Classification of Functioning, Disability and Health (ICF) core set for RA [4]. Therefore, it is important to measure, interpret and evaluate hand function in clinical practice and include hand outcomes within the core set of outcomes to be included in trials involving people with hand RA [5]. The assessment of hand function in hand RA is crucial in determining the extent of functional loss and evaluating the outcomes of both surgical and rehabilitative procedures/interventions [6]. The term functional assessment has been used to represent a wide range of assessment techniques and is often used inconsistently [7]. Although the clinical assessment of hand function and disability remains complex and debatable [8], it is essential to measure the progression of hand disability in RA to understand the impact of the disease, determine treatment strategies and evaluate interventions used in hand RA management.

Using the ICF terms, RA patients' hand function limitations are evaluated through measuring impairments (e.g. ROM and grip strength), whilst limitations in hand activity are documented using both performance-based measures and patient-reported outcome questionnaires [9, 10]. Hand impairment measures focus on reflecting the consequences of the disease at the bodily musculoskeletal level. Although impairment measures are relatively simple

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to obtain, they are reported to be limited in demonstrating how well patients perform their ADLs and often do not capture the full extent of patient disability [11]. Besides, for RA patients, the level of hand disability in daily life may be of greater importance to them than the level of impairment [10, 12]. Impairments of hand function can lead to both physical and psychosocial difficulties in accomplishing daily life activities [12]. Therefore, hand function can be defined as the ability to perform daily life activities [9].

Performance-based measures assess an individual's ability to perform prescribed tasks. Examples of these measures include Jebsen Taylor Hand Function Test [13] and Grip Ability Test [14]. These measures include tasks that simulate real life tasks and might not be meaningful to the patients' real-life activities. The results obtained are effort dependent and may be influenced by mood [15, 16]. This led to a shift in the focus of methods used to describe health outcomes related to the hand manifestations of RA toward patient-reported outcome measures (PROMs), which goes with a world-wide rheumatology trend for more patient-centred care [17]. PROMs of hand function are standardised and validated self-administrated questionnaires that provide quantitative information about hand use in daily life from the patients' perspective. A wide variety of hand self-reported questionnaires that assess disease symptoms and activity limitations have been used with RA patients [18]. Although hand self-reported questionnaires have been recommended with RA patients [11], consensus on which of the available instruments should be used in clinical and research setting is currently unavailable [19]. Given the vast number of available PROMs for hand function, the selection of an appropriate measure necessitates the careful consideration of their measurement properties. A scoping search identified two relevant narrative review studies reporting the psychometric properties of PROMs hand function used in arthritis population [18, 20]. However, both reviews presented evidence of the measurement properties of a few PROMs based on data available from the arthritis population in general, which does not provide RA specific evidence. Additionally, due to the nature of narrative reviews, they are not systematic or transparent in their approach to synthesis [21] hence their results are not conclusive. Considering these shortcomings, we concluded that a full systematic review is required. High-quality systematic reviews that employ up-to-date evidence synthesis and recommendations can provide a comprehensive overview of all available measures and support evidence-based recommendations in the selection of the most appropriate PROMs for a given purpose [22]. Therefore, this systematic review aims to critically appraise, compare and summarise the measurement properties (i.e. reliability, criterion validity, construct validity, and responsiveness) of all available PROMs for hand function in RA, considering the methodological quality of these studies as well as the quality of evidence. Based on findings of this review, recommendations regarding appropriate PROMs for evaluating hand function in RA will be proposed.

Methods

Design

This systematic review will be conducted in compliance with the recently published consensus-based standards for the selection of health measurement instruments (COSMIN) guideline for the systematic review of PROMs [22]. Details of the protocol are registered on the International Prospective Register of Ongoing Systematic Reviews (PROSPERO) registry (CRD42019122087). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [23] and COSMIN [22] checklist will be used to guide the conduct and reporting of this systematic review. Any protocol amendments will be reported in the systematic review publication.

Search strategy

Prior to the commencement of the present systematic review, the PROSPERO database was searched to avoid duplication of the potential review evidence. From this search, no ongoing or completed systematic reviews were identified. A three-staged search strategy will be used to identify all published studies on the psychometric prosperities and/or interpretability of hand function PROMs in hand RA that meet the inclusion criteria. First, a computerized literature search will be performed in the following databases from inception to May 2019: MEDLINE (Ovid), EMBASE (Ovid), PsycINFO (EBSCO), and CINAHL Plus (EBSCO). The search strategy will be constructed in line with the guidelines published by the COSMIN [22], and guidance from Terwee et al. (2009) [23]. Medical Subject Headings terms and free text searching will be used to reflect three key elements (1) population-RA, (2) construct-hand function, and (3) measurement properties (a sensitive and validated search filter published by Terwee et al. (2009) [23]. An example of a search strategy in MEDLINE (Ovid) is presented in Appendix 1. Second, following the review of titles and abstracts of included studies, an additional 'named measures' search will be developed and applied in each database, with search terms developed as above to reflect: (1) population-RA, (2) construct-hand function, (3) named hand function measure, and (4) measure measurement properties. Finally, the reference lists of all selected articles will be searched to achieve a more comprehensive search and identify additional relevant studies.

The search strategy will be constructed and modified for each of the databases in collaboration with an experienced librarian. All searches will be performed by two independent researchers (HA and BS) on the same day. Results will be exported to a single EndNote (version X8) library. Then duplicate records will be deleted using the EndNote automatic de-duplication option.

Eligibility criteria

To be eligible for selection, a study must focus on a PROM(s) used for measuring hand function (the construct of interest). In addition, the following inclusion and exclusion criteria will be applied:

Inclusion criteria

1. Studies reporting the assessment of one or more psychometric properties or evaluating the interpretability (e.g. determination of clinically important change) of hand function PROM(s).
2. The study population should be adults (≥ 18) with RA making up at least 50% of the total study sample.
3. Studies reporting cross-cultural validation of hand function PROM(s) in the RA population.
4. Full-text articles published in peer reviewed English language journals.

Exclusion criteria

1. Studies reporting the assessment of psychometric properties of performance based, or clinician-rated, instruments for hand function.
2. Questionnaires developed for evaluating hand function in the juvenile RA population.
3. Studies or trials evaluating the effectiveness of interventions where a hand function PROM is used as an end point.
4. Editorial letters, reviews, conference abstracts, and dissertations.

Selection of articles

Following the step of removing duplicates, the study selection process will be completed in two stages. The first stage includes examining only the titles and abstracts of the search results to eliminate all clearly ineligible publications. The second stage encompasses a full-text review of articles that appear to meet the inclusion criteria or in cases when a decision cannot be made based on the title and abstract alone. All stages will be completed by two reviewers (HA and BS) independently. At any stage, if the reviewers are unable to reach a consensus, reviewers (AMH or JA) within this review will be consulted, and disagreement will be resolved through dialogue. Reasons for exclusion at the full-text stage of screening will be recorded. The process of selection will be summarized using a PRISMA flow diagram.

Data extraction

Data from the selected studies will be extracted independently by two reviewers (HA and BS), using data collection forms adopted from the COSMIN methodology guideline [24]. The COSMIN taxonomy will be used to decide which property has been evaluated in the study [25]. Discrepancies between the two reviewers will be resolved through discussion and, if necessary, through consultation with a third reviewer (AMH or JA). Data on the following will be extracted:

1. Characteristic of the study population including the age, gender, ethnicity, disease duration, and questionnaire administration.
2. Questionnaire characteristics including name, language, response options, scoring method, domains, number of items and recall period.
3. Evidence regarding the measurement properties of the questionnaire including data analysis, and results of the measurement properties.
4. Operational characteristics such as interpretability, patient acceptability, and feasibility of administration for staff will be reported.

The interpretability and feasibility related to the measure being evaluated will be extracted and reported using the COSMIN data extraction forms designed for this purpose [24].

Assessment of the methodological quality of the included studies

The methodological quality of the included studies on a measurement property will be evaluated using the updated COSMIN risk of bias checklist [22, 26]. The updated COSMIN risk of bias checklist contains 10 domains, two for content validity and the remaining for cross-cultural validity/measurement invariance, reliability, internal consistency, measurement error, criterion validity, hypothesis testing for construct validity and responsiveness. The quality of each study on a measurement property will be assessed individually using the pertinent COSMIN box. A four-point rating scale (i.e. very good, adequate, doubtful, and inadequate) of the COSMIN checklist will be used to rate each study, with the lowest score in each category considered the final overall rating for the methodological quality in that category for the study assessed. For instance, if the measurement error was rated 'very good' in one question, but 'doubtful' on another, the overall score for measurement error would be 'doubtful'. The assessment of the included studies will be evaluated against this criterion, and a summary score will be presented. The COSMIN steering committee reached a consensus that no 'gold standard' exists for PROMs [24]. Therefore, included studies will be categorized as measuring criterion validity only when a shortened version of a PROM is compared to the original long version. Measurement properties regarding PROMs content validity require the inclusion of studies of the development of the measures as well as studies focusing on content validity and expert opinion. However, for this proposed systematic review, content validity will not be evaluated. This is because the majority of hand function PROMs commonly used with persons with rheumatic diseases were not developed to evaluate hand RA [18]. Therefore, a comprehensive evaluation of content validity of all available RA hand function PROMs should be conducted in a future systematic review. The overall interrater agreement percentages of the original COSMIN risk of bias checklist was reported to be high and interrater reliability was reasonable [27]. The new version of the COSMIN risk of bias checklist has been used in a recent systematic review of PROMs for soft-tissue facial reconstruction and demonstrated very good interrater reliability (ICC = 0.81–87) [28].

Assessment of the study results against criteria for good measurement properties

Findings from each study on the measurement properties will be evaluated using the recently updated good measurement properties criteria [22], wherein the quality of each study's results will be rated as either 'sufficient', 'insufficient', or 'indeterminate'. The assessment of the methodological quality and psychometric properties of included studies will be performed by four reviewers who will work in pairs; any discrepancies encountered will be resolved through discussion.

Evidence synthesis

The results obtained from the two assessments detailed above will be pooled and used to produce a global score for each measurement property of each PROM as outlined by the COSMIN guideline [22, 24]. Results can be sufficient (positive), insufficient (negative), inconsistent, or indeterminate by employing a '75% in agreement' rule (i.e. for a positive outcome on internal consistency, 75% or more of the studies reporting internal consistency must be positive) [24]. If the results per study are all sufficient (or all insufficient), the overall rating will also be sufficient (or insufficient). If the results are inconsistent, then exploration is warranted to determine the reasons for inconsistency. Where reasons are identified, overall ratings will be provided for relevant subgroups. Where no reasons could be found, then the overall rating will be inconsistent and in the case where inadequate information is available, the overall rating will be indeterminate.

Following the above stage, all evidence per measurement property of PROMs will be graded using the modified Grading of Recommendations Assessment, Development, and Evaluation (GRADE) approach [22, 24]. Using this approach, the quality of evidence will be graded as high, moderate, low or very low evidence. Four out of the five factors of the modified GRADE approach namely risk of bias, inconsistency, indirectness and imprecision will be used to determine the quality of the evidence. The fifth factor (i.e. publication bias) according to Mokkink et al. [24] is difficult to assess in studies on measurements properties, hence not considered in the methodology for systematic reviews of PROMs. Premised on the above, the choice to exclude publication bias in the evaluation of the overall quality of evidence of the proposed systematic review was made. If the overall rating for a specific measurement property is indeterminate, then no grading of the quality will be given since the quality of the measure cannot be decided. Detailed methods for using the modified GRADE approach is described in the COSMIN manual for systematic reviews for PROMs [24]. Two independent reviewers (HA and BS) will perform the evidence synthesis, and a third reviewer (AMH or JA) will be consulted in case of unresolved disagreement. Finally, based on the combined results of each measurement category and modified GRADE evaluation, recommendations will be formulated on the appropriateness of each identified PROM.

Conclusion

This proposed systematic review seeks to systematically identify and critically appraise PROMs used in assessing hand function in people with hand RA. It will provide a comprehensive summary of available hand function PROMs and the quality of their

measurement properties. In addition, findings of this proposed systematic review will inform the selection of PROMs evaluating hand function for both clinical and research purposes with an aim to enhance hand function assessment in routine clinical practice, service evaluation, and research.

Disclosure statement

Reviewers report no conflict of interest.

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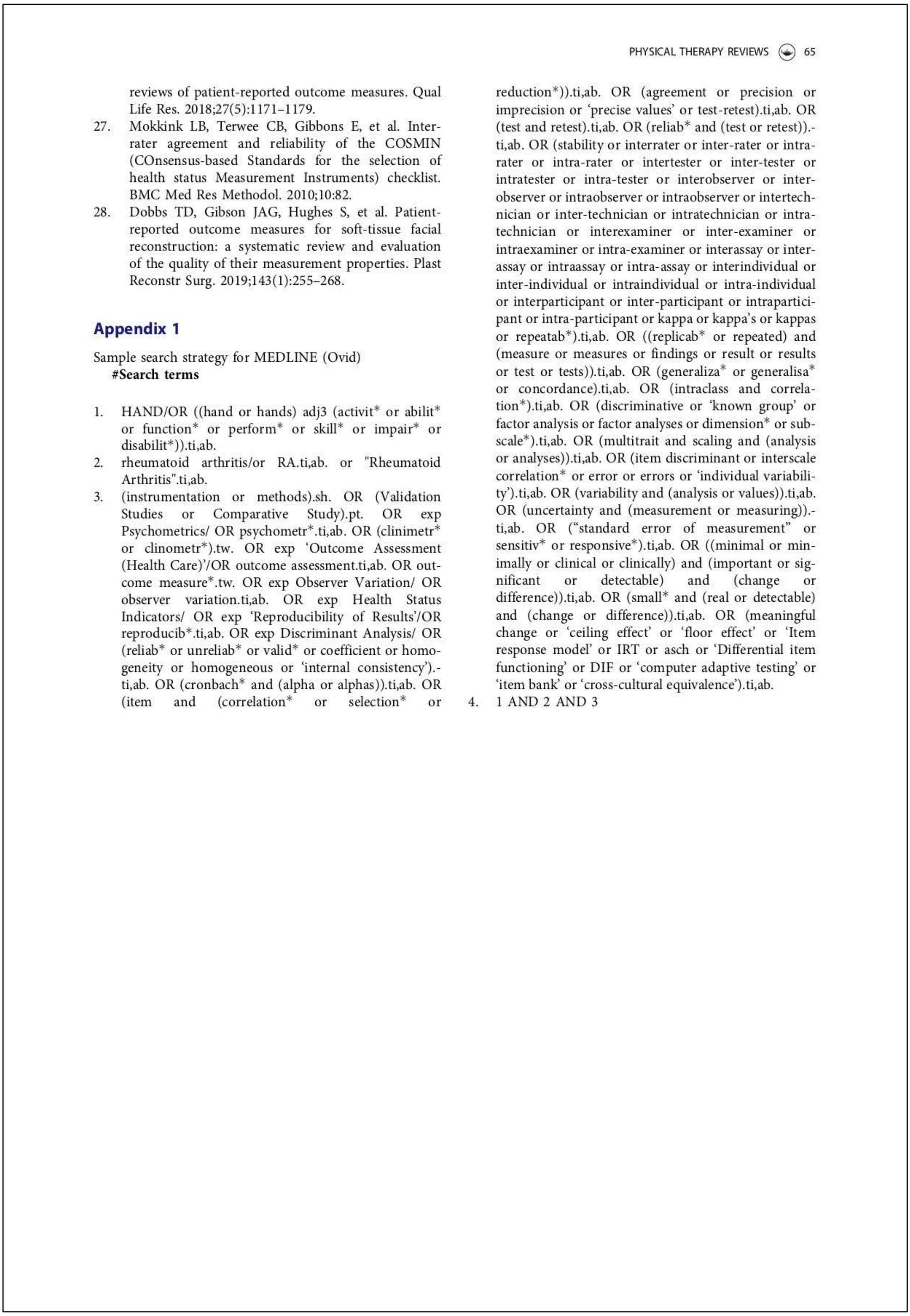
Appendix B



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Appendix 1

Sample search strategy for MEDLINE (Ovid)

#Search terms

1. HAND/OR ((hand or hands) adj3 (activit* or abilit* or function* or perform* or skill* or impair* or disabilit*)).ti,ab.
2. rheumatoid arthritis/or RA.ti,ab. or "Rheumatoid Arthritis".ti,ab.
3. (instrumentation or methods).sh. OR (Validation Studies or Comparative Study).pt. OR exp Psychometrics/ OR psychometr*.ti,ab. OR (clinimetr* or clinometr*).tw. OR exp 'Outcome Assessment (Health Care)'/OR outcome assessment.ti,ab. OR outcome measure*.tw. OR exp Observer Variation/ OR observer variation.ti,ab. OR exp Health Status Indicators/ OR exp 'Reproducibility of Results'/OR reproducib*.ti,ab. OR exp Discriminant Analysis/ OR (reliab* or unreliab* or valid* or coefficient or homogeneity or homogeneous or 'internal consistency').ti,ab. OR (cronbach* and (alpha or alphas)).ti,ab. OR (item and (correlation* or selection* or reduction*)).ti,ab. OR (agreement or precision or imprecision or 'precise values' or test-retest).ti,ab. OR (test and retest).ti,ab. OR (reliab* and (test or retest)).ti,ab. OR (stability or interrater or inter-rater or intrarater or intra-rater or intertester or inter-tester or intratester or intra-tester or interobserver or inter-observer or intraobserver or intraobserver or intertechnician or inter-technician or intratechnician or intratechnician or interexaminer or inter-examiner or intraexaminer or intra-examiner or interassay or inter-assay or intraassay or intra-assay or interindividual or inter-individual or intraindividual or intra-individual or interparticipant or inter-participant or intraparticipant or intra-participant or kappa or kappa's or kappas or repeatab*).ti,ab. OR ((replicab* or repeated) and (measure or measures or findings or result or results or test or tests)).ti,ab. OR (generaliza* or generalisa* or concordance).ti,ab. OR (intraclass and correlation*).ti,ab. OR (discriminative or 'known group' or factor analysis or factor analyses or dimension* or subscale*).ti,ab. OR (multitrait and scaling and (analysis or analyses)).ti,ab. OR (item discriminant or interscale correlation* or error or errors or 'individual variability').ti,ab. OR (variability and (analysis or values)).ti,ab. OR (uncertainty and (measurement or measuring)).ti,ab. OR ("standard error of measurement" or sensitiv* or responsive*).ti,ab. OR ((minimal or minimally or clinical or clinically) and (important or significant or detectable) and (change or difference)).ti,ab. OR (small* and (real or detectable) and (change or difference)).ti,ab. OR (meaningful change or 'ceiling effect' or 'floor effect' or 'Item response model' or IRT or asch or 'Differential item functioning' or DIF or 'computer adaptive testing' or 'item bank' or 'cross-cultural equivalence').ti,ab.
4. 1 AND 2 AND 3

Appendix C Published systematic review

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AMERICAN COLLEG
of RHEUMATOLOGY
Empowering Rheumatology Professionals

Factors Associated With Hand and Upper Arm Functional Disability in People With Rheumatoid Arthritis: A Systematic Review

Hisham Arab Alkabeya,[1] Ann-Marie Hughes,[2] and Jo Adams[2]

Objective. This original systematic review aimed to summarize evidence within observational studies on the factors associated with hand functional disability in adults with rheumatoid arthritis (RA).

Methods. A rigorous extensive systematic literature search was conducted in 6 medical databases for peer-reviewed English language observational studies that explore the factors associated with hand function for people with RA. Factors were critically classified under the domains of the International Classification of Functioning, Disability and Health (ICF) framework and health-related factors. The methodologic quality was determined using the appraisal tool for cross-sectional studies. Factors related to hand function that were investigated in ≥2 studies were explored using a best-evidence synthesis.

Results. Twenty articles from 1,271 citations met the inclusion criteria. All presented cross-sectional data (5 high-quality and 15 low-quality articles), resulting in limited evidence in the best-evidence synthesis. For the factors classified under the ICF domains, the best-evidence synthesis indicated that a diverse range of positive and negative factors were associated with hand function. However, key factors were hand strength, disease activity, and pain intensity. It is evident that few sociodemographic factors have been explored for the association with hand function.

Conclusion. Although the level of evidence was limited, modifiable factors such as grip strength, disease activity, and pain were identified as the most influential factors on hand function in people with RA. The findings of the present review indicate that important sociodemographic factors that impact hand function in individuals with RA have not yet been considered or reported in clinical research.

INTRODUCTION

Rheumatoid arthritis (RA) is an inflammatory, systemic autoimmune and chronic disease that affects approximately 1% of individuals worldwide. The disease pathogenesis remains unknown (1). Hand involvement is typically present in 80–90% of the people with RA (2) and results in stiffness, swelling, pain, range of motion (ROM) limitation, deformity, and muscle weakness (3). These impairments have a formidable impact on hand function and daily life activities (4), causing hand functional disability for a substantial percentage (81%) of people with RA (5).

Current management of RA focuses on early diagnosis and early intensive intervention with disease-modifying antirheumatic drugs (DMARDs) together with biologic medication. These new generation drugs have delivered substantial improvements in decreasing disease activity and minimizing disability (6). However, with recent analysis of cohorts of people with RA who are receiving DMARDs and biologic treatments, it is evident that hand impairments and activity limitations remain as significant problems (7). Moreover, hand problems exacerbate progressively even in patients in remission or with low disease activity (8), and hand function was reported to be substantially worse when compared to referents, despite low disease activity (9). Despite new drug advances and targeted medical treatment, hand function problems for people with RA still persist. Hand function is an important component of disability in people with RA (10). Fortuitously, hand function assessments can be sensitive tools for assessing change in hand functional status (11).

Presented by Mr. Arab Alkabeya in partial fulfillment of the requirements for a PhD degree, Southampton University, Southampton, UK.

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No potential conflicts of interest relevant to this article were reported.

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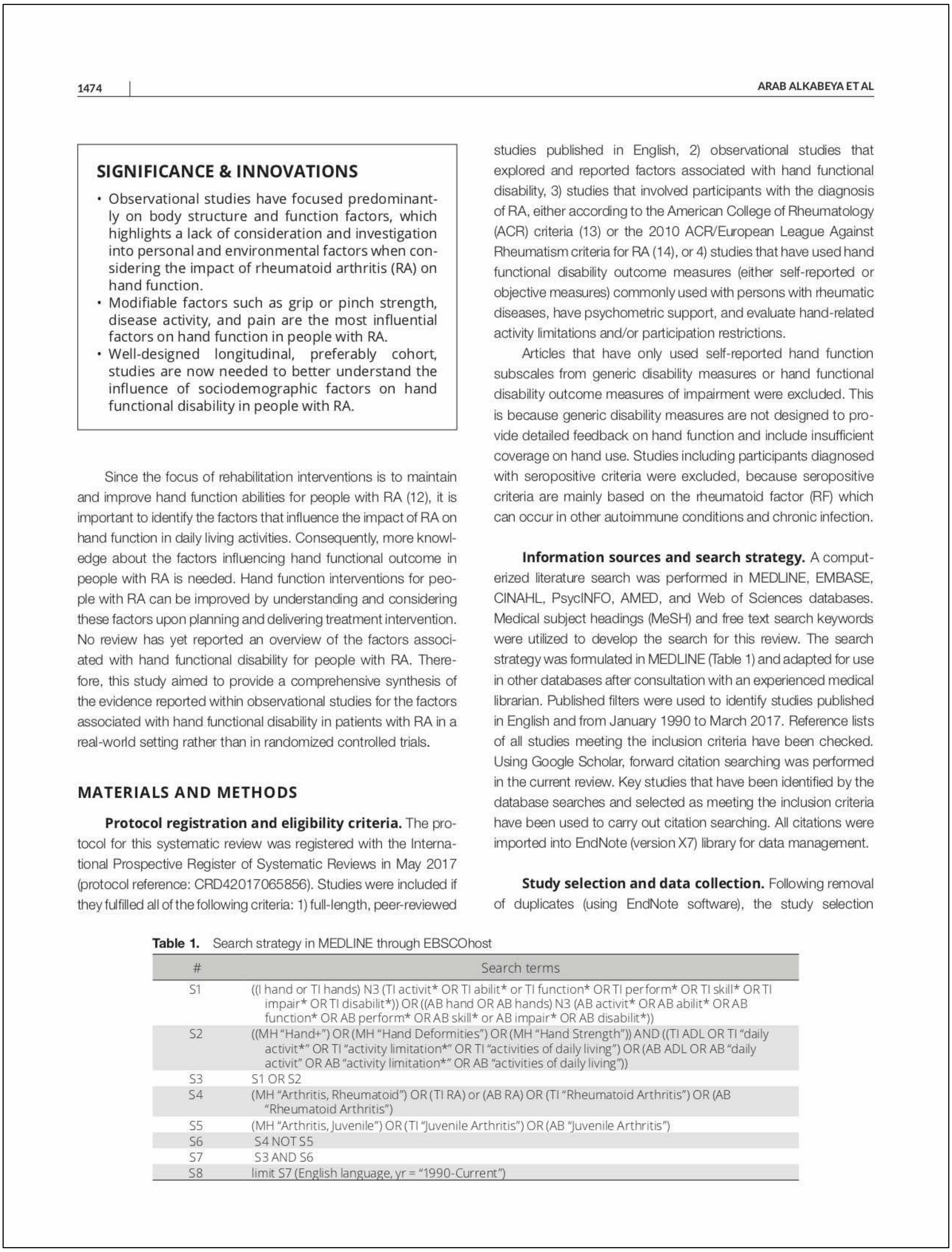
Appendix C



SIGNIFICANCE & INNOVATIONS

- Observational studies have focused predominantly on body structure and function factors, which highlights a lack of consideration and investigation into personal and environmental factors when considering the impact of rheumatoid arthritis (RA) on hand function.
- Modifiable factors such as grip or pinch strength, disease activity, and pain are the most influential factors on hand function in people with RA.
- Well-designed longitudinal, preferably cohort, studies are now needed to better understand the influence of sociodemographic factors on hand functional disability in people with RA.

Since the focus of rehabilitation interventions is to maintain and improve hand function abilities for people with RA (12), it is important to identify the factors that influence the impact of RA on hand function in daily living activities. Consequently, more knowledge about the factors influencing hand functional outcome in people with RA is needed. Hand function interventions for people with RA can be improved by understanding and considering these factors upon planning and delivering treatment intervention. No review has yet reported an overview of the factors associated with hand functional disability for people with RA. Therefore, this study aimed to provide a comprehensive synthesis of the evidence reported within observational studies for the factors associated with hand functional disability in patients with RA in a real-world setting rather than in randomized controlled trials.

MATERIALS AND METHODS

Protocol registration and eligibility criteria. The protocol for this systematic review was registered with the International Prospective Register of Systematic Reviews in May 2017 (protocol reference: CRD42017065856). Studies were included if they fulfilled all of the following criteria: 1) full-length, peer-reviewed studies published in English, 2) observational studies that explored and reported factors associated with hand functional disability, 3) studies that involved participants with the diagnosis of RA, either according to the American College of Rheumatology (ACR) criteria (13) or the 2010 ACR/European League Against Rheumatism criteria for RA (14), or 4) studies that have used hand functional disability outcome measures (either self-reported or objective measures) commonly used with persons with rheumatic diseases, have psychometric support, and evaluate hand-related activity limitations and/or participation restrictions.

Articles that have only used self-reported hand function subscales from generic disability measures or hand functional disability outcome measures of impairment were excluded. This is because generic disability measures are not designed to provide detailed feedback on hand function and include insufficient coverage on hand use. Studies including participants diagnosed with seropositive criteria were excluded, because seropositive criteria are mainly based on the rheumatoid factor (RF) which can occur in other autoimmune conditions and chronic infection.

Information sources and search strategy. A computerized literature search was performed in MEDLINE, EMBASE, CINAHL, PsycINFO, AMED, and Web of Sciences databases. Medical subject headings (MeSH) and free text search keywords were utilized to develop the search for this review. The search strategy was formulated in MEDLINE (Table 1) and adapted for use in other databases after consultation with an experienced medical librarian. Published filters were used to identify studies published in English and from January 1990 to March 2017. Reference lists of all studies meeting the inclusion criteria have been checked. Using Google Scholar, forward citation searching was performed in the current review. Key studies that have been identified by the database searches and selected as meeting the inclusion criteria have been used to carry out citation searching. All citations were imported into EndNote (version X7) library for data management.

Study selection and data collection. Following removal of duplicates (using EndNote software), the study selection

Table 1. Search strategy in MEDLINE through EBSCOhost

#	Search terms
S1	((I hand or TI hands) N3 (TI activit* OR TI abilit* or TI function* OR TI perform* OR TI skill* OR TI impair* OR TI disabilit*)) OR ((AB hand OR AB hands) N3 (AB activit* OR AB abilit* OR AB function* OR AB perform* OR AB skill* or AB impair* OR AB disabilit*))
S2	((MH "Hand+") OR (MH "Hand Deformities") OR (MH "Hand Strength")) AND ((TI ADL OR TI "daily activit*" OR TI "activity limitation*" OR TI "activities of daily living") OR (AB ADL OR AB "daily activit" OR AB "activity limitation*" OR AB "activities of daily living"))
S3	S1 OR S2
S4	(MH "Arthritis, Rheumatoid") OR (TI RA) or (AB RA) OR (TI "Rheumatoid Arthritis") OR (AB "Rheumatoid Arthritis")
S5	(MH "Arthritis, Juvenile") OR (TI "Juvenile Arthritis") OR (AB "Juvenile Arthritis")
S6	S4 NOT S5
S7	S3 AND S6
S8	limit S7 (English language, yr = "1990-Current")

process was completed in 2 stages. The first stage included examining only the titles and abstracts of the search results to eliminate all clearly ineligible publications. Secondly, a full-text review of articles that appeared to meet the inclusion criteria or in cases when a decision could not be made based on the title and abstract alone was conducted. The selection process was completed entirely by the first author. The research team was consulted where any ambiguity arose.

Pertinent data were extracted and documented by the first author, and cross-checked by the research team for completion and accuracy. A predesigned data extraction form was used to extract general information (author and year of publication), characteristics of participants (sample size, disease duration, age, and sex), study characteristics, and hand-function outcome measures, factors, and the association between factors and outcome. Factors tested for association with hand function have been categorized under the domains of the International Classification of Functioning, Disability and Health framework and health-related factors.

Assessment of methodologic quality. Three reviewers independently assessed the methodologic quality of the included articles. The first author (HA) assessed all studies included in the review, and each one of the other reviewers (JA and AMH) assessed half each of the included articles. The quality and risk of bias of the included studies were assessed using a critical appraisal checklist, to assess the quality of cross-sectional studies (the appraisal tool for cross-sectional studies [AXIS]) (15). The AXIS comprises 20 items that focus mainly on the presented methods and results. Seven questions of the AXIS are related to the quality of reporting, 7 questions are related to the study design quality, and 6 questions are related to the risk of biases. Each item was scored by the mean using the following scoring system: “yes” (Y) = 1; and “no” (N) or “don’t know” (DK) = 0. The overall score is a percentage score of all 20 items. Studies with an overall score of ≥60% were rated as high quality (16). Disagreements regarding quality assessments between the reviewers were resolved by discussion.

Best-evidence synthesis. Included studies exhibited marked heterogeneity in terms of patient characteristics, outcome measures, statistical analysis, and reporting of results. Consequently, meta-analysis was not possible and the best-evidence synthesis approach was used instead, as recommended by Slavin (17). Only factors tested for association with hand functional disability, which have been measured and reported in the same manner and investigated in ≥2 studies, were included in the best-evidence synthesis. For studies that used 2 tools to evaluate hand function and reported an association between a factor and 1 tool but no association with another tool, the following conditions were applied: If the study used a generic hand function tool and a hand specific tool, then only the results of the latter were considered. If the study used 2 specific hand function tools, then the results of the tool, which has been used more frequently in the included studies, were considered. The Van Tulder ranking system for the level of evidence (18) was used as this is widely used and contemporaneous (16) (Table 2). Initially, the studies were categorized according to the type of study design. The favored design was cohort study followed by case-control design and, at last, cross-sectional design. After that, the studies were ranked according to their methodologic quality overall score. A result was consistent if the factor was significantly associated to hand function with the same direction of the association.

