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# University of Southampton

Faculty of Environmental and Life Sciences

School of Health Sciences

# Nurses' Knowledge of, and Attitudes and Perceptions towards People with Dementia: A Mixed Method Study in Saudi Arabia

DOI

by

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## Abstract

Faculty of Environmental and Life Sciences

School of Health Science

Doctor of Philosophy

Nurses' Knowledge of, and Attitudes and Perceptions towards People with Dementia: A Mixed Method Study Saudi Arabia

by

Sara Mahmoud Yaghmour

Historically, nurses in Saudi Arabia have not received any training in recognising or caring for people with dementia. This is likely due to the prevalent cultural views of dementia as fate and undefined pathways to its care. In fact, only in 2016 was geriatric care training introduced into domestic nursing schools' curricula; however, specific knowledge relating to dementia was not part of the programme, meaning awareness of this disease is still lacking. Hence, nurses working in hospital settings may not have the appropriate knowledge and skills required to support people with dementia.

This study investigates Saudi Arabian nurses' knowledge of (cognitive expertise), attitudes toward (feelings and behaviours) and perceptions of (thoughts, concerns and interpretations of particular behaviours) the care of people with dementia in Saudi Arabia's hospitals to inform the development of future training programmes.

The study was conducted in six hospital settings in Jeddah, Saudi Arabia and uses a sequential explanatory mixed-method design, involving a survey, and diary-interviews. A self-administered paper survey was completed by 710 nurses in Jeddah hospitals. Of these, 17 nurses agreed to keep a diary and 18 attended a follow-up interview. The study includes the validated Dementia Attitude Scale and Dementia Knowledge Assessment Tool version 2 and a set of demographic questions. Findings from the survey and diary interviews were established using the pillar integration process. This process helped identify practice approaches, as well as the knowledge and attitudes of nurses working with people with dementia, and then corroborated these practices through the diary-interview key points.

Analysis of the survey identified five themes: (1) the positive association between knowledge and attitudes, (2) work environment implications on nurses' knowledge and attitudes, (3) educational and cultural backgrounds' influence on nurses' knowledge levels and attitudes, (4) links between nurses' low self-confidence and their comfort level when dealing with people with dementia and (5) nurses' basic knowledge about dementia and dementia care.

Analysis of the diary-interview data identified five additional themes: (1) the acquisition of knowledge and the belief systems of nurses, (2) attitudes that inform nurses' behaviours, (3) nurses' perceptions of living with and caring for people with dementia, (4) professional factors affecting nursing practices and (5) nurses' ideas for enhancing dementia care. The above themes are summarised in this study, including sub-themes associated with these.

Finally, the pillar integration process identified five findings. These are (1) a lack of knowledge is associated with a lack of confidence when nursing people with dementia, (2) nurses are willing to learn about dementia but information and resources are not always available, (3) nurses' attitudes, emotions and perceived communication difficulties affect their delivery of dementia nursing care, (4) stigmas, cultural norms and perceptions associated with a dementia diagnosis can have a negative impact on nursing care for people with dementia and (5) organisational factors can negatively impact the nursing care for people with dementia. The findings are discussed in the context of socio-cultural influences, the role of emotional work and the impact of the work environment. Additionally, the study provides practical recommendations to inform healthcare organisations and nursing care in the Saudi Arabian context.

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# Research Thesis: Declaration of Authorship

Print name: Sara Mahmoud Yaghmour

Title of thesis: Nurses' Knowledge of, and Attitudes and Perceptions towards People with Dementia: A Mixed Method Study Saudi Arabia

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;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. 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;
7. Parts of this work have been published as:

Published paper

- Yaghmour, S., Bartlett, R. and Brannelly, T. (2019) 'Dementia in Eastern Mediterranean countries: A systematic review', *Dementia*, 18(7-8), pp. 2635–2661.
- Yaghmour, S. (2021) ‘The impact of settings and culture on nurses’ knowledge of and attitudes and perceptions towards people with dementia: An integrative literature review’, *Nursing Open*, IN PRESS.

Conference papers

- Yaghmour, S., Bartlett, R. and Brannelly, T. (2017) Dementia in Eastern Mediterranean Countries: A Systematic Review IN: *8th International Conference on Dementia*, Dublin, 18-19 September 2017. Dublin: Journal of Alzheimer Disease and Parkinsonism 2017, 7:4 (Suppl).

- Yaghmour, S., Bartlett, R. and Brannelly, T. (2017) Eastern Mediterranean Countries and Dementia: A Systematic Review IN: *12th UK Dementia Congress*, Doncaster, 2017. Doncaster: UK Dementia Congress.
- Yaghmour, S., Bartlett, R. and Ewings, S. (2018) Hospitalised People with Dementia in Saudi Arabia: A Mixed Method Study on Nurses Working in Acute Hospital Setting IN: *9th International Conference on Dementia,* London, 24-25 September 2018. London: International Journal of Dementia Care 2018.
- Yaghmour, S., Bartlett, R. and Ewings, S. (2018) Nurses' Knowledge, Attitude, and Perceptions Toward People with Dementia: A Systematic Literature Review IN: *9th International Conference on Dementia,* London, 24-25 September 2018. London: International Journal of Dementia Care 2018.
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# Abbreviations

| | |
|---|---|
| DAS | Dementia Attitude Scale |
| DKAT2 | Dementia Knowledge Assessment Tool version 2 |
| KSA | Kingdom of Saudi Arabia |
| MOH | Ministry of Health |
| PHC | Primary Health Centre |
| RNs | Registered Nurses |

# Chapter 1 Introduction

This doctoral research thesis presents a mixed-methods study of registered nurses' (RNs) knowledge of, and attitudes towards and perceptions of people with dementia in hospital settings in Jeddah, Kingdom of Saudi Arabia (KSA). In this study, *knowledge* is understood to mean cognitive expertise; *attitudes* mean feelings and behaviours towards people with dementia and *perceptions* are thoughts, concerns and interpretations of particular behaviours exhibited by people with dementia, as well as those providing their care in hospital settings. By investigating these attributes together, the study sheds light on how nurses in the KSA support people with dementia in hospital settings.

This opening chapter presents an Introduction to the research topic along with a description of The context of patient care in the Kingdom of Saudi Arabia (KSA). This is followed by a discussion of The nursing care of patients with dementia. Finally, a note on the focus and purpose of this study, including the researcher's Positionality of the study, are highlighted.

## 1.1 Introduction to the research topic

As in many countries across the world, the population of the KSA is ageing. In 2018, the nation's population was 33 million, with an average life expectancy of 74 years and rising (Ministry of Health, 2018). Comparatively, the average life expectancy in the United Kingdom (UK) is 81, while the global life expectancy is 71 (World Health Organization, 2015; Ministry of Health, 2018). This increased life expectancy, largely due to better health, is set to have a significant impact on the well-being of the nation's older adults (Benamer *et al.*, 2008; Qannam and Bello, 2016), namely in terms of their perceived health, psychological well-being, management of chronic illnesses and functional status (Benamer *et al.*, 2008; Al-Modeer, Hassanien and Jabloun, 2013; Amr *et al.*, 2014; Ullah *et al.*, 2016).

As has been well-documented, people often need physical, social, psychological and spiritual support to maintain and promote their well- being (Al-Shahri, 2002; Ratnaike 2002, p. 79). In fact, these older adults have the highest rates of dementia in the Eastern-Mediterranean region[1], including in the KSA (8.6%) (Okasha and Boutros, 2010; Al-Modeer, Hassanien and Jabloun, 2013). Central Europe, meanwhile, has a rate of 4.6%, and the UK's is 7.1% (Prince *et al.*, 2015; Boaden, 2016). One must therefore conclude that dementia is an issue that requires immediate attention in the Eastern-Mediterranean region.

The first step in facing this problem is to understand it. In the case of the KSA, this must begin with an awareness of the disease itself. According to the World Health Organisation (WHO) (2020), dementia is a condition characterised by multiple cognitive dysfunctions; examples range from memory impairment and language problems, to loss of motor skills, speech disorders, sensory recognition problems or executive functioning disturbances (for example, among others, an inability to solve problems, manage one's time or organise social gatherings) that require assessment and treatment by psychiatrists, neurologists and/or general practitioners.

It has been argued that people from the Eastern-Mediterranean countries have reservations about recognising dementia as an illness and are reluctant to accept the diagnosis (Okasha and Boutros, 2010; Al-Modeer, Hassanien and Jabloun, 2013; Cipriani and Borin, 2015). In fact, the term dementia only began to appear in the medical literature in the KSA in the early 1990s (Ozand, Gascon and Dhalla, 1990; Al-Rajeh *et al.*, 1993; Al-Ansary and Al-Rajeh, 1994), with the most prevalent forms being Alzheimer's disease, vascular dementia and Parkinson's disease (Ogunniyi *et al.*, 1998; Benamer *et al.*, 2008). It was only later in the decade that researchers first recognised dementia as a cause of death (Ogunniyi *et al.*, 1998). Unsurprisingly, dementia is not conventionally diagnosed in the KSA, as the means to diagnosis, treatment and management of this disease are not widely available to the general population (Okasha and Boutros, 2010; Al-Modeer, Hassanien and Jabloun, 2013) and are only supported at private memory clinics in major KSA cities. Consequently, those unable to afford or access these services generally do not receive them (Alsenany and Al Saif, 2012; Al-Modeer, Hassanien and Jabloun, 2013; Amr *et al.*, 2014). Making

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[1] The Eastern-Mediterranean region comprises 22 countries: Afghanistan, Bahrain, Djibouti, Egypt, Iran, Iraq, Jordan, KSA, Kuwait, Lebanon, Libya, Morocco, Oman, Pakistan, Palestine, Qatar, Somalia, Sudan, Syria, Tunisia, United Arab Emirates, and Yemen (The International Agency for the Prevention of Blindness (2014) *Eastern Mediterranean Region*: IAPB. Available at: https://www.iapb.org/about-iapb/regions/global-network-eastern-mediterranean (Accessed: 13/05/2017.).

matters worse, is the fact that the lack of public awareness of how poorly served the population is for dementia services results in a commensurate lack of organised efforts to mobilise resources to deal with dementia and secure provisions for patient care (Alsenany and Al Saif, 2012; Al-Modeer, Hassanien and Jabloun, 2013; Amr *et al.*, 2014). While there has been a recent increase of this awareness in the KSA, it is far from sufficient; significant steps are needed to provide people with dementia with the proper care services they require.

## 1.2 The context of patient care in the Kingdom of Saudi Arabia (KSA)

It is important to understand the contextualisation of patient care in this study. Contextualisation is an interpretation theory that seeks to explain meanings in relation to context, namely, understanding the social phenomena related to specific cultural backgrounds and historical periods within which they have formerly arisen or are combated now (Ann Powers and Knapp, 2011). Healthcare in the KSA is greatly influenced by the context and cultural backgrounds of the people providing it, as well as that of the patients themselves and their caregivers (Al-Shahri, 2002; Yaghmour, Bartlett and Brannelly, 2019). In other words, it is a reflection of the shared beliefs, values and behaviours, as well as the ideations and symbols of a group of people (Banks and Banks, 2010). A chief component of Saudi culture is the Islamic religion itself in that it imbues most Saudi traditions and is rooted in the views and beliefs of the people living in the Kingdom.

When it comes to healthcare in the KSA, diseases are perceived as being caused by fate, which often manifests as an opportunity to atone for one’s sins (Khan, 1994). With this in mind, the afflicted individual is encouraged to make full use of all available means to strengthen one’s health condition (physical) and their intellectual reasoning (psychological) while sublimating oneself to God (spiritual) and seeking out support (social) (Al-Shahri, 2002). This latter component is plainly encapsulated in a saying by the Prophet Mohammad:

> All of you are guardians and responsible for your wards and the things under your care. The *Imam* (i.e. ruler) is the guardian of his subjects and is responsible for them, and a man is the guardian of his family and is responsible for them. A woman is the guardian of her husband's house and is responsible for it. A servant is the guardian of his master's belongings and is responsible for them (Khan, 1994, p. 28).

It follows, then, that Muslim families living in the Arabian Peninsula inherited the concept of being responsible for themselves and others; for example, when a family member is in need, be it physically, socially or psychologically, the whole family contributes to assist him or her. This also applies to a neighbour or even a person one has just met. Non-religious people in the kingdom are also expected to deliver this type of care as aligned with the Islamic religion. In essence, one is responsible for maintaining strong family bonds and abiding by social responsibilities, as well as treating older people with respect and younger people with empathy (Al-Shahri, 2002; Almasabi, 2013; Alwedinani, 2016).

When caring for older adults in the Kingdom, certain aspects are of prime concern: one must deal with them with gratitude for the opportunity to offer them ultimate care and unconditional love, and one must respect their needs while reminding them to be optimistic about their condition (Khan *et al.*, 2013). In simpler terms, healthcare in the KSA is based on a family and spiritual model of care. This model of care is considered family-centred and care-oriented when it comes to spiritual needs and religious aspects (Al-Shahri, 2002).

On a more practical level, Islamic rules encourage people to maintain a healthy lifestyle, including regularly practising personal hygiene, exercising, eating moderately and fasting occasionally, as well as praying and abstaining from alcohol and substance abuse (Almasabi, 2013). It also allows for care to be provided by and to members of the opposite gender (though some tribes do not allow this as it is seen to be an offence to their traditions). Gender segregation, with its corresponding restrictions on females, is rigorously adhered to by religious members of the population (although some liberal Saudis do not subscribe to this policy). This segregation, enforced from one’s teens, sees females and males separated in academic and commercial settings, within most organisations and even during family gatherings (Alwedinani, 2016). Consequently, most people are not free to express themselves to the opposite gender.

### 1.2.1 Historical context of nursing in the KSA

Many of these traditions date back to the emergence of the Islamic religion, starting in 632 AD, and have consistently maintained their influence over the modern nursing profession (see Figure 1.1). While healers were practising medicine prior to 570 AD, during the Islamic era the injured and sick were treated by groups of females called *Alasiyat*, which means 'caring with compassion' (Almalki, Fitzgerald and Clark, 2011). The founder of this practice was Rufaida Al-Asalmiya, who lived in what is now the modern KSA (Jan, 1996). Rufaida's father was a healer who assisted her in developing the profession, while the Prophet Mohammad himself ordered a tent built inside the holy mosque for her to provide nursing care and teach other women how to provide patients with physical and emotional support both as part of emergency and long-term care (Jan, 1996; Almalki, Fitzgerald and Clark, 2011). It has subsequently been acknowledged that this was the first nursing school that qualified *Alasiyat* with a code of conduct and ethics to promote preventive care, centuries before Florence Nightingale's work in the Western world (Jan, 1996; Almalki, Fitzgerald and Clark, 2011; Meleis, 2011).

In the early twentieth century, nursing and emergency care schools were opened in Makkah, the holy city in the western region, and conducted in the Arabic language (Ministry of Health, 2019a). Later, two nursing schools were established, one in the capital of the KSA, Riyadh, and the other in the second largest city, Jeddah. In cooperation with the World Health Organization (WHO), the Ministry of Health (MOH) offered a two-year degree in each school (Almalki, Fitzgerald and Clark, 2011). Two decades later, in 1979 AD, the MOH introduced changes to the programme: admission was to be limited to students who had completed their ninth grade (junior high school). The study period was later increased to three years and the programme delivered in English (Almalki, Fitzgerald and Clark, 2011). By 1982, several more nursing schools were opened across the Kingdom, and admission rules changed again to include only students who had completed twelve grades (secondary school) (Almalki, Fitzgerald and Clark, 2011; Saudi Commission for Health Specialities, 2018). Since then, nursing schools have gradually adopted curricula from nursing schools from Western countries (Ministry of Health, 2019a; Saudi Commission for Health Specialities, 2018). It is worth noting that the MOH provides free education to Saudi citizens enrolled in government schools.

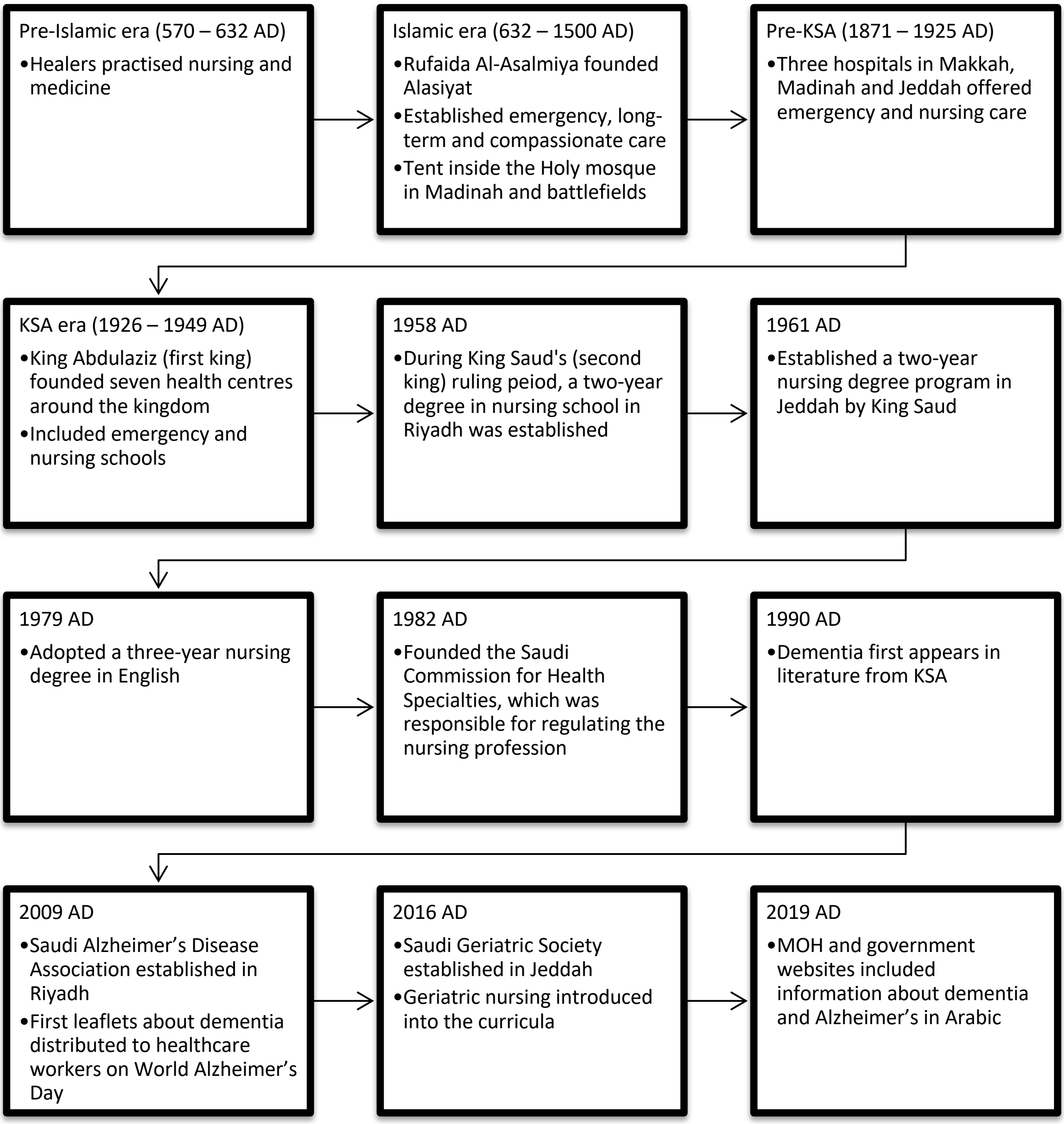

Figure 1.1 A brief history of the nursing profession and recognition of dementia in the modern KSA (Almalki, Fitzgerald and Clark, 2011; Saudi Commission for Health Specialities, 2018; Ministry of Health, 2019a; Ministry of Health, 2019b)

This growth in attention to medical care continued into the twenty-first century. In 2009, The MOH celebrated World Alzheimer’s Day within its facilities in the KSA for the first time under the theme ‘Faces of Dementia’ (Ministry of Health, 2019b). These events coincided with the establishment of the Saudi Alzheimer’s Disease Association in Riyadh. The Saudi Geriatric Society was later established in Jeddah in 2016 (Ministry of Health, 2019b). Both associations are concerned with raising public awareness of ageing diseases and providing financial, physical, social, psychological and spiritual support for individuals with dementia.

Despite these changes, no mention of dementia or Alzheimer’s was made in the WHO’s 2010–2015 global strategy and action plan on ageing and health, nor in the Saudi’s government plan, called Saudi Vision 2030 (Saudi Vision 2030, 2016; World Health Organization, 2017). However, they do reference enhancing mental health care provision to older adults (Saudi Vision 2030, 2016). Government documents, such as annual reports, websites and/or leaflets, refer mostly to Alzheimer’s rather than dementia, and the information presented is general (Saudi Commission for Health Specialities, 2018; Ministry of Health, 2019b). In other words, acceptance and recognition of dementia as a health condition is still not widespread. Nevertheless, there are signs of growing awareness.

Furthermore, while geriatric care courses were introduced into the undergraduate programme in late 2015 (Al-Aama, 2016), recent studies conducted in the KSA have reported a lack of trained personnel in the areas of dementia care, nurses in particular (Halabi and Zafar, 2010; Alsenany and Alsaif, 2014; Al-Aama, 2016; Yaghmour, Gholizadeh and Alsenany, 2016; Algahtani *et al.*, 2020). In fact, there are numerous studies in the KSA aimed at discovering the level of health professionals’ knowledge and gauging perceptions regarding older people with some form of neurological problems such as dementia. These studies have collectively reported a knowledge deficit among both medical/nursing students and faculty members (Alsenany and Alsaif, 2014; Al-Aama, 2016; Yaghmour, Gholizadeh and Alsenany, 2016). It is also apparent that there is a gap within the existing literature regarding the attitudes and perceptions of nurses tasked with the duty of caring for people with dementia and, most strikingly, there is similarly a general lack of research that includes nurses’ knowledge, attitudes and perceptions from other developing countries (Annear *et al.*, 2016b).

### 1.2.2 Modern state of the nursing profession in the KSA

The KSA, much like other nations, is facing demographic changes such as urbanisation and a shift from extended families to nuclear ones. Thus, despite the general feeling among most people in the region that sending an older adult parent to a nursing home violates a sense of sacred duty towards them, many individuals and groups are faced with situations wherein they have no other alternative (Karlin, Weil and Felmban, 2016). In other words, more older adults are being admitted to hospitals and nursing homes for care.

Consequently, the KSA is facing a severe nursing shortage. This has led to an increased demand for foreign-trained nurses, especially from India and the Philippines. In 2018, the MOH employed more Saudi nurses than non-Saudi nurses (62,685 and 42,788, respectively), while the national nursing workforce in the MOH, other government sectors and the private sector was majority non-Saudi (70,699 Saudi vs. 113,790 non-Saudi) (Ministry of Health, 2018). This is a growing trend.

The main problem is the public view of the nursing profession in the Kingdom, which faces significant challenges, including recruitment of high school students into nursing education, a poor nursing identity, and lack of awareness about the nursing profession (Elmorshedy *et al.*, 2020). Moreover, only 32.5% preferred to get nursing care by Saudis, and the nursing profession was not viewed as a respected job as 71.5% of participants would be ashamed of having a nurse in their families (Elmorshedy *et al.*, 2020).

While the above study looked at nursing in general, these views add further challenges to nurses who care for people with dementia, as will be addressed in the discussion in Chapter 8.

## 1.3 The nursing care of patients with dementia

Despite a growing body of knowledge concerning the care provided by nurses, it remains unclear what their actual experience is and how effectively nurses care for people with dementia. There are many factors discussed in the literature regarding dementia nursing care, including guidelines and frameworks for the development of nursing best practices, as well as competencies in dementia nursing care (further discussed in nursing best practices for dementia, section 2.2). Researchers agree that knowledge is considered the most important factor in developing dementia nursing care (Annear *et al.*, 2015b; Evripidou *et al.*, 2018), and that applying person-centred and compassionate care is deemed to be a core principle in utilising nursing best practices (Ericson-Lidman, Larsson and Norberg, 2014; Kupeli *et al.*, 2016; Chaudhury *et al.*, 2017; Bridges *et al.*, 2018). It is further believed that basic knowledge equips nurses with the capacity to form positive attitudes towards their care practices (Luckett *et al.*, 2019; Strøm, Engedal and Andreassen, 2019); therefore, the attitudes of nurses towards patients and their caregivers underlies their practice and competency development (Strøm, Engedal and Andreassen, 2019). Since this correlation between knowledge and attitudes has been acknowledged by most healthcare organisations (Collier, Knifton and Surr, 2015; Alzheimer's Disease International, 2019); as well as researchers (Evripidou *et al.*, 2018; Luckett *et al.*, 2019; Strøm, Engedal and Andreassen, 2019), healthcare organisations and policymakers have promoted understanding and training programmes in order to encourage positive attitudes of nurses towards people with dementia (Annear *et al.*, 2015b).

With the above in mind, a detailed examination of the key concepts is warranted.

### 1.3.1 Knowledge

The traditional definition of knowledge is that it is a true and justified belief; however, many philosophers have argued that it is more than that (Gettier, 1963; Turri, 2012). Knowledge is defined as a person's cognitive contact with reality and his/her relation to it (Greco and Sosa, 1999). Researchers identify two types of knowledge: acquaintance and propositional (Greco and Sosa, 1999). Acquaintance knowledge, on the one hand, is the unchangeable knowledge derived from experiencing reality. Propositional knowledge, on the other hand, posits that the known is only a description of what is suggested to be real.

Knowledge in nursing, as with other disciplines, is not a single collection of well-ordered information (Meleis, 2011). Thus, nursing researchers are encouraged to enlighten themselves as to the body of nursing knowledge (Decker and Hamilton, 2018). Many epistemological discussions within the literature exist regarding nursing knowledge and suggest the implementation of a theoretical framework to structure nurses' knowledge (Decker and Hamilton, 2018). These frameworks imply different levels of knowledge; inductive and deductive, ranging from most abstract to most concrete (Decker and Hamilton, 2018). In the present study, knowledge refers only to the propositional knowledge of nurses' cognitive expertise that is derived from learning and portrays their role in providing nursing care. This is expanded on in Chapter 4.

### 1.3.2 Attitudes

Social scientists relate attitudes to an individual's belief system, which may or may not be the same as those of the wider societal attitudes (Coban, Kiirca and Yurttas, 2015). It is argued that attitudes make up three classifications: affective (emotion and responses), behavioural (actions, tendencies and coping mechanisms) and cognitive (beliefs). These are known as the tripartite aspect of attitudes, whereby each influences the others differently (Bagozzi, 1978; Breckler, 1985).

In nursing, attitudes are considered crucial in understanding how nurses respond to and cope with different situations when providing care for patients. Nurses' attitudes guide their consideration of what is suitable, applicable and/or appropriate (Price, 2015). In the present study, attitude is related to the collection of feelings and/or beliefs (affective and cognitive attitudes) that drives a person's actions and intentions to act (behavioural attitudes) towards a certain topic or situation, which can thereby be identified as positive or negative.

### 1.3.3 Perceptions

Perceptions are the ability of the person to understand something that is experienced by themselves (Démuth, 2013). Nursing researchers have claimed that the concept of perception lacks theoretical integration, which continues to be an issue in interpreting nursing actions (Meleis, 2011). They further suggest that a lack of theories that incorporate nursing perceptions in practice occurs as a result of constraints in resources, workplace challenges and educational and clinical placement factors (Salifu *et al.*, 2019). Nurses are likely to hold strong beliefs about their profession, which, in turn, drives their competencies (Belete, 2015). However, it has been claimed that nurses will interpret a patient's behaviour based on public opinion of that behaviour (Girvin, Jackson and Hutchinson, 2016; Zhou *et al.*, 2016). In this study, perceptions relate to the thoughts and concerns about people with dementia, dementia care and an interpretation of other nurses' own behaviour towards the person with dementia.

## 1.4 The focus and aim of this study

The terms 'knowledge', 'attitudes' and 'perceptions' are frequently used throughout this study and form the basis of its thesis in relation to the nursing care of people with dementia. Though discussed briefly in the previous subsections within a discussion of the theoretical underpinning of these concepts within the nursing context, a deeper exploration of these terms will follow in subsequent chapters.

Most importantly, it is crucial to discover nurses' perceptions of nursing care and of their patients in order to understand the underlying beliefs that drive their attitudes (Luckett *et al.*, 2019). However, as perceptions cannot be explored without understanding their knowledge base and preconceived attitudes, these too must be investigated (Cassam, 2008; Arms, Rowan and Eusse, 2014; Faronbi *et al.*, 2017). Knowledge is the fundamental basis for providing nursing best practices, and the acquisition of this knowledge in turn forms a particular perception that leads to the formation of positive or negative attitudes.

Thus, this study aims **to explore nurses' knowledge of, attitudes towards and perceptions of the care of people with dementia in KSA hospitals**. To meet this aim, the objectives of the study are to:

a. gather data regarding nurses' knowledge of and attitudes towards dementia in the Kingdom of Saudi Arabia (KSA) using questionnaire surveys; the Dementia Knowledge Assessment Tool version 2 (DKAT2) and the Dementia Attitude Scale (DAS).

b. explore current nursing practices in regard to caring for people with dementia and gain greater insight into nurses' attitudes and perceptions regarding dementia and the care they provide to people with dementia using diaries and interviews.

c. identify learning needs of registered nurses when caring for people with dementia.

d. identify barriers faced by nurses when caring for people with dementia in Ministry of Health facilities using diaries and interviews.

In order to meet the aim and objectives of this study, these research questions will be answered:

1\. 1. How do nurses rate their own knowledge regarding dementia?
1\. 2. What are the assessment scores of nurses' knowledge of dementia using the Dementia Knowledge Assessment Tool version 2 (DKAT2)?
1\. 3. What are the assessment scores of nurses' attitudes towards working with people with dementia using the Dementia Attitude Scale (DAS)?
1\. 4. What factors are related to knowledge and attitude?

2\. 1. How do nurses perceive people with dementia and dementia care?
2\. 2. What are registered nurses' experiences with and perceptions of working with people with dementia?
2\. 3. What are the challenges/obstacles of nursing care for people with dementia in KSA facilities?

3\. 1. What are the recommendations that can be developed to inform policy and/or practice development and to improve nursing care for people with dementia in the KSA?

The findings will be used to support the care provided for these particular patients, to inform policy and best practices development in the KSA and across the Eastern-Mediterranean region and to address the gaps in the relevant literature (see Chapter 3 for further details).

## 1.5 The researcher's interest in this field

As discussed above, nursing care for people with dementia needs extensive research development, making it a major impetus for my decision to focus on this area of medicine. However, my initial motivation was based on practical reasons. Growing up in a culture that prioritises family, as well as living at home with my grandmother, parents, sisters and brothers, helped me develop strong nursing skills and provided the inspiration and motivation to choose nursing as my profession. Then, in 2004, my grandmother died following a year of suffering from a deteriorating health brought on by diabetes complications; she was hospitalised four times in different healthcare settings within that period, including medical and psychiatric wards. She clearly showed signs of dementia, but it was not diagnosed at that time. This concerned me greatly. After becoming a Registered Nurse (RN) in a cardiology ward in 2009 and observing admission cases of suspected vascular dementia, I took it upon myself to review my grandmother's condition in order to prevent the same tragedy from occurring to other patients and caregivers. My career choices thus became focused on gaining knowledge and investigating current care practices to enhance the well-being of people with dementia and improve nursing practices within KSA hospitals. As a nurse, I favour a pragmatic approach – that is, one that focuses on practical rather than theoretical concerns, and that is the approach taken in this study.

## 1.6 Positionality of the study

The pragmatic position taken by any researcher, advocates for the use of multiple sources for data collection and varied methods to address the research aim, which might require the use of inductive and deductive reasoning (see section 4.1, Using a pragmatic paradigm in this study). Pragmatism is an approach to research that is more concerned with answering a given question with practical implications as opposed to research that relies on theoretical questions or methods. In this study, this means that as no absolute truth exists in relation to the explored phenomena (dementia nursing care) within the context of the research (the KSA), the researcher undertakes the study using multiple data collection methods using abductive reasoning, thereby not necessarily getting mired in theories of nursing care or culture, but rather focusing on the real-world impact of these concepts on how dementia nursing care is delivered. This is a crucial distinction as modern practices are based on evidence-based publications; however, such knowledge is often derived from studies conducted in Western cultures that do not necessarily share the common practices and beliefs of people in developing countries. Therefore, it is important to provide equitable knowledge, as dementia affects people throughout the world, including the Middle East and countries like the KSA.

As context significantly influences nurses' responses and actions, it is vital to gain a better understanding of current dementia nursing practices within their contextual application. This naturally lends itself to adopting a paradigm of pragmatism is a key principle in addressing the research phenomena and understanding the nursing care context.

To understand current nursing practices when caring for people with dementia and to address the research aim, it was important to survey nurses to gain an overview of their knowledge and attitudes and explore their perspectives towards people with dementia. Due to the busy work environment of nurses and the limited time they could spare to help the research, scheduling face-to-face meetings was challenging. This was compounded by the nature of the research and nurses' willingness of contributing to such studies, especially when discussing a relatively unknown topic, in this case, dementia (as found from reviewing the literature in Chapter 3). To overcome these barriers, the planning phase of this study considered only including hospital RNs working for at least one year prior to the study in wards that care for people with dementia. Adapting methodologies that were suitable to nurses and addressing the KSA's cultural aspects (discussed in section 1.2) was the responsibility of the study researcher. Appropriately, a mixed-methods design that uses more than one type of data collection methods is proposed to meet these issues. Therefore, a survey questionnaire and diary-interviews were used, followed by an integration process in order to address the study's aim (detailed in Chapter 4, Methods and Methodology). Hospital nurses include bedside nurses, community nurses (who work at clinics, homecare departments, rehabilitation wards and primary health centres (PHCs), all of which are run by hospitals) and administrative nurses.

## 1.7 Summary of this chapter

Dementia is a growing problem in the KSA. Moreover, healthcare practices concerning dementia in the KSA are relatively new and developing; to aid in this development, it is important to understand certain features of the nursing care involved, particularly within the cultural or social context of life in the KSA. This study is contextualised to promote understanding of dementia care in a country where ideas are still embryonic and linked to religious beliefs. This study aims **to explore nurses' knowledge of, attitudes towards and perceptions of the care of people with dementia in KSA hospitals**. The study, therefore, adopts the pragmatic approach as a fundamental framework for this study, as the relevant reality is believed to be complex, constructed, multiple and both objective and subjective. Therefore, it was necessary to investigate nurses' current care practices alongside their personal voices in order to obtain a deeper understanding of their care for people with dementia. This current study will help close the gap in available knowledge and provide recommendations about nursing best practices regarding people with dementia in the KSA. An overview of the thesis is provided in the Appendix A.

# Chapter 2 Background

This chapter presents an introduction to dementia, including its prevalence and understanding across cultures and in the KSA in particular. It includes a discussion of dementia nursing care followed by a critical discussion of best nursing practices for people with dementia. An overview of the KSA healthcare system, especially regarding its approach to people with dementia, is highlighted for the sake of this study's context. The chapter concludes with a brief summary.

## 2.1 Introduction to dementia

Dementia is a disorder whose diagnosis is categorised under the umbrella of neurological cognitive disorders, as designated by the WHO (World Health Organization, 2020). However, dementia (as a fully developed diagnostic category) involves a number of cognitive domains, including social and occupational functioning. As some of the brain's functions decline, impairment in these two particular domains leads to memory dysfunctions and cognitive disturbances (Segal, Qualls and Smyer, 2018). Dementia, which is irreversible and often involves at least two impairments, decreases cortical functions that affect memory, learning capacity, judgment, reasoning and thinking (Staples and Killian, 2012). It is further characterised by easily recognisable symptoms such as impaired social skills, limited thinking abilities, and forgetfulness. Under these difficult conditions, people with dementia clearly require concentrated care. Dementia is progressive and the impairments increase over time. Thus, adapting to the changing needs of a person is part of the nursing care.

According to the WHO (2017), dementia mostly affects people who are over 65 years old at a rate of one in 14, with a higher rate of one in six for those aged 80 and above (Fuentes and Albala, 2014). To clarify, although cognitive ability decreases as a person grows older dementia is not a normal part of ageing (Yaghmour and Gholizadeh, 2016); rather, the risk of developing dementia increases with age. In addition, this risk begins to increase the most, by around 75%, at middle age, i.e. 45–65 years of age compared to people aged below 45 (Fuentes and Albala, 2014). These risk factors are important to note because, with proper attention and early detection, dementia can be managed and its progression slowed.

As the world's ageing populations continue to grow rapidly, the prevalence of dementia is expected to double within the next two decades (Segal, Qualls and Smyer, 2018). According to the WHO (2012), an individual is diagnosed with dementia every three seconds, and the number of people affected by dementia, globally, was estimated to be roughly 50 million in 2017 (Prince *et al.*, 2015), with approximately 850,000 in the UK and 5.5 million in the US (Prince *et al.*, 2015; Fulmer and Li, 2017). Studies have concluded that the global total will continue to rise and that by 2050 (World Health Organization, 2012). However, the exact prevalence of this disorder is a little difficult to pinpoint as its occurrence is not uniform. For example, while the rate of dementia diagnoses has decreased in the US and Canada, it rose in Australia, Africa and Asia. Moreover, evidence suggests that dementia appears to affect people from predominantly developing nations, and about 58% of these individuals are from the middle- and low-income classes; this rate is likewise expected to rise by 2050 to around 68%, with India and China forecast to have the fastest growing rate of older populations affected by dementia (World Health Organization, 2012).