Table 2. Best-evidence synthesis

Level of evidence	Description
Strong	Generally consistent findings were presented in multiple high-quality cohort studies
Moderate	One high-quality cohort study and at least 2 high-quality case–control studies, or when at least 3 high-quality case–control studies show generally consistent findings
Limited	Generally consistent findings were found in a single cohort study, or in maximum 2 case–control studies, or in multiple cross-sectional studies
Conflicting	Less than 75% of the studies reported consistent findings
No evidence	No study could be found

RESULTS

Study selection. The search of the selected databases resulted in the retrieval of 1,254 citations (MEDLINE 395; EMBASE 566; CINAL 122; AMED 54; PsychINFO 18; Web of Sciences 99), and another source search yielded 17 citations. After the removal of duplicate citations, 764 articles remained. Screening of citation titles and abstracts excluded 703 citations from the review. Out of the remaining 61 citations, 41 were excluded with reasons as presented in Figure 1. Finally, 20 articles met all inclusion criteria and were included in the present review. Hand searching for these articles resulted in the retrieval of 1 additional article, which was published in the Turkish language; thus, it was excluded. Forward citation tracking did not yield any further articles for inclusion in the review.

Study characteristics. The articles in the review were based on 19 independent studies of people with RA. Fifteen of the 20 articles (75%) were cross-sectional (2,3,19–31), 2 were case-control (32,33), and 3 were cohort studies (11,34,35). Case-control and cohort studies included in this review presented cross-sectional data on the association between factors and hand function, therefore all studies were considered to be cross-sectional, resulting in limited evidence in the best-evidence synthesis. A full overview of study characteristics of the included studies is presented in Supplementary Table 1, available on the *Arthritis Care & Research* web site at http://onlinelibrary.wiley.com/doi/10.1002/acr23784/abstract.

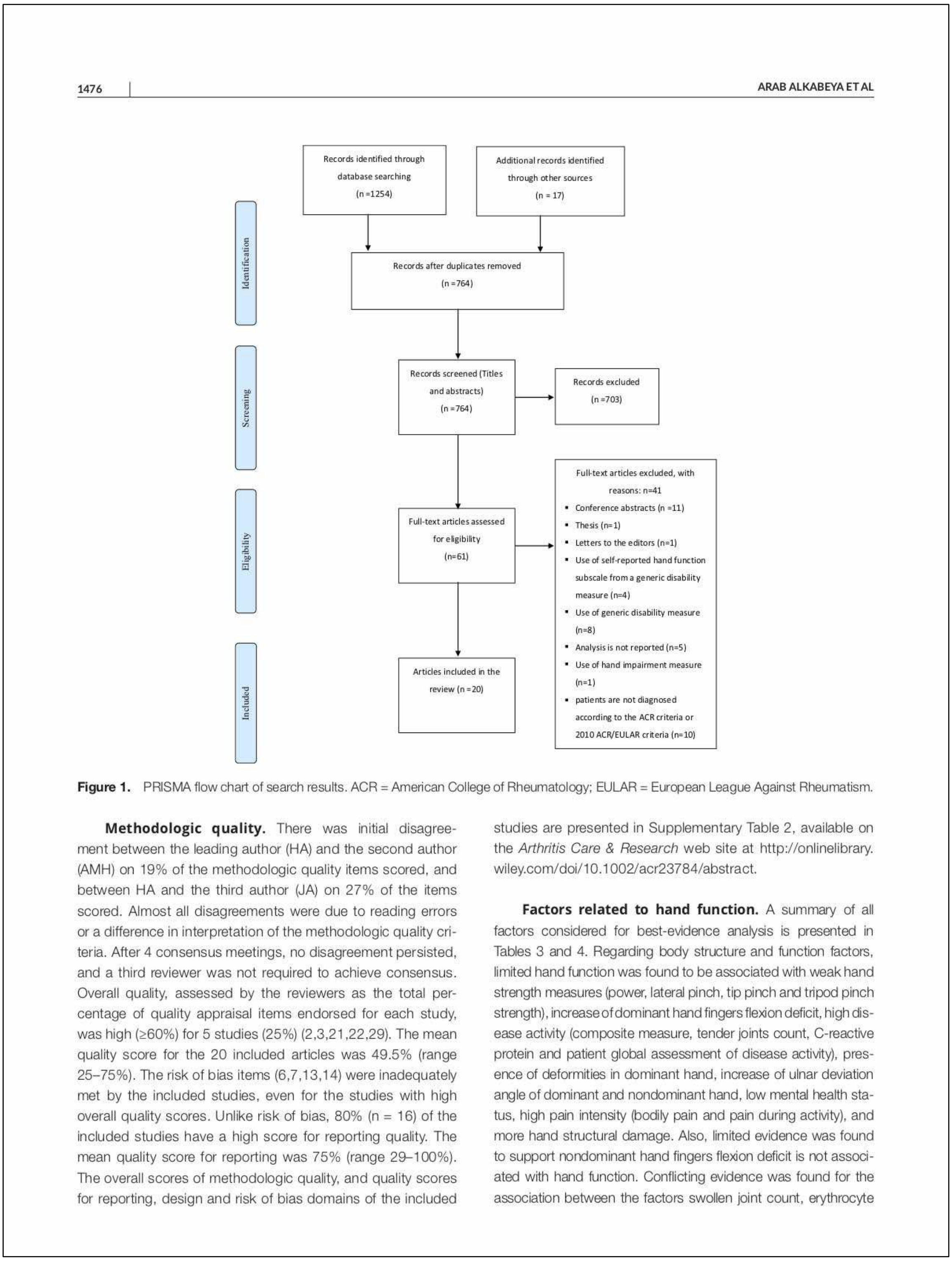


Figure 1. PRISMA flow chart of search results. ACR = American College of Rheumatology; EULAR = European League Against Rheumatism.

Methodologic quality. There was initial disagreement between the leading author (HA) and the second author (AMH) on 19% of the methodologic quality items scored, and between HA and the third author (JA) on 27% of the items scored. Almost all disagreements were due to reading errors or a difference in interpretation of the methodologic quality criteria. After 4 consensus meetings, no disagreement persisted, and a third reviewer was not required to achieve consensus. Overall quality, assessed by the reviewers as the total percentage of quality appraisal items endorsed for each study, was high (≥60%) for 5 studies (25%) (2,3,21,22,29). The mean quality score for the 20 included articles was 49.5% (range 25–75%). The risk of bias items (6,7,13,14) were inadequately met by the included studies, even for the studies with high overall quality scores. Unlike risk of bias, 80% (n = 16) of the included studies have a high score for reporting quality. The mean quality score for reporting was 75% (range 29–100%). The overall scores of methodologic quality, and quality scores for reporting, design and risk of bias domains of the included studies are presented in Supplementary Table 2, available on the *Arthritis Care & Research* web site at http://onlinelibrary.wiley.com/doi/10.1002/acr23784/abstract.

Factors related to hand function. A summary of all factors considered for best-evidence analysis is presented in Tables 3 and 4. Regarding body structure and function factors, limited hand function was found to be associated with weak hand strength measures (power, lateral pinch, tip pinch and tripod pinch strength), increase of dominant hand fingers flexion deficit, high disease activity (composite measure, tender joints count, C-reactive protein and patient global assessment of disease activity), presence of deformities in dominant hand, increase of ulnar deviation angle of dominant and nondominant hand, low mental health status, high pain intensity (bodily pain and pain during activity), and more hand structural damage. Also, limited evidence was found to support nondominant hand fingers flexion deficit is not associated with hand function. Conflicting evidence was found for the association between the factors swollen joint count, erythrocyte

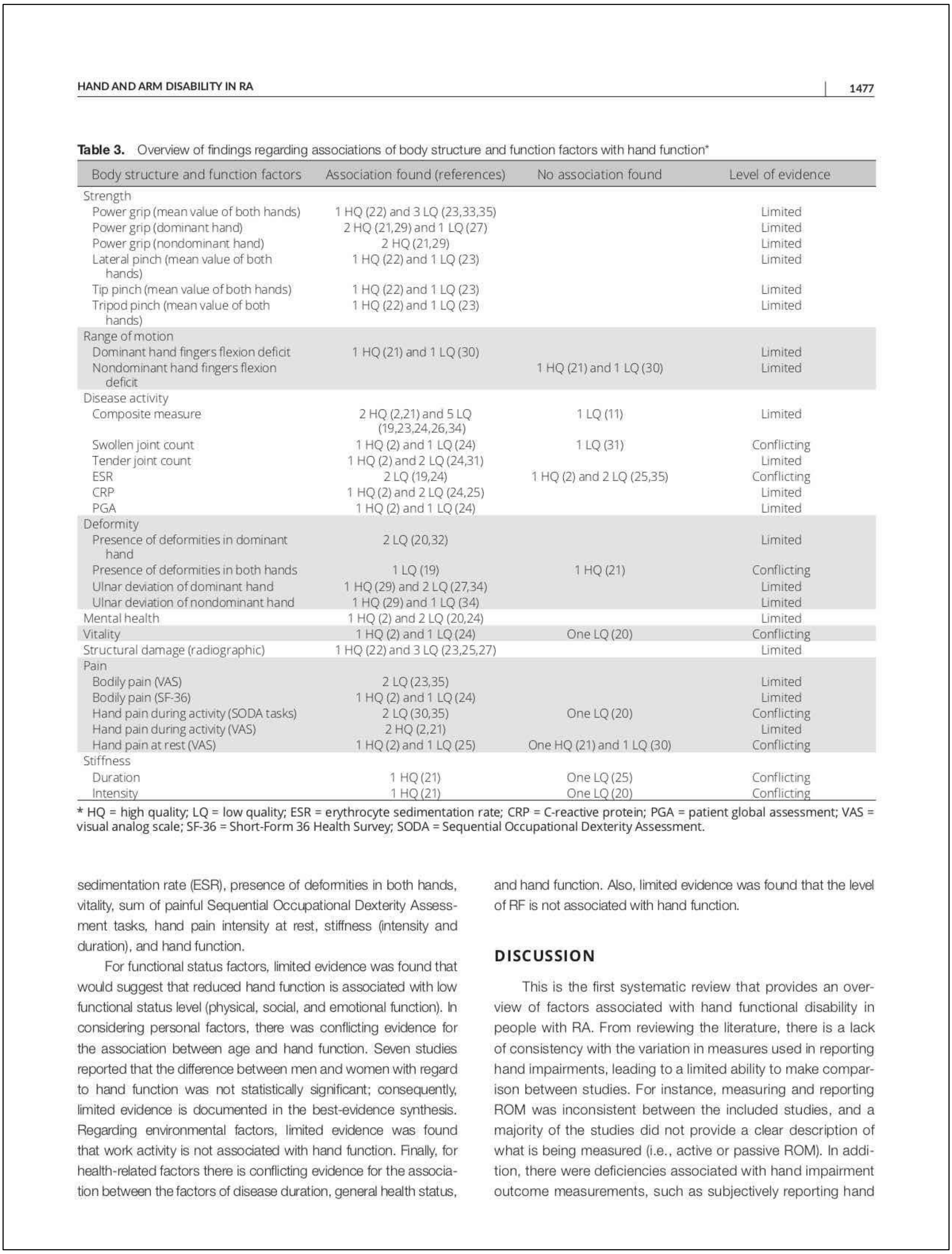


Table 3. Overview of findings regarding associations of body structure and function factors with hand function*

Body structure and function factors	Association found (references)	No association found	Level of evidence
Strength			
Power grip (mean value of both hands)	1 HQ (22) and 3 LQ (23,33,35)		Limited
Power grip (dominant hand)	2 HQ (21,29) and 1 LQ (27)		Limited
Power grip (nondominant hand)	2 HQ (21,29)		Limited
Lateral pinch (mean value of both hands)	1 HQ (22) and 1 LQ (23)		Limited
Tip pinch (mean value of both hands)	1 HQ (22) and 1 LQ (23)		Limited
Tripod pinch (mean value of both hands)	1 HQ (22) and 1 LQ (23)		Limited
Range of motion			
Dominant hand fingers flexion deficit	1 HQ (21) and 1 LQ (30)		Limited
Nondominant hand fingers flexion deficit		1 HQ (21) and 1 LQ (30)	Limited
Disease activity			
Composite measure	2 HQ (2,21) and 5 LQ (19,23,24,26,34)	1 LQ (11)	Limited
Swollen joint count	1 HQ (2) and 1 LQ (24)	1 LQ (31)	Conflicting
Tender joint count	1 HQ (2) and 2 LQ (24,31)		Limited
ESR	2 LQ (19,24)	1 HQ (2) and 2 LQ (25,35)	Conflicting
CRP	1 HQ (2) and 2 LQ (24,25)		Limited
PGA	1 HQ (2) and 1 LQ (24)		Limited
Deformity			
Presence of deformities in dominant hand	2 LQ (20,32)		Limited
Presence of deformities in both hands	1 LQ (19)	1 HQ (21)	Conflicting
Ulnar deviation of dominant hand	1 HQ (29) and 2 LQ (27,34)		Limited
Ulnar deviation of nondominant hand	1 HQ (29) and 1 LQ (34)		Limited
Mental health	1 HQ (2) and 2 LQ (20,24)		Limited
Vitality	1 HQ (2) and 1 LQ (24)	One LQ (20)	Conflicting
Structural damage (radiographic)	1 HQ (22) and 3 LQ (23,25,27)		Limited
Pain			
Bodily pain (VAS)	2 LQ (23,35)		Limited
Bodily pain (SF-36)	1 HQ (2) and 1 LQ (24)		Limited
Hand pain during activity (SODA tasks)	2 LQ (30,35)	One LQ (20)	Conflicting
Hand pain during activity (VAS)	2 HQ (2,21)		Limited
Hand pain at rest (VAS)	1 HQ (2) and 1 LQ (25)	One HQ (21) and 1 LQ (30)	Conflicting
Stiffness			
Duration	1 HQ (21)	One LQ (25)	Conflicting
Intensity	1 HQ (21)	One LQ (20)	Conflicting

* HQ = high quality; LQ = low quality; ESR = erythrocyte sedimentation rate; CRP = C-reactive protein; PGA = patient global assessment; VAS = visual analog scale; SF-36 = Short-Form 36 Health Survey; SODA = Sequential Occupational Dexterity Assessment.

sedimentation rate (ESR), presence of deformities in both hands, vitality, sum of painful Sequential Occupational Dexterity Assessment tasks, hand pain intensity at rest, stiffness (intensity and duration), and hand function.

For functional status factors, limited evidence was found that would suggest that reduced hand function is associated with low functional status level (physical, social, and emotional function). In considering personal factors, there was conflicting evidence for the association between age and hand function. Seven studies reported that the difference between men and women with regard to hand function was not statistically significant; consequently, limited evidence is documented in the best-evidence synthesis. Regarding environmental factors, limited evidence was found that work activity is not associated with hand function. Finally, for health-related factors there is conflicting evidence for the association between the factors of disease duration, general health status, and hand function. Also, limited evidence was found that the level of RF is not associated with hand function.

DISCUSSION

This is the first systematic review that provides an overview of factors associated with hand functional disability in people with RA. From reviewing the literature, there is a lack of consistency with the variation in measures used in reporting hand impairments, leading to a limited ability to make comparison between studies. For instance, measuring and reporting ROM was inconsistent between the included studies, and a majority of the studies did not provide a clear description of what is being measured (i.e., active or passive ROM). In addition, there were deficiencies associated with hand impairment outcome measurements, such as subjectively reporting hand

Table 4. Overview of findings regarding associations of functional status, personal, environmental, and health-related factors with hand function*

Factors	Association found	No association found	Level of evidence
Functional status			
Physical functioning (HAQ)	2 HQ (2,21) and 5 LQ (11,23,24,27,30)	1 LQ (19)	Limited
Physical functioning (SF-36)	1 HQ (2) and 1 LQ (24)		Limited
Social functioning	1 HQ (2) and 1 LQ (24)		Limited
Emotional role	1 HQ (2) and 1 LQ (24)		Limited
Personal factors			
Age	3 LQ (19,28,31)	4 LQ (20,26,30,34,35)†	Conflicting
Sex		1 HQ (21) and 6 LQ (19,20,26,30,31,34,35)†	Limited
Environmental factors			
Work activity		3 LQ (19,20,32)	Limited
Health related factors			
Health condition			
Disease duration	7 LQ (19,23,25,28,30,31,34,35)†	2 HQ (3,21) and 2 LQ (20,26)	Conflicting
Rheumatoid factor		3 LQ (19,23,32)	Limited
General state of health	1 HQ (2) and 1 LQ (24)	1 LQ (20)	Conflicting

* HAQ = Health Assessment Questionnaire; HQ = high quality; LQ = low quality; SF-36 = Short Form 36 Health Survey.
† Studies 34 and 35 and were considered as 1 body of evidence because both studies reported the findings from the same sample of RA patients with regard to the association between hand function and disease duration, age, and sex.

deformities with lack of detail about assessment or grading methods. Based on these observations, it is evident that protocols for assessments of hand impairments in the RA population need to be agreed and implemented. Consistency in reporting hand function is also now required.

Although quality of reporting was satisfactory for the majority of the studies identified in this review, almost all studies failed to account for and minimize systematic errors. Therefore, conclusions from this review could be at risk of bias due to weaknesses in those studies included. Improving selection and reporting of study participants, especially response rates and information about nonrespondents would address these biases and should be incorporated into future research.

This review showed that studies that consider hand disability in people with RA reported predominantly on body structure and function factors. There was a lack of consideration of, and investigation into, personal and environmental factors when considering the impact of RA on hand function. Many factors of body structure and function were significantly associated with hand functional disability. Importantly, grip strength is routinely recorded in rheumatology clinical trials. This is appropriate and relevant because grip strength is a valid indicator of disability (36), has been shown to predict later hand function (37), and contributes to hand function improvements (38) in people with RA. In this review, more than half of the included studies assessed the association between power grip strength and hand function, and all reported statistically significant relationships, regardless of the measurement or reporting method. This confirms what has been suggested by the findings of the present review—that power grip strength is a valid and reliable indicator of hand function in RA population and clinicians can have confidence in this finding for using it in clinical practice.

Disease activity variables have been found to be associated with hand function, except for ESR and swollen joint count, for which there was conflicting evidence. An explanation of this observation may be due to the fact that different hand function assessment tools cover different spectrum of functioning (39), and people with RA show unique and different clinical presentations; thus, no single disease activity variable can accurately detect every patient's disease activity at any given point in time (40). The results of the current review suggest that disease activity is a modifiable parameter that significantly contributes to hand function.

Pain in RA is the main treatment target for patients and clinicians (41). Results from studies of RA cohorts that were conducted during an era when biologic treatments were available demonstrated that pain still remains a problem and influences the performance of valued life activities (7,42). In the present review, limited evidence was found that higher intensity of bodily pain and hand pain during activity were associated with an increase of hand functional disability, and conflicting evidence was found for the association with hand pain at rest. This indicates that hand pain during activity may substantially contribute to hand functional disability. In line with these results, a recent longitudinal report on a Swedish RA cohort indicated that general pain was higher than hand pain during activity, which in turn was higher than hand pain at rest (7).

The studies included in the present review indicate an association between structural damage and hand function, and that an increase of radiographic joint damage is correlated with an increase of hand functional limitations. However, in agreement with recent evidence that radiographic joint damage is less influential in the context of modern treatment (43), the relative importance of structural damage may be of less importance in future research.

The fact that conflicting evidence was found for the association between hand function and hand stiffness duration and intensity is remarkable, since stiffness is a symptom widely experienced by patients with RA. Besides methodologic explanations (i.e., only cross-sectional studies with relatively small sample size), evidence from a systematic review of stiffness measures demonstrated that there is limited evidence to support the validity of the currently available stiffness measures (44). Furthermore, qualitative evidence suggested that patients with RA experience stiffness differently and reported stiffness in terms of impact rather than by duration or severity (45).

In examining functional status, there was limited evidence stating that reduced hand function is associated with poor physical function, social function, and emotional role. The association found between hand function and functional status measures may indicate that hand disability influences both the activity and participation level of functioning. This is because physical function measures such as Health Assessment Questionnaire (HAQ), are measuring activity limitations, whereas social functioning and emotional role scales measure participation restrictions (46).

Few personal factors have been explored for the association with hand function. Out of 12 personal factors identified as meaningful for general functioning in RA (47), only coping could be categorized as a personal factor, and was included in 1 study as a factor for hand function (34); thus, it was not included in the best-evidence synthesis. Important personal factors in relation to specific hand functional outcome are not identified. Identifying the role of these factors as determinants and modifiers of hand function can facilitate the process when evaluating and planning interventions for people with RA.

The findings of a qualitative study recruiting RA patients with hand deformity proposed that environmental factors play a significant role in hand-related activity limitations and participation restriction (48). However, in this review the impact of only a few environmental factors have been explored in relation to hand function. One factor, namely work activity, was included in the best-evidence synthesis, since it was assessed in 3 independent studies (19,20,32). However, the relative importance and influence of environmental factors might vary according to the settings and culture. For instance, low-income countries tend to have limited or fewer resources in terms of health care system, compared with high-income countries. Moreover, social support and beliefs about health disability may differ across countries. Considering these issues, important environmental factors in relation to hand functional outcomes in specific cultures and settings should be identified.

For health-related factors, conflicting evidence was found regarding the relationship between hand function and disease duration and general health status. Long disease duration was expected to be significantly associated with poor hand function, since hand impairments are prevalent and deteriorate over time in patients with long disease duration (3,8). Alongside, the limitations mentioned earlier concerning the methodologies of the included studies, a possible explanation for this finding might be related to the fact that patients with long disease duration may have adapted to their situation and they do not expect any effective treatment to be available (3). Cross-sectional studies have concluded that disease activity is the major explanatory factor for activity limitations in RA patients, with disease duration less than 10 years (36). Accordingly, disease duration may be an irrelevant factor to consider when evaluating hand function, particularly with disease duration <10 years.

This review is not without limitations. Only the first author screened the titles and abstracts. However, citations were only considered irrelevant if the title or abstract did not include any information on hand function outcomes. Moreover, the review team were consulted where any ambiguity arose during the selection process. Therefore, the possibility of removing relevant studies was low. This review was limited by the wide variation in the included studies' sample sizes (range 25–200). Accordingly, sample size may affect the results of associations reported in the included studies; small associations are significant in studies with a large sample size and not in studies with a small sample size. The studies included in this review did not all present the size of the association within their statistical analysis and reporting, so it is difficult to preclude that the results are biased by this. The studies included have used self-reported and performance-based measures of hand function or both. This probably influenced the results of this review, since, performance-based measures cover a narrow spectrum of hand functioning (39), and may not accurately reflect hand abilities (49). Furthermore, performance based and self-reported measures of hand function are not strongly associated (50). Future research may benefit from stratifying outcomes rather than combining them. The quality assessment tool (AXIS) used in this review was developed based on literature and methodologic standards; however, further studies are required to explore its test–retest reliability. Attention should be given to the disagreement (27% and 19%) between the reviewers on the methodologic quality of the study. Reducing the scoring options into "yes," "no," instead of including "don't know" may increase the simplicity of use of the AXIS and may minimize the disagreements between reviewers. The grey literature or unpublished studies were not searched as there are few studies focusing on hand function in RA patients (19); therefore, the number of extra studies identified by grey literature would also be small. Studies written in English were selected and included in the review. The percentage of all articles written in other languages was small (8%); consequently, it is unlikely that this percentage would introduce language bias into the review. Finally, of the 20 articles included in the review, 1 author (JA) involved in the present review authored 2 articles. However, to ensure that the quality assessment process was unbiased, quality assessment of these 2 articles were completed by the first and second author.

This systematic review has summarized current evidence for the factors associated with hand function in RA patients. It has also underlined areas where methodology is lacking and potential directions for future research. There are numerous factors where current evidence is limited or conflicting. These factors can be classified as modifiable (e.g., disease activity, hand strength, psychosocial factors) and nonmodifiable factors (e.g., age, sex, structural damage). Focusing on nonmodifiable factors offers little added value to improve hand function in people with RA. Therefore, modifiable factors should be of key concern as some of these factors can be modified with specific strategies and interventions. Before new strategies and interventions are established to improve hand function in people with RA, well-designed longitudinal studies need to be performed to get more understanding in the causality between factors and hand function. Important sociodemographic factors in relation to hand function in patients with RA need more considerations by future research.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Mr. Arab Alkabeya had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Arab Alkabeya, Hughes, Adams.
Acquisition of data. Arab Alkabeya, Hughes, Adams.
Analysis and interpretation of data. Arab Alkabeya, Hughes, Adams.

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Appendix D PRISMA Checklist (systematic review study)

Section/topic	#	Checklist item	Section
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Chapter 3
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Appendix C
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Section 3.2
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Section 3.3.1
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Section 3.3.2
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Section 3.3.3
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Section 3.3.4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Section 3.3.5 & Appendix E
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Section 3.3.7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Section 3.3.8
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Appendix F
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Section 3.3.9
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Section 3.3.10
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	Section 3.3.10

Appendix D

Section/topic	#	Checklist item	Section
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Section 3.3.9 & Section 3.4.5
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Section 3.4.1 & Figure 3-2
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Section 3.4.2 & Section 3.4.4
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Section 3.4.5 & Table 3-10
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Section 3.4.3 & Table 3-9
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Section 3.4.9, Table 3-11 & Table 3-12
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Section 3.4.5 & Table 3-10
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Section 3.5.2
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Section 3.6
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Section 3.7
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Acknowledgement in Appendix C

From: Moher D, Liberati A, Tetzlaff J, Altman DG and Group P (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 6(7): e1000097

Appendix E Main terms and search strategy: Systematic review study

1. Embase search through OvidSP

Search Date 17/3/2017		
#	Search Terms	Results
1	((hand or hands) adj3 (activit* or abilit* or function* or perform* or skill* or impair* or disabilit*)).ti,ab.	18855
2	(Hand function/ or exp hand/) and (ADL or "daily activity" or "activity limitation*" or "daily life activity").ti,ab.	321
3	1 or 2	18973
4	rheumatoid arthritis/ or RA.ti,ab. or "Rheumatoid Arthritis".ti,ab.	205680
5	juvenile rheumatoid arthritis/ or "Juvenile Arthritis" ti,ab.	17896
6	4 not 5	201785
7	3 and 6	744
8	limit 7 to (English language and yr="1990 -Current")	566

2. CINAHL search through EbscoHos

Search Date 17/3/2017		
#	Search Terms	Results
S1	((TI hand or TI hands) N3 (TI activit* or TI abilit* or TI function* or TI perform* or TI skill* or TI impair* or TI disabilit*)) OR ((AB hand or AB hands) N3 (AB activit* or AB abilit* or AB function* or AB perform* or AB skill* or AB impair* or AB disabilit*))	3,567
S2	((MH "Hand+") OR (MH "Hand Deformities")) AND ((TI ADL or TI “daily activity” or TI “activit* limitation*” or TI “activities of daily living”) OR (AB ADL or AB “daily activit*” or AB “activit* limitation*” or AB “activities of daily living”))	164
S3	S1 OR S2	3,656
S4	(MH "Arthritis, Rheumatoid") or (TI RA) or (AB RA) or (TI "Rheumatoid Arthritis") or (AB "Rheumatoid Arthritis")	20,131
S5	(MH "Arthritis, Juvenile Rheumatoid") or (MH "Arthritis, Juvenile") or (TI "Juvenile Arthritis") or (AB "Juvenile Arthritis")	2,189
S6	S4 NOT S5	19,972
S7	S3 AND S6	139
S8	limit S7 (English language , yr="1990 -Current")	122

3. Web of Sciences

Search Date 17/3/2017		
#	Search Terms	Results
#1	TI=((hand OR hands) NEAR/3 (activit* OR abilit* OR function* OR perform* OR skill* OR impair* OR disabilit*))	2064
#2	TS=(hand*) AND TI=(ADL or “daily activit*” or “activity limitation*” or “activities of daily living”)	300
#3	#2 OR #1	2330
#4	Ts="Rheumatoid Arthritis" OR TI=RA OR TI= "Rheumatoid Arthritis"	134015
#5	TS="Arthritis, Juvenile" OR TI="Juvenile Arthritis"	140
#6	#4 NOT #5	133897
#7	#6 AND #3	146
#8	limit S7 (English language , yr="1990 -Current")	99

4. MEDLINE search through EbscoHos

Search Date 17/3/2017		
#	Search Terms	Results
S1	((TI hand or TI hands) N3 (TI activit* or TI abilit* or TI function* or TI perform* or TI skill* or TI impair* or TI disabilit*)) OR ((AB hand or AB hands) N3 (AB activit* or AB abilit* or AB function* or AB perform* or AB skill* or AB impair* or AB disabilit*))	20,327
S2	((MH "Hand+") OR (MH "Hand Deformities") OR (MH "Hand Strength")) AND ((TI ADL or TI “daily activit*” or TI “activity limitation*” or TI “activities of daily living”) OR (AB ADL or AB “daily activit” or AB “activity limitation*” or AB “activities of daily living”))	676
S3	S1 OR S2	20,759
S4	(MH "Arthritis, Rheumatoid") or (TI RA) or (AB RA) or (TI "Rheumatoid Arthritis") or (AB "Rheumatoid Arthritis")	133,508
S5	(MH "Arthritis, Juvenile Rheumatoid") or (MH "Arthritis, Juvenile") or (TI "Juvenile Arthritis") or (AB "Juvenile Arthritis")	9,184
S6	S4 NOT S5	132,289
S7	S3 AND S6	542
S8	limit S7 (English language , yr="1990 -Current")	395

5. PsycINFO search through EbscoHos

Search Date 17/3/2017		
#	Search Terms	Results
S1	((TI hand or TI hands) N3 (TI activit* or TI abilit* or TI function* or TI perform* or TI skill* or TI impair* or TI disabilit*)) OR ((AB hand or AB hands) N3 (AB activit* or AB abilit* or AB function* or AB perform* or AB skill* or AB impair* or AB disabilit*))	5,870
S2	((DE "Hand (Anatomy)" or hand*) AND ((TI ADL or TI “daily activit*” or TI “activity limitation*” or TI “activities of daily living”) OR (AB ADL or AB “daily activit*” or AB “activity limitation*” or AB “activities of daily living”))	923
S3	S1 OR S2	6,633
S4	DE "Rheumatoid Arthritis" or (TI RA) or (AB RA) or (TI "Rheumatoid Arthritis") or (AB "Rheumatoid Arthritis")	3,886
S5	"Arthritis, Juvenile"	162
S6	S4 NOT S5	3,820
S7	S3 AND S6	20
S8	limit S7 (English language , yr="1990 -Current")	18

6. AMED search through EbscoHos

Search Date 17/3/2017		
#	Search Terms	Results
S1	(TI hand or TI hands) N3 (TI activit* or TI abilit* or TI function* or TI perform* or TI skill* or TI impair* or TI disabilit*)) OR ((AB hand or AB hands) N3 (AB activit* or AB abilit* or AB function* or AB perform* or AB skill* or AB impair* or AB disabilit*))	995
S2	(hand*) AND ((TI ADL or TI “daily activit*” or TI “activity limitation*” or TI “activities of daily living”) OR (AB ADL or AB “daily activit*” or AB “activity limitation*” or AB “activities of daily living”))	334
S3	S1 OR S2	1,213
S4	"Rheumatoid Arthritis" or (TI RA) or (AB RA) or (TI "Rheumatoid Arthritis") or (AB "Rheumatoid Arthritis")	1,728
S5	"Arthritis, Juvenile"	104
S6	S4 NOT S5	1,695
S7	S3 AND S6	59
S8	limit S7 (English language , yr="1990 -Current")	54

Field codes	Description
*	At the end of a term indicates that this term has been truncated (i.e. multiple endings)
ti,ab	Indicates a search for a term in title/abstract
/	MeSH heading
adj, N , NEAR	Words have to appear next to each other.
exp	Explode the subject heading, to retrieve more specific terms
TS	Topic
DE	Descriptors

Appendix F Association between hand function and all factors

1. Strength

Measure	Study	Number of trials	Reporting	HF assessment	Association found (strength of association)	No association found
Lateral pinch strength	Dogu et al. (2013)	Three consecutive measures	Mean value of both hands	DHI	(*r*=−.402, *p*=.0001)	
	DedeoĞLu et al. (2013)	Three consecutive measures	Mean value of both hands	DHI	(*r*=−.640, *p*<.00)	
	Sahin et al. (2006)	Three consecutive measures	DH	SHFT	(*r*=.558, *p*=0.001)	
				DHI	(*r*=−.49, *p*=0.001)	
	Özeri et al. (2008)	Not reported	Mean value of both hands	DHI		(*r*=−.359, *p*>.05)
Tip pinch strength	Dogu et al. (2013)	Three consecutive measures	Mean value of both hands	DHI	(*r*=−.448, *p*=.0001)	
	DedeoĞLu et al. (2013)	Three consecutive measures	Mean value of both hands	DHI	(*r*=−.640, *p*<.001)	
	Eberhardt et al. (2008)	One trial (maximal during 10s)	Mean value of both hands	GAT	(*r*=−.35, *p*<.05)	
	Andrade et al. (2016)	Not reported	DH			(*p*>.05)
Tripod pinch strength	Adams et al. (2004)	Three consecutive measures	DH and NDH	DASH	DH (*r*=−.742, *p*<.001); NDH (*r*=−.646, *p*<.001)	
				GAT	DH (*r*=−.802, *p*<.001); NDH (*r*=−.637, *p*<.001)	
	Dogu et al. (2013)	Three consecutive measures	Mean value of both hands	DHI	(*r*=−.344, *p*=.0001)	
	DedeoĞLu et al. (2013)	Three consecutive measures	Mean value of both hands	DHI	(*r*=−.653, *p*<.001)	

Appendix F

Measure	Study	Number of trials	Reporting	HF assessment	Association found (strength of association)	No association found
Power grip strength	Andrade et al. (2016)	Not reported	DH	SODA	(Beta=0.46 $p=.016$)	
	Kinikli et al. (2016)	Three consecutive measures	Mean value of both hands	DHI	($r=-.432$, $p=.019$)	
	BİRcan et al. (2014)	Three consecutive measures	DH and NDH	GAT	DH ($r=-.505$, $p<.01$); NDH ($r=-.399$, $p<.01$)	
	Durmus et al. (2013)	Three consecutive measures	Rt. and Lt.	DASH	Rt. ($r=-.492$, $p=.0001$); Lt ($r=-.412$, $p=.0001$)	
				MHQ	Rt. ($r=.526$, $p=.0001$); Lt. ($r=.573$, $p=.0001$)	
	Dogu et al. (2013)	Three consecutive measures	Mean value of both hands	DHI	($r=-.497$, $p=.0001$)	
	DedeoĞLu et al. (2013)	Three consecutive measures	Mean value of both hands	DHI	($r=-.687$, $p<.001$)	
	Özeri et al. (2008)	One trial	Mean value of both hands	DHI	($r=-.780$, $p<.01$)	
	Eberhardt et al. (2008)	One trial (maximal during 10s)	Mean value of both hands	GAT	($r=-.50$, $p<.01$)	
	Sahin et al. (2006)	Three consecutive measures	DH	SHFT	($r=.558$, $p=.0001$)	
				DHI	($r=-.49$, $p=.0001$)	
	van Lankveld et al. (1998)	Three consecutive measures	Mean value of both hands	SODA	($r=.46$, $p<.01$)	
	Adams et al. (2004)	Three consecutive measures	DH and NDH	DASH	DH ($r=-.810$, $p<.001$); NDH ($r=-.755$, $p<.001$)	
				GAT	DH ($r=-.773$, $p<.001$); NDH ($r=-.710$, $p<.001$)	

2. Range of motion

Anatomical region	Study	Measurement method	Measurement method	Movement evaluated	Reporting	HF assessment	Association found (strength of association)	No association found
Wrist	van Lankveld et al. (1998)	Individual joint motion (degrees)	Not reported	Extension, Flexion Abduction, Adduction, Pronation, Supination	Mean value of both hands	SODA	Extension (*r*=.36, *p*<.01), Flexion (*r*=.30, *p*<.01), Abduction (*r*=.36, *p*<.01), Adduction (*r*=.23, *p*<.05), Pronation (*r*=.37, *p*<.01), Supination (*r*=.28, *p*<.01)	
	Özeri et al. (2008)	Individual joint motion (degrees)	Not reported	Flexion-extension	DH	DHI	DH (*r*=−.463, *p*<.05)	
	Adams et al. (2004)	Total active motion (degrees)	Active	Flexion-extension	DH and NDH	DASH	DH (*r*=−.501, *p*=.002)	NDH (*r*=−.206, *p*=.229)
						GAT	DH (*r*=−.457, *p*=.005)	NDH (*r*=−.208, *p*=.224)
Fingers	O'Connor et al. (1999)	Movement deficits (centimetres)	Active	Flexion deficit Extension deficit	DH and NDH	SHFT	DH flexion deficit (*r*=−.50, *p*=.01) DH extension deficit (*r*=−.55, *p*<.01) NDH extension deficit (*r*=−.71, *p*<.01)	NDH flexion deficit (*r*=−.37, *p*=0.07)
						SODA	DH flexion deficit (*r*=−.71, *p*<.01) NDH flexion deficit (*r*=−.68, *p*<.01) DH extension deficit (*r*=−.60, *p*<.01) NDH extension deficit (*r*=−.85, *p*<.01)	

Appendix F

Anatomical region	Study	Measurement method	Measurement method	Movement evaluated	Reporting	HF assessment	Association found (strength of association)	No association found
Fingers	BİRcan et al. (2014)	Movement deficits (centimetres)	Active	Flexion deficit	DH and NDH	GAT	DH ($r=.26$, $p<.05$)	NDH ($r=.105$, $p>.05$)
	van Lankveld et al. (1998)	Movement deficits (centimetres)	Not reported	Flexion deficit of finger II-V	Mean value of both hands	SODA	Index finger ($r=-.30$, $p<.01$) Middle finger ($r=-.32$, $p<.01$) Ring finger ($r=-.34$, $p<.01$) Little finger ($r=-.37$, $p<.01$)	
	Özeri et al. (2008)	Individual joint motion (degrees)	Not reported	Flexion-extension of MCP, PIP, and DIP	DH	DHI		MCP ($r=.038$, $p>.05$) PIP ($r=-.238$, $p>.05$) DIP ($r=-.102$, $p>.05$)
Thumb	van Lankveld et al. (1998)	Movement deficits (centimetres)	Not reported	Flexion deficit	Mean value of both hands	SODA	($r=-.38$, $p<.01$)	
Hand and upper limb Overall ROM	Andrade et al. (2016)	Observational grading system	Not reported	Overall hand and upper limb	DH		Hand overall ROM (Beta=−4.23, $p=.018$)	Upper limb overall ROM (p>.05)

3. Disease activity

Measure	Study	Measurement method	HF assessment	Association found (strength of association)	No association found
Composite score	Belghali et al. (2017)	DAS28	bMHQ	Rt.(*r*=−.53, *p*=.022); Lt.(*r*=−.47, *p*=.032)	
	BİRcan et al. (2014)	DAS28	GAT	(*r*=.351, *p*<.01)	
	Durmus et al. (2013)	DAS28	DASH	(*r*=.618, *p*=.0001)	
			MHQ	(*r*=−.615, *p*=.0001)	
	Aktekin et al. (2011)	DAS28; SDAI; CDAI	DASH	DAS28 (*r*=.672, *p*<.05); SDAI (*r*=.586, *p*<.05); CDAI (*r*=.565, *p*<.05)	
	Birtane et al. (2008)	DAS28	DHI	(*r*=.434, *p*=.002)	
	van Lankveld et al. (1999)	DAS28	SODA	(*r*=−.32, *p*<.01)	
	DedeoĞLu et al. (2013)	DAS28	DHI	(*r*=.615, *p*=.000)	
	Eberhardt et al. (2008)	DAS28	GAT		(*r*=−.07, *p*>.05)
Swollen joint count	Durmus et al. (2013)	DAS28- clinical examination	DASH	(*r*=.380, *p*=.01)	
			MHQ	(*r*=−.537, *p*=.0001)	
	Aktekin et al. (2011)	DAS28- clinical examination	DASH	(*r*=.437, *p*<.05)	
	Özeri et al. (2008)	Grading system (not clear which joints evaluated)	DHI		(*r*=.153, *p*>.05)
	van Lankveld et al. (1998)	DAS28- clinical examination	SODA		(*r*=−.05, *p*>.05)
Tender Joint count	Durmus et al. (2013)	DAS28- clinical examination	DASH	(*r*=.578, *p*=.0001)	
			MHQ	(*r*=−.610, *p*=.0001)	
	Aktekin et al. (2011)	DAS28- clinical examination	DASH	(*r*=.585, *p*<.05)	
	Özeri et al. (2008)	Ritchie Articular Index	DHI	(*r*=.454, *p*<.05)	
	van Lankveld et al. (1998)	DAS28- clinical examination	SODA	(*r*=−.56, *p*<.01)	

Measure	**Study**	**Measurement method**	**HF assessment**	**Association found (strength of association)**	**No association found**
ESR	Belghali et al. (2017)	Laboratory	bMHQ	Rt. (*r*=−.38, *p*=.000); Lt. (*r*=−.35, *p*=.000)	
	Durmus et al. (2013)	Laboratory	DASH	(*r*=.281, *p*=.012)	
			MHQ		(*r*=−.211, *p*=.060)
	Aktekin et al. (2011)	Laboratory	DASH	(*r*=.207, *p*<.05)	
	Özeri et al. (2008)	Laboratory	DHI		(*r*=.233, *p*>.05)
	van Lankveld et al. (1998)	Laboratory	SODA		(*r*=−.04, *p*>.05)
CRP	Durmus et al. (2013)	Laboratory	DASH		(*r*=.188, *p*=.095)
			MHQ	(*r*=−.235, *p*=.036)	
	Aktekin et al. (2011)	Laboratory	DASH	(*r*=.238, *p*<.05)	
	Özeri et al. (2008)	Laboratory	DHI	(*r*=.509, *p*<.05)	
Patient's global assessment	Durmus et al. (2013)	VAS	DASH	(*r*=.592, *p*<.001)	
			MHQ	(*r*=−.568, *p*<.001)	
	Aktekin et al. (2011)	VAS	DASH	(*r*=.194, *p*<.05)	
	Özeri et al. (2008)	Not reported	DHI	(*r*=.649, *p*<.01)	
Physician's global assessment	Aktekin et al. (2011)	VAS	DASH	(*r*=.645, *p*<.05)	

4. Pain

Measure	Study	Measurement method	HF assessment	Association found	No association found
Bodily pain	Durmus et al. (2013)	SF-36 (pain scale)	DASH	(*r*=−.678, *p*=.0001)	
			MHQ	(*r*=.477, *p*=.0001)	
	DedeoĞLu et al. (2013)	VAS	DHI	(*r*=.658, *p*<.001)	
	van Lankveld et al. (1998)	VAS Pain scale of IRGL	SODA	VAS (*r*=−.53, *p*<.01); IRGL (*r*=−.39, *p*<.01)	
	Aktekin et al. (2011)	SF-36 (pain scale)	DASH	(*r*=−.759, *p*<.05)	
Hand pain during activity	Andrade et al. (2016)	Sum of painful SODA tasks	SODA		(*p*>.05)
	BİRcan et al. (2014)	VAS	GAT	(*r*=.261, *p*<.05)	
	Durmus et al. (2013)	VAS	DASH	(*r*=.603, *p*=.0001)	
			MHQ	(*r*=−.564, *p*=.0001)	
	O'Connor et al. (1999)	Sum of painful SODA tasks	SODA	(*r*=−.42, *p*=.04)	
			SHFT		(*r*=−.12, *p*=.58)
	van Lankveld et al. (1998)	Sum of painful SODA tasks	SODA	(*r*=−.54, *p*<.01)	
Hand pain at rest	Durmus et al. (2013)	VAS	DASH	(*r*=.617, *p*<.001)	
			MHQ	(*r*=−.566, *p*<.01)	
	Özeri et al. (2008)	VAS	DHI	(*r*=.543, *p*<.01)	
	BİRcan et al. (2014)	VAS	GAT		(*r*=.006, *p*>.05)
	O'Connor et al. (1999)		SODA		DH (*r*=−.38, *p*=.06); NDH (*r*=−.19, *p*=.37)
			SHFT		DH (*r*=−.39, *p*=.06); NDH (*r*=−.30, *p*=.06)
Composite pain score	(van Lankveld et al. 1999)	Sum of painful SODA tasks, VAS and IRGL pain scale	SODA	(*r*=−.560, *p*<.01)	

5. Deformity

Measure	Study	Measurement method	HF assessment	Association found (strength of association)	No association found
Presence and count of deformities	Belghali et al. (2017)	Presence of deformity in both hands	bMHQ	Rt.(*r*=−.80, *p*=.000); Lt.(*r*=−.84, *p*=.000)	
	Erol et al. (2016)	Presence of deformity in DH	DHI	(*p*=.04)	
	Andrade et al. (2016)	Presence of deformity in DH	SODA	(Beta=0.20, *p*<.0001)	
	van Lankveld et al. (1998)	Number of deformities in both hands	SODA	(*r*=−.36, *p*<.01)	
	BİRcan et al. (2014)	Presence of deformity in both hands	GAT		(*p*>.05)
Ulnar deviation	Sahin et al. (2006)	Goniometer (degrees)	SHFT	DH (*r*=−.527, *p*=.0001)	
			DHI	DH (*r*=.413, *p*=.05)	
	Adams et al. (2004)	Goniometer (degrees)	GAT	DH (*r*=.353, *p*=.035); NDH (*r*=.517, *p*=.001)	
			DASH		DH (*r*=.302, *p*=.073); NDH (*r*=.189, *p*=.269)
	O'Connor et al. (1999)	Goniometer (degrees)	GAT	DH (*r*=−.64, *p*<.01); NDH (*r*=−.57, *p*<.01)	
			SHFT		DH (*r*=−.35, *p*=.08); NDH (*r*=−.25, *p*=.22)

6. Structural damage

Measure	Study	Measurement method	HF assessment	Association found (strength of association)	No association found
Radiographic	Belghali et al. (2017)	Sharp score	bMHQ		*p*>.05
	Dogu et al. (2013)	Modified Sharp score	DHI	Both hands (*r*=.231, *p*=.03	
	DedeoĞLu et al. (2013)	Modified Sharp score	DHI	Both hands (*r*=.370, *p*<.001)	
	Özeri et al. (2008)	Modified Sharp score	DHI	Both hands (*r*=.517, *p*=.019)	
	Birtane et al. (2008)	Modified Larsen score	DHI		(*r*=.052, *p*=.784)
	Sahin et al. (2006)	Modified Sharp score	DHI	Both hands (*r*=.37, *p*<.05)	
			SHFT	(*r*=−.72, *p*<.0001)	
	van Lankveld et al. (1998)	Larsen score	SODA	(*r*=−.28, *p*<.05)	
MRI	Erol et al. (2016)	Grading system of McQueen et al. (1998)	DHI	Tenosynovitis score (*r*=.522, *p*=.003)	Erosion score (*r*=.020, *p*=.912); bone edema score (*r*=.165, *p*=.358); synovitis score (*r*=.327, *p*=.073)
Clinical examination	DedeoĞLu et al. (2013)	Rheumatoid Arthritis Articular Damage (RAAD)	DHI	(*r*=.438, *p*<.001)	

7. Vitality, mental health, stiffness, fatigue, dexterity, and functional mobility

Measure	Study	Measurement method	HF assessment	Association found (strength of association)	No association found
Vitality	Andrade et al. (2016)	SF-36 (vitality scale)	SODA		(p>.05)
	Durmus et al. (2013)	SF-36 (vitality scale)	DASH	(r=−.538, p=.0001)	
			MHQ	(r=.456, p=.0001)	
	Aktekin et al. (2011)	SF-36 (vitality scale)	DASH	(r=−.335, p<.05)	
Mental health	Andrade et al. (2016)	SF-36 (mental health scale)	SODA	(Beta=.20, p<.0001)	
	Durmus et al. (2013)	SF-36 (mental health scale)	DASH	(r=−.468, p=.0001)	
			MHQ	(r=.456, p=.0001)	
	Aktekin et al. (2011)	SF-36 (mental health scale)	DASH	(r=−.423, p<.05)	
Stiffness	Andrade et al. (2016)	Intensity (VAS)	SODA		(p>.05)
	BİRcan et al. (2014)	Duration (time)	GAT	(r=.331, p<0.01)	
		Intensity (VAS)		(r=.442, p<0.01)	
	Özeri et al. (2008)	Duration (time)	DHI		(r=.162, p>.05)
Fatigue	Andrade et al. (2016)	VAS	SODA		(p>.05)
Dexterity	Andrade et al. (2016)	Minnesota Rate of Manipulation Test	SODA		(p>.05)
Functional mobility	DedeoĞLu et al. (2013)	Signals of functional impairment (SOFI)	DHI	(r=−.643, p<.001)	
	Özeri et al. (2008)	Keitel Functional Index (hand items)	DHI	(r=.628, p=.002)	
	Eberhardt et al. (2008)	Signals of functional impairment (SOFI) (hand items)	GAT	(r=.51, p<.01)	
	Jonsson and Larsson (1990)	Locomotion score (Larsson and Jonsson 1989)	SHFT	(r=.84, p<.05)	

8. Functional status factors

Measure	Study	Measurement method	HF assessment	Association found (strength of association)	No association found
Physical functioning	Belghali et al. (2017)	HAQ	bMHQ		(*p*>.05)
	BİRcan et al. (2014)	HAQ	GAT	(*r*=.639, *p*<.01)	
	Durmus et al. (2013)	HAQ and SF-36 (physical functioning subscale)	MHQ	HAQ (r=−.732, *p*<.001), SF-36 (*r*=.520, *p*<.001)	
			DASH	HAQ (*r*=.844, *p*<.001), SF-36 (*r*=−.580, *p*<.001)	
	DedeoĞLu et al. (2013)	HAQ	DHI	(*r*=.876, *p*<.001)	
	Aktekin et al. (2011)	HAQ and SF-36 (physical functioning subscale)	DASH	HAQ (*r*=.833, p<.05), SF36 (*r*=−.699, *p*<.05)	
	Eberhardt et al. (2008)	HAQ	GAT	(*r*=.52, *p*<.01)	
	Sahin et al. (2006)	HAQ	DHI	(*r*=.86, *p*<.0001)	
			SHFT	(*r*=−.68, *p*<.0001)	
	O'Connor et al. (1999)	HAQ	SODA	(*r*=−.41, *p*=.05)	
			SHFT	(*r*=−.49, *p*=.01)	
Social functioning	Durmus et al. (2013)	SF-36 (social functioning subscale)	MHQ	(*r*=.470, *p*<.0001)	
			DASH	(*r*=−.549, *p*<.0001)	
	Aktekin et al. (2011)		DASH	(*r*=−.508, *p*<.05)	
Emotional role	Durmus et al. (2013)	SF-36 (emotional scale)	DASH	(*r*=−.538, *p*=.0001	
			MHQ	(r=.254, *p*=.023)	
	Aktekin et al. (2011)	SF-36 (emotional scale)	DASH	(*r*=−.588, *p*<.05)	

9. Personal factors

Factor	Association found		No association found[†]
	Study	Strength of association	Study
Age	Belghali et al. (2017) Adams et al. (2005b) Jonsson and Larsson (1990)	Right hand (r=−.33, p=.003); Left hand (r=−.31, p=.003) r=.054, p<.05 Women (r=.4, p<.05) ; Men (r=.38, p<.05)	Andrade et al. (2016) Birtane et al. (2008) van Lankveld et al. (1999) and van Lankveld et al. (1998) [††] O'Connor et al. (1999)
Gender			Belghali et al. (2017) Andrade et al. (2016) BİRcan et al. (2014) Birtane et al. (2008) van Lankveld et al. (1999) and van Lankveld et al. (1998) [††] O'Connor et al. (1999) Jonsson and Larsson (1990)
Educational level			Belghali et al. (2017)
Laterality			Belghali et al. (2017)
Coping			
Coping (pacing*)			van Lankveld et al. (1999)
Coping (decreasing activity**)	van Lankveld et al. (1999)	r=−.37, p<.01	

†: p>0.05; ††: The study of van Lankveld et al. (1999) and van Lankveld et al. (1998) were considered as one body of evidence, since both studies reported the findings from the same sample of RA patients with regard to the association between SODA and disease duration, age and gender.; *Pacing: tendency to adapt the level of physical activity when confronted with limitation; ** Decreasing activity: tendency to avoid physical activity when confronted with pain.

10. Environmental factors

Factor	Association found		No association found†
	Study	Strength of association	Study
Work situation			Andrade et al. (2016)
Work activity			Andrade et al. (2016) Belghali et al. (2017) Erol et al. (2016)
Treatment			
Hand-specific treatments	Belghali et al. (2017)	PT: RH (r=.71, p=.034); LH (r=.61, p=.034) OT: RH (r=.48, p=.048); LH (r=.39, p=.048) Splint: RH (r=.31, p=.02); LH (r=.31, p=.02) Surgery: RH (r=.47, p=.012); LH (r=.45, p=.012)	
Medication (symptomatic and conventional DMARDs)			Belghali et al. (2017)
Biological Treatment	Belghali et al. (2017)	RH (r=.22, p=.0024); LH (r=.22, p=.022)	
Living condition			Belghali et al. (2017)
Treatment cost			Jonsson and Larsson (1990)
Days in hospital	Jonsson and Larsson (1990)	r=.6, p<.05	

†: p>0.05; PT: Physiotherapy; OT: Occupational Therapy; RH: Right Hand; LT: left Hand; DMARDs: Disease-modifying anti-rheumatic drugs.

11. Health condition factors

Factor	Study	HF assessment	Association found (strength of association)	No association found
Disease duration	Belghali et al. (2017)	bMHQ	Rt.($r=-.33$, $p=.003$); Lt. ($r=-.31$, $p=.003$)	
	Andrade et al. (2016)	SODA		($p>.05$)
	BİRcan et al. (2014)	GAT		($r=.063$, $p>.05$)
	Adams et al. (2005b)	DASH	($r=.091$, $p<.05$)	
	O'Connor et al. (1999)	SHFT	($r=-.48$, $p<.05$	
		SODA	($r=-.62$, $p<.05$)	
	DedeoĞLu et al. (2013)	DHI	($r=.380$, $p<.001$)	
	Horsten et al. (2010)	DASH		($p=.94$) between groups
	Birtane et al. (2008)	DHI		($r=.127$, $p=.505$)
	(Jonsson and Larsson 1990)	SHFT	($r=-.54$, $p<.05$)	
	van Lankveld et al. (1999) and van Lankveld et al. (1998)	SODA	($r=-.20$, $p<.05$)	
	Özeri et al. (2008)	DHI	($r=.604$, $p<.01$)	
Rheumatoid factor (RF)	Belghali et al. (2017)	bMHQ		($p>.05$)
	Erol et al. (2016)	DHI		($p>.05$)
	DedeoĞLu et al. (2013)	DHI		($p>.05$)
Extra-articular manifestations	Belghali et al. (2017)	bMHQ		($p>.05$)
	Andrade et al. (2016)	SODA		($p>.05$)
ACR functional classification	Andrade et al. (2016)	SODA		($p>.05$)
General health status (SF-36)	Andrade et al. (2016)	SODA		($p>.05$)
	Durmus et al. (2013)	DASH	($r=-.623$, $p=.0001$)	
		MHQ	($r=.466$, $p=.0001$)	
	Aktekin et al. (2011)	DASH	($r=-.621$, $p<.05$)	

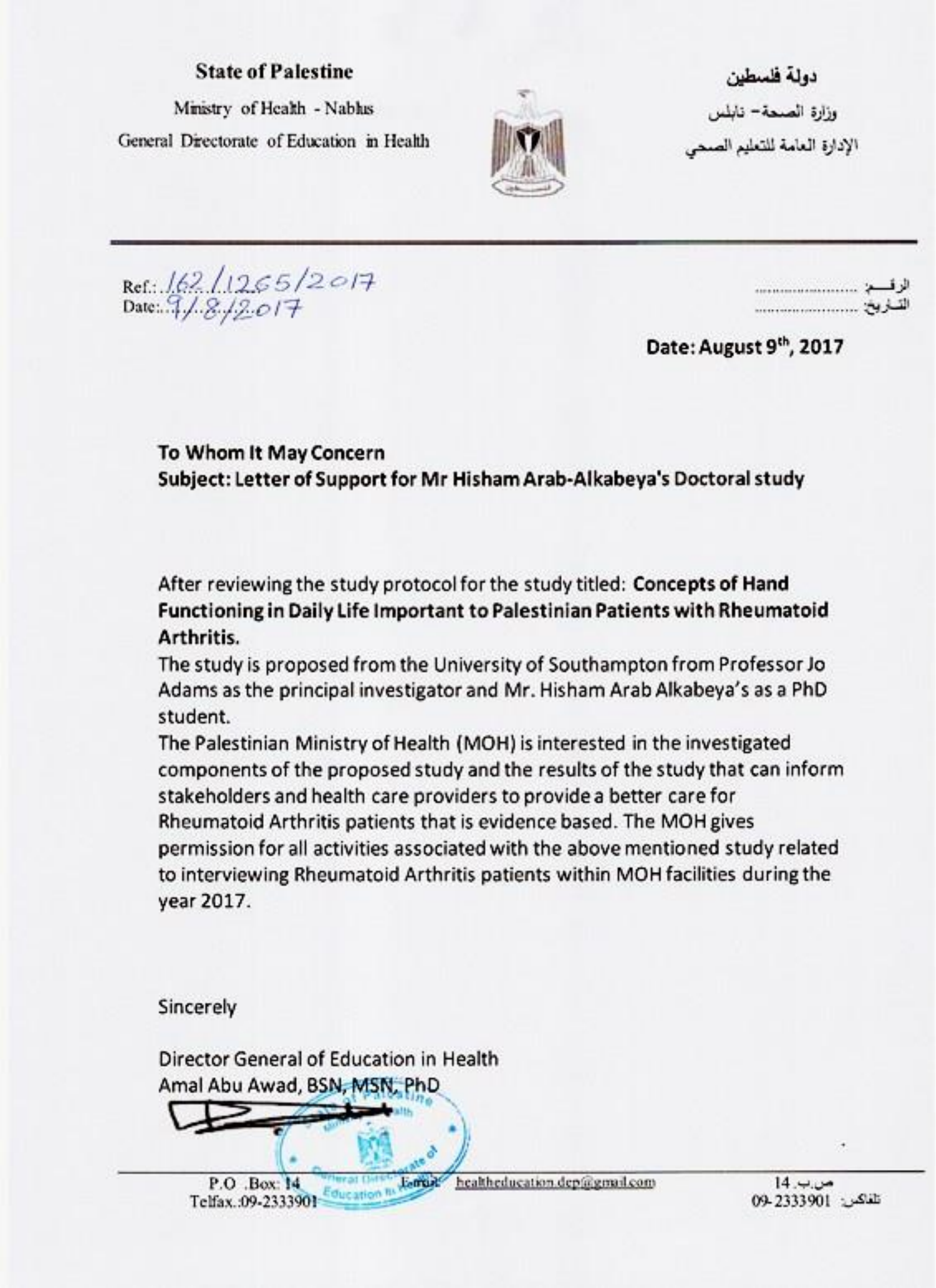
Appendix G COREQ checklist (focus group study)

Item	Checklist item	Response	Section
Domain 1: Research team and reflexivity			
Personal Characteristics			
Facilitator	Which author conducted the focus group?	Thesis author (lead researcher)	Section 5.5.3.1
Credentials	What were the researcher's credentials?	PhD student	Section 5.5.3.1 & 7.7
Occupation	What was their occupation at the time of the study?	Lecturer/ PhD student	Section 5.5.3.1
Gender	Was the researcher male or female?	Male	
Experience and training	What experience or training did the researcher have?	The researcher approached this research as a novice qualitative researcher. Specific trainings and support are reported.	Section 5.5.3.1
Relationship with participants			
Relationship established	Was a relationship established prior to study commencement?	Participants were not known to the researcher	Section 5.5.7
Participant knowledge of the interviewer	What did the participants know about the researcher?	The researcher introduced himself as a postgraduate student to the participants.	Section 5.6.1
Interviewer characteristics	What characteristics were reported about the facilitator?	Background and characteristics are outlined	Section 5.5.3.1 & 7.7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	What methodological orientation was stated to underpin the study?	Theoretical paradigm of subtle realism is discussed	Section 5.4
Participant selection			
Sampling	How were participants selected?	Purposive sampling strategy and criteria are reported	Section 5.5.5 & 5.5.7
Method of approach	How were participants approached?	By invitation letter	Section 5.5.9.1
Sample size	How many participants were in the study?	20	Section 5.7.1
Non-participation	How many people refused to participate or dropped out?	25 did not respond to the invitation letter, and two male participants dropped out	Section 5.7.1
Setting			
Setting of data collection	Where was the data collected?	Focus group sessions were conducted at Arab American University in Palestine.	Section 5.5.9.2
Presence of non-participants	Was as anyone else present besides the participants and researchers?	Only the note-taker was present in all focus group sessions	Section 5.5.3.3
Description of sample	What are the important characteristics of the sample?	Demographic data are reported	Section 5.7.1

Item	Checklist item	Response	Section
Data collection			
Interview guide	Were questions, prompts, guides provided by the author? Was it pilot tested?	A pre-piloted discussion guide was used throughout.	Section 5.5.8, 5.5.3.3 & Table 5-1
Repeat interview	Were repeat interviews carried out?	No repeat interviews were performed	Section 5.5.1
Audio/ visual recording	Did the research use audio or visual recording to collect the data?	Focus group session were audio recorded	Section 5.5.3.3 & 5.5.10.1
Filed notes	Were field notes made during and/or after the focus group?	Notes were made during and after the focus group sessions	Section 5.5.9.2
Duration	What was the duration of the focus group?	Duration of the focus groups is reported	Section 5.7.1
Data saturation	Was data saturation discussed?	Data saturation is discussed and outlined	Section 5.7.2
Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Transcripts were reviewed by the lead researcher, but not returned to participants. This is acknowledged.	Section 5.6.1
Domain 3: Analysis and findings			
Data analysis			
Number of data coders	How many data coders coded the data?	Data were coded by the lead author and verified by the not-taker.	Section 5.5.10.3
Description of coding tree	Did authors provide a description of the coding tree?	The process of forming the concepts is discussed and an illustrative example is shown.	Section 5.5.10.3, Table 5-5 & Figure 5-4
Derivation of themes	Were themes identified in advance or derived from the data?	Concepts were derived from the data	Section 5.5.10.3
Software	What software, if applicable, was used to manage the data?	No software was used, but Microsoft Word 2016 was used to manage the data	Section 5.5.10.2
Participant checking	Did participants provide feedback on the findings?	No feedback was provided by the participants. This is acknowledged	Section 5.6.1
Reporting			
Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?	Quotations were provided for the identified concepts and were identified by the focus group session and participant number within the focus group	Section 5.7
Data and findings consistent	Was there any consistency between the data presented and the findings?	The concepts were reflective of the quotation. The conclusions and recommendations were reflective of the findings	Section 5.7.3 - 5.7.6 & 5.9
Clarity of major themes	Were major themes clearly presented in the findings?	Major concepts and sub-concepts are presented	Section 5.7.3 - 5.7.6, & Figure 5-5 - 5-9
Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Diverse cases were presented	Section 5.7.4 - 5.7.6

From: Tong A, Sainsbury P and Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care* 19(6): 349-357

Appendix H Ethical approval for the focus group study in Palestine



State of Palestine
Ministry of Health - Nablus
General Directorate of Education in Health

دولة فلسطين
وزارة الصحة – نابلس
الإدارة العامة للتعليم الصحي

Ref.: 162/1265/2017
Date: 9/8/2017

الرقم: ....
التاريخ: ....

Date: August 9th, 2017

To Whom It May Concern
Subject: Letter of Support for Mr Hisham Arab-Alkabeya's Doctoral study

After reviewing the study protocol for the study titled: **Concepts of Hand Functioning in Daily Life Important to Palestinian Patients with Rheumatoid Arthritis.**
The study is proposed from the University of Southampton from Professor Jo Adams as the principal investigator and Mr. Hisham Arab Alkabeya's as a PhD student.
The Palestinian Ministry of Health (MOH) is interested in the investigated components of the proposed study and the results of the study that can inform stakeholders and health care providers to provide a better care for Rheumatoid Arthritis patients that is evidence based. The MOH gives permission for all activities associated with the above mentioned study related to interviewing Rheumatoid Arthritis patients within MOH facilities during the year 2017.

Sincerely

Director General of Education in Health
Amal Abu Awad, BSN, MSN, PhD

P.O .Box: 14
Telfax.:09-2333901
E-mail: healtheducation.dep@gmail.com
ص.ب. 14
تلفاكس: 09-2333901

Appendix I Focus group study participant documents

1. Invitation letter

a) English version

Study title: Concepts of Hand Functioning in Daily Life Important to Palestinian Patients with Rheumatoid Arthritis

(Ethics reference: Palestine 162/1265/2017; University of Southampton 30278)

Dear,

I am writing you on behalf of myself and my academic supervisors Prof. Jo Adams and Dr. Ann-Marie Hughes to formally ask if you would be interested in taking part in a research study, we are conducting. We are looking to explore daily living activities and social life situations you have experienced difficulties with due to rheumatoid arthritis affecting your hand. Furthermore, we are looking to explore what has helped you to manage your hand problems. We understand that you are an expert in these matters and want to be able to learn from you. This will help us to improve treatment for people with rheumatoid arthritis in Palestine.