## 2.2 Best practices for dementia nursing care

Caring for a person with dementia in a formal care setting involves comprehensively assessing their physical, psychological and functional needs, in addition to determining the impact of dementia on their families and caregivers (Hannan *et al.*, 2016; Registered Nurses' Association of Ontario, 2018). However, as numerous organisations and people apply different approaches towards dementia in nursing, some of the strategies may not be effective in all contexts (Registered Nurses' Association of Ontario, 2018). Furthermore, it is challenging to determine whose views, stories and accounts should be considered by nurses—those of the patient, family members, or the nursing system—within the context of the disorder treatment, evidence-based practice and management processes. This 'triangular' model of care was introduced by the Royal College of Nursing Foundation (Hannan *et al.*, 2016) and is also recommended by several researchers using different terms and approaches, such as Kitwood's Flower of Emotional Needs, person-centred care and compassionate care. These various terms and approaches all focus on treating people with dementia with dignity and assisting them in contributing actively to their own self-care.

Using frameworks involved caring for people with dementia recommended by international associations, such as Royal College of Nursing and Registered Nurses Association of Ontario, advocated the person-centred care and compassionate care then ensure maintaining the holistical care model – physical, psychological, social and spiritual – when providing the care for people with dementia.

One way in which this assistance is delivered is via a therapeutic concept for people with dementia. This includes effective communication and caregiving, which can bring people with dementia closer to the people around them (Staples and Killian, 2012). Enhanced communication skills (such as active listening, emotional responses, and creating a conducive environment) are important qualities that nurses should possess to create a sense of association with the people affected by dementia (Hannan *et al.*, 2016; Lee *et al.*, 2017).

Numerous studies support the concept that environmental adjustments are also required to accommodate empathetic relationships and create patient-friendly environments, which is considered an essential element in enhancing patients' well-being (Hannan *et al.*, 2016; Jenkins, 2016). This can be done, for instance, by differentiating bed spaces using various colours, locating sleeping areas near clearly marked toilets, and lighting sleeping areas sufficiently.

Another role that nurses have, is to explain to the patient and their caregivers the different treatments and medications, as well as their possible side effects, and to familiarise the caregivers with the available sources of support and information on particular treatments. It is therefore essential that nurses understand the medication, and are able to clearly respond to a person with dementia or his/her family members (McCann, Baird and Muir-Cochrane, 2014). This communication, relies heavily on the nurses' attitudes and perceptions, which are primarily defined by values such as respect, obligation and responsibility. This means that nurses' attitudes (particularly their thinking or feeling about people with dementia) and perceptions (ability to sense the need for changes in medication) should be in line with the treatment they administer. For example, nurses can offer personalised care by providing medications and regularly checking whether the patient is taking them as prescribed; this would help nurses take responsive measures if any concerns are noted (Lee *et al.*, 2017).

In summary, quality nursing care requires nurses to play many roles and to establish a productive therapeutic relationship with their patients. They are encouraged to show appreciation for, communicate warmly with and recognise their patients' strengths to make them feel valued and appreciated, all while maintaining positive attitudes and perceptions.

## 2.3 Nursing care for people with dementia

The opportunity to provide quality nursing care to people with dementia is a challenge that requires professional attributes. As a result, nurses must equip themselves with skills that align with the distinct factors related to their patients' conditions. The group of nurses which are the main concern throughout this study are both hospital nurses and community nurses as they are consider to be the front line of care at both hospitals and community (primary) health centres. Hospital nurses are those who work in KSA governmental hospital (study sample). As described in section 1.6, hospital nurses include bedside nurses, community nurses (who work at clinics, homecare departments, rehabilitation wards and primary health centres (PHCs), all of which are run by hospitals) and administrative nurses. Hence, this section discusses the different types of nurses within the community and hospitals, with further details outlining Saudi Arabian nurses.

This study focuses on nurses as they spend the most time with people with dementia, often taking the role of a family member when one is unavailable. Consequently, a patient's level of dependency on others determines their care requirements and the roles of caregivers within the different settings where the patient resides. This study focuses primarily on hospital nurses, namely those working in acute and community care settings.

Nurses have a duty to promote the well-being of people with dementia; however, due to the complexity of the illness it can be a challenging task that requires professional attributes. Nurses attending to persons with dementia have the responsibility of managing the individual's health problems, such as attending to blood pressure and preparing procedures, while also assisting with his or her personal care and daily living activities, such as personal hygiene, feeding, toileting and mobilisation (Doyle *et al.*, 2017).

In a hospital setting, acute care nurses are often responsible for managing a patient's condition under instructions from the physician and mental health specialists attending to them (Fukuda, Shimizu and Seto, 2015). Thus, nurses are trained to ensure that the ward environment, which can often include people with acute dementia that require critical medical attention, is comfortable and safe so as to improve patients' independence and orientation.

However, acute care nurses are often concerned only with patients in the ward in which they are working and do not provide outpatient specialist services, as hospital nursing concentrates on the region of operation rather than with extensive outreach to patients (Spencer *et al.*, 2013). Hospital nurses rarely offer rehabilitation services to people with dementia since they may see them just once. As such, they concentrate more on offering people with dementia medical services that ensure their recovery is positive and helps to improve their mental capabilities.

Community nurses, on the other hand, often deal with a diverse number of patients in their homes, in care homes or in primary health centres by providing family caregivers qualified opinions regarding the patient (Page, Keady and Clarke, 2007). Their availability, support and medical qualifications make them ideal for people with dementia since these people require constant personal and medical care regardless of where they are. During a first visit, a community nurse conducts an assessment to identify the specific dementia conditions a person has and provides practical interventions and plans to assist him or her in overcoming challenges. Community nurses also help people with dementia and their families make medical decisions and attempt to raise the caregiver's awareness of ways in which to deal with the person when the nurse is not available (Bunn *et al.*, 2015). Lastly, community nurses offer more support services, as well as follow-up and rehabilitation services to people with dementia in an attempt to assist them with their daily living.

## 2.4 Dementia nursing care in the KSA

In the KSA, people with dementia receive nursing care from four organisation types: A Ministry of Health (MOH) operated hospital, other government-run hospitals and care centres, private centres, and finally, nursing homes run by the Ministry of Social Affairs (Appendix B).

The MOH hospital provides free healthcare services to the population in a total of 274 hospitals located in the five geographical regions of the KSA (Ministry of Health, 2018). In 2016, these hospitals were served by 73,688 nurses (Ministry of Social Affairs, 2016). Of these hospitals, 18 were psychiatric and addiction hospitals, seven were convalescence hospitals and two were rehabilitation hospitals. Each major MOH hospital runs 6 to 20 Primary Health Centres (PHC), for a total of 2,282, with 18,745 nurses working in them. A total of 35,119 nurses worked in governmental hospitals other than the MOH. In the private sector, as of 2015, there were 145 hospitals and 2,670 polyclinics, in addition to four private psychiatric and neurology clinics operated throughout the Kingdom, employing 41,985 nurses (Ministry of Health, 2016). There were 12 nursing homes for older adults run by the Ministry of Social Affairs; in total, they were occupied by 668 senior adults (401 males and 267 females) (Ministry of Social Affairs, 2016).

Notably, the Western region (includes six health directorates: Jeddah, Makkah, Madinah, Ta'if, Tabouk, and Qunfidhah) has the highest number of nurses employed in MOH facilities, with the highest being in Jeddah, the principle area of focus for this study (see Table 2.1).

Table 2.1 The number of MOH nurses and facilities in the KSA

| | **Region** | | **Hospitals** | **Primary Health Centres** |
|---|---|---|---|---|
| 1 | Central | Facilities | 65 | 579 |
| | | Nurses | 18,316 | 4,265 |
| 2 | Western | Facilities | 72 | 571 |
| | | Nurses | 23,426 | 5,770 |
| 3 | North | Facilities | 33 | 205 |
| | | Nurses | 7,617 | 1,905 |
| 4 | South | Facilities | 69 | 676 |
| | | Nurses | 12,560 | 4,407 |
| 5 | East | Facilities | 35 | 251 |
| | | Nurses | 11,769 | 2,398 |

In the KSA, concerns regarding professional working environments for nurses have been a topic of discussion by Saudi researchers due to the rising need to address disagreements over the quality of care delivered to patients in hospitals (Aboshaiqah, 2016). According to the American Association of Critical-Care Nurses 2013, nurses have the role of ensuring patients receive adequate care and safety, and this is only possible if the working environment is guided by effective communication, collaboration and dependable leadership (Aboshaiqah, 2013). Appropriate staffing is another issue of present concern in that only numerous well-trained nurses can deliver care and support services to patients effectively. Currently, the KSA faces the challenge of an inadequate workforce to help execute the nursing responsibilities in the hospitals and patients' homes (Almalki, Fitzgerald and Clark, 2011). The KSA's nursing workforce is limited due to a lack of training facilities domestically, and increasing migration to Western countries by qualified staff looking to receive further training and find better employment opportunities (See also section 1.2.2).

Despite plans being undertaken to ensure the availability of enough professional local nurses, the current shortage also affects people with dementia as the level of care they require is not being adequately met. People with dementia in an acute crisis are often hospitalised in order to treat other co-morbidities (e.g. urinary tract infection, blood pressure issues, etc.) but are discharged upon their recovery from these illnesses and returned to family members to care after. Unlike in countries such as the UK, where people with dementia who live at home often receive care from their families and the assistance of professionally trained community nurses (Alboliteeh, Magarey and Wiechula, 2017), the KSA's shortage of nurses has led to higher complication rates for people due to lack of care. Therefore, further exploration of dementia care in the KSA and nurses' experiences while caring for people with dementia is highly recommended in order to explore the current care practices when caring for a person with dementia.

## 2.5 Attitudes towards dementia and its understanding across cultures

An important first step is to be aware of the change in the general attitudes in the KSA as regards dementia and dementia care. For instance, in the late 1990s, several studies examined dementia morbidity in the KSA with some declaring that it was a cause for concern (Ogunniyi *et al.*, 1998). It should be noted that at that time long-term palliative care facilities for older adults barely existed (Ogunniyi *et al.*, 1998; Yaghmour, Bartlett and Brannelly, 2019). Since then, however, dementia and geriatric studies have been incorporated into the healthcare curricula in order to facilitate a plan for infrastructure growth (Alsenany and Alsaif, 2014; Yaghmour, Gholizadeh and Alsenany, 2016), thereby signifying a change of attitudes toward dementia.

That being said, public opinion regarding dementia has much further to go in the KSA to match that of Western countries. Western literature claims that the majority of people living in developing countries such as Bangladesh and India, as well as immigrants to the West (Sayegh *et al.*, 2013; Söderman, Rosendahl and Rosendahl, 2016), believe that dementia is a part of normal ageing (McCleary and Blain, 2013; Høgsnes *et al.*, 2016; Söderman, Rosendahl and Rosendahl, 2016; Wang *et al.*, 2018a), with smaller representations from the Western community agreeing. Studies conducted by Eastern-Mediterranean researchers (Amer *et al.*, 2013; El-Tallawy *et al.*, 2013; Alushi, Hammond and Wood, 2015; Al-Aama, 2016) and South-East Asian researchers (Hu *et al.*, 2013; Wu, Wang and Wang, 2017) acknowledged the same tendencies. Many researchers have also stated that dementia's being a result of other, comorbidities may also contribute to this misunderstanding, along with a general lack of awareness of the issue (Rizzi, Rosset and Roriz-Cruz, 2014; Høgsnes *et al.*, 2016). However, a Brazilian epidemiological study found that the public's views of normal ageing is changing in response to the global efforts by healthcare organisations and education programmes to raise awareness of this issue (Rizzi, Rosset and Roriz-Cruz, 2014), as well as increased funding for research and the development of guidance for practices. For example, Alzheimer's Disease International funded the 10/66 Dementia Research Group to investigate dementia in developing countries (10/66 Dementia Research Group, 2015). That said, this group overlooked most Eastern-Mediterranean countries—including the KSA—as they only investigated low- and middle-income countries.

Many studies have also reported that dementia is often viewed negatively in Western cultures, such as Europe, Australia and America (Nolan *et al.*, 2006; Batsch and Mittelman, 2012; Alzheimer's Australia, 2017). Similar findings were gathered from the East, in Asian countries and the Eastern-Mediterranean areas (Okasha and Boutros, 2010; Al Abed, Davidson and Hickman, 2014; Al-Aama, 2016). In fact, the term dementia is increasingly associated with an emphasis on labels, such as *crazy*, and other medical terms, such as *second childhood*, *negative emotional and social responses* and *loss of status*, that are tied to the disorder as opposed to a person's humanity (Batsch and Mittelman, 2012; Benbow and Jolley, 2012; Alzheimer's Australia, 2017).

The stigma around the disease thus leads to people's negative feelings towards people with dementia, such as frustration, shame and embarrassment, as well as a general feeling of personal incompetence resulting from a lack of knowledge when dealing with them. In addition, the disorder is associated with fear, a shrinking network of friends, and fewer interactions with the rest of society, and these feelings pervade society and penetrate deeply into affected families (Batsch and Mittelman, 2012). This leaves people with dementia not only isolated and regarded as different from the rest of society (Okasha and Boutros, 2010), but it also leads to a deterioration in social interaction, a downward spiral in social relations, and a reduction in the dignity given to the person (Batsch and Mittelman, 2012; Benbow and Jolley, 2012).

In contrast, in Eastern-Mediterranean countries, older adults are regarded with respect and love; diseases like dementia are viewed more positively, with an emphasis on preserving the respect and dignity of the older adult, both by the immediate family and the extended family (Yaghmour, Bartlett and Brannelly, 2019). A literature review on the topic reveals that the high level of respect given to older people in these countries stems from a sense of duty on the part of younger people to take care of their elders when they are sick since these people are perceived not just as heads of the family but also as a source of great spiritual guidance and wisdom. Moreover, the term dementia is associated with fate and, as a result, older people usually live in their own homes with minimal support or independently, though family members may often ask for support and advice from the acute care or community care nurses when the need arises. In comparison, in the UK, a third of all people with dementia live in care homes due to their need for maximum support (Bartlett and Brannelly, 2018). Needless to say, those in the Eastern- Mediterranean countries with advanced dementia live with full-time care support at home or in care homes. Treating elder family members otherwise is viewed by society as a dereliction of the family members' duty to take care of the old, though this too is undergoing a change (as discussed in section 1.2).

## 2.6 Summary of this chapter

This chapter provides the contextual background to the study. It focuses on nursing care and perspectives in the KSA with the aim of elaborating on the condition of dementia and how it is understood across cultures. In addition, a brief discussion on nursing care and best practices recommended by healthcare organisations serves to highlight the need for conducting this study on nurses in the KSA in order to develop a broader training apparatus in the Kingdom of Saudi Arabia.

# Chapter 3 Literature Review

This chapter reviews the evidence on nurses' knowledge of, attitudes towards and perceptions of people with dementia. It should be noted at the outset that data regarding dementia in the Eastern-Mediterranean region are scarce and that epidemiological studies and studies on dementia incidence and prevalence among older adults in the region that is available has been published inconsistently over the last few decades (Yaghmour, Bartlett and Brannelly, 2019); hence, the lack of baseline data and need for this study.

Consequently, this study aims to shed light on the importance of raising awareness among healthcare professionals in this region regarding healthcare approaches shared by people from different sociocultural, religious, and linguistic backgrounds to deliver culturally sensitive care (Yaghmour, Bartlett and Brannelly, 2019). It is thus vital to study Eastern-Mediterranean caregivers who look after people with dementia in terms of their ethnic and cultural values and norms using both quantitative and qualitative methods (Yaghmour, Bartlett and Brannelly, 2019). Moreover, this study aid in promote the understanding of the healthcare workers about the Eastern-Mediterranean cultures for the betterment of dementia care in general and to enhance the older person's well-being (Yaghmour, Bartlett and Brannelly, 2019).

With the above in mind, two reviews were conducted, each under the umbrella of a specific research question:

Review #1: What is known about Dementia in Eastern-Mediterranean Countries? (section 3.1; Appendix C).

Review #2: What can be learned from international literature about dementia nursing practices from a global perspective in term of nurses' knowledge of, attitudes towards and perceptions of people with dementia? (section 3.2; Appendix D).

To answer these questions, two reviews were conducted. The review #1 used a systematic search approach to answer the first question above and has already been published in a leading journal ((Yaghmour, Bartlett and Brannelly, 2019); see Appendix C.1; section 3.1 below and Appendix C.2). Next, to answer the second question above, another review, review #2, was conducted using an integrative search of the literature that included 72 eligible articles, which has been published in another leading journal ((Yaghmour, 2021); see Appendix D; section 3.2).

## 3.1 Review #1: Studies on dementia care in the Eastern-Mediterranean region

While the countries of the Eastern-Mediterranean region share many values, cultural beliefs and a common history and heritage, there are significant differences when it comes to healthcare and government policies (Okasha and Boutros, 2010; Cipriani and Borin, 2015). Nonetheless, due to the lack of research conducted in the KSA, the search included studies from across the Eastern-Mediterranean region.

This literature review (conducted February 2017 and updated in March 2021) found and assessed 33 studies, and concluded that a significant gap in the literature exists regarding the study of dementia epidemiology, recognition and cultural acceptance, as well as the knowledge and attitudes of healthcare workers in the region (Yaghmour, Bartlett and Brannelly, 2019). In addition, 15 published studies were found when a further systematic search was conducted in July 2020, using similar research terms and inclusion criteria (see the published paper and the summary table of the updated search in the Appendix C).

Four central themes from the reviews were identified to inform the course of this study are discussed below then summarised.

## 3.1.1 Key findings of Review #1

(1) The focus on prevalence, comorbidity and gender: several studies of the Eastern-Mediterranean region investigated the prevalence of dementia among the local populations, and many of these concluded that the rate per capita is high, at 13% of the adult population and 6.4% in Saudi Arabia (Alkhunizan, Alkhenizan and Basudan, 2018). This high prevalence is linked to risk factors such as age, literacy, gender, comorbidity, heredity, smoking, epilepsy, hypertension, and diabetes (Bhalla *et al.*, 2018; El-Metwally *et al.*, 2019; El Tallawy *et al.*, 2019). Concurrently, many older adults in the region experienced at least one coexisting long-term condition at a rate of 52.8%. Dementia is associated with a variety of comorbidities including diabetes, hypertension, cardiovascular conditions, and depression (Albugami *et al.*, 2018; Abd Elaaty *et al.*, 2019; El-Metwally *et al.*, 2019; Yaghmour, Bartlett and Brannelly, 2019). In addition, evidence shows females have a higher prevalence than males (El-Metwally *et al.*, 2019; Konda *et al.*, 2019), which could be linked with lower levels of literacy in women (Yaghmour, Bartlett and Brannelly, 2019), their presence in local hospitals is lower, a situation likely influenced by cultural and/or religious norms. Therefore, it is suggested that more research is needed in order to advance the knowledge and the understanding about dementia, its prevalence and how many people are affected with dementia as it found to be higher than in developed countries. Also, more research is needed to assist policymakers to develop and review the healthcare policies related to caring for people with dementia.

(2) Role of culture and religion: the review confirms the understanding that older people in the region are highly respected and that placing them in care facilities is often considered an abandonment of one’s family duty; despite this sense of loyalty, the term dementia nevertheless carries with it a stigma in the region and is believed to be caused by ‘fate’, suggesting that cultural and religious aspects must be a consideration of future local studies.

Caring for people with dementia is the primary responsibility of the family due to cultural and religious practices (El-Metwally *et al.*, 2019), which results in the low uptake of care facility services (Yaghmour, Bartlett and Brannelly, 2019). A lack of understanding of dementia in the region (Bhalla *et al.*, 2018) is associated with stigma particularly aimed at caregivers (Werner and AboJabel, 2019; Yaghmour, Bartlett and Brannelly, 2019). Cultural and religious misconceptions heighten this stigma and prevent treatment by placing blame on the victim (Werner and AboJabel, 2019; Yaghmour, Bartlett and Brannelly, 2019). The limited presence of women, in most countries, in healthcare due to social norms also acts as a barrier to treatment for women with dementia (Yaghmour, Bartlett and Brannelly, 2019).

(3) A lack of recognition and tools: verified psychometric systems to assess dementia are lacking region-wide. The Mini-Mental State Examination is the main assessment instrument among Eastern-Mediterranean communities, despite concerns regarding its cultural appropriateness, particularly for people who have low literacy levels (low literacy rates are the norm in Eastern-Mediterranean countries, hence the concerns). Thus, assessment tools need to be upgraded and further developed to reflect measures that are culturally and socially sensitive to this part of the world.

Recognition and diagnosis are a challenge in the region due to lack of dementia awareness (Bhalla *et al.*, 2018; Algethami *et al.*, 2019; Werner and AboJabel, 2019). This is compounded by a lack of knowledge and training in healthcare, particularly in aetiology, diagnosis, and medication (Elmahdy *et al.*, 2020). Diagnosis is a significant challenge due to a gap in culturally-appropriate diagnostic tools that address barriers such as language and low literacy levels (Yaghmour, Bartlett and Brannelly, 2019). Development of valid, reliable, and internally consistent diagnostic tools is required for the region. Arabic versions of existing diagnostic tools have shown promise (Karam *et al.*, 2018; Feghali, Fares and Abou Abbas, 2019). Nevertheless, a lack of dementia awareness remains a significant problem in the KSA.

(4) Limited knowledge and training of the workforce: geriatric and dementia care have only recently been incorporated into nursing and medical curricula in the KSA, which implies an absence of healthcare workers' knowledge about dementia in the region. The effects of this finding are crucial to the future of dementia care, especially in the KSA.

The lack of adequate knowledge and training on how to support people with dementia among healthcare personnel in the region remains a major workforce issue (Albugami *et al.*, 2018; Manee *et al.*, 2019). Low public knowledge about dementia (Werner and AboJabel, 2019), widespread presence of stigma (Yaghmour, Bartlett and Brannelly, 2019), and a clear gap in medical education and training (Elmahdy *et al.*, 2020) are also factors in workplace issues. Enhanced dementia care training, the incorporation of geriatric and dementia care into nursing and medical training, and enhanced geriatric research can all help address shortcomings in healthcare in relation to dementia care and treatment in the region (Elmahdy *et al.*, 2020; Yaghmour, Bartlett and Brannelly, 2019). This study aims to include research on the knowledge of, attitudes towards, and perceptions of nurses when it comes to caring for people with dementia as a foundational support for nursing training in the KSA nursing curriculum.

### 3.1.2 Conclusion from the Review #1

The focus on *prevalence, comorbidity and gender* and *role of culture and religion* are particular and central to each individual region of the world and must be studied accordingly. In particular, it is recommended that more research be conducted in the KSA in order to advance the knowledge and understanding about the prevalence of dementia in this region and the reasons it is higher than in developed countries. This research may then assist policymakers in developing and reviewing existing healthcare policies related to caring for people with dementia in KSA healthcare settings. The matter of *tools recognition* and the *knowledge and training of the workforce*, on the other hand, clearly transcend borders and cultures. However, the review found that this lack of *recognition and tools* is simply a matter of incorporating the proper utilisation of appropriate technologies and methods as they become available. Additionally, *limited knowledge and training of the workforce* is an area from which the KSA can draw several lessons; by recognising the skills and steps necessary to improve dementia care in global settings, according to the studies reviewed, healthcare facilities in the KSA can adjust their practices and apply the means noted in these studies to local dementia care administration. Hence, this particular theme will be examined in greater detail in the following section.

This literature search uncovered a lack of knowledge and understanding about people with dementia among healthcare workers. Therefore, another literature search was conducted to explore nursing practices for people with dementia from a global perspective before conducting the study focusing on the KSA specifically.

## 3.2 Review #2: Summary of findings from global settings

The main objective of the integrative literature review (conducted in October 2019 and updated March 2021) was to synthesise a comprehensive body of evidence regarding nurses' knowledge, attitudes and perceptions regarding dementia care. Another objective was to explore nurses' experiences in terms of care in acute care hospitals and community care settings and evaluate these experiences in different regions across the world. A total of 72 articles were identified from the literature search, and these were classified into three themes (refer to the Appendix D for the full paper). The majority of the reviews included qualitative or quantitative papers, but there were five clinical trials (Yaghmour, 2021). For more details about the selected studies' contexts, such as scope, setting and participant numbers, please refer to summary table in the Appendix D.

A careful review of the relevant source material led to several conclusions that fall under specific categories of analysis. While all contribute to the understanding of nurses' knowledge of, attitudes towards and perceptions of people with dementia, their reflections on workforce issues are of greatest importance since these can inform future studies and approaches to dementia nursing care. Most importantly, these issues apply to nurses as individual human beings rather than simply professional workforce.

### 3.2.1 Key findings of Review #2

The three themes mentioned above are (1) nurses' knowledge, attitudes and perceptions regarding dementia, (2) nursing experience as a factor influencing dementia care in acute and community care settings, and (3) dementia nursing care across health regions.

The first theme reported on the knowledge, attitudes and perceptions of nurses regarding dementia care. A total of 72 studies explored this topic (Yaghmour, 2021). Most of the studies were of a high or good quality. However, the gaps that remained in addressing the first theme were that most of the studies were done using convenience sampling or purposive sampling methods. The studies revealed that most nurses had basic knowledge about dementia. However, deficiencies in specific knowledge, such as onset to end-of-life care and pain management, were frequently reported (Deasey, Kable and Jeong, 2014; Burns and McIlfatrick, 2015; Unroe *et al.*, 2015; Naughton *et al.*, 2016; Nilsson, Rasmussen and Edvardsson, 2016; Beck *et al.*, 2017). Handling the aggressive behaviour of dementia patients was challenging for many nurses, and they reported poor therapeutic relationships with staff because of this issue. The studies also revealed the role of inadequate training and the absence of lessons on dementia management in the nursing curriculum. In addition, for end-of-life care, it remains to be seen how new service initiatives may help nurses support patients during end-of-life care. In the case of studies that reported concerns related to the management of aggressive behaviour, the findings were restricted to studies done in two or three inpatient units. Thus, recruiting samples from a broader range of services can help to generalise these findings. Despite this limitation, the findings are consistent with research evidence, such as Yous et al. (2019), who argue that care delivery for dementia is challenging for nurses because they often navigate through patients' various feelings and emotions. They often experience the ethical dilemma of feelings of anger when meeting patients who show aggressive behaviour (Yous *et al.*, 2019).

In response to the low knowledge and skill level of nurses, many countries have implemented educational programmes to increase competency in dementia care for health staff. These studies highlighted the benefits of educational programmes in improving nurses' confidence, knowledge and attitudes towards dementia patients. This signifies the role of education in boosting confidence in care delivery for this health issue (de Witt and Ploeg, 2016; Eritz *et al.*, 2016; Martin *et al.*, 2016). The evidence-based findings from the current review study give a clear indication that the creation of awareness about dementia and experience in dealing with people with dementia improves both knowledge and the general skill sets that are relevant to people with dementia (Wang *et al.*, 2017a; Wang *et al.*, 2017b). Therefore, educational interventions and training programmes are an important resource for the future improvement of the competency levels of nurses in dementia nursing care as it would help enhance nurses' ability to manage pain issues that are often not verbally expressed by their patients. However, there were some quantitative surveys that used questionnaires lacking content validity. This limitation is addressed later.

The second theme concerned evaluating nurses' experiences in acute and community care settings. According to the studies, work environments and care settings play a crucial role in nurses' perceptions of their patients as well as dementia care delivery. A wide diversity in practices, along with the skills of the nurses working in both community and acute care settings, was evident in these studies with respect to dementia screening, evaluation and treatment. However, each of the settings had different limitations, and different actions were taken to enhance care. For instance, continuous professional development initiatives were evident in many community care settings (Eritz *et al.*, 2016; de Witt and Ploeg, 2016; Egede-Nissen *et al.*, 2017). In contrast, there were many studies wherein these settings were affected by a poor leadership style. A UK-based study focused on the fact that most nursing managers lacked proper knowledge of managing people with dementia; they even possessed negative attitudes towards planning for advanced care of people with dementia (Beck *et al.*, 2017). The researchers also claimed that leadership style influences the attitudes towards caring, thus negatively affecting the nurses' working atmosphere, ultimately creating a somewhat negative impact on their work experiences (Jakobsen and Sørlie, 2016). Thus, studies reported under this theme highlight the role of working environment and leadership style in dementia care. Job satisfaction and other forms of social motivation also greatly influenced the nature of the services offered by nurses to people with dementia. However, a gap remains in addressing the role of community services in improving the care experience of people with dementia. Thus, future research could evaluate how nurses' knowledge and access to community services can broaden their understanding of safety (Kable *et al.*, 2015). This will help in finding out how a care transition occurs from acute care to community care settings.

The third theme relates to experiences of dementia care in different regions of the world. It has been found that the issue of added stress and work pressure is not limited to one country or region. Studies done in Europe, the USA, and Eastern-Mediterranean countries reported these issues. Poor patient autonomy and violation of dignity in care was a major concern. For this reason, nurses are recommended to engage family members in the care to ensure that information about the patient's premorbid function and their likes/dislikes could be obtained (Sagbakken *et al.*, 2017).

### 3.2.2 Conclusion from the Review #2

Overall, the present review contributes to the understanding of the current knowledge and attitude of nurses and how their knowledge, attitudes and perceptions are enhanced or reduced by different factors in care; it gives guidance regarding the areas that need more work (Yaghmour, 2021).

In particular, the studies found that having samples from a broader range of services can help researchers draw a more generalised understanding of how nurses may navigate through the ethical dilemmas of dealing with patients' various emotions and aggressive behaviours. Moreover, the role of working environment and leadership style in dementia care is vital for job satisfaction, which influences the care offered by nurses to people with dementia. Lastly, the issue of added stress and work pressure resulting from poor patient autonomy and violation of dignity in care is a major concern that affects nurses in all regions of the world.

Thus, future research needs to focus on educational interventions and training programmes, as these are an essential component in raising nurses' competency levels in managing patients' pain issues. In addition, evaluating nurses' knowledge and access to community services can broaden their understanding of safety and help in transitioning patients from acute care to community care settings. Finally, nurses are advised to engage family members to ensure that the patient's care includes adjustments made for premorbid function and personal preferences.

This review mainly aims to synthesise the knowledge, attitudes and practices of nurses in dementia care (Yaghmour, 2021). The strength of the review is that it includes 72 articles from diverse countries. In addition, not limiting the research to any specific research design was also a strength because it ensured that diverse types of studies were reviewed. This review focused on the quality of each article. Hence, most of the studies were high-quality or good-quality papers, which were mostly evaluated using the Joanna Briggs Institute critical appraisal tools. The strength of the review is that no studies were found that had a quality appraisal score of less than 50%. For more details about selected studies context, such as scope, setting and participants' numbers, please refer to summary table in the Appendix D.

## 3.3 Conclusion and next steps

Many governments, policy makers and healthcare organisations across the world, including the WHO recognise the importance of improving the care of people with dementia. Hence, the establishment of the Global Action Plan and World Dementia Council in response to meet dementia care challenges and close the gap in care provided to people with dementia (World Health Organization, 2017; The World Dementia Council, 2018). Improving care means gathering enough evidence and information regarding the knowledge of, attitudes towards and perceptions of the individuals directly involved with people with dementia and/or their close relations (Sterns *et al.*, 2011a; Arms, Rowan and Eusse, 2014). Yet, fewer studies were conducted in the Eastern-Mediterranean countries.

The studies conducted in Eastern-Mediterranean examined dementia from multiple perspectives and settings, including nursing, emergency medicine, orthopaedic and psychiatry care settings. In particular, most Eastern-Mediterranean studies were cross-sectional, additionally, in most studies have not been conducted with nurses and it was unclear what settings have been studied. Despite the fact that demographic information was included in each study, nurses' training and experiences were not clearly investigated, nor were their working environments. Moreover, information about stress, inter-professional communication, communication skills and pain management are features lacking in studies about the Eastern-Mediterranean community.

Hence, it is evident from the background chapter and reviewed literature that there is an abundance of information available to nurses and students of dementia in the global context. This theory practice gap is striking gap within existing knowledge and inconsistencies regarding the information about nursing care for people with dementia, especially as regards knowledge of, attitudes towards and perceptions of dementia care in developing countries, including in the Eastern-Mediterranean region and particularly in the KSA. The particular nature of the theory practice gap could be specifically related to the context of the KSA. As it is still very wide and intractable due to cultural perceptions of dementia as fate, rather than a neurological health condition or disability

Moreover, taking cultural, social, religious, and educational differences into account, one cannot assume that findings in other countries apply to the KSA. Thus, the literature review serves to highlight the extent and nature of concern about older people with dementia in the KSA and the need for further research. Neglecting this can have a profound negative impact on persons with dementia, their families and the country as a whole (Annear *et al.*, 2015b).

It is therefore essential to measure dementia knowledge and attitudes and investigate perceptions among Saudi nurses in order to enable policymakers to develop effective educational interventions for nurses, as well as to ensure that people with dementia and their families get the social support they need to improve their well-being through nursing care practices (Annear *et al.*, 2016a).

This study aims to address this gap by exploring nurses' knowledge of, attitudes towards and perceptions of people with dementia and dementia care in the KSA, which makes this study significant. The path to this goal is outlined in the following chapter.

## 3.4 Summary of this chapter

The second part of the literature review, conducted in February 2017 and updated in March 2021, found and assessed a total of 118 studies from diverse countries and published between 2010 and 2021 (Yaghmour, 2021). Of these, 72 were found to be of high quality or good quality and utilised a variety of research methodologies, including qualitative, quantitative, and mixed-methods approaches. Nevertheless, gaps remained in that most of the studies were done using convenience sampling or purposive sampling methods, a detriment that would need to be addressed in future research studies.

As regards the literature from Eastern-Mediterranean countries, including the KSA, it lacks research concerning dementia and nurses' experiences and views about people with dementia, while the importance of nurses' roles in caring for people with dementia has been acknowledged worldwide (Yaghmour, Bartlett and Brannelly, 2019). Moreover, the methodological approaches used to investigate nurses' knowledge, attitudes and perceptions fail to elucidate the actual experiences, views and care provided to people with dementia as they pertain to other regions (Yaghmour, 2021). It is therefore important to explore nurses' knowledge, attitudes and perceptions using certain research methodologies that will benefit the development of guidance for practices, while considering differences in social, cultural, environmental, and other factors.

# Chapter 4 Methods and Methodology

The study used a sequential explanatory mixed-methods design, underpinned by a pragmatic paradigm. The rationale and components for this design and paradigm are defined and explained in full at the start of this chapter, following an outline of the study aims and objectives. Next, the chapter discusses the Mixed-methods design, profile of participants and population, the main data collection tools—a survey and diary-interviews—and the study setting. A further section on Ethical approvals and Ethical principles that were in place to guide this study is presented. The chapter concludes by describing the Multilingual research, as the study was conducted in English and Arabic then a highlight on the Data Analysis plan.

## 4.1 Using a pragmatic paradigm in this study

A pragmatic paradigm has been chosen for this research in conjunction with a mixed-methods approach introduced in previous studies (Teddlie and Tashakkori, 2009). The pragmatic paradigm in this study refers to a worldview that focuses on the real-world impact of nurses' knowledge, attitudes and perceptions and how dementia nursing care is delivered rather than focusing on specific theories of nursing care or culture. While it is agreed that paradigms reflect the researcher's choice of methods, which is built on personal beliefs and thoughts, some researchers acknowledge that a mixed-methods approach is a paradigm itself (Brierley, 2017), as its use supports multiple data collection methods. This approach has shown itself to be the most appropriate to address this study's aims and objectives (Teddlie and Tashakkori, 2009; O'Reilly and Kiyimba, 2015), most notably for the fact that the cultural atmosphere of the KSA allowed participants a greater opportunity to express themselves freely and openly (as will be discussed in greater detail in this chapter and in Chapter 8).

The pragmatic paradigm proposes various realities, though these do not reflect a symmetrical truth (Teddlie and Tashakkori, 2009). As everyone’s experience is unique, the explanations of and discourse about knowledge is formed by different perspectives according to ones’ emotions, experiences and means of knowledge acquisition. Thus, knowledge involves making associations between relevant variables that are then used to confirm or reject hypotheses or theories (in this study, these associations are represented by the survey). In addition, a paradigm incorporates its subscriber’s experiences and worldviews to make sense of the explored phenomena that then aids in developing new theories (in this study, the subscribers are the participants who contributed to the diary-interviews). Therefore, pragmatism allows for evolution, thereby denying rigid assumptions to influence choice between paradigms (Teddlie and Tashakkori, 2009).

With this concept in mind, and in order to provide evidence regarding current nursing care in the KSA that may aid in developing recommendations for dementia nursing practices, a mixed-methods approach was used to investigate nurses’ knowledge, attitudes and perceptions regarding the care of people with dementia. The research paradigm has three components: ontology (the view of reality’s nature and its explanation), epistemology (the approaches taken by the study researcher to acquire knowledge with a view to the relationship between what is known and what can be learned) and methodology (the researcher’s strategy in conducting the research) (O’Reilly and Kiyimba, 2015; Mason, 2018). Within this study, the ontological elements are the nurses’ knowledge of, attitudes towards and perceptions of people with dementia and how they experience dementia care. The epistemological positions were developed as a result of the researcher’s intellectual and theoretical approaches to the contributions made in the survey, diary and interviews. The methods involved the data collection, which happened sequentially (surveys, then diary-interviews), followed by an analysis of both datasets to draw together both quantitative and qualitative data, and the integration of the findings into a living view of the explored phenomenon: nurses’ knowledge of, attitudes towards and perceptions of people with dementia. In essence, each research approach informs the other by providing a basis of results on which to build while simultaneously supporting and/or explaining the other approach (Creswell, 2014).