I would like to invite you to take part in a small group discussion session. It would involve you and up to six members of the same gender sharing your experiences together with the researcher, and it will last for between one to two hours. Using a voice recorder, the discussion will be audio recorded. This recording will be destroyed once a written transcript has been made. Please read the information sheet and the consent form enclosed with this letter. The information sheet will help you to decide whether you wish to take part or not. If you are happy to take part, you will be asked to complete the consent form with the assistance of the researcher at the very start of the discussion session. Please do not hesitate to contact me if you need further information or have any questions through the contact details shown below.

I hope you will find this study interesting and thank you very much in advance for your cooperation.

Sincerely,
Hisham Arab Alkabeya
PhD student
Faculty of Health Sciences
University of Southampton
Southampton SO17 1BJ
Tel: +970595637776
Email: H.Arab-Alkabeya@soton.ac.uk

Research supervisors: Professor Jo Adams | Associate professor Ann-Marie Hughes

Invitation letter V1.0 - 24.4.2017

b) Arabic version

UNIVERSITY OF Southampton

مفاهيم الأداء الوظيفي لليدين في الحياة اليومية للمرضى الفلسطينيين الذين يعانون من مرض التهاب المفاصل الروماتزمي

(رقم الموافقه الاخلاقيه للبحث: فلسطين2017/1265/162 جامعة ساوثهامبتون -بريطانيا 30278)

سيدتي / سيدي

انني أكتب لكم نيابة عن نفسي وعن مشرفي الأكاديميين البروفيسور جو آدمز والدكتور آن-ماري هيوز ونود ان نسألك رسميا إذا كنت قد تكون مهتما/ مهتمة في المشاركة في دراسة بحثية نقوم بأجرائها. نحن نتطلع إلى استكشاف التجارب الحياتية لمرضي التهاب الروماتيزم فيما يتعلق في الصعوبات في تنفيذ النشاطات اليومية والمشاركة في الفعاليات الاجتماعية نتيجة مرض الروماتيزم الذي أثر على الأداء الوظيفي لليدين. إضافة الى ذلك فإننا نتطلع الى معرفة ما هي العوامل التي ساعدتك لتدبر مشاكل اليدين لديك. نحن نتفهم ان لديك الخبرة الكافية في هذا المجال وذلك فإننا نود ان نتعلم منك. هذا البحث سوف يساعد في اعداد اهداف علاجية تهم مرضى الروماتيزم الذين يعانون من مشاكل في اليدين إضافة الي المساعدة في اعداد خطط علاجيه مناسبه لمرضى الروماتيزم.

أود أن أدعوكم للمشاركة في حلقة نقاش جماعية مكونه من مجموعة صغيرة من المرضى. وستشمل حلقة النقاش لغاية سته مرضى من نفس الجنس، حيث ستستمر المقابلة من 1-2 ساعة. سنقوم باستخدام جهاز لتسجيل الصوت كي نقوم بتسجيل المقابلة والحوار الذي سيدور ما بين أعضاء المجموعة. ونحيطكم علما بان هذا التسجيل سوف يتلف عند الانتهاء من كتابته من قبل الباحث. يرجى قراءة ورقة المعلومات المرفقة والتي تشمل جميع المعلومات المتعلقة بهذه الدراسة والتي ستساعدك على اتخاذ قرار المشاركة او عدم المشاركة. إذا كنت ترغب في المشاركة في هذه الدراسة فإنك ستقوم بملأ استمارة الموافقة على المشاركة في هذا البحث بمساعده الباحث وذلك قبل اجراء حلقة النقاش الجماعي. من فضلك لا تتردد في الاتصال بي حسب المعلومات المدونة ادناه إذا كنت تريد مزيدا من المعلومات.

كلي امل أن تجد هذه الدراسة مثيرة للاهتمام وشكرا جزيلا لكم مقدما لتعاونكم

مع الاحترام
هشام عرب الكعبية
طالب دكتوراه
جامعة ساوثهامبتون
كلية العلوم الصحبة
البريدي الالكتروني: H.Arab-Alkabeya@soton.ac.uk
هاتف: 972595637776 +

مشرفي البحث : البروفسور جو آدمز | الدكتوره آن-ماري هيوز

دعوه للمشاركه في دراسة V1.0 – 24.4.2017

2. Participant Information Sheet

a) English version

UNIVERSITY OF Southampton

Participant Information Sheet

Study: Concepts of Hand Functioning in Daily Life Important to Palestinian Patients with Rheumatoid Arthritis

(Ethics reference: Palestine 162/1265/2017; University of Southampton 30278)

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?
This study is part of my PhD project at the Faculty of Health Sciences, University of Southampton, UK. I am a registered rehabilitation specialist and an academic at Arab American University-Palestine. The overall aim of this study is to understand the important concepts of hand function for Palestinian patient with Rheumatoid Arthritis. It is well known that patients experience difficulties in daily living activities and social life due to Rheumatoid Arthritis affecting their hands. Unfortunately, little is known about the difficulties in daily living activities and social life Palestinian patients experience due to Rheumatoid Arthritis affecting their hands. Therefore, we would like to find out the impact that rheumatoid arthritis affecting your hands may have on your daily living activities and social life. We are also keen to listen to your experiences about the environmental (e.g. living condition) personal factors (e.g. coping) that impact on your ability to manage your problems in daily living activities and social life due to RA affecting your hand(s). Exploring these issues would facilitate discussion and recommendations on the most appropriate evaluation tool(s) to use in order to facilitate the setting of patient-oriented treatment goals and the establishment of appropriate interventions to the Palestinian Rheumatoid Arthritis patients.

Why have I been chosen?
You have been invited to take part in this study because you have been diagnosed with rheumatoid arthritis; and you have experienced the impact of this disease in your ability to use your hand in everyday activities and social life.

What will happen to me if I take part?
If you want to take part, you will need to contact me on my work phone listed below. You will be invited to come to a group discussion involving you and up to six members of the same gender at the Faculty of Health Sciences, Arab American University at a convenient time and date. The Arab American University campus map is included in this pack, to help you find the room easily. The discussion session will last for about 1-2 hours and you will be with up to six patients of the same gender. Before the group discussion start, you will be asked to give your consent and ask any questions regarding the procedure or any concern you may have. Then, you will be given your travel expenses and asked to sit and help yourself to refreshments. You will be informed about the location of the bathroom and invited to use it prior to the group discussion.
Prior to group discussion the researcher will welcome all group members, provide an overview of the topic of discussion, and explain the group discussion rules. After that, the researcher will start the group discussion where he will ask the group members questions about their experiences of hand functional problems in daily life activities. Then you will have an opportunity to discuss the difficulties you have experienced with the group members. The group discussion will be recorded through using digital audio recorder. The researcher’s colleague will attend the group session and she will be taking notes.

Are there any benefits in my taking part?
There is unlikely to be any personal benefit to you. However, the information obtained from this study will inform health care professionals about what the everyday activities and social life situations Palestinian patients with Rheumatoid Arthritis have experienced difficulties due to Rheumatoid Arthritis affecting their hands. Additionally, it will allow Palestinian health care professionals to select better ways of assessing and treating hands of people with Rheumatoid Arthritis.

Are there any risks involved?

We do not anticipate any risk or harm to you by taking part in this study. This focus group is not intended to be upsetting but may raise issues for you. However, we understand that you may be distressed talking about your condition and the difficulties you have experienced in your daily life. Thus, you are free to withdraw at any time without giving a reason.

Will my participation be confidential?

YES. Your name will not be used in any documentation except the consent form. The researcher will give each person a code number to ensure anonymity and confidentiality. All data will therefore be anonymised. Personal identifiable information given during group discussions such as professional roles, names and places will be omitted or changed in the written transcription, aiming not to disclose identifiable information about participants. We will not use your name in any reports or any other information that could personally identify you. Therefore, you will not be identifiable in any presentation or publications based upon this research. All study documents will be stored in a locked cabinet in the researcher's office at the Faculty of Health Sciences, Arab American University-Palestine. The audio-recorded materials will be transferred and kept in the researcher's password protected laptop. The researcher will keep all data generated from this study in accordance with the University of Southampton research data management policy, which requires that all significant data will be kept for least ten years after the study has finished. Anonymised data will be available for open access in line for University of Southampton and Research Council United Kingdome policy on Open Access Data.

What happens if I change my mind?

If you do not want to continue, you can change your mind any time during the group discussion session. If that happens, just tell the researcher and you will be able to withdraw. You will be supported by the researcher to withdraw and you do not have to give any reason for this. If you wish to withdraw your data, the researcher will remove your contribution.

What happens if something goes wrong?

In the unlikely case of concern or complaint about this study, you should contact the researcher on +972595637776 or +447599623946 or send email to H.Arab-Alkabeya@soton.ac.uk. If you would like to make a complaint about this study or talk to someone outside of the research team you should contact the Research Governance office (Address: University of Southampton, Building 37, Highfield, Southampton SO17 1BJ; Tel: +44(0)2380595058, Email: rgoinfo@soton.ac.uk . If you remain unhappy and wish to complain formally, the Research Governance office can provide you with details about the University of Southampton Complaints procedure.

Where can I get more information?

If you would like to discuss the research, I will be happy to answer questions you might have. Please contact Hisham Arab Alkabeya on +972595637776 or +447599623946, Email to H.Arab-Alkabeya@soton.ac.uk

What should I do next?

If you are interested to take part in this study, you can contact the researcher directly by phone or email to address provided below.

Thank you for taking the time to read this information sheet.
This information sheet is for you to keep.

For further information, please feel free to contact the researcher
Researcher: Hisham Arab Alkabeya, PhD student
Faculty of Health Sciences, University of Southampton, Southampton SO17 1BJ
Tel: +447599623946 (UK), +972595637776 (Palestine)
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   Telephone: (023) 8059 5191
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b) Arabic version

UNIVERSITY OF
Southampton

Participant Information Sheet- Arabic version

معلومات عن الدراسة

مفاهيم الأداء الوظيفي لليدين في الحياة اليومية للمرضى الفلسطينيين الذين يعانون من مرض التهاب المفاصل الروماتزمي

(رقم الموافقه الاخلاقيه للبحث: فلسطين2017/1265/162, بريطانيا30278)

يرجى قراءة هذه المعلومات بعناية قبل اتخاذ قرار بالمشاركة في هذا البحث. إذا كنت ترغب في المشاركة في هذه الدراسة سوف يطلب منك التوقيع على استمارة الموافقة.

ما هو هدف الدراسة؟

هذه الدراسة هي جزء من مشروع الدكتوراه الذي أقوم بدراسته في كلية العلوم الصحية، جامعة ساوثهامبتون -بريطانيا. الباحث الرئيسي لهذه الدراسة هو اخصائي تأهيل وأكاديمي في الجامعة العربية الأمريكية – فلسطين. تهدف هذه الدراسة الى التعرف على مفاهيم تهم المرضى الفلسطينيين الذين يعانون من التهاب المفاصل الروماتيزم فيما يخص الأداء الوظيفي لليدين لتنفيذ الأنشطة اليومية. أن مرضى التهاب المفاصل الروماتزمي يعانون من صعوبات تتعلق في تنفيذ الأنشطة اليومية والمشاركة في الأنشطة الاجتماعية نتيجة تأثير مرض الروماتيزم على الأداء الوظيفي لليدين. في فلسطين نحن لا نعرف كثيرا عن هذه الصعوبات التي يواجها المرضى. بالتالي، فإن هذه الدراسة تهدف الي التعرف على هذه الأنشطة اليومية التي يجد مرضى التهاب المفاصل الروماتيزم صعوبة في تنفيذها اضافة الى التعرف على العوامل البيئية (مثل ظروف المعيشة) او الشخصية (مثل القدرة على التأقلم) التي كان لها دور في تسهيل او عرقلة تنفيذ الأنشطة اليومية والمشاركة في الأنشطة الاجتماعية. ان نتائج هذه الدراسة سوف تساعد كثيرا في وضع واعداد اهداف علاجية لليدين تهم مرضى الروماتيزم، كما انها ستساعد في على تقديم خدمات علاجية مناسبة ومرضية للمرضى.

لماذا تم اختيارك كمشترك في الدراسة؟

لقد وجهت الدعوة لك للمشاركة في هذه الدراسة لأنك تعاني من مرض التهاب المفاصل الروماتيزم، ولديك الخبرة الكافية كيف أثر هذا المرض على قدرتك على استخدام يديك في تنفيذ والمشاركة في الأنشطة اليومية المختلفة .

ماذا سيحدث لك عند المشاركة؟

إذا كنت قررت المشاركة، سوف تحتاج إلى الاتصال في الباحث عن طريق الهاتف او البريد الالكتروني حسب المعلومات الموجودة في نهاية هذه النشرة. بعد ذلك سوف يطلب منك الحضور الي كلية العلوم الصحية في الجامعة العربية الأمريكية في وقت وتاريخ مناسبين ومريحين يتم الاتفاق عليهم لاحقا عند اتصالك بالباحث. الدراسة هي عباره عن حلقة نقاش جماعيه وحوار تستمر لمدة 1-2 ساعة، وتتألف لغاية 6 من المرضى من نفس الجنس .

قبل بداية النقاش سوف يطب منك ان تملأ استمارة الموافقة على المشاركة في البحث بمساعدة الباحث وستتاح لك الفرصة لتسال أي سؤال عن البحث او اية استفسارات أخرى تهمك. ومن ثم سوف تعطى تكاليف السفر ويطلب منك الجلوس والاستمتاع بالضيافة. قبل بداية النقاش سيقوم الباحث بالترحيب بجميع المشاركين ومن ثم سيقوم بإعطاء مقدمه عن موضوع وعن قواعد النقاش والحوار. بعد ذلك سيقوم الباحث بطرح عدد من الأسئلة تتعلق بالتعرف على المشاكل التي واجهتها في تنفيذك ومشاركتك في الأنشطة اليومية والاجتماعية، حيث ستقوم انت وباقي أعضاء المجموعة في حلقة النقاش الجماعية بمناقشة هذه الصعوبات. سيقوم الباحث بالإضافة الى زميلته بأخذ ملاحظات عن النقاش الذي سيدور إضافة الي تسجيل صوتي للمقابلة الجماعية والحوار. سيتم طلب تسجيل الصوت قبل البدء في المقابلة الجماعية.

ما هي الفوائد من المشاركة بالدراسة؟

من غير المحتمل أن يكون هناك أي منفعة شخصية لك من خلال مشاركتك في هذه الدراسة، ومع ذلك، فإن المعلومات التي سيتم الحصول عليها من هذه الدراسة سوف تكون ذات قيمه عالية في تعرف مقدمي الرعاية الصحية والتأهيل على الأنشطة اليومية والفعاليات الاجتماعية التي تواجه مرضى التهاب المفاصل الروماتزمي نتيجة تأثير المرض على اليدين لديهم. بالإضافة إلى ذلك، فإن هذا البحث سيعرف أخصائي الرعاية الصحية على العوامل البيئية والشخصية التي كان لها دور في تسهيل او عرقلة مشاركة وتنفيذ مرضى الروماتيزم للأنشطة اليومية و الاجتماعية. وبالتالي في هذه المعلومات ستمكن اخصائي الرعاية الصحية والتأهيل من استخدام أدوات تقييم مناسبه للمرضى الفلسطينيين الذين يعانون من الروماتيزم ونتيجة لذلك تحسين الخدمات الصحية المقدمة لهم.

ما هي المخاطر من المشاركة بالدراسة؟

نحن لا نتوقع أي خطر أو ضرر لك من خلال المشاركة في هذه الدراسة. ومع ذلك، نحن نتفهم أنه قد تشعر ببعض التوتر عندما تقوم بالتحدث علن حالتك الصحية والصعوبات التي واجهتها في حياتك اليومية نتيجة مرض الروماتيزم. وبالتالي، أنت حر في الانسحاب في أي وقت دون إبداء اية أسباب.

هل ستكون مشاركتي سرية؟

نعم. لن يتم استخدام الأسماء في أي وثائق باستثناء استمارة الموافقة. فإن الباحث سيقوم باستخدام الرموز للدلالة على المشارك وذلك لضمان سريته وعدم الكشف عن هويته. وبالتالي فان جميع البيانات التي سيتم جمعها ستكون بشكل مجهول دون الإشارة الى اية مشارك. خلال النقاش إذا تم ذكر أي معلومات تعريفيه مثل أسماء اشخاص او أماكن فانه سيتم حذفها سواء في عملية كتابة حلقة النقاش الجماعية او في ايه تقارير اخرى وذلك بهدف التقليل من مخاطر ان يتم تتبع أي معلومات ونسبها لأي مشرتك. لن يتم استخدام اسمك في أي تقارير، بدلا عن ذلك سيتم إعطاء كل مشترك رقم يدل عليه وذلك لضمان سريته. الوثائق التابعة لهذا البحث سيتم تخزينها ف في خزانة مقفلة في مكتب الباحث في كلية العلوم الصحية، الجامعة العربية الأمريكية. وسيتم نقل المواد المسجلة الصوت والاحتفاظ بها في جهاز الكمبيوتر المحمول التابع للباحث والمحمي بكلمة مرور سريه لا يعرفها الا الباحث. جميع البيانات التي تم إنشاؤها من هذه الدراسة سيتم الاحتفاظ بها وفقا لسياسة إدارة البيانات البحثية جامعة ساوثهامبتون ، والتي تتطلب أن جميع البيانات سيتم الاحتفاظ بها لمدة عشر سنوات بعد الانتهاء من الدراسة .

ماذا يحدث إذا قمت بتغيير رأيي؟

إذا كنت لا ترغب في الاستمرار، يمكنك تغيير رأيك في أي وقت خلال حلقة النقاش الجماعية. إذا حدث ذلك، فقط أخبر الباحث بذلك وستكون قادر على الانسحاب. سيقوم الباحث بمساعدتك على الانسحاب وذلك دون ان تبدي اية اسباب. إذا كنت ترغب بان يتم حذف بياناتك ومشاركتك سيقوم الباحث بحذفها .

ماذا سيحدث إذا حدث خطأ ما؟

في حال كان لديك اية تحفظات او شكوى على هذه الدراسة، فانه يجب عليك الاتصال بالباحث الرئيسي (هشام عرب الكعبية) لهذه الدراسة على رقم هاتف رقم: 972595637776، أو إرسال بريد إلكتروني إلى H.Arab-Alkabeya@soton.ac.uk. إذا كنت ترغب في تقديم شكوى حول هذه الدراسة أو التحدث إلى شخص من خارج فريق البحث يجب عليك الاتصال بمكتب إدارة البحوث (العنوان: جامعة ساوثهامبتون ، بناية رقم 37، هايفيلد، ساوثمبتونSO17 1BJ ، هاتف: +44 (0) 2380595058، البريد الإلكتروني rgoinfo@soton.ac.uk :إذا كنت لا تزال غير راضي وترغب في تقديم شكوى رسمية، يمكن لمكتب إدارة البحوث ان يزودك بجميع التفاصيل المتعقلة بإجراء الشكاوى في جامعة ساوثهامبتون .

اين يمكنني الحصول على مزيد من المعلومات؟

إذا كنت ترغب في مناقشة هذه الدراسة، سنكون سعداء بالرد على اية أسئلة قد تكون لديكم. يرجى الاتصال على الباحث الرئيسي هشام عرب الكعبية على الرقم: +972595637776 البريد الإلكتروني H.Arab-Alkabeya@soton.ac.uk

ماذا على أن أفعل بعد ذلك؟

إذا كنت ترغب في المشاركة في هذه الدراسة، يمكنك الاتصال بالباحث مباشرة عن طريق الهاتف أو البريد الإلكتروني إلى العنوان المذكور أدناه.

شكرا لك لإعطاء الوقت الكافي لقراءة هذه النشرة من المعلومات. نشرة المعلومات هذه هي لك لتحتفظ بها.

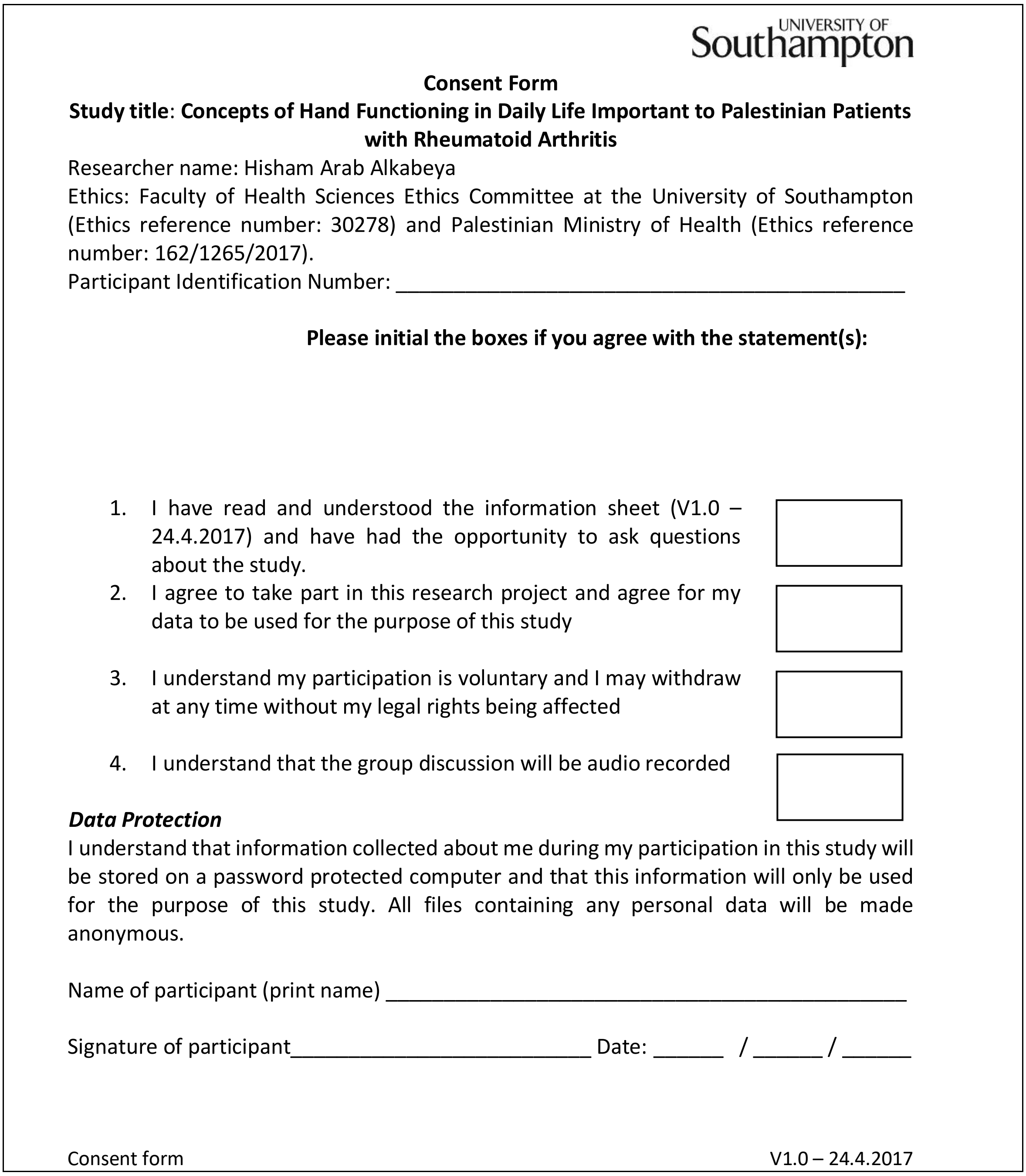
لمزيد من المعلومات، لا تتردد في الاتصال بالباحث
الباحث: هشام عرب الكعبية، طالب دكتوراه، كلية العلوم الصحية , جامعة ساوثهمبتون
تلفون : 00972595637776
بريد الكتروني: H.Arab-Alkabeya@soton.ac.uk

المشرفين:

1. البروفسور جو آدمز ، كلية العلوم الصحية , جامعة ساوثهمبتون
   تلفون :00442380595287
   بريد الكتروني: ja@soton.ac.uk
2. الدكتوره آن-ماري هيوز , كلية العلوم الصحية , جامعة ساوثهمبتون
   تلفون :00442380595191
   بريد الكتروني: A.Hughes@soton.ac.uk

3. Consent form

a) English version



UNIVERSITY OF Southampton

Consent Form

Study title: Concepts of Hand Functioning in Daily Life Important to Palestinian Patients with Rheumatoid Arthritis

Researcher name: Hisham Arab Alkabeya

Ethics: Faculty of Health Sciences Ethics Committee at the University of Southampton (Ethics reference number: 30278) and Palestinian Ministry of Health (Ethics reference number: 162/1265/2017).

Participant Identification Number: ____

Please initial the boxes if you agree with the statement(s):

1. I have read and understood the information sheet (V1.0 – 24.4.2017) and have had the opportunity to ask questions about the study. ☐
2. I agree to take part in this research project and agree for my data to be used for the purpose of this study ☐
3. I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected ☐
4. I understand that the group discussion will be audio recorded ☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name) ____

Signature of participant__________________________ Date: ______ / ______ / ______

Consent form V1.0 – 24.4.2017

b) Arabic version

UNIVERSITY OF Southampton

استمارة موافقة

عنوان الدراسة: مفاهيم الأداء الوظيفي لليدين في الحياة اليومية للمرضى الفلسطينيين الذين يعانون من مرض التهاب المفاصل الروماتزمي

اسم الباحث: هشام عرب الكعبية
مرجع الموافقة الأخلاقية للبحث كلية العلوم الصحية بجامعة ساوثهامبتون (رقم المرجع: 30278)
ووزارة الصحة الفلسطينية (رقم المرجع: 2017/1265/162)
رقم المشترك:____

يرجى التوقيع في المربع إذا كنت توافق على هذه العبارات

1) لقد قرأت وفهمت ورقة المعلومات (V1.0 – 24.4.2017) وأتيح لي الفرصة لطرح الأسئلة حول الدراسة ☐
2) أنا أوافق على المشاركة في هذا المشروع البحثي وأوافق على استخدام البيانات الخاصة بي لغرض هذه الدراسة ☐
3) اعرف ان اشتراكي هو طوعي، ولدي الحرية الكاملة بالانسحاب في اي وقت ممكن, بدون ابداء اي اسباب وبدون ان تتأثر حقوقي الشرعية ☐
4) اعرف ان هذه المقابلة الجماعية سيتم تسجيلها بالصوت ☐

حماية البيانات

وأنا أفهم أن المعلومات التي تم جمعها عني خلال مشاركتي في هذه الدراسة سيتم تخزينها على جهاز كمبيوتر محمي بكلمة مرور وأنه سيتم استخدام هذه المعلومات فقط لغرض هذه الدراسة. كل الوثائق التي تحتوي على معلومات شخصية سيتم إخفاؤها.

اسم المشترك:____

توقيع المشترك:________________________ التاريخ: ______ / _____ /_____

V1.0 – 24.4.2017 استمارة موافقة

Appendix J A focus group discussion guide: Hand picture

Appendix K Ground rules (focus group study)

Ground Rules

- **Mobile Phones should be switched off or on silent but not on vibrate.**
- **If you need to go to the bathroom, please just leave and return quietly**
- **Try to talk to each other, rather than just answer the researcher.**
- **There are no right and wrong answers. Feel free to disagree with each other and offer an alternative viewpoint. However, if you do disagree, please do so in respectful manner.**
- **All contributions are valued and will remain confidential, and anonymous. -It will be reiterated that everyone's contribution is to be kept confidential and not be discussed by members outside of the group – participants will be asked if they can agree to this**
- **Please try not to talk over the top of each other, as this makes transcription of the groups almost impossible and we want to hear your viewpoint.**
- **The researcher may be stopping the group if these ground rules are not being followed.**

Appendix L STROBE checklist (cross-sectional study)

Item	**Recommendation**	**Section**
Title	Indicate the study's design	Chapter 6
Introduction		
Background/rationale	Explain the scientific background and rationale	Section 6.2
Objectives	State specific objectives	Section 6.3
Methods		
Study design	Present key elements of study design	Section 6.4.1
Setting	Describe the setting, locations, and relevant dates	Section 6.4.2
Participants	Give the eligibility criteria, and the sources and methods of selection of participants	Section 6.4.3 & 6.4.4
Variables	Clearly define all outcomes and exposures	Section 6.4.6
Data sources	Give sources of data and details of methods of assessment	*Section 6.4.6*
Bias	Describe any efforts to address potential sources of bias	
Study size	Explain how the study size was arrived at	Section 6.4.4
Quantitative variables	Explain how quantitative variables were handled in the analyses	Section 6.4.6.2
Statistical methods	Describe all statistical methods	Section 6.4.1
	Explain how missing data were addressed	Section 6.5.2
Results		
Participants	Report numbers of individuals at each stage of study	Figure 6-2
	Give reasons for non-participation	Figure 6-2
Descriptive data	Give characteristics of study participants	Section 6.5.3
	Indicate number of participants with missing data for each variable of interest	Section 6.5.2
Outcome data	Report summary measures	Section 6.5.5 – 6.5.7
Main results	Give adjusted and unadjusted estimates and measures of precision	Section 6.5.8
Discussion		
Key results	Summarise key results with reference to study objectives	Section 6.5.9
Limitations	Discuss limitations of the study	Section 6.8
Interpretation	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies	Section 6.6.1 – 6.6.4
Generalisability	Discuss the generalisability (external validity) of the study results	Section 6.8

From: von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP and Initiative S (2007) The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Prev Med* 45(4): 247-251

Appendix M Cross-sectional study participant documents

1. Invitation letter

a) English version

UNIVERSITY OF Southampton

Invitation letter

Study title: Hand Function in Palestinian People with Rheumatoid Arthritis

(Ethics reference: Palestine 162/126/2019; University of Southampton 47047)

Dear,

I am writing to you on behalf of myself and my academic supervisors Prof. Jo Adams and Dr. Ann-Marie Hughes to formally ask if you would be interested in taking part in a research study, we are conducting. We are looking to explore the impact of rheumatoid arthritis on your ability to use your hands in daily life activities. Furthermore, we are looking to explore the association between your ability to use your hands to perform daily life activities and your personal and social characteristics. We hope that the findings of our research will help inform and improve the treatment for people living with rheumatoid arthritis in Palestine.

I would like to invite you to take part in an assessment session that will last approximately one and half-hours. If you are willing to take part, we would be grateful if you could fill in and answer demographic and personal questionnaires and have your hands examined by the researcher. The session will take place in the rehabilitation unit within your rheumatology clinic. Please read the information sheet enclosed with this letter. The information sheet will help you to decide whether you wish to take part or not. If you have any questions, then please do ask the researcher. If you are happy to take part, you will be asked to complete a consent form, with the assistance of the researcher, at the very start of the assessment session.

If you need further information or have any questions, please contact me through the contact details shown below.

Sincerely,
Hisham Arab Alkabeya
PhD student
Faculty of Health Sciences
University of Southampton
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Invitation letter V1.0 - 20.12.2019

b) Arabic version

UNIVERSITY OF Southampton

الأداء الوظيفي لليدين للمرضى الفلسطينيين الذين يعانون من مرض التهاب المفاصل الروماتزمي

(رقم الموافقه الاخلاقيه للبحث: فلسطين 2019/126/162 , جامعة ساوثهامبتون –بريطانيا 47047)

سيدتي / سيدي

أكتب لكم نيابة عن نفسي وعن مشرفي الأكاديميين البروفيسور جو آدمز والدكتور آن-ماري هيوز ونود ان نسألك رسميا إذا كنت قد تكون مهتما/ مهتمة في المشاركة في دراسة بحثية نقوم بأجرائها. نحن نتطلع لاستكشاف تأثير التهاب المفاصل الروماتيزمي على قدرتك على استخدام يديك في أنشطة الحياة اليومية. علاوة على ذلك ، نحن نتطلع إلى استكشاف العلاقة بين قدرتك على استخدام يديك لأداء أنشطة الحياة اليومية وخصائصك الشخصية والاجتماعية. نأمل أن تساعد نتائج هذا البحث في تحسين علاج الأشخاص المصابين بالتهاب المفاصل الروماتيزمي في فلسطين.

أود أن أدعوكم للمشاركة في جلسة تقييم تستمر لمدة ساعة ونصف تقريبًا. إذا كنت على استعداد للمشاركة ، سنكون ممتنين إذا كان بإمكانك ملء الاستبيانات الديموغرافية والشخصية والإجابة عليها وأن يفحص الباحث يديك. ستعقد الجلسة في وحدة إعادة التأهيل داخل عيادة أمراض الروماتيزم التي تعالج بها. يرجى قراءة ورقة المعلومات المرفقة بهذه الرسالة. ستساعدك ورقة المعلومات على تحديد ما إذا كنت ترغب في المشاركة أم لا. إذا كانت لديك أية أسئلة ، فالرجاء سؤال الباحث. إذا كنت سعيدًا بالمشاركة ، سيُطلب منك إكمال نموذج الموافقة ، بمساعدة الباحث ، في بداية جلسة التقييم. من فضلك لا تتردد في الاتصال بي حسب المعلومات المدونة ادناه إذا كنت تريد مزيدا من المعلومات.

كلي امل أن تجد هذه الدراسة مثيرة للاهتمام وشكرا جزيلا لكم مقدما لتعاونكم

مع الاحترام
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دعوه للمشاركه في دراسة

V1.0 – 20.12.2019

2. Participant Information Sheet

a) English version

Participant Information Sheet

Study Title: Hand Function in Palestinian People with Rheumatoid Arthritis

(Ethics reference: Palestine 162/126/2019; University of Southampton 47047)

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?
This study is part of my PhD project at the School of Health Sciences, University of Southampton, UK. I am a registered rehabilitation specialist and an academic at Arab American University-Palestine. The overall aim of this study is to explore and report hand function in Palestinian people with Rheumatoid Arthritis. It is well known that patients experience difficulties in daily living activities due to Rheumatoid Arthritis affecting their hands. Unfortunately, little is known about the Palestinian RA patients' hand function and the difficulties in daily living activities they have due to Rheumatoid Arthritis. Therefore, we would like to find out the impact of rheumatoid arthritis on your ability to use the hands in daily life activities. We are also keen to understand the factors that may influence the ability to use your hands in daily life. Understanding the impact of Rheumatoid Arthritis on the ability to use your hands in daily life activities and identifying the factors that contribute to this ability would contribute to informing effective interventions for Palestinian Rheumatoid Arthritis patients.

Why have I been chosen?
You have been invited to take part in this study because you have been diagnosed with rheumatoid arthritis. This study will involve up to 69 participants from three different rheumatology clinics in the Northern region of Palestine.

What will happen to me if I take part?
If you would like to take part in our study, you will be invited to one individual assessment session carried out by the researcher at the rehabilitation unit located within your usual rheumatology clinic. The assessment session will be conducted by the researcher on the same day you have an appointment for follow up at the rheumatology clinic. The rehabilitation unit is next to the rheumatology clinic and to help you find the rehabilitation unit easily the researcher will be waiting you in front of the rheumatology clinic reception. The assessment session will last approximately one and a half hours. Before the assessment session start, you will be asked to give your consent and given the time to ask any questions regarding the procedure or any concern you may have.
The assessment session will be conducted in a convenient room at the rehabilitation department and comprises two parts. In the first part, you will be asked to complete questionnaires related to your demographics such as your age, education level and living arrangements, personal characteristics such as your coping and self-efficacy and living conditions such as your family support. In the second part, the researcher will examine your hands, and this will include measuring your hands' joints range of motion, evaluating your grip strength. You will be given break time during the assessment session and refreshments will be provided.

Are there any benefits in my taking part?
There is unlikely to be any personal benefit to you. You will receive more assessments and examination on your hands than if you did not take part in this study. The information obtained from this study will inform health care professionals about what the status of hand function among the Palestinian patients with Rheumatoid Arthritis. Additionally, it will allow Palestinian health care professionals to understand the factors that contribute to hand function and contribute to selecting better ways of treating and supporting Palestinian people with Rheumatoid Arthritis affecting their hands.

Are there any risks involved?
We do not anticipate any risk or harm to you by taking part in this study. However, we understand that you may feel that the assessment session is long, and we will offer you breaks and refreshments. Furthermore, you are free to withdraw at any time without giving a reason.

What data will be collected?
In the first part of data collection we will ask you to fill in and answer a number of questionnaires. These questionnaires are designed to provide information about you as a person as well as how well you think you can use your hands in daily life activities. The questionnaires will include sections that ask about your individual characteristics as well as your social and family support. In the second part of data collection, the researcher will examine your hand function. This will include measuring your thumb and wrist movement as well as your grip strength. All research data will be stored in paper form and will be securely kept in a locked filling cabinet in the researcher's office. You will be assigned a unique study ID and your data will be stored using this unique ID number on a password protected computer for analysis purposes. The principal investigator and supervisory team of this research only will have access to the data.

Will my participation be confidential?
Your participation and the information we collect about you during the course of the research will be kept strictly confidential. Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Your name will not be used in any documentation except the consent form. The researcher will give each person a code number to ensure anonymity. All data will therefore be anonymised. We will not use your name in any reports or any other information that could personally identify you. Therefore, you will not be identifiable in any presentation or publications based upon this research. All study documents will be stored in a locked cabinet in the researcher's office at the Faculty of Health Sciences, Arab American University-Palestine. All data will be transferred and kept in the researcher's password protected laptop. Personal data will be kept until data analysis is complete and then will be deleted, whereas all other data generated from this study in accordance with the University of Southampton research data management policy, which requires that all significant data will be kept for least ten years after the study has finished. Anonymised data will be available for open access in line for University of Southampton and Research Council United Kingdom policy on Open Access Data.

What happens if I change my mind?
You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. If you do not want to continue, just tell the researcher and you will be able to withdraw. You will be supported by the researcher to withdraw and you do not have to give any reason for this. If you wish to withdraw your data, the researcher will remove your contribution.

What will happen to the results of the research?
Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

Where can I get more information?

For further information, please feel free to contact the researcher and supervisory team.
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What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk). In the unlikely case of concern or complaint about this study, you should contact the researcher or the supervisory team as showed above.

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) .

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read this information sheet. This information sheet is for you to keep.

Appendix M

a) Arabic version

معلومات عن الدراسة

عنوان الدراسة: الأداء الوظيفي لليدين للمرضى الفلسطينيين الذين يعانون من مرض التهاب المفاصل الروماتزمي

(رقم الموافقه الاخلاقيه للبحث: فلسطين 2019/126/162, جامعة ساوثهامبتون –بريطانيا 47047)

أنت مدعو للمشاركة في الدراسة البحثية المذكورة أعلاه. لمساعدتك في تحديد ما إذا كنت ترغب في المشاركة أم لا ، من المهم أن تفهم سبب إجراء البحث وما الذي سيشمله. يرجى قراءة المعلومات أدناه بعناية وطرح الأسئلة إذا كان أي شيء غير واضح أو إذا كنت ترغب في مزيد من المعلومات قبل أن تقرر المشاركة في هذا البحث. قد ترغب في مناقشتها مع الآخرين ولكن الأمر يرجع لك لتحديد ما إذا كنت ستشارك أم لا. إذا كنت سعيدًا بالمشاركة ، سيُطلب منك التوقيع على نموذج الموافقة.

ما هو هدف الدراسة؟

هذه الدراسة هي جزء من مشروع الدكتوراه الذي أقوم بدراسته في كلية العلوم الصحية، جامعة ساوثهامبتون -بريطانيا. الباحث الرئيسي لهذه الدراسة هو اخصائي تأهيل وأكاديمي في الجامعة العربية الأمريكية – فلسطين. الهدف العام من هذه الدراسة هو فحص وتقييم الاداء الوظيفي لليدين عند المرضى الفلسطينين المصابين بالتهاب المفاصل الروماتزمي. من المعروف أن المرضى يعانون من صعوبات في أنشطة الحياة اليومية بسبب التهاب المفاصل الروماتزمي الذي يصيب أيديهم. لسوء الحظ ، لا يوجد معلومات عن الاداء الوظيفي لليدين للمرضى الفلسطينين المصابين بالتهاب المفاصل الروماتزمي , والصعوبات في أنشطة الحياة اليومية التي يعانون منها بسبب هذا المرض. لذلك ، نود معرفة تأثير التهاب المفاصل الروماتزمي على قدرتك على استخدام اليدين في أنشطة الحياة اليومية. نحن حريصون أيضًا على فهم العوامل التي قد تؤثر على القدرة على استخدام يديك في الحياة اليومية. إن فهم تأثير التهاب المفاصل الروماتزمي على القدرة على استخدام يديك في أنشطة الحياة اليومية وتحديد العوامل التي تساهم في هذه القدرة سيساهم في تحسين التدخلات العلاجية الفعالة للمرضى الفلسطيني المصابين بهذا المرض.

لماذا تم اختيارك كمشترك في الدراسة؟

لقد وجهت الدعوة لك للمشاركة في هذه الدراسة لأنك تعاني من مرض التهاب المفاصل الروماتيزم. ستشمل هذه الدراسة ما يصل إلى 69 مشاركًا من ثلاث عيادات مختلفة لأمراض الروماتيزم في المنطقة الشمالية من فلسطين.

ماذا سيحدث لك عند المشاركة؟

إذا كنت ترغب في المشاركة في هذه الدراسة ، فسيتم دعوتك إلى جلسة تقييم فردية واحدة يقوم بها الباحث في وحدة إعادة التأهيل الموجودة في عيادة الروماتيزم التي تتلقى العلاج بها. سيتم إجراء جلسة التقييم من قبل الباحث في نفس اليوم الذي لديك موعد للمتابعة في عيادة الروماتيزم. تقع وحدة إعادة التأهيل بجوار عيادة الروماتيزم ولمساعدتك في العثور على وحدة إعادة التأهيل بسهولة ، سينتظرك الباحث أمام استقبال عيادة الروماتيزم. تستمر جلسة التقييم حوالي ساعة ونصف الساعة. قبل بدء جلسة التقييم ، سيُطلب منك إعطاء موافقتك وإعطائك الوقت لطرح أي أسئلة تتعلق بالإجراء أو أي مخاوف قد تكون لديك. سيتم إجراء جلسة التقييم في غرفة مريحة في قسم إعادة التأهيل وتتألف من جزأين. في الجزء الأول ، سيُطلب منك إكمال الاستبيانات المتعلقة بمعلوماتك الديمواغرافيه والشخصية مثل عمرك ومستوى التعليم وترتيبات المعيشة والخصائص الشخصية مثل التأقلم والفعالية الذاتية وظروف المعيشة مثل دعم عائلتك. في الجزء الثاني ، سيقوم الباحث بفحص يديك وهذا يشمل قياس مدى حركة مفاصل يديك ، وتقييم قوة قبضتك. سيتم منحك وقت راحة خلال جلسة التقييم.

ما هي الفوائد من المشاركة بالدراسة؟

من غير المحتمل أن يكون هناك أي فائدة شخصية لك. سوف تتلقى تقييمات وفحوصات ليديك أكثر مما لو لم تشارك في هذه الدراسة. إن المعلومات التي تم الحصول عليها من هذه الدراسة ستبلغ أخصائيي الرعاية الصحية عن حالة وظيفة اليد لدى المرضى الفلسطينيين المصابين بالتهاب المفاصل الروماتزمي. بالإضافة إلى ذلك، سيسمح للعاملين في الرعاية الصحية الفلسطينية بفهم العوامل التي تساهم في وظيفة اليد والمساهمة في اختيار طرق أفضل لعلاج ودعم الفلسطينيين المصابين بالتهاب المفاصل الروماتزمي الذي يؤثر على أيديهم.

ما هي المخاطر من المشاركة بالدراسة؟

لا نتوقع أي خطر أو ضرر لك من خلال المشاركة في هذه الدراسة. ومع ذلك ، فإننا نتفهم أنك قد تشعر بأن جلسة التقييم طويلة وسنقدم لك فترات راحة ومرطبات. علاوة على ذلك ، لك الحرية في الانسحاب في أي وقت دون إبداء أسباب.

ما هي البيانات التي سيتم جمعها؟

في الجزء الأول من جمع البيانات ، سنطلب منك ملء عدد من الاستبانات والإجابة عليها. تم تصميم هذه الاستبانات لتوفير معلومات عنك كشخص وكذلك مدى اعتقادك أنه يمكنك استخدام يديك في أنشطة الحياة اليومية. ستشمل الاستبانات أقسامًا تسأل عن صفاتك الفردية بالإضافة إلى دعمك الاجتماعي والعائلي. في الجزء الثاني من جمع البيانات ، سيفحص الباحث وظيفة اليد. سيشمل ذلك قياس حركة الإبهام والمعصم بالإضافة إلى قوة قبضتك. سيتم تخزين جميع بيانات البحث في شكل ورقي وسيتم حفظها بشكل آمن في خزانة مقفلة في مكتب الباحث. سيتم اعطاءك رقم مشترك فريد وسيتم تخزين بياناتك باستخدام هذا الرقم على جهاز كمبيوتر محمي بكلمة مرور لأغراض التحليل. الباحث الرئيسي والفريق الإشرافي من هذا البحث هم فقط من يستطيع الوصول إلى البيانات.

هل ستكون مشاركتي سرية؟

سيتم الاحتفاظ بمشاركتك والمعلومات التي نجمعها عنك أثناء البحث في سرية تامة. يجوز فقط لأعضاء فريق البحث والأعضاء المسؤولين في جامعة ساوثهامبتون الوصول إلى بيانات عنك لأغراض المراقبة و / أو لإجراء مراجعة للدراسة للتأكد من امتثال البحث للوائح المعمول بها. قد يحتاج الأفراد من السلطات التنظيمية (الأشخاص الذين يتحققون من أننا نجري الدراسة بشكل صحيح) إلى الوصول إلى بياناتك. من واجب كل هؤلاء الأشخاص الحفاظ على سرية معلوماتك كمشارك في البحث.

لن يتم استخدام اسمك في أي وثائق باستثناء نموذج الموافقة. سيعطي الباحث رقم لكل مشترك لضمان عدم الكشف عن هويته. وبالتالي ستكون جميع البيانات مجهولة المصدر. لن نستخدم اسمك في أي تقارير أو أي معلومات أخرى يمكن أن تحدد هويتك الشخصية. لذلك ، لن يتم التعرف عليك في أي عرض أو منشورات بناءً على هذا البحث. سيتم تخزين جميع الوثائق الدراسية في خزانة مقفلة في مكتب الباحث في كلية العلوم الصحية ، الجامعة العربية الأمريكية - فلسطين. سيتم تخزين البيانات وحفظها في الكمبيوتر المحمول للباحث والذي هو محمي بكلمة مرور. سيتم الاحتفاظ بالبيانات الشخصية حتى اكتمال تحليل الدراسة ثم سيتم حذفها ، في حين أن جميع البيانات الأخرى التي تم إنشاؤها من هذه الدراسة وفقًا لسياسة إدارة البيانات البحثية بجامعة ساوثهامبتون ، والتي تتطلب الاحتفاظ بجميع البيانات المهمة لمدة عشر سنوات على الأقل بعد انتهاء الدراسة. ستكون البيانات مجهولة المصدر متاحة للوصول المفتوح وفقًا لسياسة جامعة المملكة المتحدة ومجلس البحوث في المملكة المتحدة بشأن بيانات الوصول المفتوح.

ماذا يحدث إذا غيرت رأيي؟

لديك الحق في تغيير رأيك والانسحاب في أي وقت دون إبداء سبب وبدون التأثير على حقوقك. إذا كنت لا ترغب في المتابعة ، فقط أخبر الباحث وستكون قادرًا على الانسحاب. سيتم دعمك من قبل الباحث للانسحاب وليس عليك تقديم أي سبب لذلك. إذا كنت ترغب في سحب بياناتك ، فسيزيل الباحث مساهمتك.

ماذا سيحدث لنتائج البحث؟

ستبقى التفاصيل الشخصية الخاصة بك سرية للغاية. لن تتضمن نتائج البحث المتاحة في أي تقارير أو منشورات معلومات يمكن أن تحدد هويتك مباشرة دون موافقتك.

أين يمكنني الحصول على مزيد من المعلومات؟

لمزيد من المعلومات ، لا تتردد في الاتصال بالباحث وفريق الإشراف.

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ماذا يحدث إذا كانت هناك مشكلة؟

إذا كان لديك قلق بشأن أي جانب من جوانب هذه الدراسة ، فيجب عليك التحدث إلى الباحثين الذين سيبذلون قصارى جهدهم للإجابة على أسئلتك. إذا كنت غير راضٍ أو لديك شكوى حول أي جانب من جوانب هذه الدراسة ، يرجى الاتصال بمدير النزاهة والحوكمة بجامعة ساوثامبتون (023 8059 5058، rgoinfo@soton.ac.uk)
في حالة القلق أو الشكوى غير المتوقعة بشأن هذه الدراسة ، يجب عليك الاتصال بالباحث أو فريق الإشراف كما هو موضح أعلاه.

إشعار خصوصية حماية البيانات

تجري جامعة ساوثهامبتون بحثًا وفقًا لأعلى معايير نزاهة البحث. بصفتها منظمة تمولها الحكومة ، يجب على الجامعة التأكد من أن ذلك يخدم المصلحة العامة عندما نستخدم معلومات التعريف الشخصية عن الأشخاص الذين وافقوا على المشاركة في البحث. هذا يعني أنه عندما توافق على المشاركة في دراسة بحثية ، سنستخدم معلومات عنك بالطرق المطلوبة ، وللأغراض المحددة ، لإجراء وإكمال مشروع البحث. بموجب قانون حماية البيانات ، تعني "البيانات الشخصية" أي معلومات تتعلق وقادرة على تحديد هوية شخص حي. يمكن الاطلاع على سياسة حماية البيانات في الجامعة التي تحكم استخدام الجامعة للبيانات الشخصية على موقعها على الإنترنت . (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page)

تخبرك ورقة معلومات المشاركين هذه عن البيانات التي سيتم جمعها لهذا المشروع وما إذا كان هذا يتضمن أي بيانات شخصية. يرجى سؤال فريق البحث إذا كان لديك أي أسئلة أو غير واضح ما هي البيانات التي يتم جمعها عنك.

يوفر إشعار الخصوصية الخاص بنا للمشاركين في البحث مزيدًا من المعلومات حول كيفية جمع جامعة ساوثامبتون لبياناتك الشخصية واستخدامها عندما تشارك في أحد مشاريعنا البحثية ويمكن العثور عليها على http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

سيتم استخدام أي بيانات شخصية نجمعها في هذه الدراسة فقط لأغراض إجراء بحثنا وسيتم التعامل معها وفقًا لسياسات الجامعة بما يتماشى مع قانون حماية البيانات. إذا تم استخدام أي بيانات شخصية يمكن التعرف عليك مباشرة منها ، فلن يتم الكشف عنها لأي شخص آخر دون موافقتك ما لم يطلب القانون من جامعة ساوثهامبتون الكشف عنها.

يتطلب قانون حماية البيانات أن يكون لدينا سبب قانوني صالح ("الأساس القانوني") لمعالجة بياناتك الشخصية واستخدامها. إن الأساس القانوني لمعالجة المعلومات الشخصية في هذه الدراسة البحثية هو لأداء مهمة تتم من أجل المصلحة العامة. لن يتم استخدام البيانات الشخصية التي تم جمعها للبحث لأي غرض آخر.

لأغراض قانون حماية البيانات ، فإن جامعة ساوثهامبتون هي "مراقب البيانات" لهذه الدراسة ، مما يعني أننا مسؤولون عن رعاية معلوماتك واستخدامها بشكل صحيح. ستحتفظ جامعة ساوثهامبتون بمعلومات يمكن التعرف عليها عنك لمدة 10 سنوات بعد انتهاء الدراسة وبعد ذلك سيتم إزالة أي رابط بينك وبين معلوماتك.

لحماية حقوقك ، سنستخدم الحد الأدنى من البيانات الشخصية اللازمة لتحقيق أهداف الدراسة البحثية. ومع ذلك ، قد تكون حقوق حماية البيانات الخاصة بك - مثل الوصول إلى هذه المعلومات أو تغييرها أو نقلها - محدودة ، حتى تكون مخرجات البحث موثوقة ودقيقة. لن تفعل الجامعة أي شيء ببياناتك الشخصية التي لا تتوقعها بشكل معقول.

إذا كان لديك أي أسئلة حول كيفية استخدام بياناتك الشخصية ، أو ترغب في ممارسة أي من حقوقك ، فيرجى الرجوع إلى صفحة الويب الخاصة بحماية البيانات بالجامعة (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) حيث يمكنك تقديم طلب باستخدام نموذجنا عبر الإنترنت. إذا كنت بحاجة إلى مزيد من المساعدة ، فالرجاء الاتصال بمسؤول حماية البيانات بالجامعة (data.protection@soton.ac.uk)

نشكرك على تخصيص بعض الوقت لقراءة ورقة المعلومات هذه. ورقة المعلومات هذه لك لتحتفظ بها

3. Consent form

a) English version

UNIVERSITY OF Southampton

Consent Form

Study title: Hand Function in Palestinian People with Rheumatoid Arthritis

Researcher name: Hisham Arab Alkabeya

Ethics: Faculty of Health Sciences Ethics Committee at the University of Southampton (Ethics reference number: 47047) and Palestinian Ministry of Health (Ethics reference number: 162/126/2019).

Participant Identification Number: ____

Please initial the boxes if you agree with the statement(s):

1. I have read and understood the information sheet (V1.0 - 20.12.2018) and have had the opportunity to ask questions about the study. ☐
2. I agree to take part in this research project and agree for my data to be used for the purpose of this study. ☐
3. I understand my participation is voluntary and I may withdraw at any time for any reason without my participation rights being affected. ☐
4. I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous. ☐

Name of participant (print name) ____

Signature of participant__________________________ Date: ______ / ______ / ______

Name of researcher (print name) ____

Signature of researcher _________________________ Date: ______ / ______ / ______

b) Arabic version

UNIVERSITY OF
Southampton

استمارة موافقة

عنوان الدراسة: مفاهيم الأداء الوظيفي لليدين في الحياة اليومية للمرضى الفلسطينيين الذين يعانون من مرض التهاب المفاصل الروماتزمي

اسم الباحث: هشام عرب الكعبية
مرجع الموافقة الأخلاقية للبحث: كلية العلوم الصحية بجامعة ساوثهامبتون (رقم المرجع: 47047)
ووزارة الصحة الفلسطينية (رقم المرجع: 2019/126/162)
رقم المشترك:____

يرجى التوقيع في المربع إذا كنت توافق على هذه العبارات

1) لقد قرأت وفهمت ورقة المعلومات (V1.0 – 20.12.2019) وأتيح لي الفرصة لطرح الأسئلة حول الدراسة ☐

2) أنا أوافق على المشاركة في هذا المشروع البحثي وأوافق على استخدام البيانات الخاصة بي لغرض هذه الدراسة ☐

3) اعرف ان اشتراكي هو طوعي، ولدي الحرية الكاملة بالانسحاب في اي وقت ممكن, بدون ابداء اي اسباب وبدون ان تتأثر حقوقي الشرعية ☐

4) وأنا أفهم أن المعلومات التي تم جمعها عني خلال مشاركتي في هذه الدراسة سيتم تخزينها على جهاز كمبيوتر محمي بكلمة مرور وأنه سيتم استخدام هذه المعلومات فقط لغرض هذه الدراسة. كل الوثائق التي تحتوي على معلومات شخصية سيتم إخفاؤها ☐

اسم المشترك:____

توقيع المشترك:______________________ التاريخ: ______ / _____ /_____

اسم الباحث:____

توقيع الباحث:______________________ التاريخ: ______ / _____ /_____

v1.0 - 20.12.2019 استمارة موافقة

Appendix N Clinical research questionnaire (cross-sectional study)

a) English version

Site	☐☐☐	Participant ID	☐☐☐
Date	☐☐☐☐☐☐		

Research Clinical Questionnaires

Hand function in Palestinian People with Rheumatoid Arthritis

- **Completing the questionnaires**
  - Please answer all questions yourself. There are no wrong or right answers.
  - Please do not hesitate to ask the researcher if you need clarifications, the researcher will be happy to explain any question for you.
  - If you have problems in reading questions or statements, please inform the researcher who will be happy to read them for you.
  - Please when you finish please check that you have answered all the questions.

Hisham Arab Alkabeya, PhD student

University of Southampton- UK

Appendix N

Section 1: Demographic Information

Please answer each question as accurately as possible by ticking the box of the correct answer or filling in the space provided.

1. **Gender**: ☐ Male ☐ Female

2. **Date of Birth**:____

3. **Are you Right or Left-handed?** ☐ Right ☐ Left ☐ Not clear one or the other

4. **Marital status** ☐ Single ☐ Married ☐ Separated ☐ Divorced ☐ Widowed

5. **Which one of the statements below best describes your living arrangements?**

☐ Living alone
☐ Living with a spouse
☐ Living with a spouse and unmarried children
☐ Other, please specify:____

6. **Which of the following best describes the area you live in?** ☐ City ☐ Village ☐ Camp

7. **Which one of the statements below best describes your personal responsibilities regarding dependent children?**

☐ I am not a carer for any dependent children
☐ I am the prime carer of a dependent child/children
☐ I am a carer of a dependent child/children but someone else is the prime carer
☐ I equally share the care of a dependent child/children
☐ Other please specify:____

8. **Which one of the statements below best describes your personal responsibilities regarding dependent other(s)?**

☐ I am not a carer for any dependent other(s)
☐ I am the prime carer of a dependent other(s)
☐ I am a carer of a dependent other(s) but someone else is the prime carer
☐ I equally share the care of a dependent other(s)
☐ Others, please specify:____

9. **Educational level**

☐ Primary education
☐ Diploma/ higher education
☐ Postgraduate degree
☐ Secondary education
☐ Bachelor's degree
☐ Other please specify: _______________

10. **Employment status**

☐ Self-employed
☐ Full time employed
☐ Retired
☐ Looking after home
☐ Unable to work
☐ Other specify:____________________

11. **Please specify your profession:** ____

12. What is your approximate average monthly household income?

☐ Less than 1500 NIS
☐ 1500-2400 NIS
☐ 2500-340 NIS
☐ 3500-4400 NIS
☐ 4500-5400 NIS
☐ More than 5500 NIS

Please go to the next page →

Section 2: Therapeutic data

Please answer each question as accurately as possible by ticking the box of the correct answer or filling in the space provided.

1. **Date of diagnosis**: ____

2. **Please indicate how long it took you to be diagnosed with rheumatoid arthritis since your symptoms started?**
   - ☐ Less than 2 months
   - ☐ 2 -6 months
   - ☐ 7-11 months
   - ☐ 1-2 years
   - ☐ 3-4 years
   - ☐ More than 5 years

3. **Have you received rehabilitation treatments (physiotherapy or occupational therapy) for your hands within the past six months?**
   a) Physiotherapy ☐ Yes ☐ No
   b) Occupational therapy ☐ Yes ☐ No

4. **Have you had surgery in your hand(s) in the past six months?** ☐ Yes ☐ No
   If YES, in which hand (s) you had the surgery:
   - ☐ Right hand
   - ☐ Left hand
   - ☐ Both hands

5. **Have you used hand splints in the past six months?** ☐ Yes ☐ No

6. **Over the past six months have you had hand pain and problems?** ☐ Yes ☐ No

Please go to the next page →

Section 3: Hand function and personal data

1. QuickDASH

Please rate your ability to do the following activities in the last week by circling the number below the appropriate response.

		No Difficulty	Mild Difficulty	Moderate Difficulty	Severe Difficulty	Unable
1.	Open a tight or new jar.	1	2	3	4	5
2.	Do heavy household chores (e.g., wash walls, floors).	1	2	3	4	5
3.	Carry a shopping bag or briefcase.	1	2	3	4	5
4.	Wash your back.	1	2	3	4	5
5.	Use a knife to cut food.	1	2	3	4	5
6.	Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.).	1	2	3	4	5
		Not at all	Slightly	Moderately	Quite a bit	Extremely
7.	During the past week, to what extent has your arm, shoulder or hand problem interfered with your normal social activities with family, friends, neighbours or groups?	1	2	3	4	5
		Not limited at all	Slightly limited	Moderately limited	Very limited	Unable
8.	During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder or hand problem?	1	2	3	4	5
	Please rate the severity of the following symptoms in the last week. (circle number)	None	Mild	Moderate	Severe	Extreme
9.	Arm, shoulder or hand pain.	1	2	3	4	5
10.	Tingling (pins and needles) in your arm, shoulder or hand.	1	2	3	4	5
		No Difficulty	Mild Difficulty	Moderate Difficulty	Severe Difficulty	So much difficulty that I can't sleep
11.	During the past week, how much difficulty have you had sleeping because of the pain in your arm,	1	2	3	4	5

Page 3 of 9

Please go to the next page →

2. The Patient Health Questionnaire (PHQ-4)

Over the last 2 weeks, how often have you been bothered by the following problems?

Please respond to each item by circling the number below the appropriate response.

	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	1	2	3	4
2. Not being able to stop or control worrying	1	2	3	4
3. Little interest or pleasure in doing things	1	2	3	4
4. Feeling down, depressed, or hopeless	1	2	3	4

3. Vitality (SF-36)

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling by circling the number below the appropriate response.

How much of the time during the past 4 weeks?

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1. Did you feel full of pep?	1	2	3	4	5	6
2. Did you have a lot of energy?	1	2	3	4	5	6
3. Did you feel worn out?	1	2	3	4	5	6
4. Did you feel tired?	1	2	3	4	5	6

4. Brief Michigan Hand Outcomes Questionnaire (bMHQ)

This question asks you for your view about your hands. If you are unsure about how to answer the question, please give it the best answer you can. Please respond to the question by circling the number below the appropriate response

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I am satisfied with the	1	2	3	4	5

Please go to the next page →

5. Brief COPE

These items deal with ways you 've been coping with stress in your life. Specifically, any problems associated with your overall health in the past several months. (you have not had any health problems in the last several months. then rate the items based on how you have been coping with any stress in your life. across the past several months. There are many ways to try to deal with problems. These items ask what you've been doing to cope with these problems. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not-just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

Please respond to each item by circling the number below the appropriate response.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real."	1	2	3	4
4. I've been getting emotional support from others	1	2	3	4
5. I've been giving up trying to deal with it.	1	2	3	4
6. I've been taking action to try to make the situation better.	1	2	3	4
7. I have been refusing to believe that it has happened.	1	2	3	4
8. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
9. I've been getting help and advice from other people.	1	2	3	4
10. I've been criticizing myself	1	2	3	4
11. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
12. I've been trying to come up with a strategy about what to do.	1	2	3	4
13. I've been getting comfort and understanding from someone.	1	2	3	4
14. I've been giving up the attempt to cope.	1	2	3	4
15. I've been looking for something good in what is happening.	1	2	3	4
16. I've been making jokes about it.	1	2	3	4
17. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
18. I've been accepting the reality of the fact that it has happened.	1	2	3	4
19. I've been expressing my negative feelings	1	2	3	4
20. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
21. I've been trying to get advice or help from other people about what to do.	1	2	3	4
22. I've been learning to live with it.	1	2	3	4
23. I've been thinking hard about what steps to take.	1	2	3	4
24. I've been blaming myself for things that happened.	1	2	3	4
25. I've been praying or meditating.	1	2	3	4
26. I've been making fun of the situation.	1	2	3	4

Page 5 of 9

Please go to the next page →

6. Multidimensional Scale of Perceived Social Support (Family subscale)

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement by circling the number below the appropriate response.

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. My family really tries to help me	1	2	3	4	5	6	7
2. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
3. I can talk about my problems with my family.	1	2	3	4	5	6	7
4. My family is willing to help me make decisions.	1	2	3	4	5	6	7

7. The Brief Resilience Scale (BRS)

Please indicate the extent to which you agree with each of the following statements. Please respond to each item by circling the number below the appropriate response.

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1.	I tend to bounce back quickly after hard times	1	2	3	4	5
2.	I have a hard time making it through stressful events.	1	2	3	4	5
3.	It does not take me long to recover from a stressful event.	1	2	3	4	5
4.	It is hard for me to snap back when something bad happens.	1	2	3	4	5
5.	I usually come through difficult times with little trouble	1	2	3	4	5
6.	I tend to take a long time to get over setbacks in my life.	1	2	3	4	5

8. Single-item Health Literacy Screening (SILS)

This question asks you “How confident are you filling out medical forms by yourself?”

Please respond to the question by ticking one box. Use “✓” to indicate your answer.

Extremely	Quite a bit	Somewhat	A little bit	Not at all
☐	☐	☐	☐	☐

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Please go to the next page →

9. Arthritis Self-efficacy Scale (ASES) - 8-items

For each of the following questions, please circle the number that corresponds to how certain you are that you can do the following tasks regularly at the present time.