The mixed methods design is used to enrich the study by maintaining a holistic view from the data (both the quantitative and the qualitative data), as well as to utilise in its analysis and integration in order to produce comprehensive findings and a transparent conclusion about current nursing practices in the KSA. The survey and diary-interviews methods were used in this study for several pragmatic reasons. First, the survey provides the researcher with flexibility as regards quantitative approaches to data collection and provides an established support system based on existing and validated questionnaires. The diary-interviews method, on the other hand, offers a more direct path toward qualitative data collection. The sequential data collection was chosen to enhance data sustainability. Conducting a survey for the nurses can give a general view of what their knowledge and attitudes are, which is then used to inform the findings of the diary-interview data sets that present and explain the knowledge, attitudes and perceptions (see Figure 4.1 for design pathway). The quantitative findings are needed to inform the qualitative part when collecting the diary-interviews data.

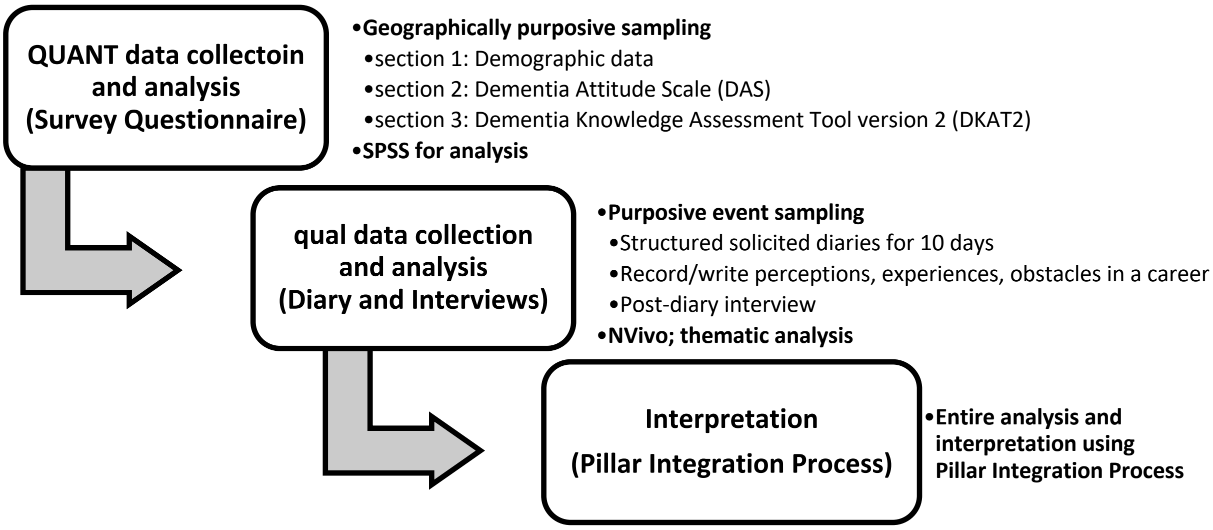

Figure 4.1 The sequential explanatory mixed-methods design

## 4.2 Mixed-methods design

Several studies have proven the benefits of using a pragmatic paradigm when combining qualitative and quantitative designs in terms of satisfying both concept and process domains, wherein the former focuses on the purposes, objectives and questions of the study, while the latter looks at the experiential side of the data (see Table 4.1). Many researchers have defined mixed-methods research as combining, including and collecting elements of both quantitative and qualitative data; this is done to broaden and extend the researcher’s understanding by integrating both datasets (Johnson, Onwuegbuzie and Turner, 2007; Andrew and Halcomb, 2009) and to allow for a comprehensive investigation of the studied phenomena in its various aspects to be highlighted (Teddlie and Tashakkori, 2009; Creswell, 2014). Other researchers have declared that some research questions require both quantitative and qualitative data sets in order to be answered fully (Creswell, 2014; Curry and Nunez-Smith, 2014). Therefore, with a mixed-methods design, quantitative and qualitative datasets complement each other very well, even if sometimes the results may disagree (Johnson, Onwuegbuzie and Turner, 2007), and including both methods in the research design is significant in that it can enrich and strengthen the combined methods (Flick, 2018).

Table 4.1 A comparison between qualitative and quantitative paradigms

| | **Quantitative methods** | **The mixed methods** | **Qualitative methods** |
|---|---|---|---|
| Concept domain: purpose, questions, objectives | Positivism | Pragmatism | Constructivism |
| | Deductive | Abductive | Inductive |
| | Objective | Objective and subjective | Subjective |
| | Confirmation | Confirm and understand | Understanding |
| | Explanatory | Explain and Explore | Exploratory |
| Process domain: experiential | Numeric data | Different types of data | Narrative data |
| | Instrumental-based questions | Different types of questions | Open-ended questions |
| | Pre-planned design | Pre-planned and embedded design | Emergent/embedded design |
| | Probability sample | Different sampling strategy | Purposive sample |
| | Statistical analysis | Statistical and textual analysis | Text and image analysis |
| | Statistical interpretation | Statistical and thematic interpretation | Themes, patterns interpretation |

Studies using a single research method may only reveal half the truth of the studied phenomena (Flick, 2018). Therefore, combining both quantitative and qualitative research methods can improve the significance of the study by maintaining a more holistic view of the research problem (Teddlie and Tashakkori, 2009). Moreover, crucial differences are often found in the quantitative and qualitative findings, wherein different patterns may be discovered. Given the importance of conducting a mixed methods study is to enrich the study by maintain a holistic view from the data (both the quantitative and the qualitative data), its analysis and integration in order to assist in reporting a transparent conclusion for nurses who are providing care for people with dementia.

Researchers frequently highlight the dichotomy of using both quantitative and qualitative methods (Teddlie and Tashakkori, 2009; Creswell, 2014), which offer extensive and optimised benefit. For example, the quantification of the observed reality is more often a core element during conducting the research, whereas in the qualitative research method, the emphasis is on the articulation of the observed reality and the understanding of its interpretation. Ultimately, each offers the researcher a different base from which to take a further step towards the stated aims of the study.

A mixed-methods design involving both types of data, quantitative and qualitative, is used to collect data in a study in one of the following ways: sequentially (as in this study) and/or concurrently (Andrew and Halcomb, 2009; Creswell, 2014). The sequential data collection was chosen to enhance the data sustainability. Conducting survey for the nurses can give a general view on what their knowledge and attitudes are, this is used to inform the finding of the diary-interview data. The quantitative findings are needed to inform the qualitative part when collecting the diary-interviews data. The mixing of data can occur during the data collection process or in the analysis stage; in this study it was done by joining the statistical interpretation of the surveys with the diary-interviews analysis in order to build thematic pillars from the joint analysis of the key points identified in each. This is the hallmark of the mixed-methods research design and was used to produce a holistic view in this study about current nursing practices in the KSA.

This study used mixed methods at several stages. In the literature search stage and the formulation of the research questions, only one method was applied using either an explorative research question or a confirmative one, the results of which were either deductive or inductive. These reasoning concepts were detected in the perceptions of the participants. Therefore, some findings were identified from previous studies and moved into a generalised conclusion (inductive reasoning), while others were identified and transformed from principles generally believed to be true to more accurate and specific conclusions (deductive reasoning). Later, in the development stage of the research design and the data collection and analysis processes, both methods were applied using abductive (deductive and inductive) logic, both objectively and subjectively to confirm and understand the phenomena observed (Creswell, 2014; Punch, 2016).

A popular design for this type of study (abductive) is the sequential explanatory mixed-methods design and it is one commonly used by researchers, including the present study. This design involves collecting and analysing quantitative data first and then the qualitative data in consecutive stages. In this case, the quantitative aspect involves collecting information using a cross-sectional survey to identify nurses' knowledge and attitudes in regards to people with dementia and the care provided to them in the KSA. This is followed by a qualitative process involving the collection of data using diary-interviews in order to gain a much deeper insight and understanding into nurses' knowledge of, attitudes towards and perceptions of people with dementia. This second method helps to observe and explain both their knowledge and attitudes within the study's context and determine the particular perceptions, beliefs or cultural components involved when caring for people with dementia (Teddlie and Tashakkori, 2009; Creswell and Clark, 2011; Creswell, 2014). In the present study, the quantitative survey and qualitative diary-interviews were combined at different times in the data integration process to aid in the development of the implications for nursing practices and/or recommendations to improve the nursing care of people with dementia in the KSA. The research design is extensively discussed in the following sections.

A cross sectional survey was conducted to gain foundational knowledge about nurses' knowledge of and attitudes towards people with dementia who visited or were hospitalised in KSA hospitals. A cross-sectional survey is a quantitative method that provide a view on what is happening of specific population at one moment time.

Following completion of the survey, diary interviews were conducted with a self-selecting sample of survey respondents. Diary-interview method is a qualitative method that involves participants keeping a record of their experiences, which are routine records of participants' experiences that could capture rich data on individual events, beliefs and/or feelings (Zimmerman and Wieder, 1977).

Both stages of the data collection are outlined below.

### 4.2.1 Survey

Questionnaire surveys can be used to collect a large amount of quantitative data. In quantitative studies, researchers tend to use surveys to reflect their interest in describing social phenomena as expressed in numbers to predict assumptions that can be measured systematically and assessed scientifically (Nardi, 2014). To do this, they mostly use a cross-sectional design that considers the collection of all relevant information at once. Moreover, in any survey research, it is claimed that attitude scales are the most frequently used type of questionnaire as they most accurately reveal the participants' opinions and feelings on the topic in question (Tashakkori, Teddlie and Teddlie, 1998; Nardi, 2014). These questionnaires include knowledge-based questions that enable researchers to understand how much people know about the topic and to discover group differences across the study's samples (Nardi, 2014). Furthermore, survey questionnaires could allow for generalisations from a small sample of cross-sectional data and from participants' demographics, knowledge and attitudes, which can, in turn, have positive implications for practice (Creswell, 2014).

Since the aim of the present survey is to identify nurses' knowledge and attitudes concerning people with dementia in MOH facilities, two validated tools were selected and administered to Registered Nurses' (RNs) working for the MOH in the Western region of the KSA. These tools measure the knowledge and attitudes of professionals and other people caring for persons with dementia. Hence, the final draft of the questionnaire survey included three sections: 1) demographic and personal information, 2) the Dementia Attitude Scale (DAS) and 3) the Dementia Knowledge Assessment Tool version 2 (DKAT2) (note: demographic information was always positioned first, but the DAS and the DKAT2 could be answered in any order and the questions were randomised). Together, these three sections aimed to identify nursing practice approaches and the knowledge and attitudes of nurses working with people with dementia. The answers also helped to clarify the relationships between nurses' knowledge and attitudes and their education and experiences (Further discussion of the tools can be found in Section 4.4.2: Survey section 2: Dementia Attitude Scale (DAS) and Survey section 3: The Dementia Knowledge Assessment Tool version 2 (DKAT2)).

The questionnaires themselves were self-administered, which is one of the most commonly used approaches to data collection (Nardi, 2014) as it is beneficial for the researcher in terms of time and cost savings and enables the researcher to approach large numbers of participants in the targeted population (Nardi, 2014). Moreover, the questionnaire as well as its administration, are supported in the published literature with evidence of their reliability, validity and feasibility (Nardi, 2014).

The questionnaire aims to describe or explain a reality (specific phenomena) in order to produce rich data. The quantitative data collected using this tool focuses on exploring possible correlations between relevant variables and describing levels of knowledge and attitudes. The purpose of using a pre-existing questionnaire is to maximise its validity; the obtained results can be more reliably compared with other studies due to their established baseline responses that have been assessed using the same tools. Furthermore, questionnaires are useful for minimising any response bias in a sensitive or disregarded area of social desirability. As noted by the researchers conducting studies in this area (mentioned in the background and the literature review), people in this field feel ashamed of diagnosing dementia and there is a stigma related to dementia and its wordings.

### 4.2.2 Diary-Interviews

The diary-interviews method is a qualitative method that involves participants keeping a record of their experiences, which are routine records of participants' experiences that could capture rich data on individual events, beliefs and/or feelings (Zimmerman and Wieder, 1977). As they are kept under the direction of the researcher, hence being termed *solicited diary*, these diaries allow researchers to investigate and analyse particular issues, as well as gain an insight of current participants' practices (Hyers, 2018). This process is accompanied by an interview for further discussion and explanation of the entries therein (Bartlett, 2012). That said, it can be argued certain topics or circumstances within some cultures require the adoption of methods other than interviews to gain a rich insight into the aspect under study (Teddlie and Tashakkori, 2009; Bartlett, 2012; Brinkmann and Kvale, 2015; Punch, 2016). For example, in the KSA, it is common for a woman to be chaperoned by a man during an interview as a male guardian must be present. Diaries, therefore, present a further pragmatic approach for the researcher by allowing the participants to overcome the difficulties that are often encountered when a person of one gender is asked to express his or her opinions, perceptions and thoughts to someone of a different gender, as the participant is able to provide information in their own time and without the researcher being present, as was the case in this study (see section 4.3.2 Diary-Interviews sample and recruitment).

These qualitative methods are used in nursing research to explore phenomena in depth (Brinkmann and Kvale, 2015; Mason, 2018), and authors have claimed that interviews are useful methods for gathering detailed information regarding a topic and to encourage participants' engagement and contribution (Hyers, 2018) by allowing them to express their views openly and freely without the limits of a questionnaire. In addition, following a diary with interviews provides the study with greater strength, rigour, breadth and depth (Bartlett, 2012). See Chapter 8 for further details of the benefits of this method.

On a more practical level, participants were asked to enter a record in their diaries of their daily experiences at the end of their working shift and to do this for ten working days throughout one calendar month (refer to section 4.4.3 Diary booklet). This timeframe was considered a practical length to avoid participants' fatigue and to allow for a sufficient collection of data.

The study researcher had contacted the diary participants through SMS texts to set a date and time for the interview at their convenience (see section 4.4.4 for interview schedules and settings). The in-depth, semi-structured interview gave the participants the opportunity to discuss their diaries' entries and to state their opinions and views on their knowledge, attitudes and perceptions regarding people with dementia and dementia care, as well as the actual experiences of nursing (Bartlett, 2012; Bartlett and Milligan, 2015).

### 4.2.3 Data integration

The hallmark of mixed-methods research is the integration of quantitative and qualitative types of data (Fetters , Curry  and Creswell, 2013). As mentioned by mixed-methods social scientists, analysing mixed-methods data employs at least one of the following analytical skills: merging (following a thread), connecting (triangulation protocol), creating a mixed-methods matrix (meta-matrix) and transforming (Jupp, 2006; Moran-Ellis *et al.*, 2006; O'Cathain, Murphy and Nicholl, 2010). In the present study, the data were mixed during the analysis process and integrated using the following analytical approaches: intuitive merging, category/theme matrix, cross-case matrix and transformation using the pillar integration process guidance (Johnson, Grove and Clarke, 2019) (more on this in section 4.8.3). During the merging process (known by both terms *parallel* and *separate*), the data were independently analysed and then holistically interpreted to create unified pillar themes (further discussion of the pillar integration process can be seen in Chapter 7).

## 4.3 Participants and Population

Data were collected from RNs working at MOH facilities in Jeddah between March and July 2018. It worth mentioning that Jeddah is the second largest city in the KSA after Riyadh, the capital city (Jeddah 4.7 million, Riyadh 7.2 million (KSA 34.27 million)). As noted in the Table 4.3 below, six out of 14 Jeddah hospitals were included in the study. Almost 60 per cent (3,200) of all nurses who are working in the KSA were working in these 14 hospitals in Jeddah (see Table 4.2**Error! Reference source not found.**). The two central hospitals, which provide various healthcare services, are located in central and southern Jeddah. In addition, two newly established hospitals that provide healthcare services to people living in northern and eastern Jeddah, including the surrounding suburbs, were also included. Further, one rural hospital, which is the biggest amongst the rural hospitals and closer to Jeddah's centre, was included. Of the specialised hospitals in the city, the sole psychiatric hospital was included. The six MOH hospitals included are (1) King Abdullah Medical Complex (KAMC), (2) King Fahad General Hospital (KFGH), (3) East Jeddah General Hospital (EJGH), (4) King Abdulaziz Hospital (KAH), (5) Althagur General Hospital (ALT) and (6) The Psychiatric and Mental Health Hospital (PSY). These hospitals were chosen to maintain a valid and appropriate sample that could be representative of the wider population.

Table 4.2 Expected sample size calculated

| | **Number of Facilities** | **Registered Nurses** | **Expected sample size calculated*** |
|---|---|---|---|
| **Western region** | 72 | 29,196 | |
| **Jeddah City** | 14 | 6,980 | |
| **Included hospitals** | 6 | 3,200 | |
| **Areas of care for people with dementia** | 8 wards within | 2,099 | 610 |

**Key:** * Sample size calculated using national the Australian Statistical Service and a statistician's advice

Table 4.3 Characteristics of Jeddah City hospitals

| # | Category (hospital type) | Hospital | RNs | | Included | Hospital Description |
|---|---|---|---|---|---|---|
| | | | within hospital | Care for dementia* | | |
| 1 | Central | KFGH | 900 | 633 | Yes | Main hospital<br>Located in the centre of Jeddah City<br>Various specialties<br>20 KM to reach** |
| 2 | | KAH | 806 | 450 | Yes | Main hospital<br>Located in southern part of Jeddah<br>Various specialties<br>30 KM to reach** |
| 3 | New, big | KAMC | 500 | 361 | Yes | Established early 2016<br>Serves north Jeddah and suburbs, including urban towns<br>25 KM to reach** |
| 4 | | EJGH | 450 | 281 | Yes | Established late 2017<br>Located in eastern part of Jeddah<br>30 KM to reach** |
| 5 | Rural | ALT | 300 | 265 | Yes | One of the rural hospitals located between Jeddah and Makkah<br>Variety of services<br>40 KM to reach** |
| 6 | | ADM | – | – | No | Located in a southern village<br>Established late 2018<br>345 KM to reach** |
| 7 | | RBG | – | – | No | Located in a northern village<br>Four hours travel time to reach (150 KM) ** |
| 8 | | LTH | – | – | No | Located in a southern village<br>230 KM to reach** |
| 9 | Specialist | PSY | 180 | 109 | Yes | 30 KM to reach** |
| 10 | | EYE | – | – | No | Eye hospital<br>Relatively small |
| 11 | | KSH | – | – | No | Infectious disease hospital |
| 12 | | MATM | – | – | No | Maternity and paediatric hospital |
| 13 | | MATA | – | – | No | Maternity and paediatric hospital |
| 14 | | ALA | – | – | No | Drug addiction hospital |
| **Total # of RNs** | | | 5,643 | 2,099 | from six hospitals | Approached almost 60% of total nurses working in Jeddah |

**Key:** * Wards where nurses are expected to care for people with dementia, according to administrators

**From researcher's starting point (place)

In Jeddah, MOH facilities have a total of 3,203 hospital beds, with a hospitalisation rate of 7.4 per 10,000 people. At the time of the present study, there were 2,523 physicians (a rate of 78.8 physicians per 100 beds) and 5,643 nurses (223.7 nurses per 100 physicians) (Table 4.3). As of 2015, 14 MOH hospitals have been operating in Jeddah, including two psychiatric hospitals (one a general psychiatry hospital and one an addiction treatment hospital) with a total of 335 beds, and 88 PHCs under the umbrella of some of these MOH hospitals. In addition, there were 330 beds for psychiatric and neurology patients in the general hospital of the MOH. In 2015, the private sector in Jeddah was operating 33 hospitals and had 398 polyclinics with 7,436 nurses; of the 3,109 beds available, 122 were for psychiatric and neurology patients (Ministry of Health, 2016).

The study inclusion criteria for participants were as follows: (1) registered nurses working for MOH facilities in Jeddah for at least one year and (2) based in a department that admits people with dementia for care at least once a month- this was to ensure that participants had exposure to people with dementia and could therefore respond to survey question and have (3) a capacity to read and write in English, as the study used validated tools in the English language. See sections 4.3.1 and 4.3.2 below for more details about sampling for survey and diary-interviews.

The region was selected because most care in MOH is free and so there is a higher density of nurses working in these hospitals. Furthermore, as a capital city, Jeddah is easy to access and has a reliable telecommunications network. All of which are important, when carrying out a relatively large-scale mixed method PhD study by oneself.

### 4.3.1 Survey sample and recruitment

The survey sample size of 610 was determined by estimating elements of the DKAT2 and DAS to within a suitable degree of precision, where precision is confirmed by a 95% confidence interval. A confidence interval (CI) represents a plausible range of values for a given statistic, such as a mean, based on the observed data. Noting that when all things being equal, a CI will become narrower as sample size increases, which may help put the following information into a more context (Field, 2018).

Based on the data presented in Table 4.3, the targeted population was 2,099 nurses working in areas that involve caring for people with dementia and who likely to encounter at least one dementia case per month. The Australian National Statistical Service sample size calculator, along with a statistician's advice, was considered when estimating the proposed sample size (Morisette and Khorram, 1998). Therefore, following consultation with one of my supervisors who is a statistician, and estimating the 5% to be sufficiently narrow, based on trying to estimate knowledge and attitude quite precisely, and a width of 5% leads you to a total of n=610 nurse responses were required to achieve a meaningful result and to narrow the confidence interval in the survey. To determine an appropriate width of this confidence interval (5%) a few factors were considered: first, the stage of the research wherein the confidence interval was to be applied, as a very early application may result in a larger width of confidence interval when assessing an overview of the studied phenomenon; second, practical considerations were taken, such as knowing the limitations of the approached wards and hospitals and being realistic in terms of achieving the desired number of nursing participants within a planned timeframe; third, achieving a balance between practicality and precision, as sometimes the addition of 100 people only increases precision by a small amount whereas at other times adding just 50 people may lead to a noticeable improvement in precision. This level of precision allowed a clearer picture of the level of dementia knowledge and attitudes among the population of interest. Hence, the sample frame was female and male RNs working in MOH facilities in the KSA (See Table 4.2**Error! Reference source not found.**).

The present study incorporated a non-probability sampling strategy (Tashakkori and Teddlie, 2010). Using the sampling method outlined above, 610 nurses were targeted for recruitment to the survey. This sampling methodology seeks external validity (generalisability) using a questionnaire that focuses on the breadth of the information sought (attitude and knowledge); the dataset generated is all numerical (Tashakkori and Teddlie, 2010).

Researchers often report a response rate of 40 to 50 per cent for surveys (Nardi, 2014). However, in similar studies conducted in the KSA the response rate has been 60 per cent (Alsenany and Al Saif, 2012; Yaghmour, Gholizadeh and Alsenany, 2016). Therefore, a total of 1,000 information sheets and questionnaires were distributed across the six MOH hospitals through their nursing education centres to the wards where nurses care for people with dementia. This was done to maximise the response rate and to avoid under-recruiting (Nardi, 2014). The 1,000 information sheets and questionnaires were given hand-to-hand to the nurses who were available at that time in each ward.

After obtaining ethical approval from the University of Southampton (29647) and the Jeddah MOH ethics boards (H-02-J-002), the participants' information sheets, consent forms and questionnaires were distributed in person in sealed envelopes to the MOH facilities (further details about ethical approval in section 4.5). This was given to the gatekeepers—an RN who is responsible for the nursing education centre—who would distribute the questionnaires to the nurses. This method has been tested in previous research and found to be the most efficient way of collecting data in this region. Approximately 170 survey papers were sent to each of the six hospitals (See Figure 5.1 CONSORT flow diagram of the survey). When the response rate to the questionnaires was found to be insufficient, at less than 30 per cent around three weeks after nurses were approached, a second survey was sent to the facilities using the same method but targeting different departments that had not been reached out to the first time. These departments included neurosurgery, day surgery, cardiology and ear, nose and throat departments.

The gatekeepers were mostly the departments' head nurses and administrative nurses' managers from the nursing education offices or nurses working at the research centres of the six hospitals. These nurses had access to all hospital departments/wards including PHCs. The study researcher met the gatekeepers personally soon after the ethics board's approval was issued. The gatekeepers had access to nurses in the wards/departments that most often care for dementia patients, according to the hospital census book and the diagnoses entered in the hospital files, which were provided. The study researcher and/or gatekeepers ensured that participants were asked to complete the self-administered printed questionnaire consisting of three sections (see Appendix E.1 and E.3). Participants were given the information sheet to read; then, those who were willing to participate were asked to complete the questionnaire. Upon completion, the researcher retrieved the documents from the gatekeepers'/directorate's office. Questionnaire instructions and information sheets were written in both English and Arabic; the consent form was in Arabic only as a requisite from the MOH ethics board (Appendix E.2). The questionnaire was in English, as it uses validated tools and nursing studies in the KSA are administered in English, as well as the fact that the main hospitals' language is English, the psychiatric hospital being the exception.

### 4.3.2 Diary-Interviews sample and recruitment

Based on the sampling strategy for the survey, a purposive event sampling strategy was then used to recruit nurses for the diary-interviews. Purposive event sampling seeks transferability using the maximum variation sampling technique, known as heterogeneous sampling, to explore nurses' knowledge, attitudes and perceptions in order to generate the narrative data. This sampling was done according to the criteria in Table 4.4. The target sample for the diary-interviews was 20 nurses as the study's researcher could reasonably expect to collect this many and analyse them in the time available for the study. An attempt was made to over-recruit participants to maximise the level of data saturation and prepare for potential dropouts. For qualitative studies, data saturation is more important than the number of participants recruited (Teddlie and Tashakkori, 2009). The term saturation refers to the point at which no more data is being generated by the participants, i.e. no additional information is collected despite there being more participants. (Teddlie and Tashakkori, 2009). Thus, 20 nurses were targeted to maximise the differences among them in terms of their qualifications, learning backgrounds, experiences, wards and job titles.

Table 4.4 Diary-interviews selection criteria

| Selection criteria | Reason |
|---|---|
| Survey participant | Participants showed willingness to participate in the diary-interviews |
| Based in a setting that admits people with dementia, with direct and frequent contact with them | To ensure participants' acknowledgment of care that results in effective responses |
| Qualified as a registered nurse for at least one year; mixture in years of experience | To detect best responses and to analyse their confidence with varied experiences |
| Different job titles and qualifications from both genders | To incorporate views from a diverse group of nurses from different backgrounds and care levels |

The researcher tried to recruit the nurses for the interviews directly after collecting the questionnaire from the gatekeepers. The surveys were scanned once and reviewed by the study researcher, who then reached out to the willing participants and met with them in their wards. Thus, 20 selected participants who had consented to participate in the second part of the study were invited to keep a diary for ten working days, which would then be followed by a semi-structured interview. The diary-interviews participant information sheets were sent via email to willing participants across the six hospitals (Appendix F.1). As incentive to join, participants were offered a certificate of appreciation from the University of Southampton and King Abdulaziz University as compensation for their time (Appendix F.3).

## 4.4 Data collection tools and settings

### 4.4.1 Pilot study

Pilot-testing the research design to ensure its viability is important as it deepens the understanding of the research process (Nardi, 2014). In the present study, the questionnaire was piloted following the same recruitment procedure mentioned earlier; initially, five qualified nurse participants from the KSA were invited to take part in the pilot study via email. They were given the information sheet and the questionnaire to test the survey questions, ensure that item wording and format were understandable and clear to the targeted participants and that a reasonable timeframe was allocated for its completion. The participants were recruited according to the inclusion criteria explained earlier to reflect the population of interest (section 4.3). Following the same governance procedures mentioned in Section 4.3.1 Survey sample and recruitment, the questionnaire along with the participant information sheet and Arabic consent form were sent to them after their agreement to participate. These forms were used in the main study to indicate whether any revisions were needed to improve the clarity of the questions. After conducting the survey, the pilot study participants were asked to reflect upon (1) the clarity of the instructions and participant's information sheet, (2) structure and layout, (3) wording and language and (4) timing. It was concluded from the pilot study that no explicit modifications were needed in the elicitation study. However, some participants asked for both languages on the participant information sheet to ensure clarity about the study. Data from people who participated in piloting the research design were not used in the main study.

Two nurses who also completed the diary-interview component of the study comprised the pilot for that section. The original plan was to send daily SMS reminders to nurses regarding the diary; however, in the pilot stage the reminders resulted in nurses being apologetic for not having their entries done. Thus, it was decided to send reminders twice weekly rather than daily. To minimise participants' fatigue they were also asked if they had any difficulties making entries in the diary booklet; the most notable feedback was that 'everything is clear, the only struggle is to identify the cases.'

The interview pilot was conducted with the two interview participants to ensure that the questions were clear and understandable. One interview was conducted in English, and the other in Arabic. No adjustments to the interview questions or procedure were needed for interviews with one exception: the question ‘What do you believe about caring for people with dementia?’ was not clear in either language. The interviewees required significant explanation to understand the intended meaning of the term ‘believe.’ Therefore, the question was changed as follows: ‘When caring for a person with dementia, what do you think about the care given to them? Another iteration was given as, ‘How do your internal beliefs or thinking affect the care provided to them?’

Based on the results of the pilot study, both English and Arabic languages were used in the participant information sheet. Only minor changes were made to the diary and interview and no changes were needed for the questionnaire used in the present study.

### 4.4.2 The survey questionnaire

Research evidence suggests, the most significant way to improve the care provided to people with dementia is to improve the knowledge, attitudes and skills of nursing professionals (Annear *et al.*, 2015a). First, however, we need to know what nurses know about caring for people with dementia. It is therefore important to use tools that measure the knowledge levels and attitudes of nurses. Consequently, this study used a survey questionnaire containing three sections. The first section consists of 20 questions that provide information regarding the background and demographics of the participants, including their qualifications and work information (see Survey section 1: personal data). Participants were also asked whether they were willing to participate in the diary-interviews. If so, they were requested to provide their contact information. The second section is based on the validated DAS (Survey section 2: Dementia Attitude Scale (DAS)), and the third section on the DKAT2 (Survey section 3: The Dementia Knowledge Assessment Tool version 2 (DKAT2)) (Appendix E.4 Authors permission to use both tools). The tools are described and discussed in the following sections.

### *Survey section 1: personal data*

This survey section consisted of 20 questions related to four categories of personal circumstances; (1) environmental characteristics, (2) personal demographics, (3) experience characteristics and (4) educational characteristics (Figure 4.2).

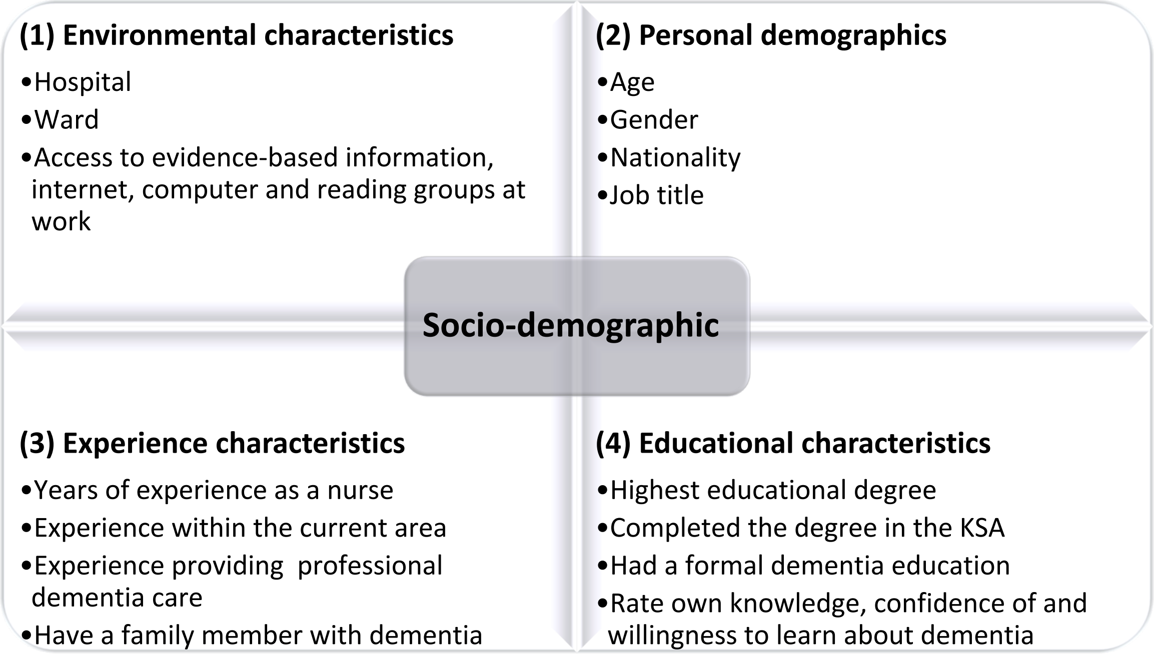

Figure 4.2 Socio-demographic factors (four categories of variables)

To gather data about where participants worked, the survey included questions about environmental characteristics include questions about the hospitals (six categories; KAMC, KFGH, EJGH, KAU, ALT, PSY) and wards (29 categories; Table 4.5) and whether participants have access to evidence-based information, reading groups, a computer or internet at work (yes/no questions). The personal demographics questions include age range (when the study researcher previously conducted studies in the KSA it was found that participants do not like to report their ages or provide their dates of birth; thus, questions related to age usually have missing data). The survey included questions about gender (male/female), nationality (Saudi, Filipino, Indian or other) and job title (bedside nurse, community nurse or administrative nurse).

Table 4.5 Wards categories

| Wards category | Included wards |
|---|---|
| Clinics | Out-patient department (community nurses) |
| | PHC (community nurses) |
| Convalescence departments | Extended medical department |
| | Home care (community nurses) |
| | Rehabilitation |
| Emergency departments | Emergency department |
| Intensive care units | Intensive care unit |
| | Burns |
| Mixed wards | Medical/surgical |
| | Neurology |
| | Cardiology |
| | Neurology and cardiology |
| | Neuro-surgery |
| | Ear, Nose & Throat |
| Medical wards | Medical |
| | Kidney |
| | Nephrology |
| | Urology |
| | Renal |
| Surgical wards | Surgical |
| | Orthopaedic |
| Psychiatry wards | Acute psychiatry ward |
| | Chronic psychiatry ward |

Questions about the experience characteristics included ranges of years of experience as a nurse (1–3, 4–5, 6–10, 11+) and experience within the current area in years (<1, 1–3, 4–5, 6–10, 11+). There were yes/no questions asking if they had ever provided professional care for a person with dementia and/or if they had a family member with this condition. Questions about educational characteristics related to the participants' highest educational degree (diploma, bachelor, master or doctoral degree), followed by two yes/no questions: was the degree completed in the KSA, and had they ever received any formal education on dementia? Finally, three Likert-scale questions were given with scores ranging from one to five, in which participants were asked to rate their own knowledge about dementia, their own level of confidence in caring for a person with dementia and their willingness to learn about dementia. The last question in the survey asked if the participant was willing to take part in the diary-interviews phase, and, if so, to provide their contact details.

The socio-demographical factors in this study is divided into four categories of variable. Information about nursing participants that were collected using the above mentioned categories is assist to provide important context in this study.

### ***Survey section 2: Dementia Attitude Scale (DAS)***

Numerous tools are available to assess attitudes towards people with dementia, such as Nurse Attitude scale (Katsuki *et al.*, 2008). The present study used the Dementia Attitude Scale (DAS), which uses a seven-point Likert scale; scores range from 20 to 140, with higher scores reflecting positive attitudes (O'Connor and McFadden, 2010). With this tool, dementia is referred to as Alzheimer's disease and related disorders (ADRD), so it is not sensitive to attitudes towards people with particular forms of dementia such as early onset dementia or Lewy-body dementia. The DAS was selected for this study, as it is considered a valid and reliable tool and perhaps the most widely used tool to assess healthcare professionals' attitudes towards caring for persons with dementia (O'Connor and McFadden, 2010). The DAS has been used in the USA and the UK, as well as Australia, Switzerland, Malta, China, and Korea (Sterns *et al.*, 2011b; George, Stuckey and Whitehead, 2013; Scerri and Scerri, 2013; Arms, Rowan and Eusse, 2014; George, Stuckey and Whitehead, 2014; Roberts *et al.*, 2015; Kimzey, Mastel-Smith and Alfred, 2016; Loizeau, Kündig and Oppikofer, 2016; Banerjee *et al.*, 2017; Scerri and Scerri, 2017; Sheaff, Sherriff and Hennessy, 2018). The scale has been translated into Croatian (Ćoso and avrinac, 2016), Chinese (Wang *et al.*, 2017b) and German (Loizeau, Kündig and Oppikofer, 2016; Blaser and Berset, 2019), though not yet into Arabic; this is the first study to use the tool in English in a Middle-Eastern country.

The DAS is popular because it is sensitive to the three key components (tripartite aspect) of attitude, namely, the affective, behavioural and cognitive aspects, and is therefore useful for forming a complete understanding of attitude, which earlier scales were not able to measure (Brodaty, Draper and Low, 2003; Leung *et al.*, 2013). The DAS authors developed a list of 46 items for the interviews, and reduced these down to 20 using factor analysis to ensure that superfluous or inappropriate questions were removed, and that the questions were mapped to the underlying traits of attitude mentioned above. This process increases the validity of the questionnaire and ensures the scores are a believable representation of a person's attitude.

The DAS tool developers combined the affective and behavioural aspects of attitude under a 'social comfort' factor, while the cognitive aspect was referred to as the 'dementia knowledge' factor. This two-factor approach makes the DAS tool valuable tool and widely applicable to many studies (Lea *et al.*, 2015). It measures an individual's feelings towards people with dementia that affect his or her attitude, the affective component (Zimmerman *et al.*, 2005). In addition, it is used to measure the combination of knowledge and emotions, the behavioural component, through which an individual develops a pattern of behaviour towards a person with dementia based on their knowledge of dementia and their emotions at that particular moment in time (Hughes *et al.*, 2008; Wortmann, 2014).

The DAS has already been used in a number of studies that measured people's attitudes towards people with dementia, including those of nursing, medical and/or social work students (George, Stuckey and Whitehead, 2013; Scerri and Scerri, 2013; Arms, Rowan and Eusse, 2014; George, Stuckey and Whitehead, 2014; Roberts and Noble, 2015; Garrie, Goel and Forsberg, 2016; Kimzey, Mastel-Smith and Alfred, 2016; Lokon, Li and Parajuli, 2017; Maharaj, 2017; Heuer *et al.*, 2020). Other studies explored the attitudes of caregivers, including nurses (Han *et al.*, 2014; Scerri and Scerri, 2017; Sheaff, Sherriff and Hennessy, 2018; Blaser and Berset, 2019). A further study compared nurses' attitudes with those of people from the general public towards people with dementia (Kane, Murphy and Kelly, 2020).

The DAS' high reliability was confirmed when tested by the developer, as it had a Cronbach's alpha of 0.85. It also correlates significantly with other cognate tests, such as the Old People Scale (which has demonstrated its reliability in measuring ageism), the Fabroni Scale of Ageism, and the Interactions with Disabled Persons Scale (Spector and Orrell, 2010). Thus, the DAS has a construct validity that gives it solid psychometric properties and convergent validity when compared to other tests. Furthermore, since the DAS has a consistent factor structure across two or more samples it has strong replicability across several independent samples; this means that it is possible to obtain similar results to other samples without compromising the quality of the results. This makes the sample independent and, hence, an essential tool for testing people's attitudes towards people with dementia (O'Connor and McFadden, 2010; Stirling *et al.*, 2010). Lastly, the DAS is a paper-and-pencil instrument that can be easily administered and completed within a few minutes. It is very user-friendly and can be efficiently administered without incurring the costs associated with administering many items to uncooperative people (O'Connor and McFadden, 2010). In summary, the DAS is a valid and reliable tool that has shown consistent results in collecting and analysing data on attitudes towards people with dementia over the last decade.

### *Survey section 3: The Dementia Knowledge Assessment Tool version 2 (DKAT2)*

Numerous tools are available to assess individuals' knowledge about people with dementia, such as The Alzheimer's Disease Knowledge Scale (Carpenter *et al.*, 2009). The present study used the DKAT2 tool, which was developed to assess the knowledge of professionals and caregivers working with people with dementia (Annear *et al.*, 2015b). The Dementia Knowledge Assessment Tool version 2 (DKAT2) is applicable across a wide range of dementia types and is not specific to one or two issues. Therefore, it can be applied to different diseases related to dementia, providing a broad base under which various comprehensive interventions (such as better educational programmes and resources) could be pursued (Robinson *et al.*, 2014). The reliability and validity of the DKAT2 have been confirmed consistently by studies conducted using this tool and had high internal validity results (Cronbach's alpha coefficient of 0.781) when tested by the developers. In addition, the DKAT2 is easy to administer and complete because it contains relatively few items. According to Toye et al., (2014), it can be completed within 10 to 15 minutes. This makes it very user friendly and allows easy analysis and conclusions. It has mostly been used in Australia and the USA, as well as in several studies in Japan, China, Cyprus, Turkey, Germany, Brazil and Portugal (Robinson *et al.*, 2014; Eccleston *et al.*, 2015; Lea *et al.*, 2015; Mullan and Sullivan, 2016; Matsuda *et al.*, 2018; Luckett *et al.*, 2019). While it is translated into Japanese, Spanish, Portuguese and Chinese (Annear, Otani and Li, 2017; Parra-Anguita *et al.*, 2018; Zhao *et al.*, 2020), this was its first use in English in the Eastern-Mediterranean region.

The DKAT2 in the second section of the questionnaire contains 21 questions about dementia and dementia care that require a ‘true’, ‘false’ or ‘do not know’ answer. The participants’ scores range from 0 to 42, with a higher score indicating more knowledge (Annear *et al.*, 2015b). The DKAT2 was built from the Dementia Knowledge Assessment Scale, which was developed in response to the shortcomings of the Alzheimer’s Disease Knowledge Scale (Annear *et al.*, 2016a), and was designed to measure knowledge changes in those who were participating in a dementia programme (Low and Anstey, 2009). It included measuring the foundational level of knowledge of care providers about dementia. This excluded the family members of people with dementia, who were key in helping the person with dementia make healthcare decisions. However, because advanced dementia limits the participation of people with dementia, it is necessary to support those working with people with dementia in healthcare and in end-of-life care when making decisions (Samsi and Manthorpe, 2014).

The development of the DKAT2 focused on professionals and caregivers who work with people with dementia. This tool is concerned with people in the late stages of dementia and is meant to assess dementia knowledge in older adult care environments (Toye *et al.*, 2013). As such, the statements (questions) in the DKAT2 are divided into two groupings: (1) dementia and its progress, which covers the basic characteristics of dementia and its symptoms and progression (13 statements); and (2) support and care, which covers dementia diagnoses, assessments, treatments and prevention (8 statements).

In summary, the quantitative part in this study used a cross-sectional survey method that have three questionnaire sections. The questionnaire survey in this study used two validated tools that are reliable. In addition to collecting the personal data of the participants that is classified into four main categories of socio-demographical factors.

### 4.4.3 Diary booklet

A diary template was printed, along with instructions on how to complete it, and given to all participants who signed the consent form. The diary booklets were printed and provided in order to make data entry for the participants easier, reduce cost and time for the participants who want it in print and have the diary entry instruction available at all time. In addition, these participants were offered voice recorders by the study researcher (Appendix F.4). SMS reminders were sent to participants twice weekly throughout one calendar month, or until they had completed ten entries.

In the diary-keeping phase of the study, participants were asked to record information concerning the care they provided to people with dementia every time they provided this care for ten days – that is, event sampling (Bartlett and Milligan, 2015). This included how they felt about that care, what their perceptions and attitudes were, whether they feel confident, how they thought their education and culture affected the care they provide and what their assumptions and reactions might be. Finally, participants were asked to record their feelings, opinions, and any recommendations or suggestions regarding the changes they wish to see with respect to confidently providing patients with the best level of care and the potential outcomes.

### 4.4.4 Interview schedule and setting

Once participants had completed ten days’ diary entries, or when they contacted the researcher in response to the last SMS sent, a semi-structured interview was arranged and conducted. The interview schedule included questions that guided the researcher during the study (see appendix F.6). Interview schedules were developed prior to conducting the data collection. The interviews were conducted at the participants’ workplaces and at their convenience to ensure their safety and to acknowledge the cultural essentials of the interviewer and the interviewees. Privacy and a quiet environment were provided as much as possible during these interviews. (Descriptions of the interviews’ contexts and issues are given in Chapter 6: Interviews section).

A day before the interview, SMS confirmations specifying the interview time and place were sent to the participants. In preparation for the interview, the study researcher read the interview protocol, consent form, and participant information sheet; the researcher then retrieved the participant's survey form and ensured that two voice recorders were charged, blank, and ready for use.

The diary booklet was given to the researcher on the day of the interview. The study researcher had an opportunity to skim through the diary booklet before the interview started. During the interview, the interviewee was greeted and thanked by the study researcher for taking part in the study. During that time, the participant read the information sheet that had been handed to him or her. Once the participant was comfortable and ready to begin, the study researcher explained the information sheet and read the consent form, which was then signed by the researcher and the participant.

When the recording started, the interviewer followed the interview schedule and all interviews began with, 'We have started recording. I am Sara with participant (name and number). Today is (date). How are you? Firstly, I want to let you know that there are no right or wrong answers in our talk. It is just a conversation to get to know your opinion. Please feel free to be frank and share your point of view. It is important that your opinion is heard.' Each interview ended with, 'Thank you for your contribution and taking up your valuable time to talk to me!' The participant was then given the opportunity to ask or add anything (Appendix F.6).

Participants were asked to recall the emotions they felt when they were writing their diaries and to discuss some excerpts from the diary. Participants were asked about their perceptions of care and how they knew the person with dementia. Participants were asked what they thought about the care that they provided and were prompted to speak about their experiences providing care. They were also asked to recall how frequently they cared for older adults, how they were able to identify dementia and how they could recognise its symptoms.

After the interview, participants were given an appreciation certificate and thanked for their time, opinions, and effort (Appendix F.3). The recording of the interview was checked immediately for its functioning and clarity after the end of the interview (Creswell, 2014). In accordance with the data protection legislation, to maintain confidentiality audio files from both recorders were transferred through the researcher's laptop to the Southampton University J drive folder, with access only for the supervisory team. They were then transferred again to the NVivo master project file that is password-protected to make them ready for the analysis (Appendix H; H.1). To further maintain the anonymity of participants, file names followed the file naming format shown in Table 4.6. Additionally, the collected diaries were converted into Word files, with one file for every participant. These too were then transferred to the NVivo master project file (Appendix H.2).

To help ensure rigour and transparency, a brief reflexive note was written right after each interview. Comments about the interview as well as the participant were written in those notes, in addition to any concerns about the interview (Creswell, 2013; Holliday, 2016). This action is discussed further in the Thematic analysis section (P. 127).

To retain the data and enhance emergent themes, memos and reflexive diaries were used throughout the analysis process. Data triangulation was achieved by comparing, confirming and explaining the DAS and DKAT2 scores. Diary and interview data from participants in both phases were analysed to investigate the nursing care being provided. In addition, some of the survey questionnaire data were qualified and merged into themes, providing a synthesis of the study's strengths in the triangulation. These approaches helped in detecting issues that may impact current practices and attitudes. As a result, this process enhances the rigidity and repeatability of the survey and the diary-interviews, as well as the reliability and trustworthiness of the findings (**Error! Reference source not found.**).

For more information regarding analysis of the data using the integration methods please refer to section 7.2 in Chapter 7

## 4.5 Ethical approvals

Ethical approvals were sought and obtained in February, 2018 from two different authorities: (1) the Ethics and Research Governance Online version 2 (ERGO2) at the University of Southampton, submission number 29647 (Appendix G.1) and (2) from the MOH in the Western region (H-02-J-002) (Appendix G.2). Information sheets were sent to the MOH facilities via MOH research centre employee gatekeepers, who were physicians (medical consultants and specialists) and nurses who work with people with dementia and can access nurses working in such contexts.

To collect data from the KSA MOH, ethical approval was needed from the Jeddah Health Directorate. The researcher’s resume, research protocol, and consent forms were emailed to the MOH research centre office in Jeddah, along with the National Institute of Health online test certificate (Appendix G.2.1). Data sharing agreement forms were signed and sent as well in order to proceed with the application (Appendix G.2.2). Ethical approval was obtained, valid for one year from the issuing date (Appendix G.2.3).

## 4.6 Ethical principles

Several ethical principles were maintained in this study: (1) respect for the person: confidentiality, consent (decision-making), autonomy and dignity; (2) beneficence: avoiding harm to participants by minimising physical and psychological errors and maximising benefits; and (3) maintaining justice and fairness by using appropriate language (Orb, Eisenhauer and Wynaden, 2001; British Society of Gerontology, 2012; International Council of Nurses, 2012; Nardi, 2014; Brinkmann and Kvale, 2015; O’Reilly and Kiyimba, 2015; Punch, 2016). These principles were ensured for the welfare of participants and the protection of the researcher.

### 4.6.1 Respect for the person: confidentiality, consent, autonomy, and dignity

In the present study, participants read the participant information sheet and were informed that they had the right to take part in the study or withdraw at any stage after signing a consent form in either Arabic or English. By signing an informed consent form, they acknowledged their understanding that the confidentiality of participants' information is respected, participation is voluntary, and that objectivity and independence are maintained, all of which is clearly expressed in the consent form. Informed consent enabled participating nurses to make decisions, encouraged self-interest and empowered them throughout the study (Brinkmann and Kvale, 2015; O'Reilly and Kiyimba, 2015).

To maintain the participants' confidentiality, names were replaced with identification numbers or pseudonyms, and all audio files/notes were kept in a locked cabinet in a locked room. It is worth mentioning that some interviews were interrupted and in order to maintain the participants' confidentiality and privacy rooms were changed (detailed discussion available in section 6.1.3).

Data were stored in the format detailed in Table 4.6 below. During the study, the data were backed-up, managed and curated using a password-protected hard-drive with two Terabytes. Then it was stored in a locked cabinet in a locked office (see Appendix H Data management plan). In addition, all data types were saved in the NVivo file, which was encrypted, password protected and filed in a password-protected computer (more details about NVivo in section 4.8.2).

Table 4.6 Data storing format

| **Type of data (with extensive metadata)** | | **Sharing format** |
|---|---|---|
| **Survey Questionnaire Data** | A dataset with variable labels, code labels, and defined missing values, in addition to the matrix of data | Proprietary formats of statistical packages SPSS (..por), and NVivo (nvp/ nvpx) |
| **Diary-interview Data** | Textual<br>Transcripts, codes, and translated diaries and interviews | NVivo (nvp/ nvpx)<br>MS Word (.doc/.docx)<br>PDF/A or PDF (.pdf) |
| | Audio interviews | NVivo (nvp/ nvpx)<br>MPEG-1 Audio Layer 3 (.mp3)<br>Waveform Audio Format (.wav) |
| **Supported documents** | Textual<br>Reflexive diary, readme file, and cases and queries | NVivo (nvp/ nvpx) |
| **File naming** | Participant number_ Pilot study_ Survey or Diary | *00_PIL_SUR*<br>*00_PIL_DIA* |
| | Participant number_ Survey_ hospital_ ward or primary health centre | *000_SUR_HOS_WARD*<br>*000_SUR_PHC_WARD* |
| | Participant number_ Survey_ Diary_ consent, audio/scan, transcript | *000_SUR_DIA_CON,*<br>*000_SUR_DIA_AUD,*<br>*000_SUR_DIA_SCA,*<br>*000_SUR_DIA_TRA* |
| | Participant number_ Survey_ Interview_ consent, audio/scan, transcript | *000_SUR_INT_CON,*<br>*000_SUR_INT_AUD,*<br>*000_SUR_INT_SCA,*<br>*000_SUR_INT_TRA* |

The study adhered to the terms of the General Data Protection Regulation (GDPR). Survey information and participants' data are labelled and stored in accordance with strict privacy protection procedures. Participants' confidentiality has been ensured by anonymising records and removing any identifying information from study results. Hardcopies of the questionnaire data were directly entered into SPSS version 25 (IBM Corp, 2017), while the consent forms and written diaries were exported into NVivo 12 (QSR International, 2018). Then the paper copies were destroyed but diary booklets were archived. The SPSS and NVivo documents have been stored according to the MOH data share agreement and University of Southampton data protection policy. Both the SPSS and NVivo projects are password-protected files stored in a password-protected computer, and only those involved in the data analysis can access the data. The research data will be archived for a period of ten years in accordance with the data protection policy at the School of Health Sciences, University of Southampton.

Two further issues were considered while conducting the study: first was the travel between countries and the entering and storing of data. As the study was conducted in the KSA, it required the researcher to fly from Southampton to Jeddah twice in 2018; the first trip lasted three months to collect both the survey questionnaire and diary-interviews data as planned. As the proposed number of survey questionnaire participants was large, the researcher divided the work into two different trips, but the second trip was for a shorter period. The second issue was entering the survey data into the password-protected computer in the KSA and leaving all the paper data in a locked cabinet in a locked room there.

### 4.6.2 Beneficence and harm avoidance

The research did not involve any physical risk to participants; however, it was possible that some could experience potential emotional distress during the diary-interviews component. Therefore, the interviews took place in a quiet, private room, and participants were assured that their participation was voluntary and confidential. The researcher planned to contact the MOH gatekeeper and/or nursing department in the event that one participant disclosed neglectful and/or unlawful practices, for example abuse of a person with dementia.

In terms of health and safety issues, there were two main concerns for the researcher. The first concern was travel, as women in the KSA were not allowed to drive until July 2018, which necessitated hiring a driver. To minimise risk, private transport was used in the form of a male guardian and/or family private driver. Second, Saudi Arabian culture forbids women to be present alone with a man anywhere other than in the workplace. Therefore, since different genders were being interviewed, the interviews were conducted in participants’ workplaces to minimise any potential risk.

### 4.6.3 Maintain justice

Power and responsibility are important principles while conducting research (O'Reilly and Kiyimba, 2015). It is thus crucial for a researcher to separate the clinical role from the research role. Some researchers have argued that this is a challenging process; however, they have observed that participants tend to be more open to researchers than they are to doctors (Brinkmann and Kvale, 2015; O'Reilly and Kiyimba, 2015).

Positionality, which considers the nature and relationship of the study context as a part of the ethically reflexive position, is another important principle (O'Reilly and Kiyimba, 2015). Thus, the researcher must consider the cultural context of the research and other sociological factors and be sensitive to the language used (Brinkmann and Kvale, 2015; O'Reilly and Kiyimba, 2015). Therefore, a *reflexive diary* was used to ensure transparency of the researcher's positionality, personal thoughts and values, all of which could influence the research process, data collection and analysis (Walker, Read and Priest, 2013). It was useful from an epistemological and ethical viewpoint, and in a pragmatic sense, to use reflexivity as an approach in the study (Mason, 2018). Reflexivity in mixed-methods research allows inherent comprehension of the study and analysis of its important components (O'Reilly and Kiyimba, 2015). Reflexive diaries aim to report information about the researcher and methods within the research context. The researcher's feelings, thoughts, beliefs, challenges and obstacles in conducting the study were reported. Regarding the method, information about the data collection, decisions and reasons behind them were also reported (Teddlie and Tashakkori, 2009; Walker, Read and Priest, 2013). This allowed for an exploration of the researcher's background and experience, which may have shaped the study, as was an analysis of the reflexivity that holds the potential interpretation of the method (Creswell, 2014). This guarantees the study's objectivity and trustworthiness.

## 4.7 Multilingual research

This study used both the Arabic and English languages in the research design and to develop the research methodology with consideration of ethical issues, data collection and analysis, as well as writing up representation and reflexivity issues. This process is called *researching multilingually,* which supports development of the researcher's competence (Holmes *et al.*, 2013, p. 287). The aim of this is to ensure confidentiality and support the appropriateness of the decisions made throughout the research process (Holmes *et al.*, 2016).

Researching multilingually is ‘methodologically challenging and epistemologically productive’ (Holmes *et al.*, 2013, p. 291), as a better understanding from different sources of information is created when using this methodology. Researching multilingually also offers opportunities for cross-disciplinary research with a wider scope, and it benefits from a lower prospective bias as opposed to a one-sided perspective. This is achieved by allowing participants to express themselves in the way they find comfortable, which results in nurses of different cultural and linguistic backgrounds to be more likely to respond. Using different languages, individual and shared views were constructed to establish insider positioning with participants. Thus, this study’s findings will overcome the challenge of the inclusion of Western perspectives and will consolidate the topic. Hence, participants can express their emotions and perspectives easily. Incorporating both Arabic and English languages in the research process allows the researcher to access more accurate and present data, cultural values principles and beliefs that are embedded in a language. On the other hand, it is a complex process due to the need to translate into English in the reporting and also in discussing the data within the doctoral research study process. Also, its complexity relates to language ideologies and data management. Lastly, one must consider the inherent language hierarchies in Arabic and conduct the research without invoking any harmful ideologies of language.

Usually, the researcher is concerned with maximising the data possibilities with consideration of the process complexities. Therefore, a three-part model for developing researcher competence vis-à-vis researching multilingually has been used to elucidate the illustration of both languages within the study (Holmes *et al.*, 2016). The three-parts are (1) realisation, (2) consideration and (3) informed and purposeful decision making. This model helps in understanding and explaining the process of researching multilingually.

*Realisation* refers to a researcher becoming aware of the study’s possibilities. These possibilities include both the researcher’s own linguistic abilities and those of the participants. In addition, it includes the availability of information and the data collected before, during and after the fieldwork experience. Using the Arabic language generated more data and supported the understanding of explored phenomena.

*Consideration* refers directly to the participants. In the researching of multilingual possibilities and complexities, the main possibilities are gaining a rich insight and building trust between the researcher and the study’s participants. The complexity of the process can be summarised in three main points: data availability, translation and transcribing and importing data. In terms of the available data, the nursing policies and codes of practice within Saudi hospitals were in English while government and hospital data were only available in Arabic. Although almost all the nurses working in the six hospitals were English speakers, none of them have English as their mother tongue. Indeed, only half of them have Arabic as their mother tongue. This increased the need to incorporate data in other languages such as Arabic, which led to the rise of translation and transcribing challenges. Finally, SPSS software can only input data in English; the NVivo software can import both languages but there are many defaults and difficulties in using the Arabic language in this software.

*Informed and purposeful decision making* is the last aspect of the three-part multilingual study model. To develop this aspect, four issues need to be clarified to promote an effective multilingual study: first generating and analysing the data, when the dataset is ready for analysis after the collection phase using the language originally used by the study researcher and the participants. Then it is prepared for analysis in the language used with an explanation of where it is used and by whom. After that, there is the representation of the data within the thesis, which is in this study was in English and some Arabic. Finally, there is a reflection of the data when moved between languages (discussed further in Chapter 8).

The process of researching multilingually in the study involved two stages. The first occurred when both Arabic and English literature and government data were searched and used to identify the research problem and formulate the research questions (KSA government publications included the number of hospitals, nurses and other statistics that were mostly published and available in Arabic). Both languages were then used again during the second stage, the designing of the study and the data collection and analysis (refer to section 4.8), which required directly translating findings from Arabic into English. Both languages were used as well in the participant information sheets, diary instructions and interview schedules. This information was translated by the study researcher and reviewed by two experts: a bachelor student in linguistics studies and a bachelor student working on an Arabic language study. Some of the diary entries and interviews were also in Arabic and were translated and transcribed into English and then entered into NVivo in English only. To validate this process, a linguistics specialist, who is a native Arabic speaker, checked the transcripts and modified them as needed. The data were represented in English throughout the thesis. With the above in mind, it should be noted that finding resources regarding dementia in English in the KSA was challenging. A reflection on the use of both languages is discussed in Chapter 8, Section 8.5.

## 4.8 Data Analysis

According to the study design, quantitative data (surveys) were collected before the qualitative data (diary-interviews), which made it possible to select participants for the diary-interviews from the survey participants. Both objectivity (from the survey data) and subjectivity (from the diary-interviews data) accommodates abductive epistemological reasoning, which creates an interactive process of data analysis that fits exploratory studies when looking through the data (Mason, 2018). Objective reality can be indicated by discovering nurses' knowledge and attitudes using the survey (Punch, 2016; Mason, 2018). Subjectivity, using the diary-interviews, involves specific local and constructed realities that are based on experience within society. In this study, the realities were based on the nurses' experiences with people with dementia (Punch, 2016). This helps us to understand the meanings of nurses' perceptions as a central reality when studying nurses and their attitudes, leading to a better understanding of the extent of their practices (Punch, 2016; Mason, 2018). A pragmatic approach thus proved optimal for achieving the research objectives and addressing the questions that, in turn, enhanced data interpretation. In terms of epistemology, the pragmatic approach in this study aids the mixed-methods approach as it makes the nurses' experiences the main concern; this was done in order to confirm the uncertainty of nursing practices by studying the reality of their situations (Morgan, 2014). Also, the pragmatic approach, which uses abductive logic that involves both inductive and deductive logic, was utilised to investigate nursing practices and offer recommendations.

Deductive logic, on the one hand, was used in the data analysis phase to support the investigation of knowledge and the attitudes of nurses to inform policies and guidance on practices for nursing people with dementia in the KSA. During the data interpretation, the participants' values and beliefs played a major role in accepting their external realities, together with producing the desired outcomes by providing enlightenment on, and reasons for, their perceptions and practices (Teddlie and Tashakkori, 2009; Creswell, 2014). The analysis is value-bound, and its logical paradigm is abductive. Consequently, it uses both objective and subjective points of view as the knower and the known are attached (Teddlie and Tashakkori, 2009; Creswell, 2014).

Data were managed, stored and analysed using two computer-assisted software packages to ensure the reliability of the results and safe storage of what was a large dataset. SPSS version 25 was used for the quantitative data (IBM Corp, 2017), as this study needed specific analysis tools to develop an understanding of the collected data, and NVivo 12 for organising and analysing the qualitative data and synthesising the dataset during the integration process (QSR International, 2018). It was also used to obtain scores for the DAS and DKAT2, as the researcher is familiar with the programme and has used it in previous studies.

The study data were extractions from the survey questionnaire scores, the narrative of the diary-interviews participants, the diary booklet, the interview transcripts and the researcher's reflexive diary. All of these information sources count as data and are discussed in the subsections independently.

### 4.8.1 Survey

The scores for the second section of the DAS were calculated within the range of 20 and 140, with positive attitudes being related to higher scores. A score of 1 indicates the most negative attitude, and 7 indicates the most positive. The third section's scores were labelled as 0 (for incorrect responses and 'do not know' responses) and 2 (for a correct response). This was followed by adding the scores, which ranged from 0 to 42, with a higher score indicating greater knowledge.

It was planned that missing data would be summarised for each question (frequency and percentages), but no formal methods would be used to account for missing information. Descriptive statistics were used for demographic data, using means and standard deviations, medians and quartiles, or frequencies and percentages where appropriate (determined by the type and shape of the data). The overall DAS and DKAT2 scores were summarised using the mean and standard deviation (or medians and quartiles, as appropriate) as well as a 95% confidence interval for the mean in order to estimate the knowledge and attitude scores of the sample. Individual questions were summarised using the frequencies and percentages of positive/correct responses to represent the statements with the most positive/correct responses and aid in identifying the gaps in knowledge and attitudes.

A multiple linear regression analysis was conducted to analyse the variables within the SPSS file. This type of analysis is performed to construct a model and understand the relationships between variables. However, to use the multiple linear regression analysis, eight assumptions needed to be tested to ensure that the data were appropriate for use with the multiple regression model (Laerd Statistics, 2015; Field, 2018). Two assumptions were related to the design of this study: (1) the dependant variable should be measured on a continuous scale and (2) two or more independent variables need to be tested. A further six assumptions are related to the nature of the data collected: (3) there were linear relationships between the dependent variables and the independent variables, (4) data were independent of observations, (5) there was no homoscedasticity in the data and (6) there was no multicollinearity in the data, which occurs when two or more independent variables are highly correlated with each other. The last two assumptions are that data (7) must have no significant outliers and (8) have approximately normally distributed residual (errors).

Finally, a correlation analysis was planned as well to explore the relationship between the DKAT2 and DAS scores. The correlation analysis was used to quantify the association between two continuous variables, which in this study were knowledge and attitudes.

### 4.8.2 Diary-Interviews

Due to the volume and complexity of the datasets, the NVivo 12 was used for storing and coding both data types: the SPSS data from the survey questionnaire (as cases in the software) and the qualitative data collected from the diary-interviews (QSR International, 2018). The quantitative data were exported into NVivo (after they were analysed in SPSS) along with the audio files and transcripts. From the diary-interviews. Diary-interviews data were in both Arabic and English. Therefore, the researcher stored the data within NVivo and translated the Arabic data into English after it had been transcribed by the study researcher. To minimise any translation bias created by language differences, some words remained in Arabic, but the coding and themes were in English. Hence, thematic analysis and coding within the NVivo analytical software was applied in English. However, the participants were provided with the translated transcripts to ensure that their intended meaning had not been changed and to minimise translation bias.

Thematic analysis is the most common analysis type used in qualitative studies (Creswell, 2014). It is useful when a pattern needs to be identified from the dataset. The inductive process is not predetermined by the researcher; therefore, applying this analysis aids in validating the identified themes.

Thematic analysis includes six phases as shown in Braun and Clarke (2006). Getting to know the data by transcribing, translating, understanding, reviewing and marking preliminary thoughts are considered the first phase. Then, close reading is done to assist the first and second cycle of data coding (Braun and Clarke, 2006; Mason, 2018). Coding at this level is done according to the objectivity of what participants wrote and said and what was written and mentioned in the survey narrative and reflexive diary. This is done to produce initial codes with consideration of the complete dataset. After that, a second cycle of coding is recommended to ensure that reliable and distinct themes have been identified. The next stage is an interpretative reading of the data, which is the third cycle of coding and the generation of themes. This is achieved together with the final level of reflexive reading, which positions the researcher's reflections and interpretations of the data. This reading is also done to make sense of the data's narrative and interpretation from the researcher's point of view, which depends on capturing the relationship between certainly and inextricably involved within the data in the process of generating and interpreting the data (Mason, 2018). Afterwards, the identified themes are reviewed and their relationships to the coded extract and the dataset is checked. As a result, a thematic map was generated (see Chapter 6, Section 6.2). The interpretative codes were generated during the third cycle of coding, which generates concept themes, while the first and second cycle of coding is mostly descriptive. After that, names should be produced for each theme and given a clear definition. Finally, the analysis should be reported and discussed.

Table 4.7 The six phases of the thematic analysis process

| # | Phase | Process description |
|---|---|---|
| 1 | Know the data | Transcribe, translate, understand, review and mark preliminary thoughts |
| 2 | Produce initial codes | Coding according to objective reading of the data<br>(First and second coding cycle) |
| 3 | Search for themes | Interpretative reading of the data<br>(Third coding cycle) |
| 4 | Review identified themes | Analyse narrative, illustrate extracts |
| 5 | Define themes | Generate thematic map and create story analysis |
| 6 | Report findings | Quotation, data extraction and report final analysis |

### 4.8.3 Data Integration

The survey data were analysed using both descriptive and inferential statistics; soon after the survey data were analysed using SPSS, the diary-interviews data were analysed (after transcription and coding in three cycles) using thematic analysis. The results were interpreted and reported together. An embedded link was created between the questionnaire (diary-interviews participants only), diary entries and interview transcripts. In addition, meta-data tags were created to indicate the demographic and contextual aspects that were not available in the diary or interview data. Then, the researcher's experiences and thoughts were coded in a reflexive code.

The records of the researcher's experiences and thoughts were managed using a reflexive diary that had been recorded during the data collection (when meeting the gatekeepers, distributing and collecting the paper questionnaires, when meeting the participants for recruitment to the diary-interview component, and before and after each interview) and during data analysis (survey statistical analysis, qualifying the questionnaire and thematic analysis of the diary and interviews). This action is discussed further in the Thematic analysis section (P. 127). See section 4.4.4 for more details.

As mentioned in Section 4.2.3, data can be integrated using at least one of following techniques: triangulation, following a thread, meta-matrix or data transformation. In the present study, data were integrated in two stages. First, when questionnaire data were transformed from quantitative to qualitative using a qualifying technique, a data transformation technique was applied. Then, the results were merged into the themes identified. This was done to identify similarities and/or differences between the responses to a written survey and the diary-interviews participants' views. Second, meta-matrixes were used to visualise the study's findings and to help in the dissemination. This methodological integration is meant to maximise the data contents of the current attitudes, knowledge and perceptions of nurses caring for people with dementia.

It has been asserted that the visual presentation of the data and the synthesis is a significant feature of data integration. Scholars of mixed methods recommend more articulation of the integration process and have used joint displays to enrich the mixed-methods approach with insights of its obtained findings (O'Cathain, Murphy and Nicholl, 2010; Johnson, Grove and Clarke, 2019). Researchers had developed a four-stage technique to aid the integration process so as to enrich studies with analytical techniques for joint display approaches. This Pillar Integration Process assists researchers in maximising synthesis prospects and minimising their bias. These four stages are listing, matching, checking, and pillar-building as shown in Figure 4.3 (Johnson, Grove and Clarke, 2019). Therefore, the data is visually presented using joint displays in the Pillar Integration Process (Johnson, Grove and Clarke, 2019). It is a flexible technique that aids the researcher in reporting the findings in a table (as shown in Figure 4.3 below).  To read the table, begin with the outside columns for both quantitative and qualitative data to complete the joint display. Then move to the centre for the themes to emerge. Establish column headings to list, match, check, and later build pillars from the data to direct the integration process and accomplish the findings’ conclusion.

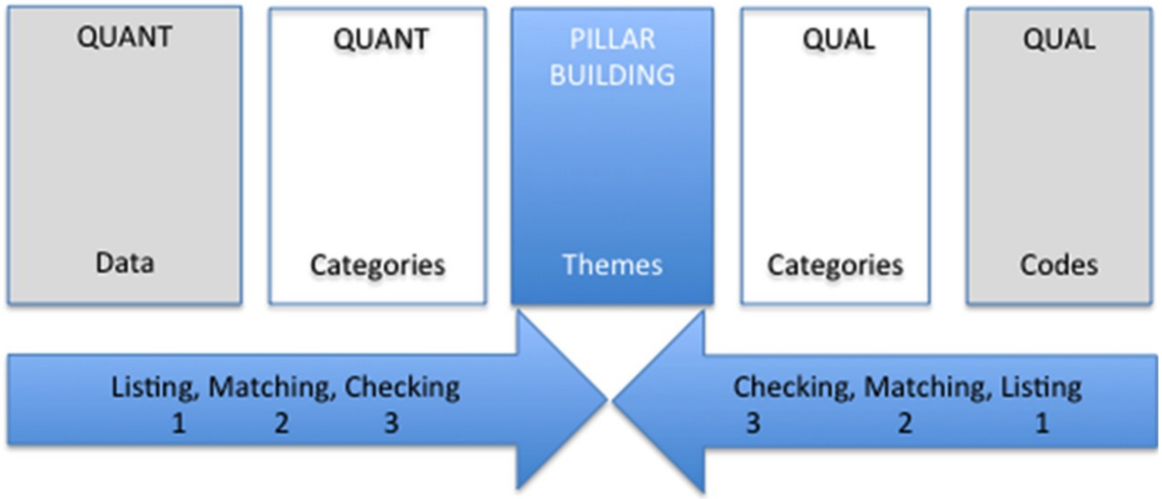

Figure 4.3 Visual representation of the Pillar Integration Process (Johnson, Grove and Clarke, 2019)

## 4.9 Summary of this chapter

The methods and methodology chosen for this study have been described in this chapter. The decision to use a mixed-methods research design has enabled the researcher to explore nurses' knowledge of, attitudes towards, and perceptions of people with dementia and dementia care in an holistic way. By using a cross-sectional survey and diary-interviews, a rounded view of the current care practice was elicited. This guided the researcher in identifying nurses' knowledge and attitudes about dementia in the KSA using two validated assessment tools. Further exploration of their current practices was maintained when using the diary-interviews method in order to gain greater insight into nurses' attitudes and perceptions regarding dementia and the care they provide to people with dementia. This guided the researcher to identify nurses' learning needs and their barriers and obstacles when caring for people with dementia in MOH facilities. The findings of this mixed-methods study is presented in four chapters: Survey Analysis and Conclusion, Diary-Interview Analysis and Conclusion, Dataset and Pillar Integration and Discussion. The next chapter presents and explains the survey findings, in relation to the research questions and objectives of this study (Section 1.4 and Chapter 5).

# Chapter 5 Survey Analysis and Conclusion

This chapter reports the quantitative data analysis from the survey and concludes the key themes identified from the analysis. This chapter is structured as follows: first is the summary of the survey data that includes sampling and response rates (5.1 Survey data); this is followed by the statistical analysis of the results, divided into two main parts: descriptive statistics and inferential statistics (section 5.2 Statistical analysis; Descriptive statistics and Inferential statistics); finally the key findings from the survey data analysis are highlighted, followed by the chapter summary (sections 5.3 and 5.4).

The presentation of the quantitative findings is primarily guided by two objectives: (a) gather data regarding nurses' knowledge of and attitudes towards dementia in the Kingdom of Saudi Arabia (KSA) using questionnaire surveys; the Dementia Knowledge Assessment Tool version 2 (DKAT2) and the Dementia Attitude Scale (DAS); and (c) identify learning needs of registered nurses when caring for people with dementia. To achieve these aims, the survey targeted RNs working in six different hospitals in the city of Jeddah.

The survey consisted of a quantitative questionnaire organised into three sections that aimed to address these overarching questions:

1. 1. How do nurses rate their own knowledge regarding dementia?
1. 2. What are the assessment scores of nurses' knowledge of dementia using the DKAT2?
1. 3. What are the assessment scores of nurses' attitudes towards working with people with dementia using DAS?
1. 4. What factors are related to knowledge and attitude?

## 5.1 Survey data

This section presents the study sample and response rates among the recruited survey participants, including the CONSORT flow chart. The CONSORT flow chart (Figure 5.1) shows the flow of the present study, including the number of RNs within the six hospitals, those working in areas that admit people with dementia, the number of surveys distributed and collected in each facility, the number of nurses who agreed to participate in the diary-interviews and the numbers of RNs who ultimately participated in the diary-interviews.