1.	How certain are you that you can decrease your pain quite a bit?	very uncertain	1	2	3	4	5	6	7	8	9	10	very certain
2.	How certain are you that you can keep your arthritis or fibromyalgia pain from interfering with your sleep?	very uncertain	1	2	3	4	5	6	7	8	9	10	very certain
3.	How certain are you that you can keep your arthritis or fibromyalgia pain from interfering with the things you want to do?	very uncertain	1	2	3	4	5	6	7	8	9	10	very certain
4.	How certain are you that you can regulate your activity so as to be active without aggravating your arthritis or fibromyalgia?	very uncertain	1	2	3	4	5	6	7	8	9	10	very certain
5.	How certain are you that you can keep the fatigue caused by your arthritis or fibromyalgia from interfering with the things you want to do?	very uncertain	1	2	3	4	5	6	7	8	9	10	very certain
6.	How certain are you that you can do something to help yourself feel better if you are feeling blue?	very uncertain	1	2	3	4	5	6	7	8	9	10	very certain
7.	As compared with other people with arthritis or fibromyalgia like yours, how certain are you that you can manage pain during your daily activities?	very uncertain	1	2	3	4	5	6	7	8	9	10	very certain
8.	How certain are you that you can deal with the frustration of arthritis or fibromyalgia?	very uncertain	1	2	3	4	5	6	7	8	9	10	very certain

Please go to the next page →

9. The Brief Illness Perception Questionnaire (IPQ)

For the following questions, please circle the number that best corresponds to your views.

How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

0	1	2	3	4	5	6	7	8	9	10
not at all affected emotionally										extremely affected emotionally

Please list in rank-order the three most important factors that you believe cause your illness. The most important causes for me:

1: ____

2: ____

3: ____

Please go to the next page →

10. Beliefs about medicines questionnaire (BMQ)

Your views about medicines prescribed for you

- We would like to ask you about your personal views about medicines prescribed for you.
- These are statements other people have made about their medicines.
- Please indicate the extent to which you agree or disagree with them by ticking the appropriate box. Use "✓" to indicate your answer.
- There are no right or wrong answers. We are interested in your personal views

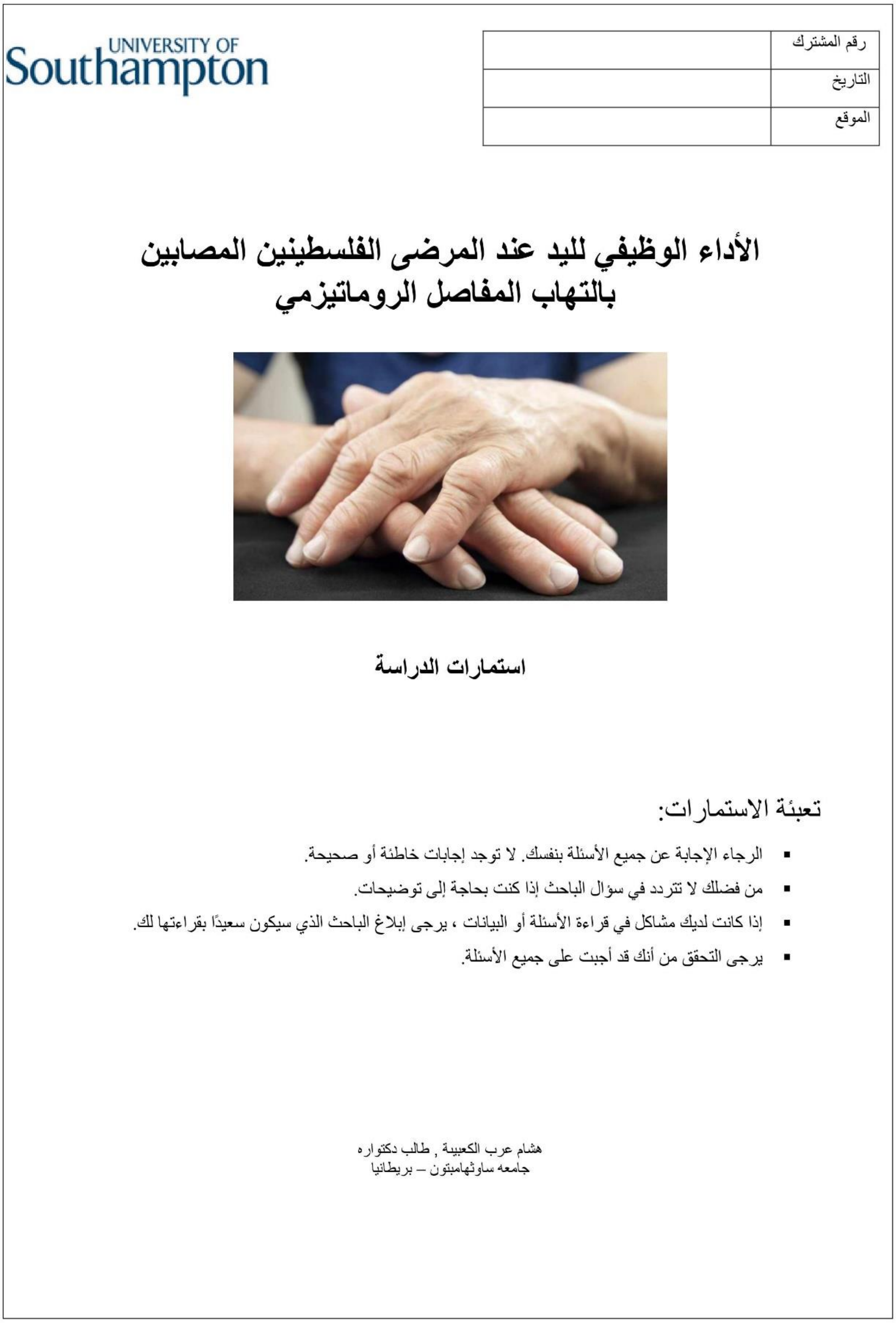
		Strongly agree	Agree	uncertain	Disagree	Strongly disagree
1.	My health, at present, depends on my medicines	☐	☐	☐	☐	☐
2.	Having to take medicines worries me	☐	☐	☐	☐	☐
3.	My life would be impossible without my medicines	☐	☐	☐	☐	☐
4.	Without my medicines I would be very ill	☐	☐	☐	☐	☐
5.	I sometimes worry about long-term effects of my medicines	☐	☐	☐	☐	☐
6.	My medicines are a mystery to me	☐	☐	☐	☐	☐
7.	My health in the future will depends on my medicines	☐	☐	☐	☐	☐
8.	My medicines disrupt my life	☐	☐	☐	☐	☐
11.	I sometimes worry about becoming too dependent on my medicines	☐	☐	☐	☐	☐
12.	My medicines protect me from becoming worse	☐	☐	☐	☐	☐

All standardized questionnaires included in this booklet have been copied with permission

End of questionnaire

Thank you for your participation

b) Arabic version



رقم المشترك	
التاريخ	
الموقع	

الأداء الوظيفي لليد عند المرضى الفلسطينين المصابين بالتهاب المفاصل الروماتيزمي

استمارات الدراسة

تعبئة الاستمارات:

- الرجاء الإجابة عن جميع الأسئلة بنفسك. لا توجد إجابات خاطئة أو صحيحة.
- من فضلك لا تتردد في سؤال الباحث إذا كنت بحاجة إلى توضيحات.
- إذا كانت لديك مشاكل في قراءة الأسئلة أو البيانات ، يرجى إبلاغ الباحث الذي سيكون سعيدًا بقراءتها لك.
- يرجى التحقق من أنك قد أجبت على جميع الأسئلة.

هشام عرب الكعبيبة , طالب دكتواره
جامعه ساوثهامبتون – بريطانيا

الجزء الأول: المعلومات الديموغرافية

يرجى الإجابة على كل سؤال بأكبر قدر ممكن من الدقة عن طريق وضع علامة في خانة الإجابة الصحيحة أو ملء المساحة المتوفرة.

1. **الجنس** ☐ ذكر ☐ انثى

2. **تاريخ الميلاد:**____

3. **ما هي اليد السائدة** ☐ اليد اليمنى ☐ اليد اليسرى ☐ غير واضح واحده او الاخرى

4. **الحالة الاجتماعية**

☐ اعزب / عزباء ☐ متزوج/ متزوجه ☐ منفصل/ منفصلة ☐مطلق/ مطلقة ☐ ارمل/ ارملة

5. **اي من العبارات التالية تصف ترتيباتك المعيشية:**
   - ☐ أعيش لوحدي
   - ☐ أعيش مع زوجي / زوجتي لوحدنا
   - ☐ أعيش مع زوجي / زوجتي والأولاد غير المتزوجين
   - ☐ غير ذلك, حدد:______________________________

6. **اي من التالي يصف المكان الذي تعيش فيه ؟**
   - ☐ مدينة
   - ☐ قرية
   - ☐ مخيم

7. **اي من العبارات التالية تصف مسؤولياتك في العناية والرعايه في الأولاد الذين هم تحت رعايتك**
   - ☐ انا لست الشخص الذي يقوم على رعاية وعناية الأولاد
   - ☐ انا الشخص الأساسي المسؤول عن رعاية وعناية الأولاد
   - ☐ انا أقوم برعاية وعناية الأولاد ولكن هناك شخص اخر هو المسؤول الأساسي
   - ☐ اتشارك بالتساوي رعاية وعناية الأولاد مع شخص اخر
   - ☐ غير ذلك , حدد:______________________________

8. **اي من العبارات التالية تصف مسؤولياتك في رعاية وعناية الأشخاص الاخرين (مثل الأب,الأم)**
   - ☐ انا لا أقوم برعاية اشخاص اخرين
   - ☐ انا الشخص الأساسي المسؤول عن رعاية وعناية اشخاص اخرين
   - ☐ انا أقوم برعاية وعناية اشخاص اخرين ولكن هناك شخص اخرهو المسؤول الأساسي
   - ☐ اتشارك بالتساوي رعاية وعناية الأولاد مع شخص اخر
   - ☐ غير ذلك , حدد:______________________________

يتبع ←

9. التحصيل الاكاديمي
☐ ابتدائي ☐ اعدادي ☐ ثانوي
☐ دبلوم ☐ بكالوريوس ☐ دراسات عليا

10. الحالة الوظيفية
☐ اعمل لحسابي الشخصي ☐ اعمل بوظيفة بدوام كامل ☐ متقاعد
☐ تدبير المنزل ☐ غير قادر على العمل ☐ غير ذلك, حدد:____________

11. ما هي مهنتك؟____

12. ما هو المعدل التقريبي لدخلك الشهرى (دخل الأسره الشهرى)؟

☐ اقل من 1500 شيكل
☐ 2400-1500 شيكل
☐ 3400-2500 شيكل
☐ 4400-3500 شيكل
☐ 5400-4500 شيكل
☐ اكثر من 5500 شيكل

الجزء الثانى: المعلومات الطبية

يرجى الإجابة على كل سؤال بأكبر قدر ممكن من الدقة عن طريق وضع علامة في خانة الإجابة الصحيحة أو ملء المساحة المتوفرة.

1. تاريخ التشخيص:____

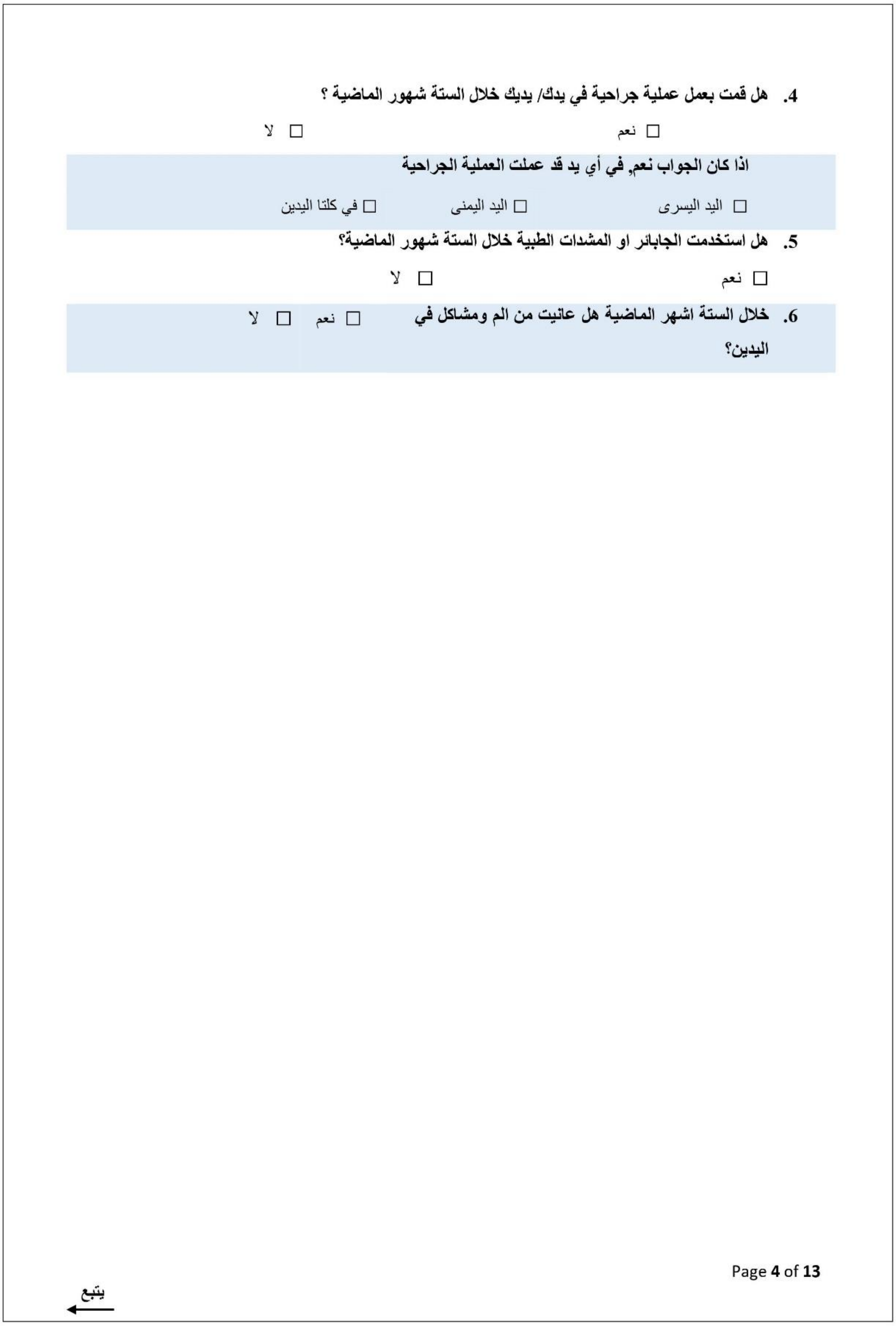
2. كم المده الزمنية التي استغرقتها كي تحصل على تشخيص التهاب المفاصل الروماتيزمي من الوقت الذي بدأت لديك أعراض المرض؟

☐ اقل من شهرين
☐ 6-2 شهور
☐ 11-7 شهر
☐ 2-1 سنه
☐ 4-3 سنين
☐ اكثر من 5 سنوات

3. هل تلقيت علاجات تأهيلة (علاج طبيعي أو وظيفي) ليديك خلال الستة شهور الماضية؟

▪ علاج طبيعي	☐ نعم	☐ لا
▪ علاج وظيفي	☐ نعم	☐ لا

يتبع ←



4. **هل قمت بعمل عملية جراحية في يدك/ يديك خلال الستة شهور الماضية ؟**

☐ نعم ☐ لا

اذا كان الجواب نعم, في أي يد قد عملت العملية الجراحية

☐ اليد اليسرى ☐ اليد اليمنى ☐ في كلتا اليدين

5. **هل استخدمت الجبائر او المشدات الطبية خلال الستة شهور الماضية؟**

☐ نعم ☐ لا

6. **خلال الستة اشهر الماضية هل عانيت من الم ومشاكل في اليدين؟** ☐ نعم ☐ لا

يتبع ←

إعاقات الذراع والكتف واليد (مختصر)

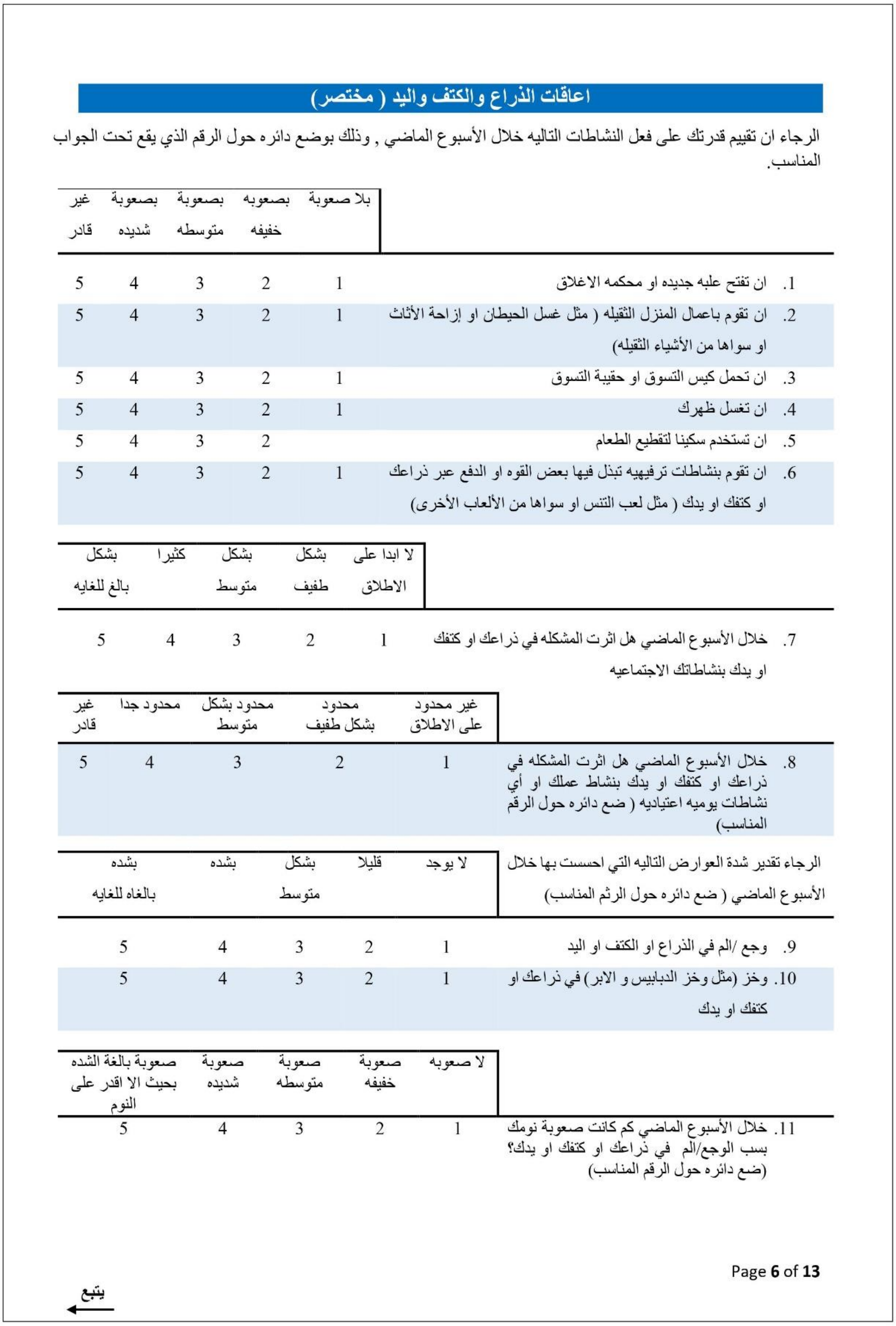
تعليمات

تستفسر هذه السلسلة من الأسئلة عن الحالات / الأعراض التي تحس بها في ذراعك، أو كتفك، أو يدك وعن مقدرتك على تأدية نشاطات معينة. الرجاء أن تجيب على *كل* سؤال، بناءً على حالتك خلال الأسبوع الماضي،

و ذلك بوضع دائرة حول الرقم المناسب. إذا لم تسنح لك الفرصة لتأدية نشاط ما خلال الأسبوع الماضي، فالرجاء أن تقدّر بأفضل ما تستطيع لتختار الجواب الأقرب إلى الدقة. عند إجابتك علي الأسئلة، ليس مهماً أي يد أو ذراع تستخدم لتمارس نشاطك سواء كانت اليد المصابة أو السليمة.

الرجاء أن تجيب بناءً على مقدرتك بغض النظر عن الطريقة التي تؤدي بها العمل.

يتبع ←



اعاقات الذراع والكتف واليد (مختصر)

الرجاء ان تقييم قدرتك على فعل النشاطات التاليه خلال الأسبوع الماضي , وذلك بوضع دائره حول الرقم الذي يقع تحت الجواب المناسب.

	بلا صعوبة	بصعوبه خفيفه	بصعوبة متوسطه	بصعوبة شديده	غير قادر
1. ان تفتح علبه جديده او محكمه الاغلاق	1	2	3	4	5
2. ان تقوم باعمال المنزل الثقيله (مثل غسل الحيطان او إزاحة الأثاث او سواها من الأشياء الثقيله)	1	2	3	4	5
3. ان تحمل كيس التسوق او حقيبة التسوق	1	2	3	4	5
4. ان تغسل ظهرك	1	2	3	4	5
5. ان تستخدم سكينا لتقطيع الطعام		2	3	4	5
6. ان تقوم بنشاطات ترفيهيه تبذل فيها بعض القوه او الدفع عبر ذراعك او كتفك او يدك (مثل لعب التنس او سواها من الألعاب الأخرى)	1	2	3	4	5

	لا ابدا على الاطلاق	بشكل طفيف	بشكل متوسط	كثيرا	بشكل بالغ للغايه
7. خلال الأسبوع الماضي هل اثرت المشكله في ذراعك او كتفك او يدك بنشاطاتك الاجتماعيه	1	2	3	4	5

	غير محدود على الاطلاق	محدود بشكل طفيف	محدود بشكل متوسط	محدود جدا	غير قادر
8. خلال الأسبوع الماضي هل اثرت المشكله في ذراعك او كتفك او يدك بنشاط عملك او أي نشاطات يوميه اعتياديه (ضع دائره حول الرقم المناسب)	1	2	3	4	5

الرجاء تقدير شدة العوارض التاليه التي احسست بها خلال الأسبوع الماضي (ضع دائره حول الرثم المناسب)	لا يوجد	قليلا	بشكل متوسط	بشده	بشده بالغاه للغايه
9. وجع /الم في الذراع او الكتف او اليد	1	2	3	4	5
10. وخز (مثل وخز الدبابيس و الابر) في ذراعك او كتفك او يدك	1	2	3	4	5

	لا صعوبه	صعوبة خفيفه	صعوبة متوسطه	صعوبة شديده	صعوبة بالغة الشده بحيث الا اقدر على النوم
11. خلال الأسبوع الماضي كم كانت صعوبة نومك بسب الوجع/الم في ذراعك او كتفك او يدك؟ (ضع دائره حول الرقم المناسب)	1	2	3	4	5

يتبع ←

استبيان صحة المريض

يشكل هذا الاستبيان جزءا مهما من عملية تقديم افضل رعاية صحية ممكنه لك , وستساعد اجاباتك في فهم المشكلات التي قد تعاني منها الرجاء الاجابه على كل سؤال بأكبر قدر من الصراحه وذلك بوضع دائره حول الرقم الذي يقع تحت الجواب المناسب.

ما مدى انزعاجك من أي من مشكلة من المشكلات التالية خلال الأسبوعين الأخيرين؟	ابدا	عدة ايام	اكثر من نصف الايام	كل يوم تقريبا
1. قلة الاهتمام او المتعة عند القيام بالاشياء	1	2	3	4
2. الشعور بالضيقة او الاكتئاب او اليأس	1	2	3	4
3. الشعور بالتوتر, العصبية او القلق	1	2	3	4
4. عدم القدرة على إيقاف قلقلك وهمومك او السيطره عليها	1	2	3	4

النشاط والحيوية

الأسئلة التالية تتعلق بكيفية شعورك وطبيعة سير الأمور معك **خلال الأسابيع الأربعة الماضية**, الرجاء إعطاء إجابة واحده لكل سؤال بحيث تكون الإجابة الأقرب الى الحالة التي كنت تشعر بها وذلك بوضع دائره حول الرقم الذي يقع تحت الجواب المناسب.

	في كل الاوقات	في معظم الاوقات	في كثير من الاوقات	في بعض الاوقات	في قليل من الاوقات	لم اشعر في وقت من الاوقات
1. شعرت بانك ملئ بالحيوية والنشاط؟	1	2	3	4	5	6
2. كانت لديك طاقة كبيرة؟	1	2	3	4	5	6
3. شعرت بأنك منهك (استنفذت قواك)	1	2	3	4	5	6
4. شعرت بأنك تعبان	1	2	3	4	5	6

الرضى عن مظهر اليدين

السؤال التالي يسأل عن وجهة نظرك تجاه يديك. اذا كنت غير متأكد كيف تجيب السؤال , اعطي الإجابة القريبة وذلك بوضع دائره حول الرقم الذي يقع تحت الجواب المناسب.

	موافق بشدة	موافق	غير مؤكد	غير موافق	غير موافق بشده
انا راضي عن مظهر يدي/ يداي	1	2	3	4	5

Page **7** of **13**

يتبع ←

الدعم الاجتماعي

نحن مهتمون بكيفية شعورك حول العبارات التالية. اقراء كل عبارة بعناية وأشر كيف تشعر تجاه كل عبارة وذلك بوضع دائره حول الرقم الذي يقع تحت الجواب المناسب.

	اعترض بشدة	اعترض باعتدال	اعترض قليلا	حيادي	أوافق قليلا	أوافق باعتدال	أوافق بشدة
1. عائلتي تحاول مساعدتي	1	2	3	4	5	6	7
2. احصل على مساعدى عاطفية ودعم من عائلتي	1	2	3	4	5	6	7
3. بامكاني التحدث عن مشاكلي مع عائلتي	1	2	3	4	5	6	7
4. عائلتي ترغب في مساعدتي لاتخاذ القرارت	1	2	3	4	5	6	7

قياس المعرفة والممارسة الصحيّة

	للغاية	الى حدما	نوعا ما	قليلا	غير واثق
كم أنت واثق من قدرتك على تعبئة الاستمارة الطبية بنفسك؟	1	2	3	4	5

يتبع ←

مقياس التأقلم المختصر

هذه البنود تتعلق مع الطرق التي كنت تستخدمها للتأقلم مع الضغوضات في حياتك. تحديدًا أي مشاكل مرتبطة بصحتك بشكل عام في الأشهر القليلة الماضية. (اذا لم يكن لديك أي مشاكل صحية في الأشهر القليلة الماضية قم بتقييم العناصر بناءًا على كيفية تعاملك مع أي ضغوضات في حياتك خلال الأشهر القليلة الماضية). كل بند يتعلق بطرق معينة للتأقلم. أريد أن أعرف إلى أي مدى كنت تفعل ما تحتويه هذه البنود. لا تجيب على أساس ما إذا كان يبدو أنها مفيده أم لا ، فقط إذا كنت تفعل ذلك أم لا. حاول تقييم كل بند على حدة في عقلك .استعمل المقياس ادناه من 1 الي 4 لتقييم كل بند من البنود من خلال وضع دائرة حول الرقم المناسب.

	أنا لم أفعل ذلك على الإطلاق	لقد فعلت هذا قليلا	لقد كنت أفعل هذا بشكل متوسط	لقد فعلت هذا كثيرا
1. تحولت إلى العمل أو الأنشطة الأخرى لتصفية ذهني	1	2	3	4
2. ركّزت جهودي على القيام بشيء حيال الوضع الذي انا فيها	1	2	3	4
3. كنت أقول لنفسي "هذا ليس حقيقيا".	1	2	3	4
4. حصلت على الدعم العاطفي من الاخرين	1	2	3	4
5. تخليت عن محاولة التعامل مع الموقف	1	2	3	4
6. اتخذت اجراءات في محاولة لجعل الوضع يبدو أفضل.	1	2	3	4
7. كنت ارفض أن اصدق أنه ما حدث قد حدث فعلا	1	2	3	4
8. قلت أشياء حتى اتخلص او اهرب من من المشاعر غير السارة المتعلقة بالحدث	1	2	3	4
9. حصلت على المساعدة والمشورة من أشخاص آخرين.	1	2	3	4
10. حاولت أن أرى الموقف في صورة مختلفة، لجعله يبدو أكثر إيجابية.	1	2	3	4
11. انتقدت نفسي.	1	2	3	4
12. حاولت الخروج باستراتيجية حول ما يجب القيام به.	1	2	3	4
13. حصلت على الراحة والتفهم من شخص ما.	1	2	3	4
14. تخليت عن محاولة التأقلم مع الموقف	1	2	3	4
15. بحثت عن شيء جيد في ما يحدث.	1	2	3	4
16. صنعت و قلت النكات حول هذا الموضوع.	1	2	3	4
17. فعلت أ شياء لاقلل من التفكير في الموقف ، مثل الذهاب إلى السينما ، ومشاهدة التلفزيون والقراءة وأحلام اليقظة ,النوم، أو التسوق.	1	2	3	4
18. قبلت بواقع الحقيقة أنه حدث	1	2	3	4
19. عبرت عن مشاعري السلبية.	1	2	3	4

يتبع ←

	أنا لم أفعل ذلك على الإطلاق	لقد فعلت هذا قليلا	لقد كنت أفعل هذا بشكل متوسط	لقد فعلت هذا كثيرا
.20 حاولت أن أجد الراحة في ديني و معتقداتي الروحية.	1	2	3	4
.21 حاولت الحصول على مشورة أو مساعدة من الآخرين حول ما يجب القيام به.	1	2	3	4
.22 تعلمت كيفية العيش معه.	1	2	3	4
.23 فكرت مليا في الخطوات التي يجب اتخاذها.	1	2	3	4
.24 لومت نفسي عن الأشياء التي حدثت.	1	2	3	4
.25 صليت أو لجأت الى التأمل.	1	2	3	4
.26 سخرت من هذا الموقف.	1	2	3	4

مقياس القدرة على الصمود المختصر

يرجى الإشارة إلى مدى موافقتك على كل عبارة من العبارات التالية وذلك بوضع دائره حول الرقم الذي يقع تحت الجواب المناسب.

	ارفض بشدة	ارفض	محايد	اقبل	اقبل بشدة
.1 أميل إلى استعادة توازني سريعاً بعد الأوقات الصعبة.	1	2	3	4	5
.2 أجد صعوبة عندما أمر بأحداث ضاغطة.	1	2	3	4	5
.3 لا أخذ وقت طويل لأتعافى من الأحداث الضاغطة.	1	2	3	4	5
.4 يصعب على أن استرجع وضعي سريعاً عندما تحدث أشياء سيئة.	1	2	3	4	5
.5 عادة أمر خلال الأوقات الصعبة بصعوبة بسيطة.	1	2	3	4	5
.6 أميل لأخذ وقت طويل للتغلب على النكسات التي تمر بي في حياتي.	1	2	3	4	5

يتبع ←

استبيان إدراك المرض

للأسئلة التالية ، يرجى وضع دائرة حول الرقم الذي يتوافق بشكل أفضل مع وجهات نظركم

إلى أي حد يؤثّر مرضكم على حياتكم؟

صفر	1	2	3	4	5	6	7	8	9	10
لا يؤثر عليها أبد										يؤثر عليها بشدة

كم تظنون أنّ مرضكم سيدوم؟

صفر	1	2	3	4	5	6	7	8	9	10
لمدة قليلة جدا										الى الابد

كيف تقيّمون سيطرتكم على المرض؟

صفر	1	2	3	4	5	6	7	8	9	10
لا سيطرة على الاطلاق										سيطرة هائلة

كم تظنون أن علاجكم يمكن أن يساعدكم؟

صفر	1	2	3	4	5	6	7	8	9	10
لا يساعدني على الاطلاق										مفيد الى اقصى درجة

الى اي درجة تشعرون بعوارض مرضكم؟

صفر	1	2	3	4	5	6	7	8	9	10
لا عوارض على الاطلاق										عوارض حادة جدا

إلى أي حد يسبب لكم مرضكم القلق؟

صفر	1	2	3	4	5	6	7	8	9	10
لا قلق على الاطلاق										قلق هائل

كيف تقيّمون فهمكم لمرضكم؟

صفر	1	2	3	4	5	6	7	8	9	10
لافهمة على الاطلاق										افهمة بوضوح فائق

كم يؤثّر عليكم مرضكم على الصعيد العاطفي؟ (مثلا يثير غضبكم، يخيفكم، يحزنكم أو يسبب لكم الاحباط ...)