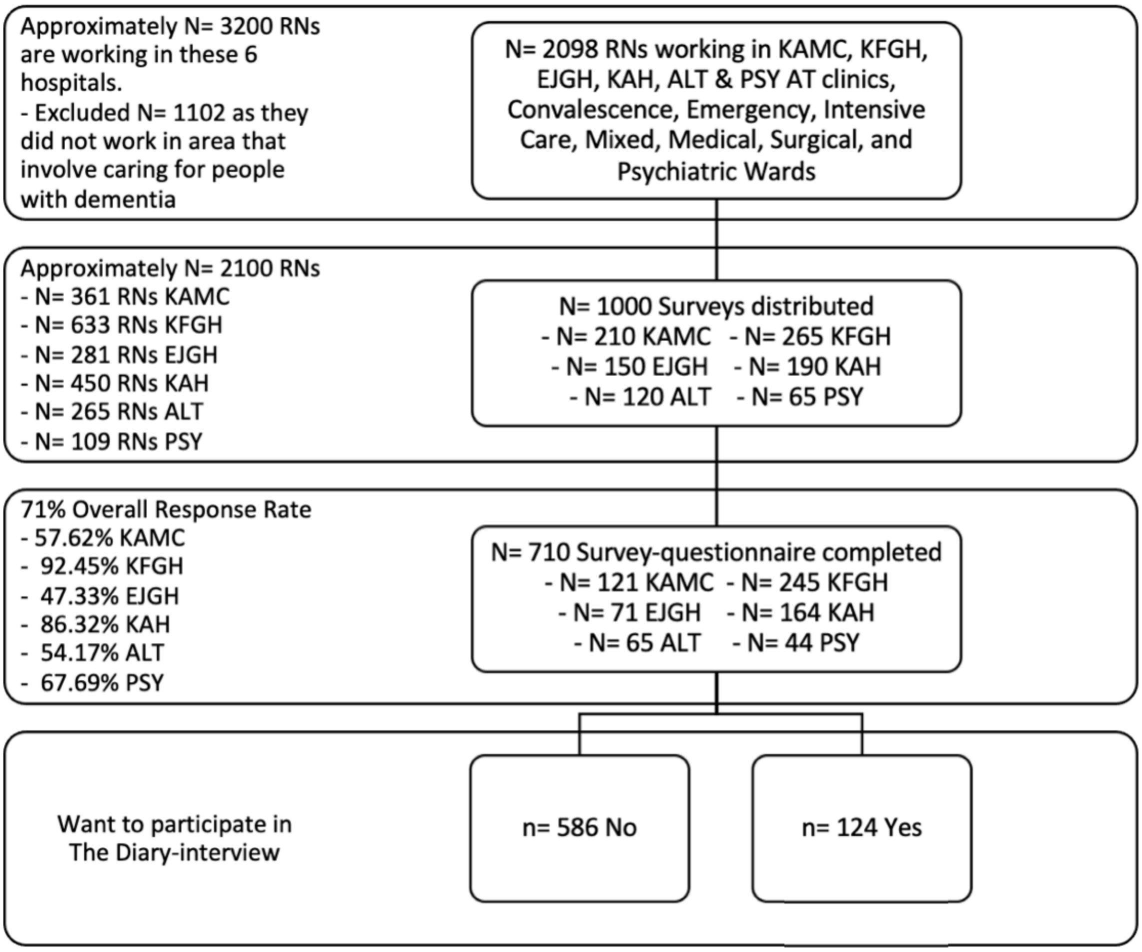

Figure 5.1 CONSORT flow diagram of the survey

One thousand surveys were distributed to 29 wards (later grouped into eight ward categories) among the six hospitals in Jeddah. These varied care settings employed 2098 RNs with direct experience working with people with dementia. Of the thousand nurses given a survey, 71% (710 nurses) responded, thus not only meeting but surpassing the minimum threshold set out before the study, as discussed in Chapter 4. Among the central hospitals KFGH and KAH and the specialist hospital PSY, the response rate was high (92.4%, 86.3%, 67.7%, respectively), while the rural hospital ALT and the newly constructed hospitals KAMC and EJGH had lower response rates (54.2%, 57.6%, 47.3%, respectively).

The survey data were collected between March and July 2018 using the procedure described in section 4.3.1. The participants' data from the survey's first section as well as the survey responses from both the second and third sections were then entered in their entirety into the SPSS software programme (version 25) between May and July 2018. No questions were left blank by participants.

The eight ward categories mentioned above are: (1) clinics that include out-patient departments and PHC participants; (2) convalescence departments that include extended medical units, homecare departments and rehabilitation departments; (3) emergency departments; (4) intensive care units, including the burn unit; (5) mixed wards that include mixed medical/surgical, neurology and cardiology departments; (6) medical wards, including general medicine, urology, kidney, renal and ear, nose and throat wards (ENT); (7) surgical wards, including general surgical departments, orthopaedic and neurosurgery wards; and (8) psychiatric wards, including female/male acute and chronic care wards. More details about each ward are presented in the next section.

## 5.2 Statistical analysis

This analysis is based on the 710 RNs' responses to the survey. The two main components of the data's statistical analysis were conducted using the SPSS version 25 software, namely the descriptive statistics and the inferential statistics (IBM Corp, 2017).

The descriptive statistics include means and standard deviations (SD) and/or frequencies and percentages of the collected data. These details apply to the variables within the four categories of the first section of the survey: environmental characteristics, personal demographics, experience characteristics and educational characteristics (as shown in the previous chapter Figure 4.2**Error! Reference source not found.**). Then, the overall scores' mean ± SD for the DAS and DKAT2 (sections two and three of the survey) are reported, and individual questions are summarised using the frequencies and percentages of positive responses (for the attitude questionnaire) and correct responses (for the knowledge questionnaire). Hence, frequencies and percentages are reported for all variables according to their category (Table 5.1; Table 5.2; Table 5.3; Table 5.4), as are the means and SD for nurses' own ratings of their knowledge, confidence and willingness to learn about dementia and their attitude and knowledge scores (Table 5.5). Also, frequencies and percentages are reported for individual questionnaire statements (Table 5.6; Table 5.7), in order to describe the sample's main characteristics and identify further potential variables that could be useful in understanding nurses' knowledge of and attitudes towards people with dementia.

The inferential statistics section includes the application of the eight assumptions of linear regression; which involves the multiple regression model (unadjusted, partially adjusted and fully adjusted) that were outlined in the previous chapter. This allows for making predictions and providing explanations for both attitude and knowledge scores among the study participants. Further, a Pearson Correlation Test was conducted to understand the association between the DAS and DKAT2 scores. While attitude and knowledge are central to this study's objectives, it is worthwhile considering how all four categories of variables relate to the outcomes of present interest. Therefore, knowledge and attitude scores will be the dependant variables within the regression model, which also assumed that environmental characteristics, personal demographics, educational characteristics and experience characteristics (a grouping of independent variables) were worth looking at in order to meet this study's objectives. The regression is meant to help understand the factors that might influence the knowledge and attitudes of nurses.

### 5.2.1 Descriptive statistics

#### *Environmental characteristic*

More than half of the survey participants were working at the central hospitals (KFGH 245, KAH 164, Table 5.1), with slightly more than one quarter working in the newly constructed hospitals (KAMC 121, EJGH 71, Table 5.1). Approximately 15% were working at the rural hospital and the psychiatry hospital (ALT 65, PSY 44, Table 5.1).

From the wards accessed, a similar quantity of survey responses were obtained from medical wards (19.3%), clinics (18.2%), mixed wards (15.1%), emergency departments (14.5%) and surgical wards (12.8%). However, fewer responses were obtained from the intensive care units (6.5%) and psychiatry departments (4.4%). The majority of the RNs surveyed did not have access to reading groups (94.8%), evidence-based materials (72.4%), the internet (63.5%) or computers (62.8%) at their workplaces.

Table 5.1 Frequencies and percentages of the environmental characteristics

| **Variables** | | **Frequency** | **Percentage** |
|---|---|---|---|
| Hospital | KAMC | 121 | 17 |
| | KFGH | 245 | 34.5 |
| | EJGH | 71 | 10 |
| | KAH | 164 | 23.1 |
| | ALT | 65 | 9.2 |
| | PSY | 44 | 6.2 |
| Ward | Clinics | 129 | 18.2 |
| | Convalescence departments | 66 | 9.3 |
| | Emergency departments | 103 | 14.5 |
| | Intensive care units | 46 | 6.5 |
| | Mixed wards | 107 | 15.1 |
| | Medical wards | 137 | 19.3 |
| | Surgical wards | 91 | 12.8 |
| | Psychiatric wards | 31 | 4.4 |
| Access to evidence-based materials at work | Yes | 196 | 27.6 |
| | No | 514 | 72.4 |
| Access to the internet at work | Yes | 259 | 36.5 |
| | No | 451 | 63.5 |
| Access to a computer at work | Yes | 264 | 37.2 |
| | No | 446 | 62.8 |
| Access to reading groups at work | Yes | 37 | 5.2 |
| | No | 673 | 94.8 |

### *Personal demographics*

Nurses in their twenties made up the bulk of the study group (Table 5.2). Almost half of the survey participants were Saudi (45.2%), while more than a quarter were Indian (26.8%) and another quarter Filipino (25.9%). Other nationalities (2.4%), included Sudanese, Egyptian, Yemeni, Jordanian, and Tunisian nurses (all Eastern-Mediterranean countries). The majority of the RNs (87.9%) were female and bedside nurses (70.4%), while community nurses, including clinic nurses and home care nurses, made up 19.7% of the survey respondents. Administrative nurses, including charge nurses, head nurses and supervisors were a cumulative 9.8%.

Table 5.2 Frequencies and percentages of the personal demographics

| **Variables** | | **Frequency** | **Percentage** |
|---|---|---|---|
| Age range (years) | 21-25 | 68 | 9.6 |
| | 26-30 | 294 | 41.4 |
| | 31-35 | 190 | 26.8 |
| | 36-40 | 77 | 10.8 |
| | 41-45 | 43 | 6.1 |
| | 46-50 | 27 | 3.8 |
| | 51-55 | 8 | 1.1 |
| | 56+ | 3 | 0.4 |
| Gender | Male | 86 | 12.1 |
| | Female | 624 | 87.9 |
| Nationality | Saudi | 321 | 45.2 |
| | Indian | 190 | 26.8 |
| | Filipino | 183 | 25.8 |
| | Other | 16 | 2.3 |
| Job title | Bedside nurse | 500 | 70.4 |
| | Clinic nurse | 130 | 18.3 |
| | Charge nurse | 37 | 5.2 |
| | Head nurse | 27 | 3.8 |
| | Supervisor | 6 | 0.8 |
| | Home care | 10 | 1.4 |

### *Experience characteristics*

Table 5.3 illustrates the study participants' experience characteristics. In terms of years of experience, almost a quarter of the study participants (23.4%) were new RNs with one to three years of experience. More than a quarter (28.9%) had four to five years of experience, while almost one third (31.7%) had six to ten years of experience. RNs with more than 11 years' experience represented the smallest number among those who contributed to the survey, at 16%. However, in terms of years of experience as a nurse working in the same area, few RNs (9%) had less than one year of experience, and only 7.6% had more than 11 years of experience; most of these nurses (43.7%) had one to three years of experience, almost a quarter (22.1%) had four to five years, and fewer than a quarter (17.6%) had six to ten years of experience within their current working area.

In terms of providing professional care to people with dementia, almost half (42.1%) of the RNs provided dementia care, while the rest (57.9%) did not. Also, the vast majority (82.5%) of the RNs did not have a family member with dementia; however, a significant proportion (17.5%) did have family members with dementia.

Table 5.3 Frequencies and percentages of the experience characteristics

| Variables | | Frequency | Percentage |
|---|---|---|---|
| Years of experience | 1-3 | 166 | 23.4 |
| | 4-5 | 205 | 28.9 |
| | 6-10 | 225 | 31.7 |
| | 11-20 | 86 | 12.1 |
| | 20+ | 28 | 3.9 |
| Experience within current area | <1 | 64 | 9 |
| | 1-3 | 310 | 43.7 |
| | 4-5 | 157 | 22.1 |
| | 6-10 | 125 | 17.6 |
| | 11-20 | 43 | 6.1 |
| | 20+ | 11 | 1.5 |
| Provided professional care for people with dementia | Yes | 299 | 42.1 |
| | No | 411 | 57.9 |
| Have a family member with dementia | Yes | 124 | 17.5 |
| | No | 586 | 82.5 |

### *Educational characteristics*

Educational characteristics are summarised in Table 5.4. The majority of the study participants had a bachelor degree in nursing (56.9%) or a diploma (41.7%). However, only 1.4% held master degrees in nursing, and none had received a doctoral degree. Almost half of the participants (45.5%) completed their nursing degrees in the KSA. Only 11.8% had received formal dementia education or had attended a workshop about dementia.

Table 5.4 Frequencies and percentages of the educational characteristics

| **Variables** | | **Frequency** | **Percentage** |
|---|---|---|---|
| Highest educational degree | Diploma | 296 | 41.7 |
| | Bachelor | 404 | 56.9 |
| | Master | 10 | 1.4 |
| Complete degree in KSA | Yes | 323 | 45.5 |
| | No | 387 | 54.5 |
| Attended formal dementia education course or workshop | Yes | 84 | 11.8 |
| | No | 626 | 88.2 |

For the five-point Likert scale, mean ± SD analyses were used with the variables when participants were asked to rate their knowledge of dementia, their confidence in caring for people with dementia and their willingness to learn about dementia (Table 5.5). The mean of the 710 participants' own ratings of their knowledge was 2.5 ± 0.7. There were slightly higher findings for participants' own ratings of their confidence in caring for people with dementia, with a mean of 2.6 ± 0.8. The mean for their willingness to learn about dementia was 3.1 and the SD was wider, at 1.1.

Table 5.5 Means and Standard Deviations (SD) of the educational characteristics

| Variables | | means | SD |
|---|---|---|---|
| Rate own knowledge of dementia | Min. 1 Max. 5 | 2.5 | 0.7 |
| Rate own confidence to care for people with dementia | Min. 1 Max. 5 | 2.6 | 0.8 |
| Willingness to learn about dementia | Min. 1 Max. 5 | 3.1 | 1.1 |

### *Dementia Attitude Scale (DAS)*

As discussed in Chapter 4, Survey section 2: Dementia Attitude Scale (DAS) the DAS tool covers the tripartite aspects of attitudes. The table below (Table 5.6) shows the rates of responses given by the 710 RNs to the 20 statements related to dementia, which were divided into two categories: comfort (affective/emotional and behavioural) and knowledge (cognitive). Answers were designated as positive, negative or undecided. The scores for these responses were cumulatively calculated from the scores obtained using the seven-point Likert scale, with a consideration of the revised score statements. The positive responses ranged between 36.8% and 79.2%, and the negative responses ranged between 13.9% and 51%; the undecided responses ranged between 6.6% and 24.8%. The negative responses' scores were revised which means lower scores were assigned to that particular statement in order to adjust the participants responses and report a meaningful interpretation.

Table 5.6 DAS questionnaire statements and responses

| | | Statement | Positive response | Negative response | Undecided |
|---|---|---|---|---|---|
| Comfort (Affective/Emotional & Behavioural) | 1 | It is rewarding to work with people who have ADRD | 415 (58.4%) | 203 (28.6%) | 92 (13%) |
| | 4 | I feel confident around people with ADRD | 369 (52%) | 201 (28.3%) | 140 (19.7%) |
| | 5 | I am comfortable touching people with ADRD | 431 (60.7) | 163 (23%) | 116 (16.3%) |
| | 13 | I feel relaxed around people with ADRD | 331 (46.6%) | 203 (28.6%) | 176 (24.8%) |
| | 2 | I am afraid of people with ADRD* | 550 (77.5%) | 106 (15%) | 54 (7.6%) |
| | 6 | I feel uncomfortable being around people with ADRD* | 430 (60.6%) | 182 (25.7%) | 98 (13.8%) |
| | 8 | I am not very familiar with ADRD* | 261 (36.8%) | 362 (51%) | 87 (12.3%) |
| | 9 | I would avoid an agitated person with ADRD* | 334 (47.1%) | 290 (40.8%) | 86 (12.1%) |
| | 16 | I feel frustrated because I do not know how to help people with ADRD* | 300 (42.2%) | 293 (41.3%) | 117 (16.5%) |
| | 17 | I cannot imagine caring for someone with ADRD* | 433 (61%) | 165 (23.2%) | 112 (15.8%) |
| Knowledge (Cognitive) | 3 | People with ADRD can be creative | 357 (50.3%) | 230 (32.4%) | 123 (17.3%) |
| | 7 | Every person with ADRD has different needs | 561 (79%) | 102 (14.4) | 47 (6.6%) |
| | 10 | People with ADRD like having familiar things nearby | 475 (66.8%) | 130 (18.2%) | 105 (14.8%) |
| | 11 | It is important to know the past history of people with ADRD | 563 (79.2%) | 99 (13.9%) | 48 (6.8%) |
| | 12 | It is possible to enjoy interacting with people with ADRD | 453 (63.8%) | 160 (22.6%) | 97 (13.7%) |
| | 14 | People with ADRD can enjoy life | 400 (56.3%) | 213 (20.9) | 97 (13.7%) |
| | 15 | People with ADRD can feel when others are kind to them | 447 (63%) | 167 (23.6%) | 96 (13.5%) |
| | 18 | I admire the coping skills of people with ADRD | 439 (61.8%) | 134 (18.9%) | 137 (19.3%) |
| | 19 | We can do a lot now to improve the lives of people with ADRD | 544 (76.6%) | 102 (14.3%) | 64 (9%) |
| | 20 | Difficult behaviours may be a form of communication for people with ADRD | 490 (69%) | 128 (18.1%) | 91 (12.8%) |

**Key:** * Negative statements
- ADRD= Alzheimer's disease and related disorders (O'Connor and McFadden, 2010)

The statements with the most positive responses were associated with the cognitive aspect of attitude. Most participants (79.2%) admit the importance of knowing the history of the person with dementia. A similar number of participants (79%) agreed that a person with dementia has different needs. Also, 76.6% of participants agreed with the statement, ‘We can do a lot now to improve the lives of people with Alzheimer’s disease and related disorders (ADRD)’. Almost 70% of participants agreed with the statement, ‘Difficult behaviours may be a form of communication for people with ADRD.’ The rest of the cognitive statements were agreeable to 50-67% of the participants (as shown in Table 5.6).

In contrast, the statements with the most negative responses were associated with the affective and behavioural aspects of attitudes. Most nurses (51%) agreed that they are not very familiar with dementia. Also, 41.3% of nurses feel frustrated by the care they provide to people with dementia, while more than 40% agreed with the statement, ‘I would avoid an agitated person with ADRD.’

The undecided statements were higher in the comfort category than in the knowledge category. A quarter of the study participants were undecided about the statement, ‘I feel relaxed around people with ADRD,’ while 19.7% were undecided about the statement, ‘I feel confident around people with ADRD’ and 19.3% about the statement, ‘I admire the coping skills of people with ADRD.’ A further 17.3% were undecided about the statement, ‘People with ADRD can be creative.’ Around 16% of participants were undecided about the statements, ‘I feel frustrated because I do not know how to help people with ADRD,’ ‘I am comfortable touching people with ADRD’ and ‘I cannot imagine caring for someone with ADRD.’

### ***Dementia Knowledge Assessment Tool version Two (DKAT2)***

The DKAT2 scores of the 710 RNs were calculated using the SPSS software. The minimum score obtained was zero and the maximum was 38. The higher the score obtained, the more knowledge recorded (more about scoring can be found 4.8.1). The mean was 24.1 ± 6.5, which is considered to be an average to low knowledge score noted. No one scored 42, which was the highest possible score. More details on means and SD according to participant characteristics can be found in Appendix I.

As discussed in Chapter 4, Section 4.4.2, the DKAT2 tool covers knowledge about dementia and its progress, as well as its support and care. The following table shows the number of responses obtained from the 710 RNs who completed the survey that are labelled ‘correct’, ‘incorrect’, and ‘do not know’, which are the given response options in the actual questionnaire (please refer to Table 5.7 for correct and incorrect statements). The responses were in reference to specific statements about dementia. The total ‘correct’ responses ranged between 20.6% and 90.3%, while ‘incorrect’ responses ranged between 6.2% and 69.2%; the ‘do not know’ responses ranged between 3.5% and 22.1%.

Table 5.7 DKAT2 questionnaire statements and responses

| Statement | | | Responded ‘Correct’ | Responded ‘Incorrect’ | Responded ‘Don’t know’ |
|---|---|---|---|---|---|
| Dementia and its progress | 1 | Dementia occurs because of changes in the brain | 641<br>(90.3%) | 44<br>(6.2%) | 25<br>(3.5%) |
| | 2 | Brain changes causing dementia are often progressive | 588<br>(82.8%) | 84<br>(11.8%) | 38<br>(5.4%) |
| | 3 | Alzheimer’s disease is the main cause of dementia | 449<br>(63.2%) | 156<br>(22%) | 105<br>(14.8%) |
| | 4 | Blood vessel disease can also cause dementia | 392<br>(55.2%) | 200<br>(28.2%) | 118<br>(16.6%) |
| | 5 | Confusion in an older person is almost always due to dementia* | 238<br>(33.5%) | 403<br>(56.8%) | 69<br>(9.7%) |
| | 6 | Only older adults develop dementia* | 374<br>(52.7%) | 291<br>(41%) | 45<br>(6.3%) |
| | 8 | Incontinence always occurs in the early stages of dementia* | 224<br>(31.5%) | 357<br>(50.3%) | 129<br>(18.2%) |
| | 9 | Dementia likely limits life expectancy | 366<br>(51.5%) | 226<br>(31.8%) | 118<br>(16.6%) |
| | 11 | People who have dementia may develop problems with visual perception (understanding or recognising what they see) | 532<br>(74.9%) | 116<br>(16.3%) | 62<br>(8.7%) |
| | 12 | Sudden increases in confusion are characteristic of dementia* | 146<br>(20.6%) | 491<br>(69.2%) | 73<br>(10.3%) |
| | 13 | Uncharacteristic distressing behaviours may occur in people who have dementia (e.g., aggressive behaviour in a gentle person) | 463<br>(65.2%) | 156<br>(22%) | 91<br>(12.8%) |
| | 14 | Difficulty swallowing occurs in late stages dementia | 370<br>(52.1%) | 183<br>(25.8%) | 157<br>(22.1%) |
| | 15 | Movement (e.g., walking, moving in bed or chair) is limited in late stage dementia | 466<br>(65.6%) | 141<br>(19.9%) | 103<br>(14.5%) |

| Statement | | | Responded 'Correct' | Responded 'Incorrect' | Responded 'Don't know' |
|---|---|---|---|---|---|
| Support and care | 7 | Knowing the likely cause of dementia can help to predict its progression* | 477<br>(67.2%) | 135<br>(19%) | 98<br>(13.8%) |
| | 10 | When a person has late-stage dementia, families can help others to understand the person's needs | 595<br>(83.8%) | 68<br>(9.6%) | 47<br>(6.6%) |
| | 16 | Changing the environment (e.g., putting on CD, opening or closing the blinds) will make no difference to person who has dementia* | 312<br>(43.9%) | 299<br>(42.1%) | 99<br>(13.9%) |
| | 17 | When a person who has dementia is distressed, it may help to talk to them about their feelings | 429<br>(60.4%) | 184<br>(25.9%) | 97<br>(13.7%) |
| | 18 | It is important to always correct a person who has dementia when they are confused* | 237<br>(33.4%) | 396<br>(55.8%) | 77<br>(10.8%) |
| | 19 | A person who has dementia can often be supported to make choices (e.g., what clothes to wear) | 522<br>(73.5%) | 138<br>(19.4%) | 50<br>(7%) |
| | 20 | It is impossible to tell if a person who is in the later stages of dementia is in pain* | 234<br>(33%) | 328<br>(46.2%) | 148<br>(20.8%) |
| | 21 | Exercise can sometimes be of benefit to people who have dementia | 516<br>(72.7%) | 87<br>(12.3%) | 107<br>(15.1%) |

**Key:** * Incorrect statements

Participants evidently know that dementia is progressive and is caused by changes in the brain (83.8% and 90.3%) and that people with dementia may develop visual problems, movement limitations and distressing behaviours (74.9%, 65.6% and 65.2%, respectively). Most nurses also agreed that Alzheimer's is the main cause of dementia (63.2%). However, in regard to dementia's progress, participants were incorrect in their responses about dementia stages and complications, such as confusion (69.2%, 56.8%) and incontinence (50.3%). Nearly half of the participants believe that dementia is part of normal ageing (41%).

In the support and care category, participants responded correctly to statements about the support needed by the families of people with dementia (83.8%), the need to assist them in making decisions (73.5%), the benefits of exercising (72.7%), helping people with dementia express their feelings (60.4%) and predicting dementia progression by knowing its likely causes (67.2%). Conversely, incorrect responses were associated with statements about communicating with a person with dementia and changing the environment: 'It is important to always correct a person who has dementia when he/she is confused' (55.8%), 'It is impossible to tell if a person who is in the later stages of dementia is in pain' (46.2%) and 'Changing the environment will make no difference to person who has dementia' (42.1%).

The highest number of ‘do not know’ responses were associated with statements about dementia’s progression and its characteristics, such as difficulty swallowing (22.1%) and incontinence (18.2%). Additionally, the ‘Blood vessel disease can also cause dementia’ and ‘Dementia is likely to limit life expectancy’ statements had 16.6% ‘do not know’ responses. From the support and care statements, the statement least known, with 20.8% of participants responding that they did not know, was, ‘It is impossible to tell if a person who is in the later stages of dementia is in pain.’

### 5.2.2 Inferential statistics

The inferential statistics were carried out using two types of analysis using the SPSS. This was done to gain more insight from the collected surveys in terms of nurses’ knowledge and attitudes and the contributing factors that led to such results. Firstly, a multiple linear regression analysis was performed to construct a model based on all independent variables and understand the relationships between variables, including the application of the eight assumptions inherent to this analysis (see section 4.8.1). Successful application of the eight assumptions ensures the model’s appropriateness and the validity of the data (Laerd Statistics, 2015; Field, 2018). Next, a correlation analysis was performed to explore the relationship between the DKAT2 and DAS scores. This analysis was used to quantify the association between knowledge and attitudes.

#### ***The application of the eight assumptions of linear regression***

The variables within the four categories mentioned above—environmental characteristics, personal demographics, experience characteristics and educational characteristics—were considered independent variables. This is to test the data in a multiple linear regression analysis using dementia attitude scores and knowledge scores as two dependant variables. As dependant variables were identified on the continuous scale (DAS and DKAT scores) and more than two independent variables needed to be tested, the first two assumptions for linear regression were met. Noting that to approach the regression, three models were developed – unadjusted, partially, and fully adjusted results – the assumption checking primarily applies to the full model (see the next section for more details see subheading The multiple regression models in section 5.2.2).

The remaining assumptions can be examined after being fit into the model. Therefore, the standard multiple regression procedure (fully adjusted R squared model, Table 5.8 in the next section) was run twice using the SPSS, the first time using the DAS scores as the dependent variable and then the DKAT2 scores as another dependent variable.

To meet the third assumption requirements, the linearity was tested in two steps for each dependent variable; first, by investigating if a linear association existed between the dependent (DAS and DKAT2 scores) and independent variables in general using a scatterplot, and then by investigating if an association exists between the DAS and DKAT2 scores and each variable. The data were likely to be linear, as indicated by the scatterplots below (Figure 5.2 and Figure 5.3). When variables were tested individually, linearity was indicated in most variables.

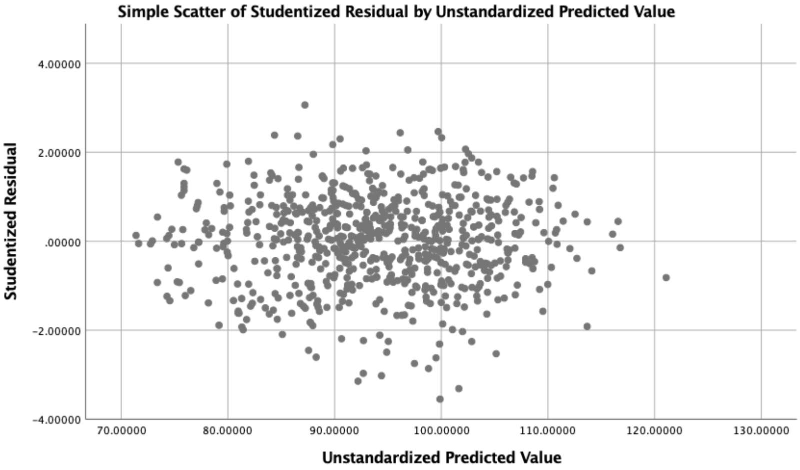

Figure 5.2 The linear association between the DAS score and independent variables collectively

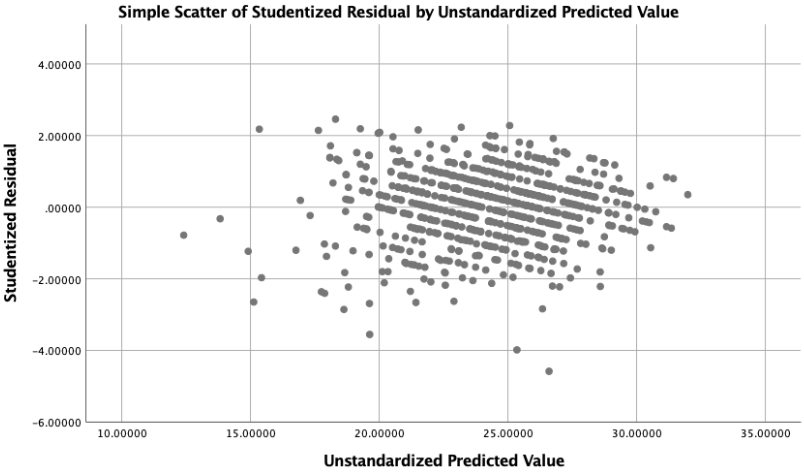

Figure 5.3 The linear association between DKAT2 score and independent variables collectively

The independence of observations assumption can be checked in two stages. First, at the time of collecting the data, as the data generating process that was used assumed that the data were independent of observation (described extensively in sections 4.3.1, 5.1). Then, in the model summary table, the independence residuals were assessed by a Durbin-Watson statistic of 1.9 (DAS) and 1.8 (DKAT2). As the values were still under 2, it can be accepted that no independent errors (residuals) existed. Noting that there may be some factors that lead to dependence such as hospital and ward, but that the final model build will control for these factors, and hence this requirement of the fourth assumption of linear regression was met.

Moving toward the fifth assumption, an equal variance for all variables of the predicted DAS and DKAT2 scores were present in the homoscedasticity. Using the previously generated plots, it shows that there is no increase or decrease in the spread residuals when moving across the predicted values.

Assumption six deals with multicollinearity. If two or more independent variables are highly correlated with each other, this leads to calculating issues in the multiple regression model and problems with understanding which variable contributes to the variance explained. This is called a multicollinearity; therefore, data must not show multicollinearity in order to attain assumption six requirements. To identify this correlation, coefficients and tolerance/VIF values were inspected. Looking at the correlations schedule, from the standard multiple regression procedure, the correlations must have values of no more than 0.7 (Laerd Statistics, 2015; Field, 2018). All values were under 0.7, except for ‘PSY hospital and PSY ward’ and ‘Community nurse and Clinics ward’, for which the values were 0.83 and 0.86, respectively. Looking next at the coefficient tables, the tolerance values were greater than 0.1 (the lowest is 0.17, for the Clinics ward variable). Hence, if multicollinearity were a problem, that would be seen in the results from the regression analysis (i.e., the parameter estimates and confidence intervals become extremely large/small), which does not seem to be the case. From these results, we can be fairly confident that there is no problem with multicollinearity within the data.

Meeting the requirements of the seventh assumption involves inspecting unusual points within the data. These unusual points are outliers, or high leverage points and highly influential points. No outliers were detected from for either DAS or DKAT2 test. From the data, leverage values were between 0.02 and 0.15, which is considered safe. Finally, since the Cook’s Distance values that appeared for each case have shown that all values are under 1, it is possible to investigate the last assumption.

In checking the normality of the residuals, histograms and then P-P plots were inspected. From the histograms for both the DAS and DKAT2 scores it appears that the data were approximately normally distributed (Figure 5.4 and Figure 5.5). Also, P-P Plots of the regression standardised residuals show an approximately normally distributed result, with a non-concerning deviation from normality for DKAT2 scores (Figure 5.6 and Figure 5.7). More regression standardised residuals are available in appendix I.1.

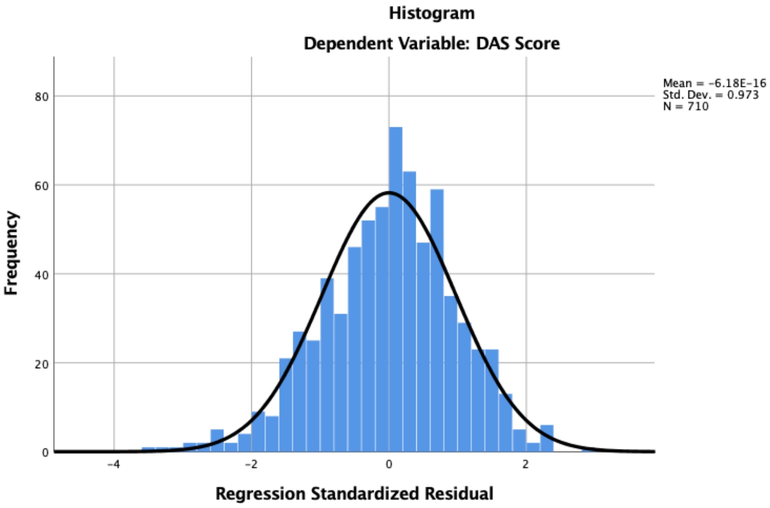

Figure 5.4 The standardised residual histogram for DAS scores

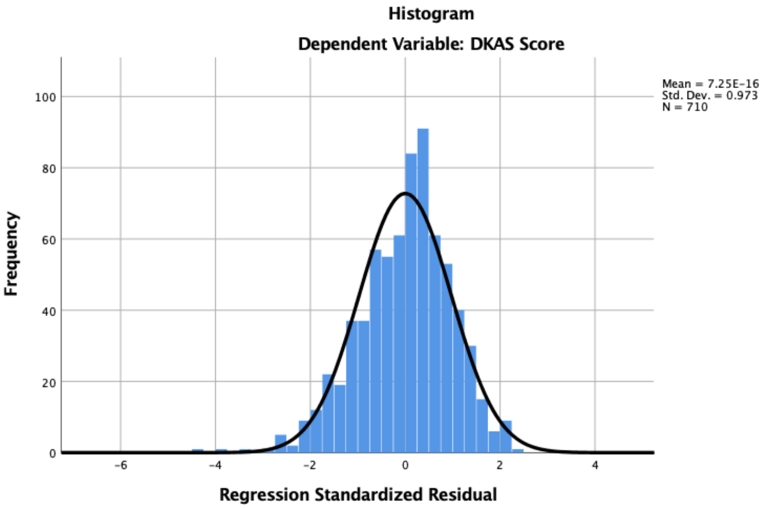

Figure 5.5 The standardised residual histogram for DKAT2 scores

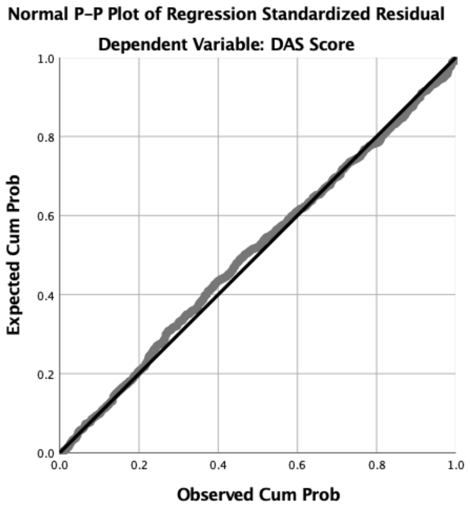

Figure 5.6 P-P Plot of regression standardised residual for DAS scores

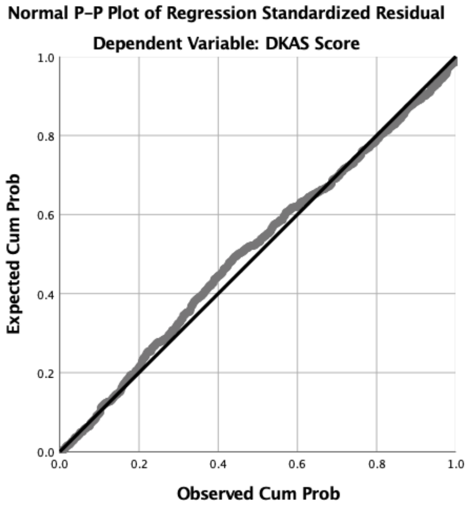

Figure 5.7 P-P Plot of regression standardised residual for DKAT2 scores

In conclusion, the eight assumptions were successfully fitted into the multiple linear regression model. Hence, the present study used this model to analyse the data collected from RNs working in the Jeddah MOH care facilities.

### *The multiple regression models*

The multiple regression analysis tests were run in the SPSS several times for each dependent variable to have three kinds of multiple regression models: an unadjusted model, a partially adjusted model and a fully adjusted model (as explained in Table 5.8).

Table 5.8 Multiple Linear regression models

| **Linear Regression model** | **Includes** |
|---|---|
| Unadjusted R squared | Tests for each independent variable on its own in a regression model<br>Environmental characteristics (six independent variables), personal demographics (four independent variables), experience characteristics (four independent variables) and educational characteristics (six independent variables)<br>Results in twenty regression models for each dependant variable |
| Partially adjusted R squared | Four regression analyses for the four groups (environmental, personal, educational and experience characteristics)<br>Results in four regression models |
| Fully adjusted R squared | Standard multiple regression procedure<br>One model run for each dependant variable |

From the results that appeared in SPSS, three important elements were reported (Appendix I.1). The adjusted R squared ($R^2$) model detected the amount of variance accounted for by the variables in the model. The adjusted model also accounts for reporting the $R^2$ to the scores calculated and Confidence Intervals (CI) and P values. Then the B coefficient values are reported for each model to inspect the associations between each variable (or level of categorical variable) on the outcome within the three models. CIs are related to the B values that are estimated in the regression model. A wide CI represents uncertainty in the parameter that the B coefficient estimates; uncertainty means it is harder to draw more definite conclusions. This is important in order to understand the variables and detect the factors that result in high or low scores in both DAS and DKAT2 tests, with consideration of the CI upper and lower bonds and P values to ensure that these variables influence the scores reported.

The adjusted $R^2$ for the overall DAS model was 30.2%, which is a moderate size effect according to (Evans, 1996). Smaller effects, ranging from weak to moderate, are found in the partially adjusted regression model. Education characteristics grouping seems far more informative than the other groupings (See Table 5.9).

Table 5.9 Adjusted $R^2$ for DAS scores

| | **Partially adjusted $R^2$** | **Fully adjusted $R^2$** |
|---|---|---|
| Environmental Characteristics | 0.055 | 0.302 |
| Personal Demographics | 0.091 | |
| Experience Characteristics | 0.023 | |
| Education Characteristics | 0.261 | |

On the other hand, the adjusted $R^2$ for the overall DKAT2 model was 16.3%, which is also considered a moderate size effect (Evans, 1996). A weak effect was found in the partially adjusted regression model (Experience Characteristics 1.2%; Personal Demographics 6.8%; Environmental Characteristics 7.5%; Education Characteristics 9.7%). See Table 5.10.

Table 5.10 Adjusted $R^2$ for DKAT2 scores

| | **Partially adjusted $R^2$** | **Fully adjusted $R^2$** |
|---|---|---|
| Environmental Characteristics | 0.075 | 0.163 |
| Personal Demographics | 0.068 | |
| Experience Characteristics | 0.012 | |
| Education Characteristics | 0.097 | |

In terms of the environmental factors, working in mixed wards, convalescence departments and clinic wards relates to having more positive attitudes toward people with dementia among the three models (B 4.9; 3.1; 2). However, the CI is considered wide (1.2–8.6; -1–7.3; -4.6–8.6). Having wide CI could means that the scores vary among the study participants that is uncontrolled feature of the data, also it probably relates to the small sample size in the categories. Although the results suggest a mean increase of 4.9 for mixed wards compared to the reference category, the data are consistent with a much smaller difference (1.2) and much larger difference (8.6). These values (1.2, 4.9 and 8.6) might lead to a different conclusion that could be considered in a later interpretation. For instance, from these results it might be confidently asserted that mixed wards nurses score noticeably higher than other wards as 1.2 is still quite a big difference; conversely, all wards are fairly similar if 8.6 is a small difference in attitude. Both emergency departments and psychiatry wards reflect more negative attitudes among the study participants, yet, the CI is wide (-5.4–1.7; -10.4–8.3). The B values changed across the models of unadjusted, partially adjusted and fully adjusted models, suggesting that they articulated other variables and may have interfered with the models to yield such a result. For example, having access to evidence-based materials at work relates to holding more positive attitudes (B 2.5, CI 0.3–5.8). However, having access to reading groups, computers and the internet relates to more negative attitudes (B -3.3; -1.4; -0.06 and CI -7.8–1; -3.5–0.6; -2.1–2). See Table 5.11.

Noteworthy to mention that within the following tables the P value and CI is presenting the association at the fully adjusted model.

Table 5.11 Linear regression analysis of DAS scores with environmental characteristics variables

| DAS scores and Environmental Characteristics | Coefficient B | | | CI* | | P value* |
|---|---|---|---|---|---|---|
| | Unadjusted | Partially Adjusted | Fully Adjusted | Lower bond | Upper bond | |
| Clinics | 1.9 | 0.2 | 2.0 | -4.6 | 8.6 | 0.549 |
| Convalescence departments | 5.7 | 5.0 | 3.1 | -1.0 | 7.3 | 0.138 |
| Emergency departments | 0.8 | -0.5 | -1.8 | -5.4 | 1.7 | 0.316 |
| Intensive care unit | 2.7 | 2.9 | -0.3 | -4.9 | 4.2 | 0.893 |
| Mixed wards | 9.2 | 6.5 | 4.9 | 1.2 | 8.6 | 0.010 |
| Medical wards** | | | | | | |
| Surgical wards | -0.2 | -0.2 | 0.0 | -3.3 | 3.5 | 0.971 |
| Psychiatry | 3.3 | 4.0 | -1.0 | -10.4 | 8.3 | 0.827 |
| Evidence-based materials at work*** | -0.7 | 0.3 | 2.5 | 0.3 | 4.8 | 0.026 |
| Reading groups at work*** | -5.6 | -4.2 | -3.3 | -7.8 | 1.0 | 0.137 |
| Computer at work*** | -3.5 | -2.3 | -1.4 | -3.5 | 0.6 | 0.173 |
| Access to internet at work*** | -2.8 | -2.0 | -0.0 | -2.1 | 2.0 | 0.954 |

**Key:** * The CI and p-values relate to the fully adjusted model

** Reference category

*** No as a reference category

Conversely, working in medical wards relates to higher scores in knowledge. Working in mixed wards relates to higher scores in the unadjusted model but lower scores in the adjusted model (B 1.0; -0.8). The opposite is true for psychiatric nurses, who demonstrated low scores in the unadjusted model but higher ones in the adjusted model (B -2.1; 1.7). Working in wards other than medical and psychiatry relates to lower knowledge across all models, especially ED and surgical (significant P values 0.000; 0.001). Reading groups and computer access at work relate to higher scores in knowledge about dementia (B 1.1; 0.4 and -0.9–3.2; -0.6–1.4). Surprisingly, having access to evidence-based materials and the internet at work relates to lower dementia knowledge across all models (B -0.9; -0.4), with slightly narrow CI (-1.9–0.2; -1.4–0.6). See Table 5.12.

Table 5.12 Linear regression analysis of DKAT2 scores with environmental characteristics variables

| DKAT2 scores and Environmental Characteristics | Coefficient B | | | CI* | | P value* |
|---|---|---|---|---|---|---|
| | Unadjusted | Partially Adjusted | Fully Adjusted | Lower bond | Upper bond | |
| Clinics | -2.4 | -2.6 | -3.0 | -6.2 | 0.0 | 0.055 |
| Convalescence departments | -1.2 | -1.6 | -2.2 | -4.2 | -0.2 | 0.029 |
| Emergency departments | -3.2 | -3.2 | -3.7 | -5.4 | -2.0 | 0.000 |
| Intensive care unit | -1.3 | -1.1 | -1.7 | -3.9 | 0.4 | 0.119 |
| Mixed wards | 1.0 | -0.3 | -0.8 | -2.6 | 1.0 | 0.377 |
| Medical wards** | | | | | | |
| Surgical wards | -3.0 | -2.9 | -2.7 | -4.4 | -1.1 | 0.001 |
| Psychiatry | -2.1 | 3.2 | 1.7 | -2.7 | 6.1 | 0.444 |
| Evidence-based materials at work*** | -1.9 | -1.5 | -0.9 | -1.9 | 0.2 | 0.117 |
| Reading groups at work*** | 0.1 | 0.7 | 1.1 | -0.9 | 3.2 | 0.279 |
| Computer at work*** | -0.0 | 0.2 | 0.4 | -0.6 | 1.4 | 0.472 |
| Access to internet at work*** | -0.8 | -0.9 | -0.4 | -1.4 | 0.6 | 0.448 |

**Key:** * The CI and p-values relate to the fully adjusted model

** Reference category in the partially and fully adjusted models

*** No as a reference category

In terms of the personal demographic factors, more positive attitudes were noted by the participants aged between 31 and 40 (B 1.5, CI -0.8–3.9). Participants aged 41 and above demonstrated more negative attitudes in the full model but positive ones in the unadjusted one, yet with a wide CI (B -2.8; 0.7, CI -7.4–1.7). Being female suggests having more positive attitudes (B 3.2, CI 0–6.5). All nationalities other than Saudi demonstrated more positive attitude scores across all models. In the unadjusted and partially adjusted models, Filipino nurses tended to score ten points higher (10.3, 10.1) than Saudi nurses, while Indian nurses and nurses of other nationalities scored five points higher than Saudi nurses (B Indian 5.5, 5.6; others 3.3, 4.2) with significant P values for Filipino and Indian nurses (P 0.0). When considering other variables, this number goes down, yet is still relatively high but with a wide CI (Filipino B 4.9 CI -0.3–10.2; Indian B 1.9 CI -3.2–7.1; Others B 1.2 CI -6.2–8.6). See Table 5.13.

Table 5.13 Linear regression analysis of DAS scores with personal demographic variables

| **DAS scores and Personal Demographic** | **Coefficient B** | | | **CI*** | | **P value*** |
|---|---|---|---|---|---|---|
| | **Unadjusted** | **Partially Adjusted** | **Fully Adjusted** | **Lower bond** | **Upper bond** | |
| 21-30 years** | | | | | | |
| 31-40 years | 1.6 | 1.5 | 1.5 | -0.8 | 3.9 | 0.199 |
| 41+ years | 0.7 | -1.7 | -2.8 | -7.4 | 1.7 | 0.219 |
| Gender (male/female)*** | 5.7 | 3.7 | 3.2 | 0.0 | 6.5 | 0.047 |
| Saudi** | | | | | | |
| Indian | 5.5 | 5.6 | 1.9 | -3.2 | 7.1 | 0.460 |
| Filipino | 10.3 | 10.1 | 4.9 | -0.3 | 10.2 | 0.066 |
| Other | 3.3 | 4.2 | 1.2 | -6.2 | 8.6 | 0.751 |
| Bedside nurse** | | | -4.7 | -13.7 | 4.2 | 0.302 |
| Community nurse | -0.4 | 1.1 | -5.6 | -16.3 | 5.1 | 0.305 |
| Administrative nurse | 5.0 | 6.1 | -1.3 | -10.8 | 8.0 | 0.774 |

**Key:** * The CI and p-values relate to the fully adjusted model

** Reference category

*** Female as a reference category

Similarly, nurses aged 31 to 40 had more knowledge about dementia across all models with a narrow CI (B 0.2, CI -0.91–1.31). Also, nurses older than 41 demonstrated lower knowledge scores in the fully adjusted model with a narrow CI (B -0.4, CI -2.5–1.8). Filipino and Indian nurses demonstrated high scores across all models (B 2.2; 0.8) with significant P values in the partially adjusted model (0.000; 0.002). Hence, nurses identifying as Filipino or Indian were observed to have higher knowledge scores compared to Saudi nurses, and although the difference was statistically significant in the partially adjusted model, this was reduced when controlling for other factors in the full model (See Table 5.14).

Table 5.14 Linear regression analysis of DKAT2 scores with personal demographic variables

| **DKAT2 scores and Personal Demographic** | **Coefficient B** | | | **CI*** | | **P value*** |
|---|---|---|---|---|---|---|
| | **Unadjusted** | **Partially Adjusted** | **Fully Adjusted** | **Lower bond** | **Upper bond** | |
| 21–30 years** | | | | | | |
| 31–40 years | 0.0 | 0.1 | 0.2 | -0.9 | 1.3 | 0.724 |
| 41+ years | 0.4 | 0.0 | -0.4 | -2.5 | 1.8 | 0.745 |
| Gender (male/female) | 2.4 | 1.7 | 1.4 | -0.1 | 2.9 | 0.075 |
| Saudi** | | | | | | |
| Indian | 2.3 | 1.9 | 0.8 | -1.6 | 3.2 | 0.524 |
| Filipino | 4.0 | 3.6 | 2.2 | -0.7 | 4.7 | 0.080 |
| Other | 0.4 | 0.4 | -1.2 | -4.7 | 2.3 | 0.511 |
| Bedside nurse** | | | -0.1 | -4.4 | 4.1 | 0.954 |
| Community nurse | -1.1 | -0.6 | 0.5 | -4.5 | 5.5 | 0.838 |
| Administrative nurse | 1.4 | 1.7 | 1.4 | -3.0 | 5.8 | 0.540 |

**Key:** * The CI and p-values relate to the fully adjusted model

** Reference category

In terms of experience characteristics, working as a nurse for four to five years is associated with a more negative score in attitudes toward people with dementia (B -3.2, CI -6.3– -0.2). Being a nurse with more than 11 years of experience demonstrates a more positive attitude score (B 5.5) with significant P value in the partially adjusted model (0.000), yet with a wide CI recorded (0.6–10.4). Interestingly, working in the current area for less than five years results in more positive attitudes, while working in the same area for more than six years leads to negative scores. Providing professional care for people with dementia does relate to more positive attitudes in the full model (B 0.1, CI -1.9–2.2), but having a family member with dementia relates to more negative attitudes in the full model (-1.5, CI -4.2–1.2) though not in the unadjusted and partially adjusted models (B 1.8, 1.7). See Table 5.15.

Table 5.15 Linear regression analysis of DAS scores with experience characteristics variables

| DAS scores Experiences Characteristics | Coefficient B | | | CI* | | P value* |
|---|---|---|---|---|---|---|
| | **Unadjusted** | **Partially Adjusted** | **Fully Adjusted** | **Lower bond** | **Upper bond** | |
| 1–3 years of experience** | -1.1 | | | | | |
| 4–5 years of experience | -2.0 | -.2 | -3.2 | -6.3 | -0.2 | 0.036 |
| 6–10 years of experience*** | | 4.5 | -0.1 | -3.4 | 3.1 | 0.926 |
| 11+ years of experience | 1.5 | 8.9 | 5.5 | 0.6 | 10.4 | 0.028 |
| <1 years in the current ward | 0.8 | 2.6 | -1.3 | -5.6 | 2.8 | 0.526 |
| 1–3 years in the current ward*** | | 1.5 | -0.3 | -3.2 | 2.4 | 0.785 |
| 4–5 years in the current ward** | -1.2 | | | | | |
| 6–10 years in the current ward | -2.9 | -5.3 | -3.5 | -7.0 | 0.0 | 0.053 |
| 11+ years in the current ward | -2.0 | -7.7 | -7.5 | -13.0 | -2.1 | 0.006 |
| Provided professional care for people with dementia**** | -0.3 | -0.8 | 0.1 | -1.9 | 2.2 | 0.874 |
| Had a family member with dementia**** | 1.8 | 1.7 | -1.4 | -4.2 | 1.2 | 0.291 |

**Key:** * The CI and p-values relate to the fully adjusted model

** Reference category in the partially and fully adjusted models

*** Reference category in the adjusted model

**** No as a reference category

More than 11 years’ experience as a nurse is associated with higher knowledge scores (B 1.27, CI -1.03–3.57), while experience of four to ten years demonstrates lower knowledge scores with a narrow CI (four to five B -1.4, CI -2.8–0.06; six to ten B -0.4, CI -1.9–1.2). Nurses who worked six to ten years within the same area had lower knowledge scores across the models (B -1.6, CI -3.2–0.1). Also, nurses with less than one year of experience in the present area showed lower knowledge scores (B -0.4, CI -2.4–1.6). However, working in the current area for one to five years resulted in higher scores (B 0.02, CI -1.3–1.4). Providing professional care for people with dementia relates to lower knowledge scores across the models with a narrow CI (B -0.9, CI -1.9–0.1). Similarly, having a family member with dementia is associated with lower dementia knowledge scores in the full model (B -1.0, CI -2.3–0.3) but not in the unadjusted and partially adjusted models (B 0.02, 0.4). See Table 5.16.

Table 5.16 Linear regression analysis of DKAT2 scores with experience characteristics variables

| DKAT2 scores Experience Characteristics | Coefficient B | | | CI* | | P value * |
|---|---|---|---|---|---|---|
| | Unadjusted | Partially Adjusted | Fully Adjusted | Lower bond | Upper bond | |
| 1–3 years of experience** | 0.83 | | | | | |
| 4–5 years of experience | 0.12 | -0.50 | -1.37 | -2.81 | 0.06 | 0.062 |
| 6–10 years of experience*** | | 0.32 | -0.37 | -1.94 | 1.19 | 0.640 |
| 11+ years of experience | 1.11 | 1.41 | 1.27 | -1.03 | 3.57 | 0.281 |
| <1 years in the current ward | -0.44 | 0.42 | -0.42 | -2.41 | 1.57 | 0.678 |
| 1–3 years in the current ward*** | | 0.75 | 0.02 | -1.32 | 1.36 | 0.975 |
| 4–5 years in the current ward** | -0.85 | | | | | |
| 6–10 years in the current ward | -2.02 | -1.78 | -1.57 | -3.24 | 0.09 | 0.065 |
| 11+ years in the current ward | 0.12 | -0.38 | -0.22 | -2.76 | 2.31 | 0.862 |
| Provided professional care for people with dementia**** | -0.95 | -1.06 | -0.90 | -1.90 | 0.08 | 0.072 |
| Had a family member with dementia**** | 0.02 | 0.43 | -1.03 | -2.32 | 0.25 | 0.116 |

**Key:** * The CI and p-values relate to the fully adjusted model

** Reference category in the partially and fully adjusted models

*** Reference category in the adjusted model

**** No as a reference category

In terms of educational characteristics, more positive attitudes across all models were accounted for participants holding bachelors and master degrees with a significant P value (0.003) in the partially adjusted model (B 2.7, CI 0.1 – 5.3). A significant association was found between attitude scores and rating one's own confidence when caring for people with dementia and when they are willing to learn about dementia (0.002; 0.000). See Table 5.17.

Table 5.17 Linear regression analysis of DAS scores with educational characteristics variables

| **DAS scores Educational Characteristics** | **Coefficient B** | | | **CI*** | | **P value*** |
|---|---|---|---|---|---|---|
| | **Unadjusted** | **Partially Adjusted** | **Fully Adjusted** | **Lower bond** | **Upper bond** | |
| Diploma** | | | | | | |
| Bachelor and Master | 8.3 | 3.6 | 2.7 | 0.1 | 5.3 | 0.039 |
| Completed degree in KSA*** | 7.8 | -0.0 | -1.2 | -6.4 | 3.8 | 0.628 |
| Had formal dementia education*** | 7.1 | 3.6 | 3.2 | -0.1 | 6.6 | 0.059 |
| Rate own knowledge | 6.5 | -0.0 | -0.1 | -2.1 | 1.8 | 0.872 |
| Rate own confidence | 6.5 | 2.9 | 2.7 | 1.0 | 4.4 | 0.002 |
| Rate willingness to learn about dementia | 6.4 | 4.6 | 4.4 | 3.3 | 5.5 | 0.000 |

**Key:** * The CI and p-values relate to the fully adjusted model

** Reference category in the partially and fully adjusted models

*** No as a reference category

Having formal dementia education is associated with more positive attitude towards people with dementia (B 3.2, CI -0.1–6.6), as well as higher knowledge (B 0.7, CI -0.9–2.3). Also, participants with bachelors' and masters' degrees scored higher in knowledge with narrow CI (B 1.0, CI -0.2–2.3). Higher knowledge scores were also found among participants who rated their knowledge and confidence as high, as well as those who showed their willingness to learn about dementia. See Table 5.18.

Table 5.18 Linear regression analysis of DKAT2 scores with educational characteristics variables

| DKAT2 scores<br>Educational Characteristics | Coefficient B |  |  | CI* |  | P value* |
|---|---|---|---|---|---|---|
|  | Unadjusted | Partially Adjusted | Fully Adjusted | Lower bond | Upper bond |  |
| Diploma** |  |  |  |  |  |  |
| Bachelor and Master | 2.67 | 1.05 | 1.03 | -0.20 | 2.26 | 0.102 |
| Completed degree in KSA*** | 2.97 | 1.04 | -0.33 | -2.74 | 2.08 | 0.789 |
| Had formal dementia education*** | 2.00 | 1.11 | 0.69 | -0.89 | 2.27 | 0.392 |
| Rate own knowledge | 2.22 | 1.07 | 1.05 | 0.12 | 1.99 | 0.027 |
| Rate own confidence | 1.70 | 0.37 | 0.37 | -0.42 | 1.17 | 0.360 |
| Rate willingness to learn about dementia | 1.44 | 0.59 | 0.40 | -0.10 | 0.91 | -.116 |

**Key:** * The CI and p-values relate to the fully adjusted model

** Reference category in the partially and fully adjusted models

*** No as a reference category

### *Bivariate Pearson Correlation test*

To understand the association between knowledge and attitudes, a two-tailed Pearson Correlation Test was conducted. As the associations in the data were linear and no outliers were noted, it fit into a Pearson R analysis. The test result indicates there was positive association between DAS and DKAT2 scores as demonstrated by a correlation of 0.334 (CI 0.267 – 0.397). This presents a significant correlation at the 0.01 level (2-tailed). This is also implicit in the following graph, wherein the more knowledge nurses have about dementia the more positive the attitudes they hold towards people with dementia (Figure 5.8).

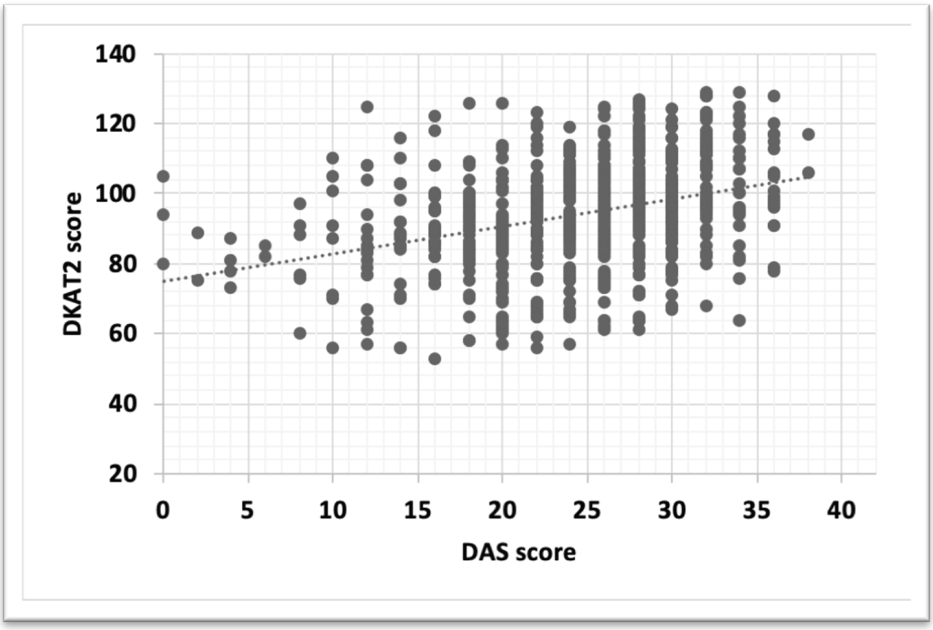

Figure 5.8 The association between DAS and DKAT2 scores

## 5.3 Key points from the survey analysis

This study is the first to explore hospital nurses' knowledge and attitudes towards people with dementia and dementia care (apart from the published literature review discussed earlier (Yaghmour, 2021)). It included a total of 710 RNs who were working with even distribution across eight different ward types within six hospitals. Most (57.6%) were young adult (21–40 years old) female (87.9%) bedside nurses (70.4%) from the central hospitals. The descriptive statistics confirmed that nurses' knowledge about people with dementia could be considered moderate (with scores ranging from zero to 38 on a scale of 0 to 42), and that their attitudes towards them is generally positive (with scores ranging between 53 and 129 on a scale of 20 to 140).

The concept map below demonstrates the main findings from the statistical analysis of the questionnaire that are discussed in this section (Figure 5.9 Survey’s main findings). The multiple linear regression analyses identified the important factors that influence nurses’ knowledge of and attitudes towards dementia with a positive linear correlation between knowledge and attitudes scores present in the Bivariate Pearson Correlation Test. This positive correlation agrees with previous studies, as was highlighted in the review #2 (Yaghmour, 2021) in literature review chapter (3.2); however, there are some instances where this is not the case. This is likely due to other contributing factors that led to differences in the results. For instance, working in a psychiatric ward is associated with higher knowledge about dementia but with more negative attitudes. The opposite applies to working in mixed wards, convalescence departments and clinics, where nurses hold more positive attitudes but with lower knowledge levels.

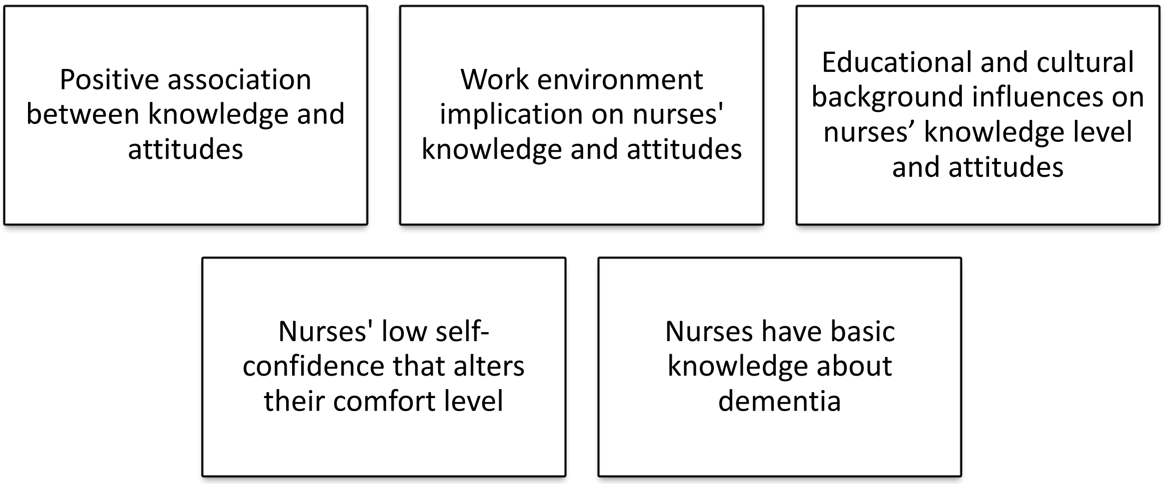

Figure 5.9 Survey’s main findings

Nurses’ working environments, including the availability of resources and the differences between wards, have evident implications on participants’ knowledge and attitudes. The availability of resources at work is suggested as a force that alters the knowledge and attitudes of nurses; notably, the availability of evidence-based materials at work is associated with positive attitudes and significantly lower knowledge. This is likely due to the lack of training received about familiarisation with using the evidence-based materials and these materials’ being newly incorporated into MOH facilities (Ministry of Health, 2018). Higher knowledge is noted when reading groups and computers are accessible to nurses at their workplaces, while internet access is linked to lower knowledge and more negative attitudes. Working in wards that admit patients with a variety of diagnoses is associated with positive attitudes but with lower knowledge. Interestingly, working in emergency departments and surgical wards significantly demonstrates more negative attitudes and lower knowledge among all participants. Some researchers suggest that nurses at emergency departments struggle to administer medication (Fry, Arendts and Chenoweth, 2017; Yaghmour, 2021), and perceive people with dementia as disturbances in their work environments, which adds pressure to their work; thus, they hold more negative attitudes towards people with dementia (Deasey, Kable and Jeong, 2014; Sharpp and Young, 2016; Hunter *et al.*, 2017; Yaghmour, 2021). Some researchers also suggest that most patients hospitalised in surgical departments, such as orthopaedic, are older adults who are at risk of having dementia (Moonga and Likupe, 2016; Yaghmour, 2021) (Further discussed in Chapter 9).

It is evident that nurses who have spent up to five years working within the same ward have significantly higher knowledge levels and more positive attitudes. However, those with more than six years, but less than 11 years, were found to have significantly lower knowledge and to form the most negative attitudes. It could be inferred that nurses' initial interest led to this result, though routine and repetitive treatment of certain cases over a long period of time diminishes this interest and allows for the development of negative attitudes. That being said, administrative nurses had the most knowledge and most positive attitudes, unlike the community nurses; however, it is evident that community nurses hold more positive attitudes and knowledge than acute care nurses as discussed in the literature review (3.2 section; (Yaghmour, 2021)). Notably, lower knowledge was found to be linked to nurses experienced in caring for people with dementia at hospitals and/or when having a family member with dementia. Despite nurses with professional dementia care experience holding more positive attitudes, those with family members with dementia are noted to have more negative attitudes. This may be a result of the stigma and the cultural norms about dementia and the available resources, as well as the level of awareness. Knowledge was found to be elevated and attitudes enhanced when participants indicated that they had formal dementia education. It is worth mentioning that other variables may contribute to this result, as having a family member with dementia in the unadjusted $R^2$ was found to be significantly associated with higher knowledge and more positive attitudes. These contributing variables could be working experience, gender and level of education and/or academic institution, which shows its implication in this study.

Educational and cultural backgrounds likewise influence nurses' knowledge levels and attitudes. Statistically significant links were found between positive attitudes and high dementia knowledge among Filipino and Indian nurses. Also, other Eastern-Mediterranean nurses scored higher in their knowledge and attitudes than Saudi nurses. This could be a result of the education system and the nursing curricula that has included geriatric nursing only in recent years. It may also be attributable to the cultural norms and awareness levels or to the distribution of qualifications among the study sample, which has fewer Saudi nurses with bachelors and masters degrees (Refer to appendix I.2 for more information regarding nationalities). Another statistic of significance relates participants with bachelors and masters degrees to more positive attitudes and higher knowledge. Furthermore, participants' own ratings regarding their knowledge about dementia and their readiness to learn about dementia with confidence when providing care are reflected in their knowledge and attitudes scores. However, it was noted that nurses' who rated their knowledge as high tended to have more negative attitudes. A previous study concluded that there is a significantly positive association between knowledge scores and nurses' own ratings (Yaghmour, Gholizadeh and Alsenany, 2016).

The self-confidence and comfort levels of nurses also impacted the results. It was noted from the statements in the questionnaire that participants not familiar with dementia held negative attitudes about their own care provision as they felt frustrated because they wanted to provide the person with dementia with assistance. Also, some nurses would avoid agitated people with dementia. Yet, approximately a quarter of the study sample were not confident in providing dementia care, did not feel relaxed around people with dementia and did not want to care for or touch them, figures that are higher than those found in previous studies (refer to 3.3 and 7.3 sections). Thus, this indicates a negative attitude regarding nurses' affective and behavioural aspects, while the cognitive aspect was considered more positive among them, with participants being uncertain, to some extent, regarding the person with dementia's coping skills and creativity.

Finally, the survey's responses indicate a significant basic knowledge about dementia; most participants understand that dementia occurs in the brain and is progressive, and that Alzheimer's disease is one of its main causes. Some participants were also aware of dementia's complications, such as visual problems, mobility limitations and behavioural changes, but not with its confusion or urinary incontinence issues. Further discussed in 7.3.

## 5.4 Summary of this chapter

The quantitative findings have provided some fascinating insights into nurses working in the KSA. The questionnaire shows that nurses' knowledge was low-moderate with a positive association between knowledge and attitudes scores. Also, the knowledge level and attitude scores were impacted by the nurses' work environment, including availability of resources, as well as their educational and cultural backgrounds, their self-confidence level and the effects on their comfort level when caring for people with dementia. Furthermore, the learning needs of registered nurses when caring for people with dementia was identified by finding the associations between the scores obtained in the survey and nurses' qualifications, educational backgrounds, experiences and resources available at work, as well as data from the diary-interviews, wherein nurses expressed their ideas for enhancing dementia nursing care.

Yet, many unanswered questions were raised from the survey's findings that require further investigation to gain deeper insights into current nursing practices and to identify the barriers and obstacles that could change these results. This was achieved by supporting the quantitative results using qualitative findings (Diary-Interview Analysis), which are presented in the next chapter (Chapter 6). The quantitative and qualitative results are integrated in Chapter 7, followed by a discussion in Chapter 8.

# Chapter 6 Diary-Interview Analysis and Conclusion

This chapter presents and explains the qualitative analysis and concludes the key themes identified from the analysis of the diary-interviews. The purpose of this analysis was to explore current nursing practices in regard to caring for people with dementia and gain greater insight into nurses' attitudes and perceptions regarding dementia and the care they provide to people with dementia using diaries and interviews. In addition, diaries and interviews provided data on theidentify barriers faced by nurses when caring for people with dementia in Ministry of Health facilities using diaries and interviews. This insight was achieved by posing the following questions:

2. 1. How do nurses perceive people with dementia and dementia care?
2. 2. What are registered nurses' experiences with and perceptions of working with people with dementia?
2. 3. What are the challenges/obstacles to administering nursing care for people with dementia in KSA facilities?

This chapter is structured as follows: first, it provides a summary of the diary-interviews data, including the profile of the qualitative data and both diary and interview participants' characteristics (section 6.1: Diary-Interviews Data). Next, the six phases of the thematic analysis are presented (as discussed in section 4.8.2 Diary-Interviews), which includes the main findings (section 6.2: Thematic analysis). Finally, there is a brief highlight from the diary-interviews data analysis and a summary of the present chapter (sections 6.3 and 6.4).

## 6.1 Diary-Interviews Data

This section presents an overview of the profile of the diary-interviews participants, including their demographics, personal characteristics, experience, education and information on knowledge, confidence and attitudes. This is followed by an explanation of the procedures used to collect the diary data and conduct the interviews, as well as their descriptions.

The diary-interviews data were collected in person from diarists between April and August 2018 in Jeddah. Nurses were recruited to complete a diary over 10 days reporting on their dementia care experiences and then take part in one face-to-face interview. NVivo 12 was used to store and code the data from the diaries and interviews (QSR International, 2018). Participants' names were replaced with a 'P' followed by a number ranging from one to 26, as the total number of recruited participants was 26, of which a total of 18 completed both components, namely, the diary and interview. It should be noted that for P17 there was only an interview and no diary entries (the participant had not had the chance to provide care for a person with dementia due to her working as a ward supervisor in a busy central hospital).

### 6.1.1 Recruiting participants

Following the recruitment procedures mentioned in section 4.3.2, a total of 124 RNs expressed a willingness and were contacted for the diary-interviews (17.5% of all nurses who completed the questionnaire; Table 6.1). Recruitment emails that includes participants information sheet and consent form were sent in four separate batches in 2018: April 4–6 and 10–18, May 24, and July 10. Only 96 email invitations could be sent since the other 28 RNs had not provided their email addresses, names, or other contact information. Sixty-five of the RNs did not respond to the email, 25 had provided wrong email addresses and only six replied to the email. Of those six RNs, four were ultimately recruited (P03, P12, P13, P14). The other two replied that they had new roles that limited their contact with people with dementia. Because there were no responses to the invitation emails from most of the RNs contacted, a slight change was made in the recruitment procedure. The new procedure was to recruit the RNs by leaving the survey questionnaires with the hospital gatekeepers to be handed to the RNs directly. After collecting the filled-in questionnaires from the gatekeepers, they were scanned by the study researcher. After scanning the survey, the researcher then contacted the RNs who had agreed to participate and met with them in their wards. For the RNs who were not readily available, the gatekeepers' help was sought to hand over the researcher's business card with instructions for those RNs who wanted to get in touch with the researcher. This procedure ultimately secured 22 more participants, of which three had been recruited before completing the survey (P07, P09, P26). Thus, both recruiting procedures yielded a total of 26 nurses willing to participate in the diary-interviews.

Table 6.1 Frequencies and percentages of survey participants who agreed to be contacted to be recruited for the diary-interviews

| **Variables** | | **Frequency** | **Percentage** |
|---|---|---|---|
| **Willing to participate in the diary-interviews** | Yes | 124 | 17.5 |
| | No | 586 | 82.5 |
| **Recruited** | Yes | 23 | 3.3 |
| | No | 687 | 96.7 |

Half of the recruited participants for the diary-interviews were working at the central hospitals; nine were working at KFGH (P12, P13, P14, P16, P17, P21, P23, P24, P25) and four at KAH (P01, P18, P20, P22). Seven participants were working at the psychiatric hospital (P01, P05, P06, P07, P08, P10, P11), five at the newly constructed hospital (three at EJGH (P03, P04, P15) and two at KAMC (P02, P26)), and one was working at a rural hospital (P19). Refer to Figure 6.1 CONSORT flow diagram of the diary-interviews.

Participants were working in six different wards: Emergency (P02, P07, P08, P18, P19, P20, P22), Medical, including convalescence departments (P04, P12, P13, P14, P21, P26), Clinics (P09, P10, P11, P15), Surgical and Neurosurgical (P03, P16, P17, P24), Psychiatry—Acute and Chronic (P01, P05, P06), and Ear, Nose & Throat (ENT) (P23, P25). See Appendix J.1.

Nine participants withdrew from the diary part of the study for the following reasons: sickness (P10, P11), family illness (P18), personal issues (P01, P09, P26), no cases received (P07), and no reason provided (P06). Most who withdrew were from the psychiatric hospital (P01, P06, P07, P10, P11), followed by KAH (P09, P18) and KAMC (P26). Seventeen participants completed both parts of the diary-interviews (P02, P03, P04, P05, P08, P12, P13, P14, P15, P16, P19, P20, P21, P22, P23, P24, P25). As mentioned earlier, one participant completed only the interview but not the diary (P17).