صفر	1	2	3	4	5	6	7	8	9	10
لا أتأثر على الاطلاق										أتأثر بدرجة هائلة

:يرجى منكم أن تذكروا، بترتيب الأهمية، الأسباب الثلاثة التي أدت (برأيكم) إلى مرضكم. الأسباب الأكثر أهمية بالنسبة هي :

.1 ____

.2 ____

.3 ____

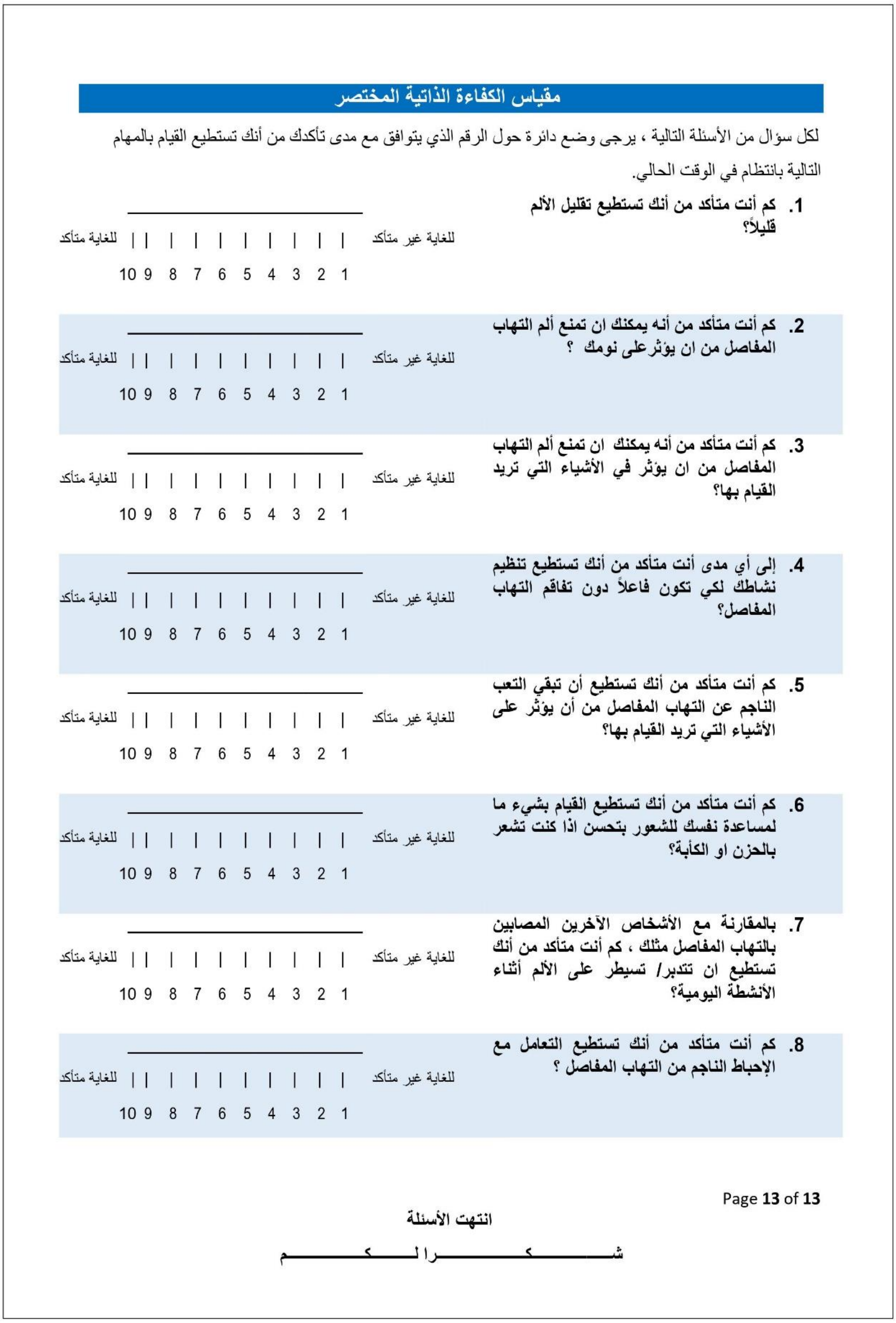
يتبع ←

وجهات نظرك حول الادوية الموصوفة لك

- نود أن نسألك عن آرائك الشخصية حول الأدوية الموصوفة لك.
- هذه هي العبارات التي ذكرها الناس الآخرين حول الأدوية الموصوفة لهم .
- يرجى اظهار كم توافق أو نختلف معهم وذلك بوضع علامة"✓" في المربع المناسب.
- لا يوجد اجابات صحيحة او خاطئة نحن مهتمون بمعرفة وجهة نظرك.
-

	موافق بشدة	موافق	غير مؤكد	غير موافق	غير موافق بشدة
1. حياتي حاليا تعتمد على ادويتي	☐	☐	☐	☐	☐
2. الحاجة إلى تناول الأدوية يقلقني	☐	☐	☐	☐	☐
3. حياتي ستكون مستحيلة دون أدويتي	☐	☐	☐	☐	☐
4. أنا في بعض الأحيان قلق بشأن الآثار الطويلة الأجل من أدويتي	☐	☐	☐	☐	☐
5. دون الأدوية سأكون مريضا جدا	☐	☐	☐	☐	☐
6. ادويتي لغز بالنسبة لي	☐	☐	☐	☐	☐
7. صحتي في المستقبل ستعتمد على أدويتي	☐	☐	☐	☐	☐
8. الحاجة إلى تناول الأدوية يعطل حياتي	☐	☐	☐	☐	☐
9. أنا في بعض الأحيان قلق بشأن الاعتماد بشكل كبير على أدويتي	☐	☐	☐	☐	☐
10. ادويتي تحميني من أن يصبح وضعي أسوأ	☐	☐	☐	☐	☐

يتبع ←



مقياس الكفاءة الذاتية المختصر

لكل سؤال من الأسئلة التالية ، يرجى وضع دائرة حول الرقم الذي يتوافق مع مدى تأكدك من أنك تستطيع القيام بالمهام التالية بانتظام في الوقت الحالي.

1. كم أنت متأكد من أنك تستطيع تقليل الألم قليلاً؟

للغاية غير متأكد ـــ للغاية متأكد

1 2 3 4 5 6 7 8 9 10

2. كم أنت متأكد من أنه يمكنك ان تمنع ألم التهاب المفاصل من ان يؤثرعلى نومك ؟

للغاية غير متأكد ـــ للغاية متأكد

1 2 3 4 5 6 7 8 9 10

3. كم أنت متأكد من أنه يمكنك ان تمنع ألم التهاب المفاصل من ان يؤثر في الأشياء التي تريد القيام بها؟

للغاية غير متأكد ـــ للغاية متأكد

1 2 3 4 5 6 7 8 9 10

4. إلى أي مدى أنت متأكد من أنك تستطيع تنظيم نشاطك لكي تكون فاعلاً دون تفاقم التهاب المفاصل؟

للغاية غير متأكد ـــ للغاية متأكد

1 2 3 4 5 6 7 8 9 10

5. كم أنت متأكد من أنك تستطيع أن تبقي التعب الناجم عن التهاب المفاصل من أن يؤثر على الأشياء التي تريد القيام بها؟

للغاية غير متأكد ـــ للغاية متأكد

1 2 3 4 5 6 7 8 9 10

6. كم أنت متأكد من أنك تستطيع القيام بشيء ما لمساعدة نفسك للشعور بتحسن اذا كنت تشعر بالحزن او الكآبة؟

للغاية غير متأكد ـــ للغاية متأكد

1 2 3 4 5 6 7 8 9 10

7. بالمقارنة مع الأشخاص الآخرين المصابين بالتهاب المفاصل مثلك ، كم أنت متأكد من أنك تستطيع ان تتدبر/ تسيطر على الألم أثناء الأنشطة اليومية؟

للغاية غير متأكد ـــ للغاية متأكد

1 2 3 4 5 6 7 8 9 10

8. كم أنت متأكد من أنك تستطيع التعامل مع الإحباط الناجم من التهاب المفاصل ؟

للغاية غير متأكد ـــ للغاية متأكد

1 2 3 4 5 6 7 8 9 10

انتهت الأسئلة

شـــــــــــكــــــــــــــرا لـــــــــكــــــــــــم

Appendix O Medical data recording sheet (cross-sectional study)

UNIVERSITY OF
Southampton

Site		Participant ID	
Date			

Medical Data Sheet

1. Medications

Please tick the yes box if the participant prescribed any of these current medications. In the second column, specify the dose for each medication the participant currently use.

Medication	Yes	Dose
Ibuprofen	☐	
Naproxen	☐	
Diclofenac	☐	
Indomethacin	☐	
Other non-steroidal anti-inflammatory	☐	
Sulfasalazine (Azulfidine)	☐	
Hydroxychloroquine (Plaquenil)	☐	
Methotrexate (Trexall)	☐	
Gold injections	☐	
Leflunomide (Arava)	☐	
Azathioprine	☐	
Prednisolone	☐	
Infliximab [Remicade]	☐	
Etanercept [Enbrel]	☐	
Adalimumab [Humira]	☐	
Other:	☐	

2. Comorbidity

The following is a list of common health problems. Please indicate if the participant currently has or not the problem by ticking either yes or no.

		Yes	No
1.	Cardiovascular disease	☐	☐
2.	Malignancies	☐	☐
3.	Infections	☐	☐
4.	Gastrointestinal disease	☐	☐
5.	Osteoporosis	☐	☐
6.	Depression	☐	☐

3. Blood test results

This section relates to information about the participants provided from blood tests.

			Result
CRP level (mg/l)	☐ Available	☐ Not available	
ESR level (mm/hour)	☐ Available	☐ Not available	
Rheumatoid factor	☐ Available	☐ Not available	☐ Positive ☐ Negative

Appendix P Procedure and data collection instructions (cross-sectional study)

1. Measuring active wrist flexion and extension ROM (Williams et al. 2015)

A) Active wrist flexion ROM

▪	**Position**	Participants will be advised sit comfortable in a chair with their forearm supported on a table on front of them, and all potentially jewellery removed. The elbow is flexed approximately 90 degrees, and the wrist is in a neutral position and the palm neither facing up nor down.
▪	**Tool**	Promedics Goniometer
▪	**Goniometer position**	Goniometer axis is placed on the back of the forearm (over the lunate) and the goniometer arms are in line with the midline of the forearm (stationary arm) and metacarpal/phalanx of the middle 3rd finger (moveable arm).
▪	**Instructions**	Participants are instructed to “bend your wrist as far as you can go with your fingers in a relaxed position” (Figure 1).
▪	**Measurement method**	Record the degrees.

B) Active wrist extension ROM

▪	**Position**	Participants will be advised sit comfortable in a chair with their forearm supported on a table on front of them, and all potentially jewellery removed. The elbow is flexed approximately 90 degrees, and the wrist is in a neutral position and the palm neither facing up nor down.
▪	**Tool**	Promedics Goniometer
▪	**Goniometer position**	Goniometer axis is placed on the palmar side of the forearm (over the lunate) and the goniometer arms are in line with the midline of the forearm (stationary arm) and metacarpal/phalanx of the middle 3rd finger (moveable arm).
▪	**Instructions**	Participants are instructed to “bend your wrist back as far as you can go with your fingers in a relaxed position” (Figure 2).
▪	**Measurement method**	Record the degrees.


Figure 1: Measuring wrist flexion


Figure 2: Measuring wrist extension

2. Thumb opposition (Kapandji, 1986)

The Kapandji (1986) index is a simple system of using the hand anatomical landmarks as system of reference. The client is asked to perform the following movements with the tip of the thumb (figure 3)

- **Instructions**
  1. Touch the lateral side of the 2nd phalanx of the index finger
  2. Touch the lateral side of the 3rd phalanx of the index finger
  3. Touch the tip of the index finger
  4. Touch the tip of the tip of the middle finger
  5. Touch the tip of the tip of the ring finger
  6. Touch the tip of the tip of the little finger
  7. Touch the palmar DIP crease of the little finger
  8. Touch the palmar PIP crease of the little finger
  9. Touch the proximal palmar crease of the little finger
  10. Touch the distal palmar crease of the hand
- **Measurement method** The score is the highest number that the participant can achieve (Max= 10)

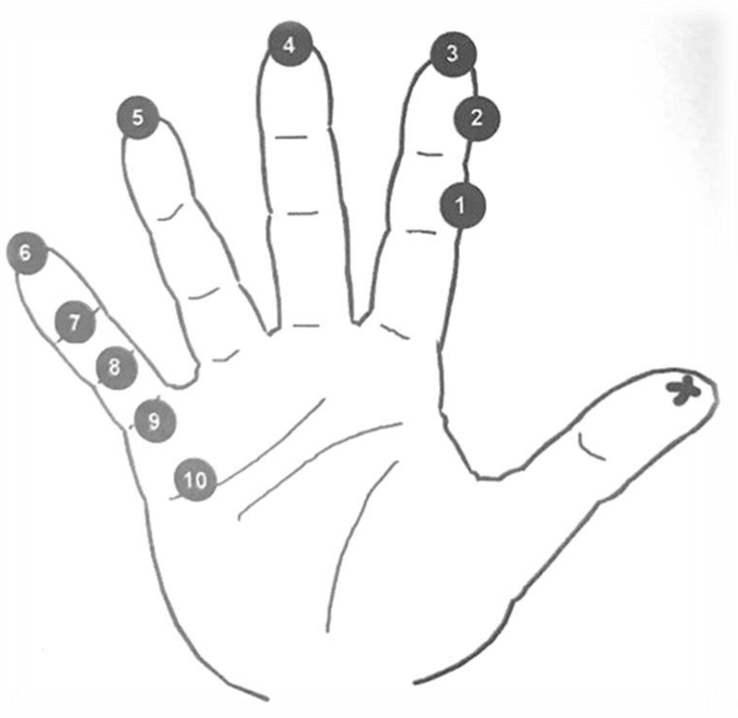


Figure 3: Kapandji test of thumb mobility

3. Power grip strength (procedures and instructions) (Mathiowetz 1991)

▪ **Position**	Participants will be seated on a chair with the shoulder adducted and naturally rotated, elbow flexed at 90 degree, forearm in natural position and wrist between zero to 30 degree flexion and between zero to 15 degree ulnar deviation (see figure 4).
▪ **Tool**	Jamar dynamometer
▪ **Instructions**	Squeeze the Jamar as hard as you can. Verbal encouragement will be 'Harder! ... Harder! ... Relax'.
▪ **Measurement method**	Record the strength value scored on the Jamar meter (Newtons and Kgs)

Figure 4: Position recommended for the use of the Jamar dynamometer

References

- Kapandji A (1986) Clinical test of apposition and counter-apposition of the thumb. Annales de chirurgie de la main : organe officiel des societes de chirurgie de la main 5(1): 67-73
- Mathiowetz V (1991) Reliability and validity of grip and pinch strength measurements. Critical Reviews in Physical and Rehabilitation Medicine 2(4): 201-12
- Williams MA, Williamson EM, Heine PJ, Nichols V, Glover MJ, Dritsaki M, Adams J, Dosanjh S, Underwood M, Rahman A, McConkey C, Lord J and Lamb SE (2015) Strengthening And stretching for Rheumatoid Arthritis of the Hand (SARAH). A randomised controlled trial and economic evaluation. Health Technol Assess 19(19): 1-222

Appendix Q Michigan Hand Questionnaire licence agreement

License Agreement #11562-umich

This license agreement is completed.

Pricing Information

Unit Price

$0.00

Quantity

1

Net Price

$0.00

Sales Tax

$0.00

Shipping

$0.00 None Selected

Total Price

$0.00

Licensee Information

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Hisham

Last Name

Arab Alkabeya

Email Address

haa1e16@soton.ac.uk

Organization

Southampton University

Title

Translation of the brief MHQ- one item to Arabic

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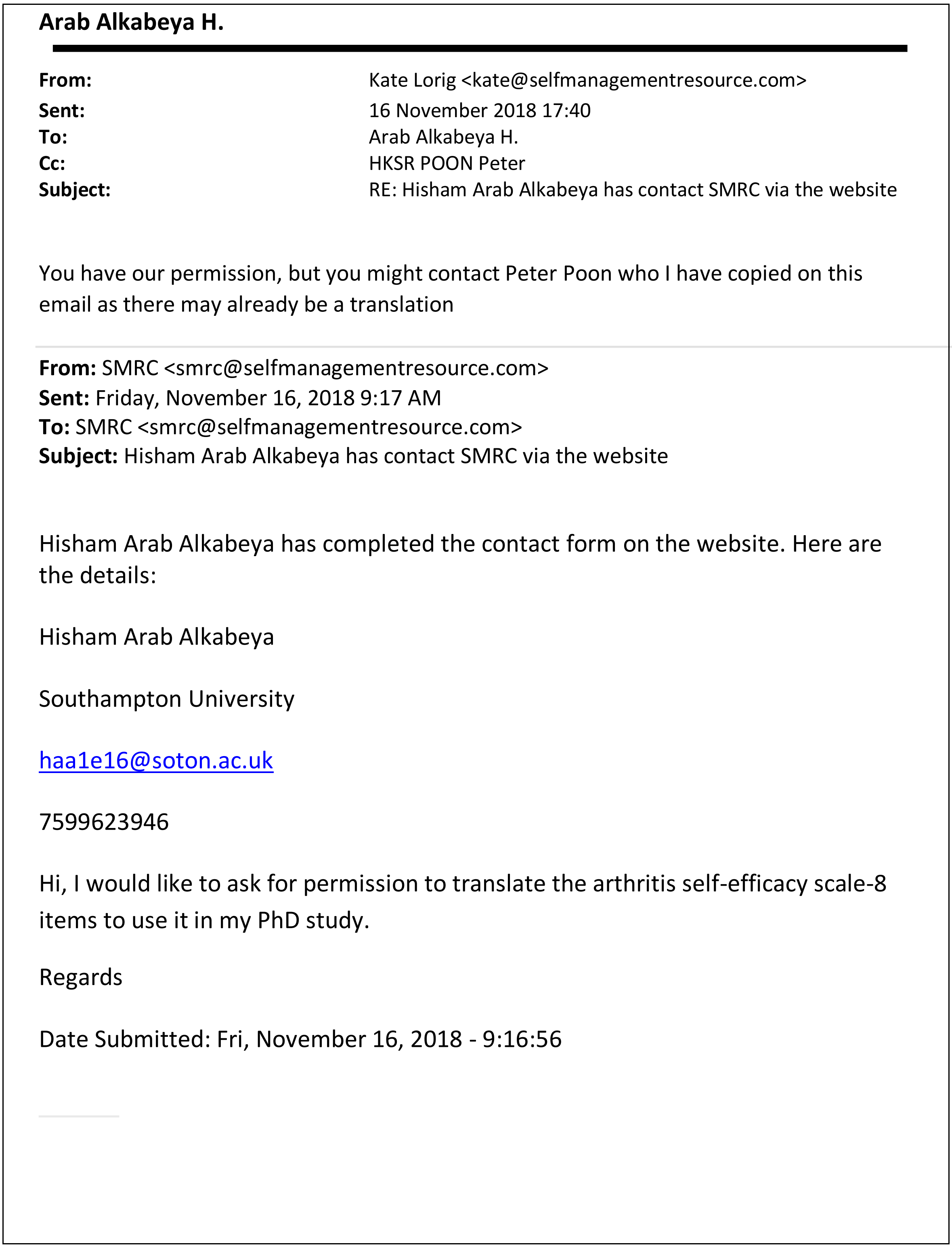
Digital downloads

This agreement includes 1 digital file, each available to the licensee for download.

- Michigan Hand Questionnaire - ZIP - 239 KB
  No expiration date or download limit set.

Appendix R Arthritis Self-Efficacy Scale-8 translation permission



Arab Alkabeya H.

From:	Kate Lorig <kate@selfmanagementresource.com>
Sent:	16 November 2018 17:40
To:	Arab Alkabeya H.
Cc:	HKSR POON Peter
Subject:	RE: Hisham Arab Alkabeya has contact SMRC via the website

You have our permission, but you might contact Peter Poon who I have copied on this email as there may already be a translation

From: SMRC <smrc@selfmanagementresource.com>
Sent: Friday, November 16, 2018 9:17 AM
To: SMRC <smrc@selfmanagementresource.com>
Subject: Hisham Arab Alkabeya has contact SMRC via the website

Hisham Arab Alkabeya has completed the contact form on the website. Here are the details:

Hisham Arab Alkabeya

Southampton University

haa1e16@soton.ac.uk

7599623946

Hi, I would like to ask for permission to translate the arthritis self-efficacy scale-8 items to use it in my PhD study.

Regards

Date Submitted: Fri, November 16, 2018 - 9:16:56

Appendix S Published analysis of the Arabic ASES-8

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2020.1748730

Taylor & Francis
Taylor & Francis Group

ASSESSMENT PROCEDURES

The Arabic Arthritis Self-Efficacy Scale-8 (ASES-8): a valid and reliable measure of evaluating self-efficacy in Palestinian patients with rheumatoid arthritis

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ABSTRACT

Background: The Arthritis Self-Efficacy Scale-8 (ASES-8) is one of the most commonly used scales to measure patient-reported arthritis-specific self-efficacy. However, evidence about the validity and reliability of ASES-8 in an Arabic-speaking arthritis population is lacking.

Objective: This study aimed to cross-culturally adapt and assess aspects of validity and reliability of the Arabic version of the ASES-8.

Methods: The ASES-8 was translated into the Arabic language using the back-translation method, and administered to 67 patients with rheumatoid arthritis (RA). Construct validation methods used exploratory factor analysis and correlating the ASES-8 scores with disease-related variables expected to be related to the arthritis self-efficacy construct. An internal consistency test was conducted. Floor and ceiling effects were considered present if more than 15% of patients achieved high (=10) and low (=1) scores on the Arabic ASES-8 for both the scale and item scores.

Results: Exploratory factor analysis demonstrated a one-factor solution (factor loadings: 0.54–0.81). ASES-8 scores were correlated with all measures assessed ($r = -0.24$ to -0.57 and $r = 0.06$–0.66), demonstrating construct validity. Internal consistency was acceptable for measures of Cronbach's alpha (0.86–0.88). The scale did not exhibit ceiling or floor effects.

Conclusions: The Arabic version of ASES-8 is valid and reliable for evaluating self-efficacy in patients with rheumatoid arthritis.

ARTICLE HISTORY
Received 11 October 2019
Revised 25 March 2020
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KEYWORDS
Rheumatoid arthritis; self-efficacy; psychometric properties; validity; reliability

➤ **IMPLICATIONS FOR REHABILITATION**

- The Arthritis Self-Efficacy Scale (ASES-8) questionnaire was translated and adapted for use in Arabic language.
- This questionnaire is a valid and reliable instrument for evaluating self-efficacy among Arabic individuals with rheumatoid arthritis.
- This will support greater use of this tool worldwide in clinical and research practices that include Arabic people.

Introduction

Self-efficacy is a psychosocial variable which has been defined as the individual's confidence to perform a specific task [1]. It is related to a person's beliefs in his/her ability, rather than actual ability. Many arthritis management interventions focus on enhancing self-efficacy because of its influence on health status and treatment outcomes and because it is potentially modifiable [2]. In rheumatoid arthritis (RA), there is a robust evidence that higher reported self-efficacy is associated significantly with lower levels of functional impairment, emotional distress and reported pain severity [3]. In addition, increased adherence with medications has also been linked with higher levels of self-efficacy [4]. As such, interventions targeting self-efficacy in the rheumatology population including patient education and self-management courses have been developed and are widely used in countries with highly developed healthcare systems to improve patients' health outcomes [5,6].

A recent systematic review study of instruments assessing self-efficacy in patients with rheumatic diseases failed to provide recommendations on the most appropriate self-efficacy instrument to use in the clinical and research field [7]. However, compared with other self-efficacy measures the Arthritis Self-Efficacy Scale (ASES) [8] has been around longer, is more applicable to arthritis [3], and has some evidence from previous studies for its validity and reliability [7,9]. The original scale was developed as part of the Stanford Arthritis Self-Management Study to evaluate perceived self-efficacy and measure change resulting from a health education intervention [8]. It contained 20 items contributing to three subscales of self-efficacy related to physical function, pain and other symptoms. Subsequently, a more practical 8-item version (ASES-8) was developed [10] which comprises two items from the ASES pain subscale, four items from the ASES other symptoms subscale, and two new items relating to preventing fatigue and pain from interfering with daily activities. The items of the ASES-8 measure the patients' confidence on a scale of one (very uncertain) to 10 (very certain). The score for the scale is the

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Table 1. Description of validity and reliability aspects [18].

Aspect	Description
Construct validity	The degree to which the scores of a PROM are consistent with hypotheses (e.g., relationships to scores of other instruments or measures) based on the assumption that a PROM validly measures the construct to be measured.
Structural validity	It is an aspect of construct validity that concern the degree to which scores of a PROM are an adequate reflection of the dimensionality of the construct to be measured. To examine structural validity, exploratory factor analysis (EFA) is used when there is no prior hypothesis regarding the dimensionality of a PROM.
Reliability (Internal consistency)	The degree of the interrelatedness among items, assuming a PROM to be unidimensional. Cronbach's alpha is the most commonly used statistical method for estimating internal consistency reliability based on the function of the average inter-correlation of the items and the number of items in a PROM.

PROM: Patient-reported outcome measure.

mean of the eight items (range = 1–10), so that higher score indicates greater self-efficacy.

Although the ASES-8 is widely used and validated in different languages [11–15], to our knowledge, an Arabic version of the ASES-8 has not been cross-culturally adapted and verified for validity and reliability in people with RA. The application of patient-reported outcome measures (PROMs) in different language and culture populations necessitates following a specific methodology to assure adequate linguistic translation and maintain the content validity of the instrument [16,17]. In addition, to develop effective and culturally relevant interventions targeting self-efficacy for Arabic-speaking RA patients, researchers require valid and reliable instruments that are culturally sensitive. Thus, without assessing the validity and reliability of a PROM, it is unknown if the instrument provides meaningful measures. The Consensus-based standards for the selection of health status measurement instruments (COSMIN) provided definitions of validity and reliability aspects for PROMs [18]. Some of the relevant aspects involved are described in Table 1.

This paper aims to report the cross-cultural adaption of the ASES-8 and examine some aspects of validity and reliability of the Arabic version of the ASES-8. Specific objectives were to: (1) examine the construct validity of the Arabic ASES-8 by using exploratory factor analysis and correlating it with measures for which the literature supports a relationship, (2) assess the reliability (internal consistency) of the Arabic ASES-8 by calculating the Cronbach's alpha, and (3) identify any ceiling or floor effects for the Arabic ASES-8.

Methods

Study design

This was a prospective, multicenter cross-sectional study to cross-culturally adapt and assess aspects of construct validity and reliability of the ASES-8 in RA.

Ethical approvals

This study was approved by both the University of Southampton School of Health Sciences Ethics panel and the Palestinian Ministry of Health. All patients provided written informed consent prior to enrolment.

Translation and cross-cultural adaption

Translation and cross-cultural adaption of the ASES-8 followed recommended guidelines for the cross-cultural adaption of health status measures [16,17]. Permission to translate the ASES-8 was obtained *via* email from Prof. Dr. Kate Lorig the original author and developer of the ASES-8. Two bilingual researchers who are rehabilitation specialists (HA & JD) translated the ASES-8 items into simplified Arabic. Another two independent bilingual linguistic professionals who were blind to the original ASES-8 back translated the generated Arabic version. All translation experts involved in the process of forward and backward translation then met and resolved any inconsistencies to produce the pre-final version of the Arabic ASES-8. Finally, face validity of the Arabic ASES-8 was assessed by seeking feedback from RA patient partner collaborators (PPI). For that reason, cognitive debriefing interviews [19] were conducted with five Palestinian RA patient partner collaborators (2 men and 3 women) with a range of educational levels, ages and disease duration to evaluate the ease of completion, relevance and clarity of the Arabic ASES-8. Modifications to the language were made according to the patients' feedback and understanding and checked with them afterward. After reaching an agreement in term of the Arabic ASES-8 wording, clarity and cultural equivalence between the researchers and the patients it was then utilized in this present study.

Participants and procedure

Potential participants were recruited from three rheumatology outpatients' clinics situated within governmental hospitals in the northern region of Palestine from March to July 2019. The inclusion criteria were: a confirmed diagnosis of RA as defined by the American College of Rheumatology (ACR) criteria [20], aged 18 years or over, willing to take part in the study and with sufficient language skills to complete assessments. Participants with an inability to complete questionnaires due to cognitive impairments, psychiatric conditions, or who were unable to read or write Arabic were excluded. Data collection sessions were conducted on the same day as the participants' medical follow ups at their rheumatology outpatients' clinic. Initially, the lead author, a qualified rehabilitation specialist and a researcher, distributed the clinical questionnaires to the eligible participants and was present to answer any questions regarding the measures and answer objectively so as not to influence the participant's responses. Following completion of the clinical research questionnaires, functional capacity tests were administrated in a standardized order.

Measures

This study was a minor element of a larger project to evaluate hand function in Palestinian people with RA. The data were collected by both self-reported and clinician assessed performance (objective) measures as detailed in the following subsections:

Demographic: Socio-demographic and disease-related variables were documented using a patient demographic questionnaire which consisted of questions about the patients' age, gender, employment status, marital status, living arrangement, education level (above or below secondary education), and disease duration.

Arthritis Self-Efficacy: Self-efficacy concerning pain and other disease-related symptoms was measured using the Arabic ASES-8 [8].

Functional capacity: Hand strength is an objective measurable, functional capacity indicator which is frequently assessed in RA. Therefore, bilateral power grip was assessed following recommended assessment protocols [21] using the Jamar Dynamometer.

RA symptoms: Participants were asked to rate their hand pain at rest (for both hands) over the past week using the valid and reliable Arabic pain numerical rating scale (NRS) [22]. In addition, participants were asked to report their hand pain experienced during grip strength tests (pain during activity) on the Arabic NRS. The Short Form 36 (SF-36) [23] vitality subscale was used to assess perception of fatigue. This scale consists of four items with standardized scores range from zero to 100, with lower scores indicating greater fatigue. The vitality subscale of the SF-36 was reported to have reasonable validity in measuring fatigue in RA [24]. Results from studies conducted in Arab countries showed that the Arabic SF-36 has satisfactorily validity and reliability in a variety of population samples [25–27].

Psychological distress: The four-item patient health questionnaire (PHQ-4) for anxiety and depression which combines the Patient Health Questionnaire-2 (PHQ-2) and the Generalized Anxiety Disorder-2 (GAD-2) was used to assess physiological distress [28]. The response options for each item range from zero "not at all" to three "nearly every day" and the total score ranges from 0 to 12 (a high score indicates that there is an underlying depressive disorder). The advantages of using the PHQ-4 is the ability to measure both depression and anxiety and provide a summary score for each one of them as well as measuring psychological distress reflected as a total score of both scales. All scales (PHQ-2, GAD-2 and PHQ-4) have well established psychometric properties to support their use with primary care patients and the general population [29–31]. The validity and reliability of the original scales (i.e., PHQ-9 and GAD-7) from which the PHQ-4 was derived have been demonstrated in the Arabic language [32].

Disability: Functional disability was measured using the short version of the Disabilities of the Arm, Shoulder and Hand (QuickDASH) questionnaire [33]. The QuickDASH is designed to assess generalised upper limb functional ability with a wide variety of upper limb disorders. It uses 11 of the original 30 items to assess impairments and activity limitations and participation restrictions of the upper extremity. Each item is scored on a five-point Likert scale, and the scores for all items are used to calculate a scale score ranging from zero (no disability) to 100 (most severe disability). The QuickDASH is now available in several languages including Arabic, and reported to have good construct validity, test–retest reliability and responsiveness to change in people with RA [34,35].

Coping: The Brief Coping Inventory (BCI) [36] was used to evaluate the coping strategies. It comprises 14 subscales that can be grouped into three scales: (1) problem-focused (active coping, planning, use of instrumental support), (2) emotion-focused (use of emotional support, positive reframing, acceptance, religion, humour), and (3) dysfunctional coping (venting, denial, substance use, behavioural disengagement, self-distraction, self-blame) [37]. Each subscale of the BCI contains two items (i.e., total number of items are 28 items) and each item is scored on a Likert scale from one "I haven't been doing this at all" to four "I have been doing this a lot". The score for each scale of the BCI is calculated by summing the relevant subscales scores. The BCI is widely used coping measure to identify the nature of coping strategies implemented by individuals for many health-relevant situations [38] and has been used with RA population [39]. The subscales of the brief BCI has reported reliability (Cronbach's alpha) ranging from 0.50 to 0.90 [36]. The brief BCI Arabic version internal consistency (Cronbach's alpha) ranged from 0.63 to 0.94 and divergent validity results suggested good construct validity [40]. The substance use scale of the BCI may introduce cultural biasness; since the statements of this scale are asking about alcohol or recreational drug use, which are not culturally accepted in Palestine. Therefore, the substance use subscale of the BCI was not included in the measure of coping for this study's Palestinian sample population.

Statistical analysis

Data were stored in a Microsoft Excel database and processed with SPSS version 26 (IBM Corp, Armonk, NY). Prior to statistical analysis the data distributions were checked for normality using a combination of visual inspection (histograms), and formal normality tests (Shapiro-Wilks test). Frequencies and percentages were presented for categorical data. Study variables were presented as mean and standard deviations for normally distributed variables and median and interquartile range for non-normally distributed variables. Internal consistency of the Arabic ASES-8 was examined by calculating the Cronbach's alpha. A value more than 0.7 has been reported as an acceptable internal consistency [41]. In addition, item internal consistency was assessed by computing a corrected item-total scale correlation (the correlation of the item designated with the summated score for all other items); a value of 0.4 and above has been recommended for supporting item internal consistency [42]. The proportion of participants with high and low scores on the Arabic ASES-8 were explored for both the scale and item scores, and a proportion >15% has been taken as an indication of the presence of floor and ceiling effect [41].

Construct validity was investigated by testing associations between ASES-8 and variables identified from previous literature as expected to be related to the Arthritis self-efficacy construct. Accordingly, Pearson's and Spearman's tests were used to examine the association between ASES-8 and disability (QuickDASH), Fatigue (SF-36 vitality subscale), coping (BCI), pain measurements (NRS), psychological distress (PHQ-4), and functional capacity measurements (grip strength). Exploratory factor analysis (EFA) was also used to examine the construct validity (structural validity) of the Arabic ASES-8. Prior to the extraction of the factors Bartlett's test of Sphericity was performed to examine whether the correlation matrix significantly differed from the identity matrix (i.e., there is a relationship among the items). Additionally, the Kaiser-Meyer-Olkin test (KMO) was used to evaluate sampling adequacy for carrying out factor analysis. The value of KMO test ranges from zero to one. It was reported that the KMO value should be above the acceptable threshold of 0.50 for carrying out factor analysis [43]. EFA was conducted using principal component analysis. Multiple criteria were used to determine the number of factors (factor retention): (1) Eigenvalues (an indication of the proportion of total variance accounted for by a factor) had to be greater than 1.0; (2) visual examination of the screen plot to determine number of eigenvalues preceding the "elbow"; (3) a loading factor of >0.4 was the cut-off point for item retention.

Results

Translation and adaptation of ASES-8

Modifications for the original ASES-8 were not required, since no conceptual or cultural difference was found. Therefore, no extensive content adaptation of the items was necessary. Based on the comments from the PPI group, the Arabic ASES-8 was clear and easy to understand. Similarly, the scale was clearly understood and was easy to administer and completed by participants within 6 min.

Sample characteristics

This study recruited sixty-seven participants with an age range between 29 and 77 years ($M = 53.4$, $SD = 11.4$) and median disease duration of 7 years (IQR 2.0–15.0). The majority of participants were female ($n = 53$, 79%), married ($n = 59$, 88%), living with others ($n = 57$, 85%), not working at the time of the interview ($n = 54$, 81%), and educational level was below post-secondary ($n = 47$, 70%). Sample characteristics are summarized in Table 2.

Descriptive scale characteristics

The mean of ASES-8 scores was 5.51 ($SD = 1.69$) and median was 5.63 (IQR 4.13–7.13). Individual results relative of each item were distributed throughout a full-scale range (1–10). For both the

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scale and item scores no floor or ceiling effects were found. With regard to the scale mean score the maximum (best score) of 8.5, as well as minimum (worse score) of 1.9 was met by 3% of the participants. Item 2 ("keeping the pain from interfering with sleep") and item 5 ("keeping the fatigue from interfering with activity") had the highest floor effect (11.9% and 10.4% respectively). Item 6 ("do something to feel better when feeling blue"), had the highest ceiling effect (10.4%) (Table 3).

Table 2. Patient characteristics ($n = 67$).

Patient characteristic	n (%)	Mean (SD)/ Median (Q1–Q3)
Gender		
Female	53 (79%)	
Male	14 (21%)	
Marital status		
Married	59 (88%)	
Other (single, divorced, widow)	8 (12%)	
Education		
<post-secondary	47 (70%)	
≥post-secondary	20 (30%)	
Living arrangement		
Living alone	10 (15%)	
Living with others	57 (85%)	
Employment status		
Working (full-time, self-employed)	13 (19%)	
Not working (retired, unable to work, looking after home)	54 (81%)	
Age (years)		53.39 (11.42)
Disease duration (years)		7.0 (2.0–15.0)
Psychological distress (PHQ-4)		5.34 (3.52)
Depression symptoms (PHQ-2)		2.70 (1.95)
Anxiety symptoms (GAD-2)		2.64 (1.82)
Fatigue (SF-36 vitality subscale)		43.06 (20.09)
Pain (NRS)		
Right hand pain at rest		2.63 (2.12)
Left hand pain at rest		2.49 (2.21)
Right hand pain during activity		4.64 (2.84)
Left hand pain during activity		4.28 (2.68)
Coping (BCI)		
Problem-focused		17.0 (13.0–20.0)
Emotion-focused		29.0 (26.0–32.0)
Dysfunctional		20.0 (16.0–23.0)
Power grip strength (Kg)		
Right hand		21.47 (9.54)
Left hand		20.74 (8.86)
Disability (QuickDASH)		45.7 (24.7)

Q: Quartile; PHQ-4: The Patient Health Questionnaire-4; PHQ-2: The Patient Health Questionnaire-2 (depression scale); GAD-2: Generalised Anxiety Disorder (GAD-2); SF-36: Short Form 36-Item Health Survey; NRS: Numerical Rating Scale; BCI: Brief Coping Inventory; QuickDASH: Shortened version of the Disabilities of the Arm, Shoulder and Hand questionnaire.

Reliability

Internal consistency of the scale was good ($\alpha = 0.88$). The corrected item-total correlation ranged from 0.44 to 0.73, indicating that all items represent the underlying one-dimensional construct. The Alpha value remained good (range = 0.86–0.88) if single items were deleted, indicating no individual item is redundant or lowering the scale's internal consistency (Table 3). The inter-item correlations were also evaluated and the results showed that no inter-item correlation exceeded the value of 0.7 (range = 0.15–0.68) indicating the absence of possible item redundancy [44].

Validity

The KMO value was 0.86, which is considered "meritorious" [45] and Bartlett's test of sphericity was significant ($\chi^2 = 255.57$, $p < 0.001$) in an exploratory factor analysis, indicating that factor analysis was feasible. Factor analysis indicated only one eigenvalue above 1.0 (4.42) and all eight items were found to load on a single factor with loadings from 0.54 to 0.81. Item number 4 "regulate your activity so as to be active without aggravating your arthritis" had the highest loading (0.81) and Item 6 "do something to help yourself feel better if you are feeling blue" had the lowest loading (0.54) (Table 3). The common variance (amount of variance that is shared among the eight items) explained by the single-factor solution was 55.29%.

Table 4 presents the correlations of the Arabic ASES-8 scores. These were significantly associated, in the anticipated directions, with arthritis symptoms (pain and fatigue), psychological distress (depressive and anxiety symptoms), disability and coping. ASES-8 scores showed moderate correlations with disability measure (QuickDASH- high score indicates more disability) ($r = -0.57$, $p < 0.001$), and fatigue (SF-36 vitality subscale - high score indicates less fatigue) ($r = 0.66$, $p < 0.001$). Associations between hand pain intensity and the Arabic ASES-8 scores were small but significant for both hands (range: $r = -0.29$ to -0.38). Anxiety and depression symptoms either correlated negatively with self-efficacy, achieving the highest coefficient in anxiety ($r = -0.50$, $p < 0.001$). Regarding the associations with coping strategies, dysfunctional coping strategies showed negative significant association ($r = -0.24$, $p = 0.05$), whereas problem-focused and emotion- focused strategies both showed positive associations but did not reach statistical significance. Finally, the associations

Table 3. Factor loadings for one-factor solution and item performance of the ASES-8.

Item no.	Item	Response options		Factor loading	Corrected item-total correlation	Cronbach's alpha if item deleted
		% floor	% ceiling			
1	How certain are you that you can decrease your pain quite a bit?	9.0	1.5	0.73	0.64	0.87
2	How certain are you that you can keep your arthritis or fibromyalgia pain from interfering with your sleep?	11.9	3.0	0.74	0.65	0.87
3	How certain are you that you can keep your arthritis or fibromyalgia pain from interfering with the things you want to do?	9.0	4.5	0.78	0.68	0.86
4	How certain are you that you can regulate your activity so as to be active without aggravating your arthritis or fibromyalgia?	6.0	4.5	0.81	0.73	0.86
5	How certain are you that you can keep the fatigue caused by your arthritis or fibromyalgia from interfering with the things you want to do?	10.4	3.0	0.80	0.71	0.86
6	How certain are you that you can do something to help yourself feel better if you are feeling blue?	1.5	10.4	0.54	0.44	0.88
7	As compared with other people with arthritis or fibromyalgia like yours, how certain are you that you can manage pain during your daily activities?	1.5	7.5	0.74	0.64	0.87
8	How certain are you that you can deal with the frustration of arthritis or fibromyalgia?	3.0	4.5	0.78	0.70	0.86

Table 4. Correlations between the Arabic ASES-8 and health-related variables.

	95% confidence interval			
Measure	Lower limit	Upper limit	Correlation coefficient	*p* value
Pain (NRS)				
Right hand pain at rest	−0.07	−0.49	−0.29	0.02
Left hand pain at rest	−0.05	−0.53	−0.31	0.01
Right hand pain during activity	−0.13	−0.52	−0.34	0.004
Left hand pain during activity	−0.16	−0.55	−0.38	0.002
Coping (BCI)				
Problem-focused	−0.15	0.32	0.09^a	0.49
Emotion-focused	−0.19	0.27	0.06^a	0.67
Dysfunctional	0.01	−0.48	-0.24^a	0.05
Psychological distress (PHQ-4)	−0.30	−0.67	−0.51	<0.001
Depression symptoms (PHQ-2)	−0.25	−0.63	−0.46	<0.001
Anxiety symptoms (GAD-2)	−0.24	−0.70	−0.50	<0.001
Fatigue (SF-36 vitality scale)	0.46	0.79	0.66	<0.001
Grip strength				
Right hand	0.07	0.48	0.28	0.02
Left hand	0.07	0.51	0.30	0.01
Disability (QuickDASH)	−0.40	−0.71	−0.57	<0.001

NRS: Numerical Rating Scale; BCI Brief Coping Inventory; [a]: Spearman's rank correlation coefficient; PHQ-4: The Patient Health Questionnaire-4; PHQ-2: The Patient Health Questionnaire-2 (depression scale); GAD-2: Generalised Anxiety Disorder (GAD-2); SF-36: Short Form 36-Item Health Survey; QuickDASH: Shortened version of the Disabilities of the Arm, Shoulder and Hand questionnaire.

Correlation coefficients are Pearson's product moment correlation coefficients unless otherwise indicated.

between self-efficacy and grip strength for both hands were significant (right hand: $r = 0.28$, $p = 0.02$; left hand: $r = 0.30$, $p = 0.01$).

Discussion

The main purpose of this secondary data analysis was to examine the factor structure, validity and reliability of the Arabic ASES-8. Kimberlin and Winterstein [46] suggested that secondary data analysis to examine the psychometric properties of outcome measures can be used, and is an acceptable method if the data set appropriately measures the variables required for the analysis. For the present analysis, a diverse set of measures collected and coded by the researcher were available to examine the construct validity including both self-reported and clinician assessed performance (objective) measures. Although this study sample included more female participants than males, this is reflective of the general RA population (women to men ratio = 3:1) [47].

There were positive experiences regarding the translation and cross-cultural adaption of the ASES-8. The initial phase was to ensure a valid content translation with respect to cultural equivalence and fluent wording of each item. During the translation phase, no problems were encountered in translation and no conceptual or cultural difference was found. The Arabic ASES-8 was well accepted by all participants, confirming the comprehensibility of the instrument. These positive experiences confirm already reported positive experiences reported with validation of the Spanish [15], German [14] and Chinese [12] version of ASES-8, suggesting the suitability of this scale for assessing disease-related self-efficacy in RA patients in different cultural settings.

Statistically significant correlations between the Arabic ASES8 scores and measures of pain, fatigue, psychological distress level (anxiety and depressive symptoms), self-reported disability, functional capacity and coping were reported. These findings are in line with cumulative evidence from rheumatology literature demonstrating that arthritis self-efficacy is a strong explanatory factor of valued physical and psychological health outcomes among people with arthritis [48]. The comparison of the ASES-8 with other validated outcome measures provided satisfactory evidence in support of the construct validity of the Arabic version of the ASES-8. It is noted, that in terms of magnitude, few statistically significant correlations were weak. However, similar correlations were reported in previous validation studies of ASES-8 [12–14]. In contrast to the previous psychometric studies of ASES-8 [12–14], hand-specific data of pain, disability and functional capacity were used in this current analysis to establish the construct validity. The strength of associations between the ASES-8 and hand pain and disability measure was similar to the preceding studies which have used generic pain and disability outcome measures [12–14]. In addition, the strength of association reported in our study between the ASES-8 and functional capacity measure (i.e., grip strength) was higher than those studies, which have used generic functional capacity measures [13,14]. These results suggest that the scale has sufficient sensitivity to reflect specific self-efficacy related to the hand and upper limb problems experienced by RA populations. Notwithstanding these issues, the correlations between the ASES-8 and coping scales were very weak and did not reach statistical significance for the problem- and emotion-focused scale of the BCI. These results were not expected since reasonable correlations (range: $r = 0.35$–0.45) were reported between the German ASES-8 version and coping strategies [14]. This seemingly paradoxical result may be explained by the small sample size in the present study and the difference in coping outcome measures between our study and the German study [14].

Exploratory factor analysis results indicated that the Arabic version of the ASES-8 comprised a one-factor structure, consistent with reports of the English [13] German [14] and Chinese [12] ASES-8, with all items loading heavily on this factor. Factor loading values for each item (range = 0.54–0.81) demonstrated that they were sufficient indicators of the one single factor. Factor analysis is usually performed on a "large" sample sizes. However, there is no consensus regarding the appropriate sample size required [49]. Watson and Thompson [50] suggested that a sample size should be between five and 10 time the number of items for the factor analysis. For the present analysis, responses on the Arabic ASES-8 collected from 67 patients with RA were used to conduct the EFA. Therefore, the sample size satisfied the requirement for the number of samples (item to participant ratio was 1:8) suggested for the factor analysis [50]. In addition, results of both Bartlett's test of sphericity and KMO test showed that EFA was feasible.

The internal consistency in this study was very good with Cronbach's alpha = 0.88, and comparable with the English (0.89) [13], and German (0.90) [14] ASES-8 values. Almost when any one of the items was removed Cronbach's alpha coefficient was decreased, which illustrate that each item (except item 6) was uniquely contributing to the overall conceptual framework of the scale. Further examination showed that item-total correlations were good (mean = 0.65), which indicate that individual items fit appropriately the scale overall. There were no floor or ceiling effects present for the Arabic ASES-8 items or average scale scores according to the widely used definition of 15% cut-off for this phenomenon [41].

There are several limitations, which exist due to the different focus of the larger study. First, due to the use of secondary data it was not possible to evaluate the test-retest reliability and the discriminate validity of the scale. Second, the sample size of the study was relatively small and could be underpowered to detect statistically significant associations. Third, the nature of the cross-sectional study design and recruiting a convenience sample preclude the possibility to draw conclusions about the causality between variables and ensure full representation from the sample. Finally, further research is needed to assess the validity and reliability of the Arabic ASES-8 in different healthcare services and from different Arabic countries, which would add to the psychometric properties of this measure.

Conclusions

This is the first analysis that provides systematic evaluation of validity and reliability of the Arabic ASES-8 in people living with RA. This will support greater use of this tool worldwide in clinical and research practices that include Arabic people. The present analysis showed acceptable levels of the validity and reliability of the ASES-8 among Arabic individuals with RA. Further research including the Arabic ASES-8 would provide insight about the advantages and shortcomings of this scale both in the clinical and research field.

Ethical approval

The permission to cross-culturally adapt the ASES-8 for the Palestinian culture was obtained from Prof. Dr. Kate Lorig the original ASES-8 scale developer. This study was approved by both the Ethical Committees of the University of Southampton School of Health Sciences and the Palestinian Ministry of Health. All procedures performed in studies involving human participants were in accordance with the declaration of Helsinki standards.

Disclosure statement

The authors declare no conflict of interest or any financial support.

Informed consent

Written informed consent was obtained from all participants prior to enrollment in this study. All participants were assured of confidentiality, anonymity, and right to withdraw at any time without giving a reason.

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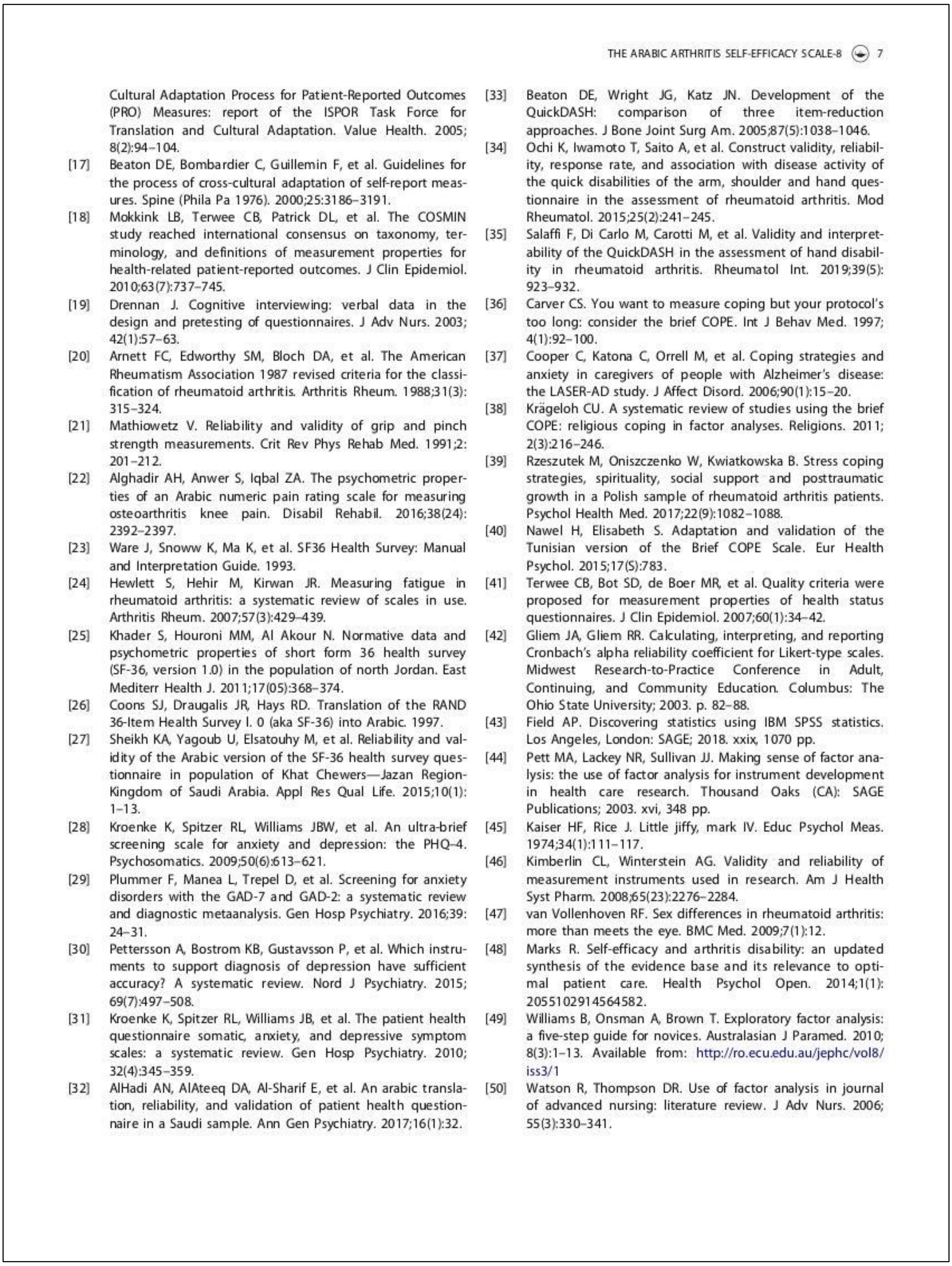

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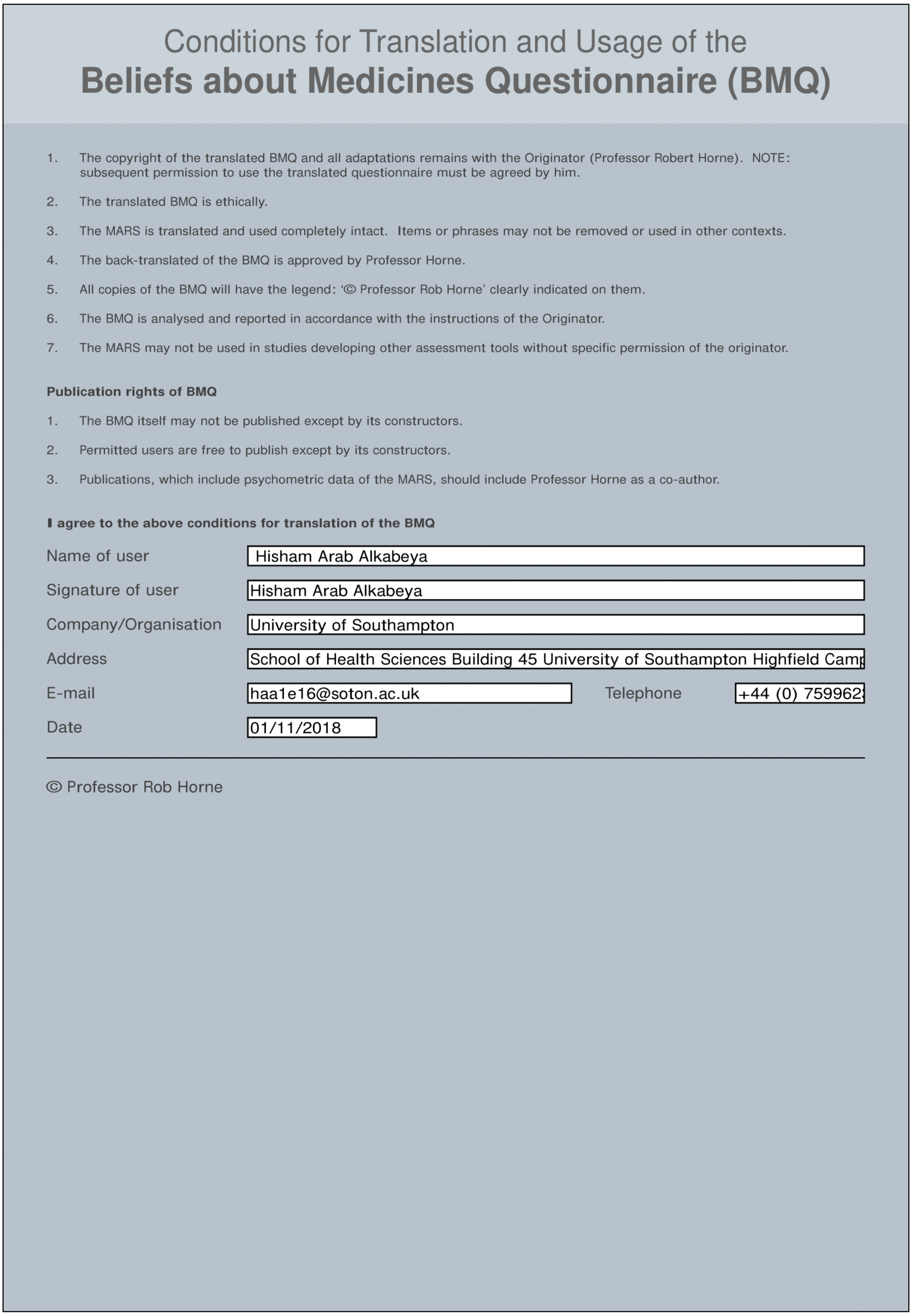
Appendix T Beliefs about Medicines Questionnaire licence agreement



Conditions for Translation and Usage of the
Beliefs about Medicines Questionnaire (BMQ)

1. The copyright of the translated BMQ and all adaptations remains with the Originator (Professor Robert Horne). NOTE: subsequent permission to use the translated questionnaire must be agreed by him.
2. The translated BMQ is ethically.
3. The MARS is translated and used completely intact. Items or phrases may not be removed or used in other contexts.
4. The back-translated of the BMQ is approved by Professor Horne.
5. All copies of the BMQ will have the legend: '© Professor Rob Horne' clearly indicated on them.
6. The BMQ is analysed and reported in accordance with the instructions of the Originator.
7. The MARS may not be used in studies developing other assessment tools without specific permission of the originator.

Publication rights of BMQ

1. The BMQ itself may not be published except by its constructors.
2. Permitted users are free to publish except by its constructors.
3. Publications, which include psychometric data of the MARS, should include Professor Horne as a co-author.

I agree to the above conditions for translation of the BMQ

Name of user: Hisham Arab Alkabeya
Signature of user: Hisham Arab Alkabeya
Company/Organisation: University of Southampton
Address: School of Health Sciences Building 45 University of Southampton Highfield Camp
E-mail: haa1e16@soton.ac.uk Telephone: +44 (0) 759962
Date: 01/11/2018

Appendix U Data recording sheet for hand assessments

UNIVERSITY OF Southampton

Site ☐☐☐ Participant ID ☐☐☐

Date ☐☐☐☐☐☐

Data recording sheet for hand assessments

4. Hand pain at rest

Please mark the scale below to show how intense your hand pain was over the last week. A zero (0) means no pain, and ten (10) means extreme pain.

Right hand

0 1 2 3 4 5 6 7 8 9 10

no pain extreme pain

Left hand

0 1 2 3 4 5 6 7 8 9 10

no pain extreme pain

5. Wrist ROM

	Score (Degrees)
▪ **Flexion – Right hand**	
▪ **Flexion- Left hand**	
▪ **Extension- Right hand**	
▪ **Extension- Left hand**	

6. Thumb opposition

	Score (0-10)
▪ **Right thumb**	
▪ **Left thumb**	

7. Power grip strength

	Score (Newtons or Kgs)
▪ **Right Hand**	
▪ **Left hand**	

8. Hand pain during activity

Please mark the scale below to show how intense your hand pain experienced during grip force.

Right hand

0 1 2 3 4 5 6 7 8 9 10

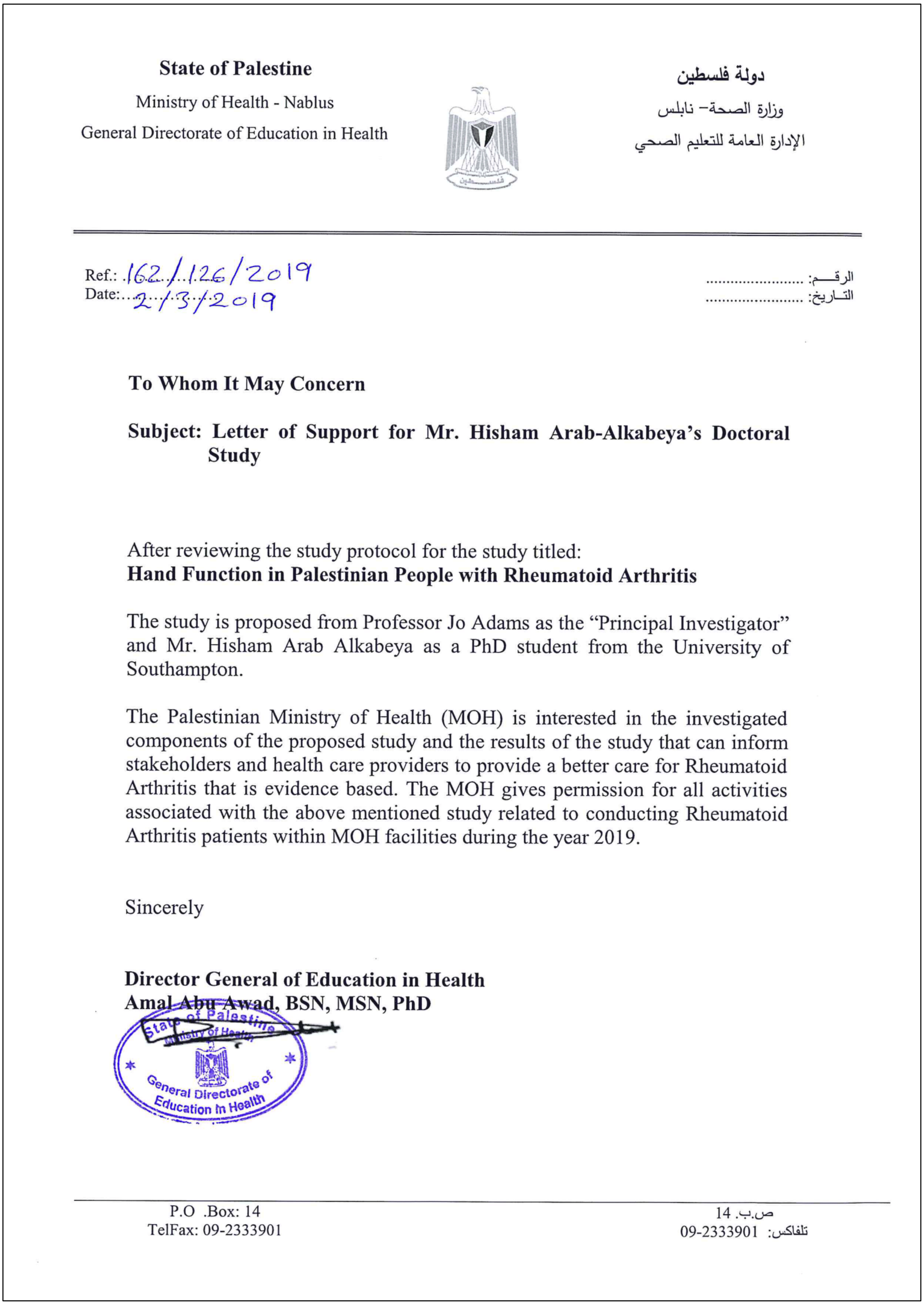
no pain extreme pain

Left hand

0 1 2 3 4 5 6 7 8 9 10

no pain extreme pain

Appendix V Ethical approval for the cross-section study in Palestine



State of Palestine
Ministry of Health - Nablus
General Directorate of Education in Health

دولة فلسطين
وزارة الصحة– نابلس
الإدارة العامة للتعليم الصحي

Ref.: 162/126/2019
Date: 2/3/2019

الرقـــم: ....
التـــاريخ: ....

To Whom It May Concern

Subject: Letter of Support for Mr. Hisham Arab-Alkabeya's Doctoral Study

After reviewing the study protocol for the study titled:
Hand Function in Palestinian People with Rheumatoid Arthritis

The study is proposed from Professor Jo Adams as the "Principal Investigator" and Mr. Hisham Arab Alkabeya as a PhD student from the University of Southampton.

The Palestinian Ministry of Health (MOH) is interested in the investigated components of the proposed study and the results of the study that can inform stakeholders and health care providers to provide a better care for Rheumatoid Arthritis that is evidence based. The MOH gives permission for all activities associated with the above mentioned study related to conducting Rheumatoid Arthritis patients within MOH facilities during the year 2019.

Sincerely

Director General of Education in Health
Amal Abu Awad, BSN, MSN, PhD

P.O .Box: 14
TelFax: 09-2333901

ص.ب. 14
تلفاكس: 09-2333901

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