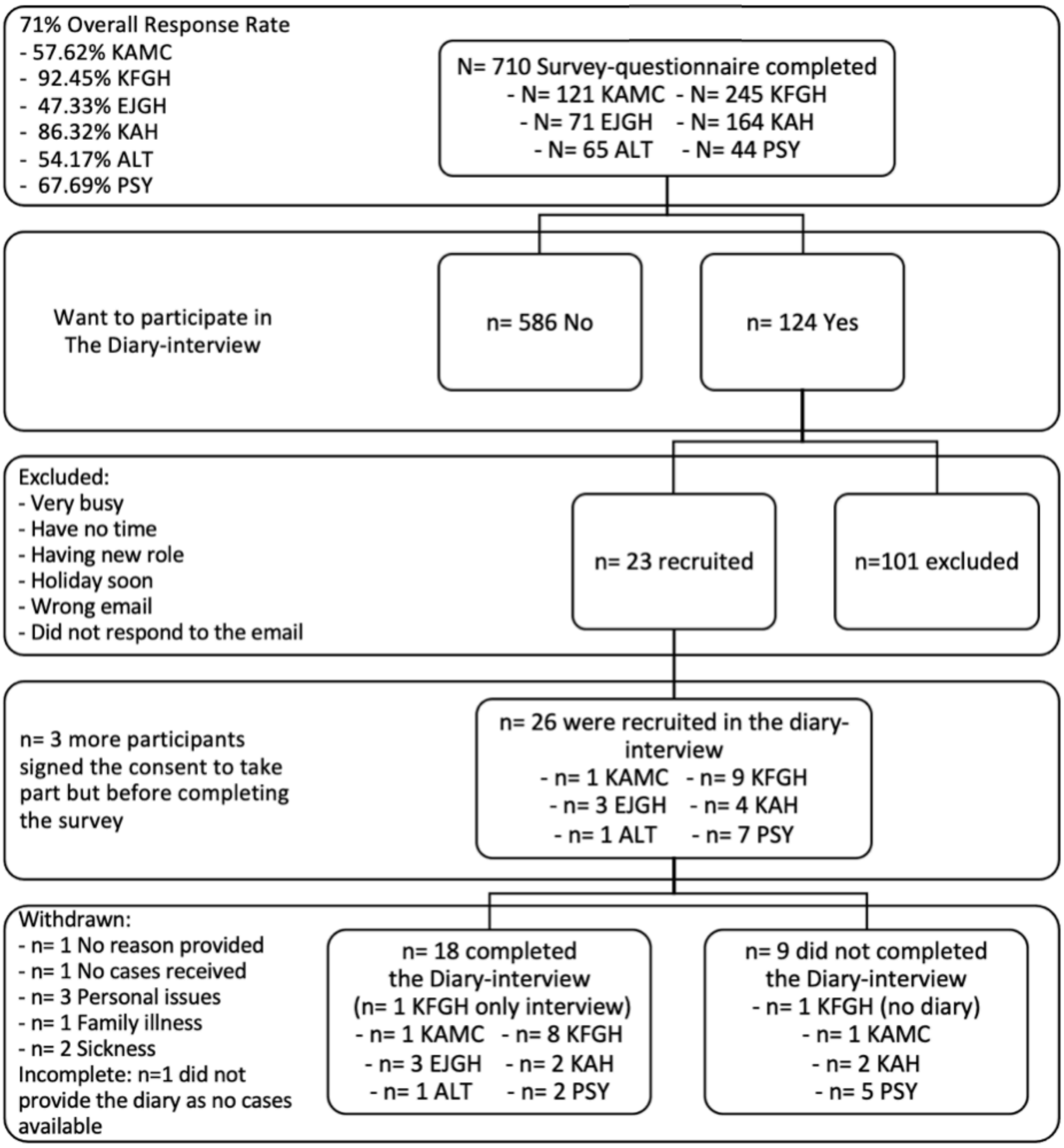

Figure 6.1 CONSORT flow diagram of the diary-interviews

It is important to note that the first attempt to merge data occurred when commencing the analysis of the diary-interviews data. This was done in two stages: firstly, participant characteristics and scores from the completed surveys were combined into one dataset; secondly, diary entry transcripts and interview transcripts were merged into one chunk.

Reporting the profile of participants followed the same procedure as in the last chapter, that is, by grouping data according to four categories—environmental characteristics, personal demographics, experience characteristics and educational characteristics—and assessing Dementia Attitude Scale (DAS) and Dementia Knowledge Assessment Tool 2 (DKAT2) scores for those who completed the diary-interviews. Characteristics of the participants were extracted and reported to gain an insight about the socio-demographical factors of the participants and their knowledge and attitudes scores obtained from the survey.

### *Demographics and environmental characteristics*

Most of the diarists were Saudi Arabians (n=11), with four Filipinos, two Indians, and one Sudanese. Additionally, most were bedside nurses (n=11). The others included administrative nurses, head nurses, and a supervisor. Most of the participants were in their late twenties except for one who was in her early twenties. Five participants were in their thirties and two in their forties. All were females except P04, P05, P08, and P19 (Table 6.2).

Table 6.2 Demographics and environmental characteristics of diary-interviews participants

| ID | Hospital | Ward | Age range | Gender | Nationality | Type |
|---|---|---|---|---|---|---|
| **P02** | KAMC | Emergency | 21-25 | Female | Saudi | Bedside |
| **P03** | EJGH | Female Surgical | 26-30 | Female | Saudi | Bedside |
| **P04** | EJGH | Medical | 31-35 | Male | Saudi | Bedside |
| **P05** | PSY | Male acute psychiatric | 36-40 | Male | Saudi | Bedside |
| **P08** | PSY | Emergency | 26-30 | Male | Saudi | Bedside |
| **P12** | KFGH | Convalescence | 26-30 | Female | Indian | Bedside |
| **P13** | KFGH | Convalescence | 26-30 | Female | Filipino | Bedside |
| **P14** | KFGH | Convalescence | 31-35 | Female | Indian | Bedside |
| **P15** | EJGH | Clinics | 26-30 | Female | Saudi | Community |
| **P16** | KFGH | Neurosurgery | 26-30 | Female | Saudi | Community |
| **P17** | KFGH | Neurosurgery | 46-50 | Female | Saudi | Supervisor |
| **P19** | ALT | Emergency | 26-30 | Male | Saudi | Head nurse |
| **P20** | KAH | Emergency | 26-30 | Female | Saudi | Community |
| **P21** | KFGH | Convalescence | 41-45 | Female | Sudanese | Bedside |
| **P22** | KAH | Emergency | 26-30 | Female | Saudi | Bedside |
| **P23** | KFGH | Ear, Nose, and Throat | 31-35 | Female | Filipino | Head nurse |
| **P24** | KFGH | Neurosurgery | 26-30 | Female | Filipino | Bedside |
| **P25** | KFGH | Ear, Nose, and Throat | 36-40 | Female | Filipino | Head nurse |

### *Experience and education characteristics*

In terms of nursing work experience, seven participants had 1 to 3 years, three had 4 to 5 years, five had 6 to 10 years and three had over 11 years' experience. Five participants stated that they had not provided care for a person with dementia before being recruited for this study. Four participants had a family member with dementia and a further four only admitted that they had a family member with dementia during the interviews but were unwilling to include this information in the survey. Please refer to Table 6.3.

In terms of education, most nurses held bachelors' degrees (n=13), four held diplomas, and one held a master's degree. All had completed their degrees in their countries of origin except P21, who had a master's degree from Saudi Arabia. Most participants did not have formal prior education in dementia except for four. However, during the interviews they stated that they had indeed studied about it while studying for their nursing degrees and diplomas (detailed in first theme 6.2.6). Please refer to Table 6.3.

Table 6.3 Experience and education characteristics of diary-interviews participants

| ID | Years of experience | Provided professional dementia care | Had a family member with dementia | Educational achievement | Degree from KSA | Had formal dementia education |
|---|---|---|---|---|---|---|
| **P02** | 1–3 | No | No | Bachelor | Yes | No |
| **P03** | 1–3 | Yes | No | Bachelor | Yes | No |
| **P04** | 1–3 | No | No | Diploma | Yes | No |
| **P05** | 6–10 | No | No | Diploma | Yes | No |
| **P08** | 1–3 | Yes | No | Bachelor | Yes | Yes |
| **P12** | 1–3 | No | No | Bachelor | No | Yes |
| **P13** | 6–10 | Yes | No | Bachelor | No | No |
| **P14** | 1–3 | No | Yes | Bachelor | No | No |
| **P15** | 6–10 | Yes | Yes | Diploma | Yes | Yes |
| **P16** | 11+ | Yes | Yes | Bachelor | Yes | No |
| **P17** | 11+ | Yes | No | Bachelor | Yes | No |
| **P19** | 4–5 | Yes | Yes | Bachelor | Yes | Yes |
| **P20** | 4–5 | Yes | No | Bachelor | Yes | No |
| **P21** | 11+ | Yes | No | Master | Yes | No |
| **P22** | 1–3 | Yes | No | Diploma | Yes | No |
| **P23** | 6–10 | No | No | Bachelor | No | No |
| **P24** | 4–5 | Yes | No | Bachelor | No | No |
| **P25** | 6–10 | Yes | No | Bachelor | No | No |

### *Information on knowledge, confidence, and attitudes*

The mean rating values of participants' own knowledge about dementia and their confidence in caring for a person with dementia were low to average. The Mean ± SD for knowledge and confidence were 2.6 ± 0.8 and 2.7 ± 0.7, respectively. However, their willingness to learn about dementia was above average (3.4 ± 0.7). Please refer to Table 6.4 and Table 6.5.

Table 6.4 Mean and SD of diary-interviews participants' own ratings and DAS and DKAT2 scores

| | | | **Mean** | **SD** |
|---|---|---|---|---|
| **Rate own knowledge of dementia** | Min. 1 | Max. 4 | 2.6 | 0.8 |
| **Rate own confidence to care for people with dementia** | Min. 1 | Max. 4 | 2.7 | 0.7 |
| **Willingness to learn about dementia** | Min. 1 | Max. 5 | 3.4 | 1.2 |
| **DAS score** | Min. 64 | Max. 129 | 103 | 18 |
| **DKAS score** | Min. 12 | Max. 34 | 25.9 | 7.2 |

Most participants rated their knowledge as average; this was followed by those who rated themselves as having low knowledge. One of the participants conceded to having no knowledge, while one claimed high knowledge. Most participants rated their confidence as average. This was followed by low confidence and no confidence. There was only one participant who claimed high confidence. Many participants were highly interested to learn about dementia, five expressed average interest or willingness to learn about dementia, while three expressed low interest; one was not willing to learn. Please refer to Table 6.5.

Table 6.5 Diary-interviews participants' own ratings on knowledge, confidence, and willingness to learn about dementia along with their DAS and DKAT2 scores

| ID | Participants' own ratings | | | Scores | |
|---|---|---|---|---|---|
| | Knowledge | Confidence | Willing to learn | Knowledge | Confidence |
| **P02** | Low | Average | Very | 99 | 26 |
| **P03** | Average | Average | High | 114 | 22 |
| **P04** | No | No | Low | 96 | 22 |
| **P05** | Low | No | No | 77 | 12 |
| **P08** | Average | Average | Very | 118 | 32 |
| **P12** | High | Average | High | 85 | 20 |
| **P13** | Average | Average | High | 101 | 30 |
| **P14** | Average | Average | High | 104 | 20 |
| **P15** | Low | Low | Low | 75 | 26 |
| **P16** | Average | Average | Average | 111 | 32 |
| **P17** | Average | Average | Very | 122 | 26 |
| **P19** | Low | Average | High | 108 | 12 |
| **P20** | Low | Low | Low | 64 | 20 |
| **P21** | Average | High | Average | 129 | 34 |
| **P22** | Average | Average | Average | 112 | 34 |
| **P23** | Average | Average | High | 115 | 32 |
| **P24** | Low | Low | Average | 100 | 34 |
| **P25** | Average | Average | Average | 123 | 32 |

As shown in Table 6.4 and Table 6.5, the DAS scores ranged from 64 to 129 (103 ± 18). The most negative attitudes were scored by two community nurses and one psychiatric nurse, while the most positive attitudes were scored by a supervising nurse and the bedside nurse with a master degree. The DKAT2 scores ranged from 12 to 34 (25.9 ± 7.2). The lowest knowledge scores belonged to two male nurses working in the psychiatry hospital and a head nurse in the rural hospital, while the highest belonged to three bedside nurses working in a convalescence, emergency and neurosurgery ward.

### 6.1.2 Diaries

Diaries were collected between April and August 2018 from 17 participants; one participant, who was working as a nursing supervisor, stated that she had no time to complete the diary entries and had not found the opportunity to care for people with dementia and observe them closely. Since participants instructed to keep diaries for 10 working days when providing nursing care for people with dementia, participants kept a diary over a period of time ranging from 6 to 112 days (39.4 ± 30). This is due to the ward they were in and the frequency of caring for patient with dementia, wards business, nurse to patient's assignment and hospitalisation of patients with dementia. Please see the Appendix J.1 for frequencies and means of the diary-interviews participants.

Five participants (27.8%) completed the full 10 days' entries and the minimum entries received were for two days (Table 6.6). SMS reminders were sent approximately twice a week; however, most were not replied to by the participants. Even when replies were received, they were mostly commenting about not having a person with dementia at that time and the difficulty of finding patients, especially since the diagnoses of dementia were not written in patients' medical files. Three of the study participants could not be contacted through SMS as they were recruited by their supervisor and the date of the interview was set just nearly two weeks after the recruitment. The other participants responded to the last SMS reminder and arranged for the interview. They informed the researcher that they had completed writing the diary entries and were ready for the interview. Please see the following section, 6.2, for the thematic analysis of the interviews.

While all participants had initially agreed to keep written diaries, one participant, after a week of recruiting, asked for a recorder to record her diaries as she thought it would be easier than writing after a long working shift. At the diary collection time, this participant informed the researcher that having written diaries was better for her after all and that she had not used the recorder. Therefore, all diaries were written using the booklet provided (Appendix F.4). Almost half of the diaries were written in Arabic (n=10) and a few had Arabic with some English (n=3). The rest were written entirely in English (Table 6.6).

Table 6.6 Diary information and follow-up

| ID | Date recruited | Number of diary entries | Diary language | Days in the study | Number of SMSs sent | Responses to SMS |
|---|---|---|---|---|---|---|
| **P02** | 04/04/2018 | 2 | Arabic/ English | 58 | 15 | 5 |
| **P03** | 10/04/2018 | 8 | Arabic | 50 | 13 | 3 |
| **P04** | 10/04/2018 | 3 | Arabic/ English | 50 | 14 | 5 |
| **P05** | 08/04/2018 | 9 | Arabic | 52 | 9 | 3 |
| **P08** | 11/04/2018 | 3 | Arabic | 50 | 16 | 6 |
| **P12** | 18/04/2018 | 10 | English | 24 | 7 | 1 |
| **P13** | 18/04/2018 | 10 | English | 17 | 4 | 1 |
| **P14** | 18/04/2018 | 10 | English | 29 | 6 | 2 |
| **P15** | 22/04/2018 | 5 | Arabic | 106 | 16 | 6 |
| **P16** | 23/04/2018 | 10 | Arabic | 20 | 4 | 2 |
| **P19** | 02/05/2018 | 4 | Arabic | 29 | 11 | 1 |
| **P20** | 07/05/2018 | 8 | Arabic/ English | 25 | 7 | 3 |
| **P21** | 18/04/2018 | 10 | English | 42 | 6 | 1 |
| **P22** | 06/08/2018 | 5 | Arabic | 6 | 3 | 1 |
| **P23** | 30/07/2018 | 3 | English | 13 | 0 | 0 |
| **P24** | 30/07/2018 | 7 | English | 13 | 0 | 0 |
| **P25** | 07/08/2018 | 5 | English | 13 | 0 | 0 |

### 6.1.3 Interviews

The interviews were held over a ten-day period between 05 May and 13 August, 2018 as soon as practically possible after the diary entries period (Table 6.7). Twelve interviews were conducted by the study researcher on the first trip to Jeddah (P13, P12, P16, P14, P03, P04, P05, P21, P08, P19, P02, P20), while six interviews were conducted during the second trip (P15, P17, P23, P24, P25, P22). Interviews were conducted at participants' convenient time; consequently, the interview times were varied among participants. Seven interviews were in English, while the rest of the interviews were in Arabic. The duration of each interview was between 20 and 40 minutes (Table 6.7). Interviews were conducted and reported according to the interview schedule and protocol developed in sections 4.4.3, 4.4.4 and 4.8.2 (Creswell, 2014).

Table 6.7 Interviews information

| # | Date | Time | Location | Duration | Language | Issues |
|---|---|---|---|---|---|---|
| **P13** | 05/05/2018 | 07:00 | Nurses' room/ stock room | 38 min | English | Interrupted, changed rooms |
| **P12** | 12/05/2018 | 07:00 | Nurses' room | 29 min | English | |
| **P16** | 13/05/2018 | 11:00 | Nurses' room | 30 min | Arabic | |
| **P14** | 17/05/2018 | 11:00 | Nurses' room | 33 min | English | |
| **P03** | 30/05/2018 | 05:45 | Nurses' room | 38 min | Arabic | |
| **P04** | 30/05/2018 | 07:30 | Hospital auditorium/ foyer | 33 min | Arabic | Lecture at the auditorium, changed the location |
| **P05** | 30/05/2018 | 10:00 | Hospital auditorium | 35 min | Arabic | Interrupted twice |
| **P21** | 30/05/2018 | 12:00 | Ward foyer | 32 min | Arabic | |
| **P08** | 31/05/2018 | 09:00 | Meeting room | 40 min | Arabic | |
| **P19** | 31/05/2018 | 13:00 | Triage room | 30 min | Arabic | |
| **P02** | 01/06/2018 | 19:30 | Nurses' room | 23 min | Arabic | |
| **P20** | 01/06/2018 | 03:00 | Asthma room | 30 min | Arabic | Interrupted, changed rooms |
| **P15** | 06/08/2018 | 15:00 | Auditorium foyer | 33 min | Arabic | |
| **P17** | 12/08/2018 | 13:15 | Supervisor's office | 33 min | English | Incomplete participation |
| **P23** | 12/08/2018 | 13:00 | Supervisor's office | 40 min | English | Interrupted by P17 |
| **P24** | 12/08/2018 | 14:00 | Head nurse's office | 22 min | English | |
| **P25** | 12/08/2018 | 15:00 | Head nurse's office | 30 min | English | Interrupted twice |
| **P22** | 13/08/2018 | 11:00 | Nurses' room/ ECG room | 20 min | Arabic | Interrupted, changed rooms |

Some interviews were interrupted by either a patient (P05, P20) or a member of the hospital staff (P04, P13, P22, P23, P25). In some cases, this resulted in having to move rooms to maintain confidentiality and privacy. Seven minutes into the interview with P23, the ward supervisor, herself one participant (P17), entered the room. P17 had signed the consent form before, but had not made any diary entries. Unfortunately, since nurses did not have private places or room booking services, it was decided to continue the interview with both participants after P17 declined to either wait for a few minutes or schedule the interview for a different time. As a result, the interview had to be conducted with both participants at the same time after both had agreed to this arrangement (see ethics section 4.6.1).

## 6.2 Thematic analysis

Braun and Clarke (2006) have developed a general flow model for the thematic analysis process. It involves six phases as described in 4.8.2. These six phases are successively applied in most thematic analysis studies as was done in this study.

### 6.2.1 Knowing the data

To have an overview of the data collected and to start interpreting them, they need to be ready for the analysis process (Gibbs, 2018). This is accomplished by having audio files transcribed and the dataset translated into the preferred language as needed (Gibbs, 2018). The next step is to understand and review the data by reading and rereading them and marking preliminary thoughts (Braun and Clarke, 2006).

Diary data were entered into the NVivo master file in the English language in August 2018. Although NVivo has the capability to accept both Arabic and English, it was decided to analyse the data in English as some defects within the software were discovered while using Arabic. Most of the Arabic-speaking participants used both languages and had used English terminology and expressions in their diaries as well as in the interviews (See section 4.7 Multilingual research for translation justification). As mentioned above, about half of the diaries were written in English (n=9), while the other half were written in both Arabic and English. Their translation into English was done by the study researcher; it was then translated back into Arabic by a linguistics specialist, a native Arabic speaker.

Interview data were transcribed personally by the study researcher into the NVivo master file in English as well. It used a transcription protocol that was developed to meet this study's objectives and to ensure that a standardised process was used for each transcript (Gibbs, 2018) See Appendix J.2 for transcription protocol. The data transcription was carried out between September and October 2018 and used a verbatim transcription, thus capturing every utterance, to ensure that the participants' intended meanings were not altered and to enhance data validity and reliability, in addition to increasing the researcher's familiarity with the data (Gibbs, 2018). This transcription includes grammatical errors, slang language, mispronunciations, and repetitions (Brinkmann and Kvale, 2015). Because this study aimed to capture participants' opinions and experiences, it was necessary to transcribe the non-verbal sounds, such as tones and pauses, which are considered important elements for discovery (Brinkmann and Kvale, 2015). To maintain confidentiality, identifying information that included names of organisations and settings were replaced with a substitute phrase.

The transcribed data were then linked to the diary and reflexive notes were taken using the NVivo case classification feature. This was done to aid the reflection about the method and interview style and guide the researcher in reading through the data and noting relevant themes and patterns to get a general idea of participants' perspectives and views that could answer the study questions. Hence, diary-interviews data were made ready for coding within the NVivo software.

### 6.2.2 Produce initial codes

During this phase of the thematic analysis process, two cycles of coding were done. The first cycle started in September and continued until December 2018. The codes were then reviewed in January 2019, making this the second cycle. Both cycles included line by line coding to develop the coding scheme. Then, written texts were scanned as a second step towards developing the code. Sentences and paragraphs were coded because, as most qualitative researchers suggest, coding large sections of data and paragraphs is considered the most dynamic methodology (Braun and Clarke, 2006; Brinkmann and Kvale, 2015) and this analysis required a lot of coding.

Since this study adopted an abductive logic scheme (deductive and inductive; see section 4.2), whereby initial codes were created during the study setup process in September 2018, within the master NVivo file and in accordance with the interview schedules. These codes were beliefs, feelings, perceptions, thoughts and opinions, recommendations and suggestions, types of care and words of wisdom. The following codes were added after the interviews according to the objective reading of the dataset: action after study, mental illness versus physical illness, negative thoughts, care difficulties, dementia as a disease, influences of the care provided, participants' learning and participants' reflections. In addition, quantitative data codes included the number of patients with dementia and those with suspected dementia within the ward and the participants' own ratings regarding their working shifts and their confidence when attending people with dementia. The initial codes were created during the first cycle of the coding process. Most codes were made according to one participant's own expressions and wording in this cycle. Please see the first cycle codebook in the Appendix J.3 codebook, which includes the codes, their descriptions, sources of data and the number of times referenced.

These codes were then merged during the second cycle and more were identified and complemented with more insights into the objectives of this study. Nine main codes were identified: knowledge, attitudes, perceptions, qualitative data code, type of care provided, participants' reflections, recommendations and suggestions, word of wisdoms and, finally, the researcher's reflections from the reflexive diary. Please see the second cycle codebook for the codes, their descriptions, source of data and the number of times referenced in the Appendix J.3.2 codebook.

### 6.2.3 Identifying themes

A third cycle of coding and an interpretative reading of the data took place in April 2019. A mind map and matrix were generated within NVivo, which summarises the codes and each code's key findings to better understand the data and search for themes. During this phase, all textual data were considered and relevant quotations of participants' responses were highlighted as needed, being that they are the most striking and important data that directly relates to this study's objectives with some interesting thoughts about people with dementia and dementia nursing care. In the search for themes phase, the researcher used the generated matrix analysis, in alignment with the thematic analysis process, to focus on the most remarkable impacts on the participants' individual experiences, which were then interpreted as themes. These impacts were established through the language participants used in their diary entries and interviews, as well as their continual return to these areas in order to highlight their importance. The researcher aimed to make sense of participants' experiences by introducing the participants' reality to enrich the credibility of the findings. Five main categories were identified: knowledge, attitudes, perceptions, professional factors and recommendations (see Table 6.8 below). For more details regarding the source of data and the number of times referenced see appendix J.3.

Table 6.8 Categories and codes with their descriptions from the diary and interview data

| Category | Codes | Source | Description |
|---|---|---|---|
| **Knowledge** | - Knowledge acquisition<br>- Degree (school/college)<br>- Experience<br>- Searching<br>- This study | INT | Participants' learning processes and how they gained their knowledge during their study days, work/personal experience, own reading and research and this study. Participants were asked about their source(s) of information. |
| | - Belief system<br>- Changes in the brain<br>- Suspect/recognise dementia<br>- What is Dementia? | DIA<br>INT | What a participant knows/ believes dementia is. This includes their understanding about dementia, its symptoms, personal characteristics and causes, in addition to dementia diagnosis and how a participant suspects dementia. |
| **Attitudes** | - Emotions:<br>Fear<br>Anger<br>Sadness<br>Happiness<br>Surprise<br>Love | DIA<br>INT | The emotions (affective attitudes) informing nursing care. They are categorised according to Robert Plutchik's classifications of feelings (fear, anger, sadness, happiness, surprise, & love) (Shaver *et al.*, 2001). |
| | - Patience<br>- Behaviour<br>- Desire to help | DIA<br>INT | An action (behavioural attitude) that was expressed and/or detected in participants' talks about dementia, persons with dementia and the act of caring. |

| Category | Codes | Source | Description |
|---|---|---|---|
| | - Beliefs<br>- Mental versus physical care<br>- Believe/Beliefs word query using NVivo tool | DIA<br>INT | Participants' judgments, beliefs, thoughts and opinions (cognitive attitude) on psychological and physical care |
| **Perceptions** | - Life with dementia<br>- Kids<br>- Learning<br>- Lies/not real<br>- Living with dementia<br>- Making decisions | DIA<br>INT | Living with dementia, the person-with-dementia's learning/understanding abilities and decision-making abilities as perceived by the study participants |
| | - Barriers<br>- Communication<br>- Difficulties | DIA<br>INT | Thoughts and opinions about barriers in providing care, learning and/or training several interactions like initial communication and workplace issues about the care environment including the hospital, current ward, routine and time declaimed by participants |
| | - Environment<br>- Routine<br>- Time | DIA<br>INT | Thoughts and opinions about barriers in providing care, learning and/or training several interactions like initial communication and workplace issues about the care environment including the hospital, current ward, routine and time declaimed by participants |
| **Socio-cultural factors** | - Community<br>- Culture and Society<br>- Culture and Language<br>- Experience<br>- Religion<br>- Rewarding<br>- Dementia Lexicon | DIA<br>INT | The influences of social norms, wording and religions on attitudes and perceptions and perceiving caring for people with dementia as a rewarding experience |
| | - Society<br>- Co-workers<br>- Family and relatives | DIA<br>INT | Societal influences on the care provided to people with dementia, including immediate family and relatives and personal experiences with a family member with dementia and colleagues |
| **Recommendations** | - Awareness<br>- Training and research<br>- Desire to know | DIA<br>INT | Recommendations and ideas regarding improving dementia nursing practices |
| | - Nursing care<br>- Policies<br>- Psychological support<br>- Ratio | DIA<br>INT | Recommendations and ideas for enhancing dementia nursing practices that include developing policies and supporting nursing personnel and providing psychological care for patients |
| | - Positive experience<br>- Accompaniment<br>- Environment<br>- Identification<br>- Multidisciplinary team<br>- Specialised care<br>- Therapeutic intervention<br>- Workplace | DIA<br>INT | Ideas for evolving nursing dementia practices in terms of care, environment, experience and awareness. This includes wards, tools, equipment and identification, as well as teamwork and multidisciplinary collaboration. |

**Key**: DIA: Diary
INT: Interview

### 6.2.4 Review identified themes

From the previous table, five themes were identified. (1) Acquisition of knowledge and the belief systems of nurses, (2) Attitudes informing nurses' behaviours, (3) Nurses' perceptions towards living with and caring for people with dementia, (4) Socio-cultural factors affecting nursing practices and (5) Nurses' ideas for enhancing dementia care.

In the following sections, each theme is initially introduced, represented in a diagram, and explored using extracts from the participants' transcripts. In-depth evidence and interpretation, as well as a findings synthesis (Smith, Ooms and Greenwood, 2017), is presented to support each theme. The aim is to present a substantial and discursive account to support the reader's understanding of the participants' meanings.

Transcription quotes were used to support the findings. In reporting the quotes, the letter P and the participant number (P#) were inserted and followed by data source—either Diary (DIA) or interview (INT). Please see an illustration of the themes with some of the data extracts below (Table 6.9; extended tables with codes are in the appendices J.4).

Table 6.9 Identified themes and examples of extracted data for each theme and sub-theme

| Theme | Sub-theme | Data extract |
|---|---|---|
| Theme One:<br>Acquisition of knowledge and belief systems of nurses | Nurses' knowledge acquisition | 'To be honest they did not teach us these things; unfortunately, nothing was given […] No one motivated us to learn, or called to train us, unless you had the courage to ask for it yourself.' P04 INT<br>'My source of information regarding dementia is the orientation given by this hospital.' P08 INT |
| | Nurses' belief systems | 'I always believed that caring for dementia patients is challenging. While caring and gaining experience, I noticed that some people require extra work as they are unique and different from others. Because of my knowledge from reading, it did not bother me. On the contrary, it was a challenge for me.' P03 INT<br>'Alzheimer's patients are very sensitive as everything around them is different; the disease hinders social relationships, which further builds their sensitivity. From my observations, they struggle to perform the easy tasks they used to do before and as a result they become very nervous.' P22 DIA |
| Theme Two:<br>Attitudes informing nurses' behaviours | Emotions influencing nursing care | 'Treating Alzheimer's patients is very difficult as I don't know exactly what their needs are, and I am afraid to abuse them.' P02 DIA<br>'When we needed them, they did not let us down. I hope this time we will be able to pay them back—they stood next to us during our ups and downs; they were with us every step.' P20 INT |
| | Nurses' patience is overcoming the challenges when caring for people with dementia | 'Sometimes this is exhausting because I have limited time as I care for 6 or 7 patients besides this case. I would lose my temper If I did not have patience. The situation is not easy and varies according to the work pressures of that day.' P03 INT<br>'I ask him to contribute with his own care, not only to rely on me. If every time I teach him a task I do it with patience, I believe he can learn.' P21 INT |
| | Experiential knowledge believed to overcome dementia nursing care challenges | 'I believe that if a person is well educated, reads a lot, looks for information and gains knowledge […] this may minimise or delay the occurrence [….] Using Google, I found most risk factors that may cause Alkharaf[2] are hard life events, genetics, and sometimes doing manual labour rather than cognitive work such as being journalists or teachers.' P05 INT<br>'Unlike people with physiological diseases, it is different. You have hypertension, you have diabetes, but at least you have your sane mind and you are still you. But people with dementia, they do not know what they are doing. They somehow lose themselves, so it is sad.' P24 INT |
| Theme Three:<br>Nurses' perceptions towards living with and caring for people with dementia | Perceiving a life with dementia | '… [like being] suspended between heaven and earth.' P20 INT<br>'In my opinion, when it comes to a dementia patient, the thing is to treat him as we treat children; this includes the care we give, simplifying what is difficult to understand and being flexible in communication so as to not make him feel that he is unable to communicate.' P20 DIA |
| | Communication perceived as main barrier in providing dementia nursing care | 'Never disregard the psychological status of the patient; boost the patient's contribution to his own care and communicate properly with him.' P04 DIA<br>'Because sometimes you cannot understand what they are telling you, so you need to guess. You need to… investigate what they are really saying, which I think that is one of the barriers.' P23 INT |

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[2] Alkharaf or Kharaf: the Arabic translation of dementia, it means 'unraveled' or 'lost the mind' (Yaghmour et al. 2019)

| Theme | Sub-theme | Data extract |
|---|---|---|
| | Workplace issues perceived as deterring dementia nursing care | ‘If it is time to give medicine to the patient, sometimes it takes time, too much time for them to receive the medicine. Then, after that, the care you give to other patients is also delayed.’ P13 INT<br>‘We need to spend more time on such patients as compared to the other regular patients.’ P14 DIA |
| Theme Four:<br>Socio-cultural factors affecting nursing practices | Social support for dementia nursing care | ‘Because the patient’s daughter has no idea about her mother’s disease, there is no knowledge and no cooperation at all.’ P03 DIA<br>‘[…] though her son and daughter were hiding this (dementia diagnosis) and we had not been told this clearly.’ P19 INT |
| | Societal implications on the care provided | ‘The term is hard for some families and they never believe even if the doctors tell them that he has dementia, Alzheimer’s, Kharaf, or whatever the word is. They don't believe in the disease.’ P15 INT<br>‘Usually we have restrictions for the men and for the women, especially if you are a male providing care to a female. So, this greatly affects the care because you need to assist them and when you speak to them there are some restrictions on what you can discuss here in Saudi Arabia, so it affects the care that can be provided.’ P25 INT |
| Theme Five:<br>Nurses’ ideas for enhancing dementia care | Raise awareness regarding dementia and dementia care | ‘I feel that what I know is just a drop in the ocean. Dementia is a huge subject. I would like to know more about it.’ P08 INT<br>‘…training courses for all nurses about how to treat patients with or with suspected dementia.’ P21 DIA |
| | Develop nursing policies that support caring for a person with dementia | ‘They should make one policy, like for each patient, there should be one family member supporting. This way they will listen more to the family member and they will not feel loneliness.’ P12 INT<br>‘If you admitted him (patient with dementia) in a general area with other patients, the nursing staff will have lot of responsibilities. So, I think having special nurses for them – no need to have a high degree of nursing skill but need to have good care for our patients and know how to take care of them. Like a nursing aid or nursing assistant to […] assist in hygiene and feeding the patient.’ P17 INT |
| | Nurses’ calls for organisational changes | ‘In order to deliver high-quality care, all the members of healthcare must co-operate well.’ P14 DIA<br>‘…increasing the number of staff nurses, providing equipment, providing at least a specialised ward for them. If they cannot provide a specialised hospice for them, as it may cost a lot, at least a specialised ward or department, adding entertainment to the ward and providing them with entertainment stuff.’ P16 INT |

## 6.2.5 Themes definitions

Following the thematic analysis phases explained earlier, this section highlights the findings from the diary entries and interview scripts. This was done in accordance to the themes and sub-themes identified from the themes phase (presented in Figure 6.2).

**Theme One: Acquisition of knowledge and belief systems of nurses**

- Nurses' knowledge acquisition
- Nurses' belief systems

**Theme Two: Attitudes informing nurses' behaviours**

- Emotions influencing nursing care
- Nurses' patience is overcoming the challenges when caring for people with dementia
- Experiential knowledge believed to overcome dementia nursing care challenges

**Theme Three: Nurses' perceptions towards living with and caring for people with dementia**

- Perceiving a life with dementia
- Communication perceived as main barrier in providing dementia nursing care
- Workplace issues perceived as deterring dementia nursing care

**Theme Four: Socio-cultural factors affecting nursing practices**

- Social support for dementia nursing care
- Societal implications on the care provided

**Theme Five: Nurses' ideas for enhancing dementia care**

- Raise awareness regarding dementia and dementia care
- Develop nursing policies that support caring for a person with dementia
- Nurses' calls for organisational changes

Figure 6.2 Key points from the diary-interview

This section reports the main findings from the diary and interviews data. The five themes and their sub-themes are summarised in order to explore RNs' knowledge of, attitudes towards and perceptions of people with dementia in Jeddah, KSA hospitals. The five themes provide an understanding of the current dementia nursing practices in the KSA and the barriers and obstacles faced by RNs in hospital settings.

At first, it was identified from the interview data that participants' knowledge acquisition and belief systems formed their perception towards caring for people with dementia. This, in turn, are the sub-themes that shaped the first theme: *acquisition of knowledge and belief systems of nurses*. Also, *attitudes informing nurses' behaviours* was identified from the diary and confirmed within the interviews, which is considered the second theme, with the three components of attitudes, as sub-themes, influencing nursing practice. Hence, emotions that influence nursing care were highlighted.

It was also found that nurses' patience in overcoming challenges when caring for people with dementia and experiential knowledge is believed to overcome dementia nursing care challenges. *Nurses' perceptions towards living with and caring for people with dementia* was identified as a third theme. It involves perceiving a life with dementia that was detected from the diary entries and interview scripts. After that, with more insight given to the data and codes, *socio-cultural factors affecting nursing practices* was defined as the fourth theme. This included family members, participants' colleagues, and participant's family members with dementia that made a sub-theme of social support. Moreover, there was a societal influence on a participants' attitudes and perceptions that were affected by norms based on a participant's culture and religion. Furthermore, communication and workplace issues were considered amongst the main challenges for participants that caused barriers in providing the necessary care. Finally, responding to the questions given in the diary and further discussed within the interview about providing recommendations for enhancing dementia nursing practice, a fifth theme was identified. This theme is *nurses' ideas for enhancing dementia care* that included raising awareness regarding dementia and dementia care, develop nursing policies that support caring for a person with dementia and calling for organisational changes.

As a final step of the thematic analysis, the five key points from diary-interviews data with their subthemes identified were reported and discussed in the next section.

### 6.2.6 Summarising the key points

This section reports the key points from the diary and interviews data. Five themes with their subthemes were identified, then were summarised within this section in order to explore RNs' knowledge of, attitudes towards and perceptions of people with dementia in Jeddah, KSA hospitals. The five identified themes provide an understanding of the current dementia nursing practice in the KSA and the barriers and obstacles faced by RNs in hospital settings.

### ***Theme One: Acquisition of knowledge and the belief systems of nurses***

Acquisition of knowledge and the belief systems of nurses was identified as the first theme. This includes the ontological provisions of nurses' processes of gaining knowledge and the ideologies underlying their belief systems. In consideration of one of the research's objectives, i.e. discovering nurses' perceptions, the researcher identified two key concepts, as illustrated in Figure 6.3. For example, one participant said 'My source of information regarding dementia is the orientation given by this hospital' (P08 INT). This quote exemplifies the ways nurses acquire their knowledge as one key concept. Another quote explains the other concept of the nurse's belief system: 'Alzheimer's patients are very sensitive as everything around them is different, and the disease hinders social relationships that cause their sensitivity. From my observation, they struggle to perform the easy tasks they used to do before and as a result they become very nervous' (P22 DIA).

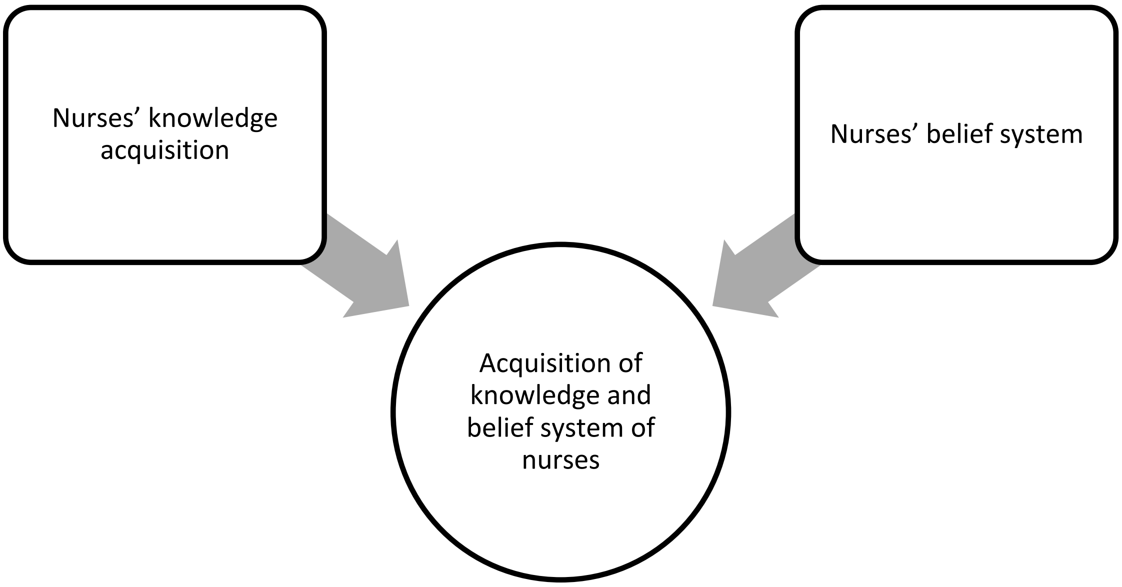

Figure 6.3 Theme one sub-themes

#### *Nurses' knowledge acquisition*

During the interviews, participants reported that their knowledge about people with dementia and dementia care was acquired during their nursing school days, their work/personal experience, individual research and/or this study.

Most of the participants (n=13) further explained that though they had come across dementia while studying for their nursing degrees, it was just one topic within the overall psychiatry course. Others said that they had acquired their knowledge about dementia during their placements in mental health and psychiatric hospitals. Even though they had received information about dementia, they seemed to be unsatisfied, as their knowledge and information about the disease was minimal and limited. One participant said, ‘In the college, we learned about it briefly […] the name of an illness with only a brief talk about it. I did not learn that much’ (P22 INT). Some participants (n=4) also claimed that they did not receive any training to care for people with dementia, saying that ‘even during the internship no one provided information. We spent the most time in the medical, surgical and operation rooms and such wards. But dementia was not anyone’s concern’ (P16 INT). Another said, ‘To be honest, they did not teach us these things; unfortunately, nothing was given […] No one motivated us to learn, or called to train us, unless you had the courage to ask for it yourself’ (P04 INT).

Most participants (n=15) acknowledged the difference between theoretical learning and practical, on-the-job training. One participant said: ‘We studied about it; however, it was just an idea: dementia, and that’s it. And when we started working, we supposed we had forgotten about it and started all over again to gain knowledge through work experience’ (P03 INT). Another participant added, ‘When you care and work with them, it’s different than when you study’ (P15 INT).

Some participants also acknowledged that their work experience had helped them develop their knowledge and improve their work with people with dementia and that it also helped them understand the many variations that existed among people with dementia. As one participant claimed, ‘Every day I became more aware and learned new things regarding these patients, knew their suffering and knew that it is not their will (intention) to talk or behave like that’ (P05 INT). Also, personal experiences with a family member who have or had dementia has evident influences on knowledge acquisition, as it not only equips nurses with knowledge but also drives them to further investigate suspected cases. One participant during the interview said, ‘[…] there are some instances I remember with my grandmother […] this should not be done, this is not the proper way, she should have done this [….] I thought that something might be wrong with her’ (P13 INT).

In addition to participants' work and personal experiences, their inquisitiveness to learn made them look for information on the internet and other available resources, with varying degrees of curiosity noted among participants. Most participants (n=11) used the internet, particularly Google Search and YouTube, to look for information about dementia. However, a few participants (n=3) mentioned the lack of available resources in Arabic regarding dementia. Participants mostly searched for dementia definitions, its types and causes and risk factors. Some of them also came across photographs of the brain and stories about people with dementia.

### *Nurses' belief systems*

The diaries showed that participants believed that persons with dementia were forgetful, confused, and challenged. The interviews further confirmed this, and participants had gone on to define dementia as a cognitive problem affecting reasoning and thinking processes as part of a progressive brain disease that was characterised by a group of symptoms caused by damage to brain cells. A person with dementia could recall from long-term memory but was forgetful in the short-term, confused and prone to delusional thoughts.

Participants stated that brain atrophy, or cerebrovascular accident (stroke), could cause dementia, while genetic disposition and heredity were considered risk factors for developing dementia. Additionally, several participants mentioned that life events and lifestyle played an important role in preventing or developing dementia and that keeping the brain busy and exercising it improved memory. One participant said:

> 'I believe that if the person is well educated, reads a lot, looks for information and gains knowledge […] this may minimise or delay the occurrence [….] Using Google, I found most risk factors that may cause Alkharaf are hard life events, genetics, and sometimes doing manual labour rather than cognitive work such as being journalists or teachers.'
>
> **(P05 INT)**

The term for dementia in Arabic is *kharaf* or *alkharaf*, which means *unrevealed*. In addition, three participants stated in their diary entries and during the interviews that dementia was caused by *gadar*, the Arabic word for *fate*. Participants also referred to it as a test from God for the person with dementia and his/her family. For example, one participant wrote in her diary:

> ‘If she (the patient with dementia) said something inappropriate or abusive or even was aggressive, I never blamed her. Latterly, she has no one but us—nurses—we are her family/daughters who will always be there, subsequent to her real family. No one deserves this disease caused by Gadar (Fate).’
>
> **(P03 DIA)**

Although some participants (n=6) were confused about dementia and Alzheimer’s and said that dementia is Alzheimer’s, some knew that Alzheimer’s is a type of dementia. One participant claimed that ‘most people say this old lady is aged and she is Kharaf. It is normal to get Kharaf, it’s a normal part of ageing […]. They think this is a part of normal ageing’ (P03 INT). A few participants (n=4) stated that dementia is not only a part of normal ageing but also argued that it was a cultural norm. A few participants (n=3) perceived that a person with dementia was *mentally incomplete* and *unrevealed*—i.e., a person with *Kharaf*.

Participants also articulated characteristics that were common to people with dementia, such as that they were unable to express their needs and struggled with communication and that they mostly had problems with gait, posture, or movement. Despite this commonality, participants acknowledged that every patient had different needs and that it required great patience. ‘He cannot express his needs! I have to discover what his needs are? […] If I was not there to help, he would be lying stiff in one place’ (P05 INT). Fifteen participants mentioned that their role was to orient people with dementia about place and time, help them establish a routine, treat them differently from the other patients and, in some cases, isolate them from other patients because seeing new faces and new people could create frustration in them.

Looking at the quantitative data within the diary entries, it is evident that the number of people diagnosed with dementia during participants' working shifts was much lower than the number of people with suspected dementia. Hence, participants were asked during the interviews about how they suspected dementia and the reasons behind that difference. Many participants referred to the process involved in diagnosing dementia and the slow system. Also, one participant said:

> 'Although at the time of admission his family told us that he had dementia, that they have a family history of dementia, some even provide numbers of how many members in the family have had dementia, but still this is not written in the file. The staff treat him physically like any other patient and ignore the dementia.'
>
> **(P21 INT)**

Additionally, participants claimed that all people with dementia had comorbidities and that, in most cases, dementia was not diagnosed but mentioned by either a patient's family or was suspected by healthcare workers. One participant added:

> 'Sometimes a dementia diagnosis is written in the file as a secondary diagnosis – Alzheimer's and Parkinson's. But the initial diagnosis is something else, which is their main reason for hospitalisation. So, it is written as secondary diagnosis: Alzheimer's and Parkinson's, like that.'
>
> **(P14 INT)**

This helped shed some light on nurses' criteria for suspecting dementia. Suspected dementia was recognised by study participants when a patient was forgetful, showed delusional behaviour, expressed unrelated thoughts and speech, had mood swings and was irritable. This greatly improved when nurses cared for patients in long-term stay. 'They behave differently from what they say and they have mood swings. Sometimes they are friendly and sometimes we are the worst enemy they have, like this' (P24 INT).

### *Theme Two: Attitudes informing nurses' behaviours*

Attitudes informing nurses' behaviours was identified as the second theme, which means nurses' actions explained their attitudes towards people with dementia. In meeting another research objective, that of gaining greater insights into nurses' attitudes regarding dementia and the care they provide to people with dementia, three key concepts were formed. These include the emotions informing nursing care (affective attitude); for example, one participant wrote, 'Treating Alzheimer's patients is very difficult as I don't know exactly what their needs are, and I am afraid to abuse them' (P02 DIA). Another concept is nurses' patience in overcoming challenges when caring for people with dementia (behavioural attitudes); one participant said, 'I ask him to contribute to his own care, not only to rely on me. If every time I teach him a task I do so with patience, I believe he can learn' (P21 INT). Another participant said, 'Unlike people with physiological diseases, it is different. You have hypertension, you have diabetes, but at least you have your sane mind and you are still you. But people with dementia, they do not know what they are doing. They somehow lose themselves and so it is sad' (P24 INT). This quote explains the last key concept, which is that experiential knowledge is believed to overcome dementia nursing care challenges (cognitive attitude). These key concepts are illustrated in Figure 6.4.

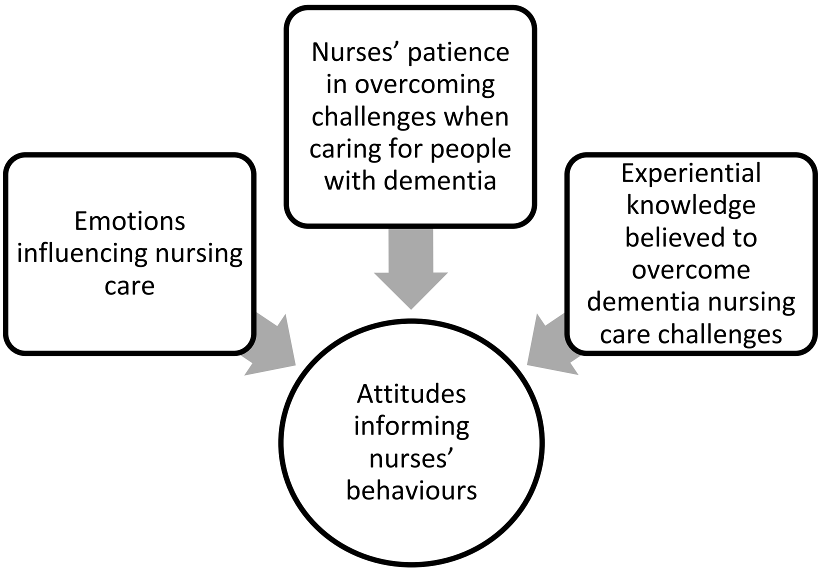

Figure 6.4 Theme two sub-themes

### *Emotions influencing nursing care*

Emotions illustrate the affective aspect of attitudes. Numerous participants (n=5) believed that caring for people with dementia is a kind of payback of benevolence received by the person from his/her loved ones:

> ‘When we needed them, they did not let us down. I hope this time we will be able to pay them back—they stood next to us during our ups and downs; they were with us every step.’
>
> **(P20 INT)**

It was gleaned from the diaries and confirmed in the interviews that nurses tend to hide their emotions from patients and colleagues and usually ignore their own feelings. Almost all the participants (n=17) showed sympathy towards people with dementia and their conditions with mainly feelings of sadness being expressed for the difficulties they faced in performing their daily activities and in communicating their needs. A few participants (n=5) blamed themselves when they could not provide the required care without the family’s or a colleague’s assistance: ‘I felt ashamed today because as a nurse I was a failure today’ (P12 DIA). Another participant added:

> ‘I cried. I felt pity for one patient, when I was first assigned to care for her […] she has stage four bedsores (advanced tissue damage caused by pressure in bony areas) in the sacrum and trochanter (lower back and hip area), also her bilateral legs and bilateral heals. The patient is conscious, she has daughters and sons. I can’t imagine how she developed bedsores if she has many daughters and sons.’
>
> **(P13 INT)**

Hence, sadness is a strong emotion that impacts nurses’ attitudes. Participants were uncertain about the care they provided to people with dementia as the latter were mostly unable to express their needs, which resulted in providing care with fear and sadness. One participant articulated, ‘Treating Alzheimer’s patients is very difficult as I don’t know exactly what their needs are, and I am afraid that I might abuse them’ (P02 DIA).

Despite this, happiness and feelings of love were expressed in all the diaries by all nurses after providing care and this was further confirmed during the interviews. For example, one participant wrote: ‘I feel proud and happy to care for them; I assisted them with the activities of daily living’ (P14 DIA). When the care has positive impacts on the persons with dementia, nurses feel satisfied and happy. Emotions of love were expressed by nurses as they showed mercy, empathy, comfort and a desire to help when they reflected on their own experiences.

However, two nurses expressed anger as a result of the aggressive behaviour of people with dementia:

> ‘I hated her because she was aggressive. She slapped my face [...] It is understandable, but your patience will sometimes be challenged and you will be like, I hate her. I do not want to work with these kinds of patients, not like this.’
>
> **(P24 INT)**

Eight nurses expressed anger as a result of the shortage and inaccessibility to healthcare facilities. Most factors that made nurses express their anger within the workplace were the lack of time, a high nurse-to-patient ratio, patient endangerment and the lack of equipment to assist with daily activities such as toileting and positioning.

### *Nurses’ patience in overcoming the challenges when caring for people with dementia*

As mentioned in the previous section, communication, time, nurse-to-patient ratios and workplace policies were added challenges in providing dementia nursing care. As a result of the lack of dementia care policy in the hospitals where they worked, most participants developed their own way of caring for people with dementia. Also, all participants acknowledged that providing the necessary nursing care requires good communication skills and patience and it differs from one person to another, which translates into the behavioural aspect of attitude.

Indeed, patience is a key component when providing nursing care for people with dementia. ‘I ask him to contribute with his own care, not only to rely on me. If every time I teach him a task I do so with patience, I believe he can learn’ (P21 INT). In fact, almost all the participants (n=17) referred to patience in their daily diary entries. It was discussed further during the interviews by all the participants as a vital segment of nursing care. It was also essential for a participant’s own psychological care in minimising the work pressure:

> ‘Sometimes this is exhausting because I have limited time as I care for six to seven patients besides this case. I would lose my temper if I did not have patience. The situation is not easy and varies according to the work pressures of that day.’
>
> **(P03 DIA)**

Some participants (n=5) suggested that caring for patience was rewarding. One participant described her care process and said:

> ‘When dealing with these people, you have to take a deep breath because you know you will encounter, like..., they will test your patience, and it is sad, really, because some of the patients you get, especially when you are busy, you usually get irritated with questioning, more questioning, and then them asking you to do anything […] But if they are irritated, sometimes you have to swallow your anger because you have to understand. So, it’s quite difficult, but I think you have to be patient with these patients. But after that it is rewarding, like, if for example, they are, they can recognise you, and really it is very rewarding taking care of this type of people for me.’
>
> **(P25 INT)**

### *Experiential knowledge believed to overcome dementia nursing care challenges*

The cognitive aspects of attitude informing participants' beliefs and the importance of developing experiential knowledge was also noted. Most participants (n=15) were uncomfortable when providing care for people with dementia as a result of being challenged:

> 'I always believed that caring for dementia patients was challenging. While caring and gaining experience, I noticed that some people need extra work as they are unique and different from others. Because of my knowledge from reading, it did not bother me; on the contrary, I found it a challenge'
>
> **(P03 INT)**

All participants suggested that they mostly provide physical care and treatment, which is the reason for attending a hospital for people with dementia. Whilst many participants acknowledged the need for providing psychological (n=8), sociological (n=10) and spiritual (n=5) care aligned with physical care, most tend to provide only medical treatments:

> 'Unlike people with physiological diseases, it is different. You have hypertension, you have diabetes, but at least you have your sane mind and you are still you. But people with dementia, they do not know what they are doing. They somehow lose themselves and so it is sad.'
>
> **(P24 INT)**

Another participant said: *'We are surgical department, they care about the fracture and wound you have. Your brain is not bothering me and I don't care about it at all'* P03 INT.

However, a few participants declared in both diary and interviews that with more experience providing nursing care for more people with dementia they can overcome the challenges of providing holistic care:

> ‘My patient has Alzheimer’s in addition to a psychosis. Today, while the physician and I were changing her wound dressing, she was calling out ‘grandma, mother, where are you?’ The patient is over 70 and all the time she was calling out for her grandmother and mother. Then her daughter said, ‘I am your grandma, I am your mother’ pretending to be the person that the patient was asking for. It was nice that she knows her mother and her disease, as well as being able to calm her down and meet her needs. This patient is elderly, her mother and grandmother died a long time ago, but her wound dressing reminded her of when she was little, that she had a caring mother. Since then every time I entered her room and she called me by a name of a person I didn’t know, I acted as that person. Her daughter taught me a new thing; she said doing this will make her not afraid when she calls and if I told her that they are dead I would scare her.’
>
> **(P03 DIA)**

Taking care of people with dementia is challenging; however, with experience and reading, participants claimed that they could overcome this challenge. One participant also claimed that ‘toleration and patience are things that we did not have while learning theoretically, but we learned them from experience when dealing with the patients’ (P15 INT). Mainly the male participants, in addition to a few females (n=5), recognised the need to try and change one’s own attitudes. One participant stated:

> ‘Sometimes they (people with dementia) are not cooperative; they get aggressive or they are in a depressed mood, and at that time we need to understand their feelings. Initially it was difficult, I was likely to lose my patience sometimes; then, when I started talking to them more, and I started reading about this more, I tried to empathise with their feelings, I tried to consider myself, like, if I was in such a position, or if I was one of them how do I want others to take care of me? So, then I changed my mind and I tried to learn more, to be more patient with them. Then, finally at last stage, I was happy’
>
> **(P14 INT)**

Hence, it was evident that participants hold positive attitudes as a result of developing experiential knowledge.

### *Theme Three: Nurses' perceptions towards living with and caring for people with dementia*

Several aspects form participants' perceptions towards living with and caring for people with dementia are identified within the third theme. Firstly, participants expressed how they perceived a life with dementia as being: one participant said, '… [like being] suspended between heaven and earth' (P20 INT). Most participants agreed that communication is perceived as a main barrier in providing dementia nursing care. One participant wrote: 'Never disregard the psychological status of the patient so as to boost the patient's contribution to the care and communicate properly with him' (P04 DIA). Also, it was found that workplace issues are perceived as deterring dementia nursing care. For instance, one participant said, 'If it is time to give medicine to the patient, sometimes it will take time, too much time for them to receive the medicine. Then, after that, the care you will give to other patients will also be delayed' (P13 INT). These acknowledged sub-themes are illustrated in Figure 6.5.

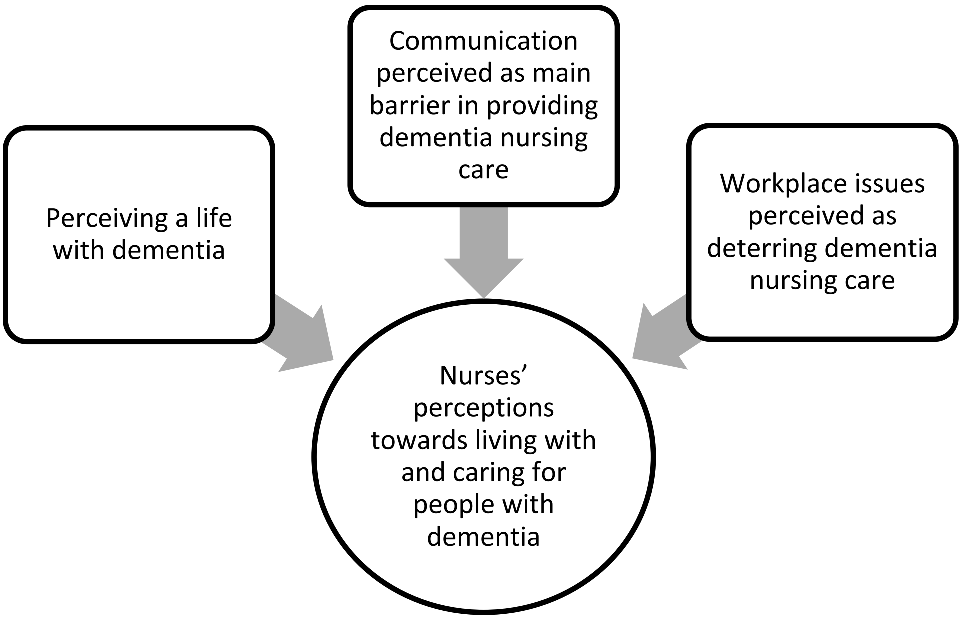

Figure 6.5 Theme three sub-themes

### *Perceiving a life with dementia*

‘Today I am a stranger to my grief, a stranger to my heart…. I stand in front of the grief, I cannot understand it and I did not want it before’ (P03 DIA). This is what a participant wrote about a person with dementia in her diary. Almost half of the participants (n=8) perceived that a person with dementia is a stranger to his or her self and living in a disorganised world. Also, several participants (n=5) saw dementia as an undesirable condition and did not want their loved ones to be affected with the disease. One participant explained it as, ‘as if I were born in a world that cannot accommodate me, this is how I imagine it feels to be an Alzheimer's patient’ (P03 DIA).

Additionally, a few participants (n=6) determined that a person with dementia was confused and confounded. One participant described the person as being ‘… [like being] suspended between heaven and earth’ (P20 INT). In a spiritual sense, a person with dementia is nowhere, neither alive nor dead. Some participants acknowledged that their patients’ behaviours and actions were not of their own will and that it was something that they did not have control over. Participants claimed this was because a person with dementia had gone through many challenges in life that caused instability and mood swings. Most participants (n=16) assumed that people with dementia could not express their feelings or needs and were, therefore, demanding on others. They needed their families to be around them; however, many people with dementia were abandoned as they were seen as a burden on their families and their families’ careers. ‘This patient had already been discharged from the hospital a long time ago but the family members don’t want to take her home’ (P12 DIA).

Almost half of the participants (n=8) perceived a person with dementia as a child who required close observation and more time spent with others. Having a person with dementia admitted to an extended convalescence in medical wards or psychiatric wards is perceived as an indicator of abandonment by their families, as expressed by all the participants working in these wards, which the researcher considers very significant.

All participants agreed that people with dementia have problems in understanding and that they are not aware of their own conditions. Nevertheless, participants preferred not to discuss dementia with a person who had it as they viewed it as an inappropriate act and something that could drain the person, cause aggression, and hurt their feelings. A few participants agreed that it was useless to argue with them regarding their conditions.

From both the diary and interview data, it was found that more than half of the participants (n=10) marked it as *difficult* for a person with dementia to learn new things in the early stages of dementia and as *impossible* in later stages. On the other hand, numerous participants (n=4) expressed during their interviews that a person with dementia is ‘smart’ and could learn new things, to some extent, if given more cooperation, encouragement, and patience from the nurses. While it is acknowledged, from the diaries and interviews, that people with dementia have trouble making decisions, a quarter of the participants (n=5) felt that leaving choices up to the patients was important for their self-esteem. However, they agreed that it was important to observe their decisions and interfere when difficulties were encountered. (Please refer to nurses’ recommendations on caring for a person with dementia, P. 160).

### *Communication perceived as main barrier in providing dementia nursing care*

All study participants reported that they assisted people with dementia in their daily life activities, feeding and hygiene in particular, and administered medication as a basic routine of their daily nursing practices. However, communication was considered the main barrier when providing nursing care for their patients. Nevertheless, participants developed their own ways to communicate with them and were mostly able to convey their meanings to the person with dementia in order to provide nursing care.

While all participants perceived people with dementia as vulnerable, since they could not express their feelings and/or needs, some (n=6) acknowledged the need to be assisted by a nurse colleague, social worker, or a family member in communicating with a person with dementia: ‘Communicating with the patient is very hard; assistance is much needed’ (P05 DIA). This assistance had a positive influence on the care provided and made the nurses feel supported. However, a patient’s aggressive behaviour and mood swings worsened the situation and added to the challenge for the participants while providing nursing care. ‘…provide medication. Today, the patient was very aggressive and she refused to take her medication until the end of the shift and I wasn’t able to give any care to the patient’ (P12 DIA).

It is worth mentioning that all non-Arabic-speaking participants considered the Arabic language and Saudi culture as crucial barriers to communication. ‘Because you cannot understand sometimes what they are telling you, you need to guess. You need to… investigate what they are really saying; so, I think that is one of the barriers’ (P23 INT). Another participant added, ‘…because I cannot change the culture; but I can adapt to the language. I can learn the language but I cannot change the culture’ (P24 INT). Participants sought assistance from Arabic-speaking staff and family members when they were available. Administrative nurses in this study made assurances that at least one Arabic-speaking nurse was available within the team during every working shift.

### *Workplace issues perceived as deterring dementia nursing care*

> ‘We as nurses and the doctors apply the necessary care, maintain patient safety and minimise the hospitalisation complications as much as possible; but this only applies to the physical. Regarding his mental problem, it is up to him personally and his family care!’ (P03 INT).

Sixteen participants, not including the community nurses, stated that their main aim as nurses was to minimise hospitalisation and provide *physical* care for patients and that a patient's mental status was not their main concern. However, participants found several faults in the care system, since providing nursing care was affected by the number of patients with dementia, a high nurse-to-patient ratio, workplace facilities, and the availability of equipment. Most importantly, all study participants said that they could only provide equivalent care to persons with dementia if they treated them as regular patients in the ward. All the participants agreed that people with dementia required more time and nursing investigations but that they could not always spend more time with them due to the busy work environment, other patients in their care and the many different tasks they had to perform. One participant asserted that 'absolutely, time and workload are barriers. We can't provide extended care for one patient as I have other patients. Each patient wants to be taken care of quickly and fast... so, this is the barrier' (P02 INT). Another participant added, 'If it is time to give medicine to the patient, sometimes it will take time, too much time for them to receive their medicine. Then, after that, the care you will give to other patients will also be delayed' (P13 INT).

Caring for a person with dementia requires spending more time with them, explaining procedures, conversing, and communicating with them. Participants acknowledged that equal time cannot be offered to patients. 'So many patients, a lot of procedures and no time. And yes, that may affect the patient with dementia' (P04 INT). Participants prioritised patients according to the severity of the cases, especially in emergency departments, where nurses tended to provide care for more critical cases than people with dementia. Participants in emergency departments (n=5) admitted that a person with dementia was treated with *unintentional negligence.* Also, when a patient was aggressive, they first provided care to calm him/her down. On the other hand, participants in out-patient departments prioritised persons with dementia. Consequently, most participants, except for the community nurses, reported that they provide care for people with dementia last as they need to spend more time with them. 'This patient is taking more time. I have to practice good time management. I provide care first to others and then to this patient as he requires more time' (P05 INT).

All bedside and community nurses (n=14) reported that they cared for seven to ten patients at the same time. 'Sometimes I care for more than 10 patients' (P02 INT). However, administrative nurses stated that the nurse-to-patient ratio was one nurse to five patients and when a person with dementia was present the ratio became one to three. However, this rule notwithstanding, they confirmed that this ratio was never implemented practically. The nurse-to-patient ratio was acknowledged by all participants as the main reason for their stress and deficiency in providing good nursing care:

> ‘This patient—an Alkharaf patient—needs special care; when you assign to him, you must not have a heavy work load. If the nurse got her time, she will give the Alkharaf patient his time. But when the nurse assigned to eight or ten patients, sure she will not have enough time to care for the Alkharaf patient.’
>
> **(P15 INT)**

Hence, participants agreed that as more time is needed to be spent with persons with dementia, the workflow is affected and causes delays that disturb other patients. A few admitted (n=4) that spending more time—even up to ten minutes during their shift—mattered and had a positive impact on the patient. This made them more cooperative and familiar to some extent with the care process. ‘The patient’s engagement and her trying to communicate, even for a short time, influences the way I care and makes me want to converse with her’ (P03 DIA). Some participants (n=5) felt bad for being busy and not spending valuable time with people with dementia. ‘It feels that I shut up about something that could help them; but really, I do not have enough time to talk or explain’ (P03 INT).

Patients needed to be approached several times to get the nursing care they required; however, most participants (n=16) claimed that patients required close observation and they preferred being accompanied by a family member:

> ‘They need our care all day. All day and night caring for them, their feeding, medication, meeting their other needs, and frequently seeing them around the place they need you near them. Frequently checking on them. Staying with them […] they need someone accompanying them all the time.’
>
> **(P16 INT)**

The work equipment and work environment are another burden for nurses working in rural, psychiatric, and central hospitals, mostly in terms of equipment in need of repair, such as side rails being broken, a lack of curtains, or a lack of safety features in toilets or the dining area. These issues added extra pressure and stress for the nurses due to the increased risk of patients falling and the need to be nearby all the time.

Additionally, hospital policies and restrictions imposed barriers in providing care, such as walking with persons with dementia within the ward, having fixed times for feeding and medications, etc.

> ‘It is from the hospital policies…these obstacles are from the policies. I cannot take the patient outside his room. There are controls that control everything. I cannot give or provide them food outside of the meal times. These things are barriers. I can help the patient to calm down in many ways such as walking around, but I am not allowed to do that.’
>
> **(P21 INT)**

### *Theme Four: socio-cultural factors affecting nursing practices*

Exploring the current practice of nurses, many socio-cultural factors were identified that affected participants’ attitudes and perceptions when caring for people with dementia. Two more key concepts linked to the research objective of identifying barriers and obstacles faced by nurses when caring for people with dementia were assumed to be associated with the fourth theme, as depicted in Figure 6.6. First, there is the social support for dementia nursing care; for example, one participant said, ‘[…] her son and daughter were hiding this (dementia diagnosis) and we had not been told this clearly’ (P19 INT). Second is the societal implications on the care provided; for example, one participant said, ‘The term is hard for some families and they never believe it even when the doctors tell them that he has dementia, Alzheimer’s, Kharaf, or whatever the word is. They don’t believe in the disease’ (P15 INT).

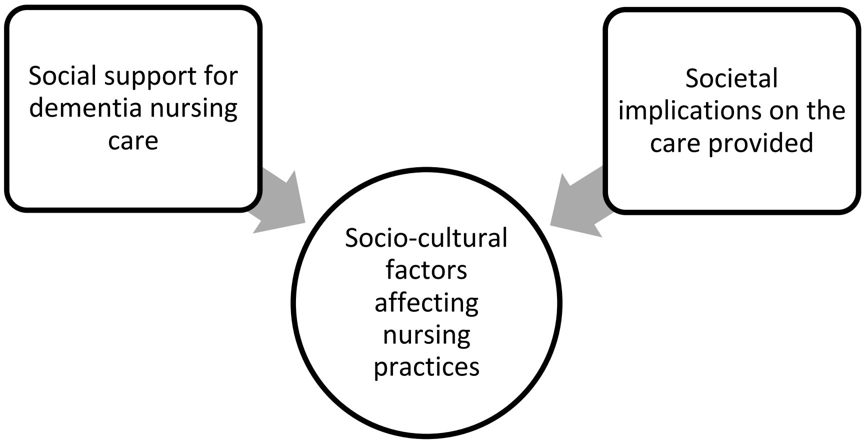

Figure 6.6 Theme four sub-themes

### *Social support for dementia care nursing*

All the participants reported that social support impacted their attitudes and perceptions when providing care for people with dementia. This social support included patients' families and relatives, their own family members with dementia, and colleagues:

> 'Society impacts the care for patients with dementia. All must contribute in the care; doctor, nurse, family, and all family members—not just one member. Every person is affected accordingly. The doctor by prescribing medications that minimise the deterioration of the case, and the nurse by how she cares and deals with him and convinces him to take the treatment. His family assist by convincing him to eat and communicate.'
>
> **(P22 INT)**

The study participants were unanimous in holding the view that caring for a person with dementia could not be applied by the nurses on their own and that it requires a collaborative care that involves patients, their families, and healthcare practitioners—including nurses, physicians, and social workers—in addition to a conducive organisational structure.

All participants also agreed that the awareness of the family members and relatives regarding dementia impacted the care provided. From the participants' diaries, it could be seen that families had negative impacts on the nurses and patients. This was due to their low levels of knowledge and awareness as suggested by most participants during the interviews. Similar comments were entered in their diaries by many participants regarding the awareness of a family member about people with dementia: 'Because the patient's daughter has no idea of her mother's disease, there is no knowledge and no cooperation at all' (P03 DIA). Again, from the same participant regarding a different person with dementia, 'Because the patient's daughter is aware of her mother's illness, she makes my work easier' (P03 DIA). Families were the main source of information to assist the participants when they wanted to communicate with the patient to provide nursing care. When a patient's family was around, the patient became cooperative and made nursing care easier. 'The family are the most important […] the only way of communicating with the patient is through his family' (P15 INT). Some Saudi nurses (n=4) observed that families had changed over the years and that nowadays families tend to leave their relatives in the hospital abandoned for days, or even months, without taking them home or answering their phone calls. This was especially noted when the person with dementia had neither a spouse nor children.

Eight of the participants had family members with dementia, although the study researcher discovered during the interviews that four of those participants preferred not to state that fact when they were recruited for the study. During the interviews, these participants talked about people with dementia and always reflected on the difficulty of living with people with dementia and complained about the available services. Then, the study researcher asked them if they had any family with dementia, which was then affirmed. It was discovered from the interviews that all participants who had family members with dementia felt ashamed of the diagnoses and isolated the family member from their extended families. Moreover, two participants who had a family member with dementia from the mother's side were less concerned. One participant said:

> 'Currently, she is not in Jeddah. I am away from her. She is my grandmother from my mother's side, not my father's, so she is in Ta'ef. I rarely visit her… not rarely, but whenever I have the opportunity to. Her boys are with her.'
>
> **(P04 INT)**

Another participant talked about his aunt, his mother's sister; 'We did not know about it at all. She is in Makkah and not here in Jeddah. Her son and daughter were hiding this and we had not been told this clearly' (P19 INT). This showed a strong relationship between cultural implications and social norms on the care provided, which results from the traditions and beliefs of the carers—including nurses and relatives of the patient.

Another influencing factor was a sense of collegiality, which greatly influenced the care provided, mostly in a positive way. Almost in every diary entry, participants referred to the important role that their colleagues played while providing the care for a person with dementia. Nurses' colleagues, in particular, had the most positive influence in providing proper care, while the most negative role was played by social workers through their absence and lack of assistance with the care of the patients. '[…] the inactive role of the social worker, they are not involved in anything. I have to wait until a major problem happens to the patient to consult the social worker!' (P03 INT). In addition, the non-diagnosing of dementia was suggested as a problem created by physicians, especially gerontologists, neurologists, and/or medical practitioners.

### *Societal implications on the care provided*

The care provided was also influenced by the social and cultural norms of the participants. In terms of the norms, it included the appropriateness of the Arabic term for dementia, the general treatment of mental illnesses in Saudi healthcare facilities and views about causes of dementia. All Arab participants (n=12) observed that it was very difficult for them to use the Arabic term for dementia when talking to people with dementia or their families. Eight of the twelve participants talked more about the word and about the acceptance of the meaning. None of them agreed to say *kharaf* as they viewed it as a disrespectful term. 'Actually, I need to remove this word from the world! From the people who use it' (P17 INT). They tended to use the terms *forgetfulness*, *memory loss*, *Alzheimer's disease*, and *old age* when discussing dementia in Arabic with people with dementia or their families. Though some participants tended to 'Alzheimer's dementia', the term Alzheimer's is frightening and shocking to many people. 'I will only say an old age disease; I will not say Kharaf. It is difficult for them—the family' (P22 INT) (Please see Theme One about nurses' belief system, P. 139)

Five participants, who worked at the surgical, emergency, and extended medical wards, were apprehensive about the care provided since most patients were receiving intervention only to treat their physical and physiological symptoms, and the healthcare system was not concerned about the psychological or mental status of the patients. ‘The doctors as well. We are the surgical department, so they care about the fracture or wound you have. A person’s brain does not bother them and they don't care about it at all’ (P03 INT). One participant added, ‘The term is hard for some families and they never believe it even when the doctors tell them that he has dementia, Alzheimer’s, Kharaf, or whatever the word is. They don’t believe in the disease’ (P15 INT). Other participants also stated that the families and society did not believe in dementia as a cognitive illness.

Spiritual and religious backgrounds also played an important role in conceptualising dementia and its causes. Eleven of the participants (Muslims: 9; Christian: 1; Hindu: 1) adhered to the positive influence of their religion when providing care to patients with dementia. The Muslim participants’ care and attitudes towards people with dementia were influenced by two obligatory aspects of Islam: honouring parents and treating older adults with gratitude and mercy. This was in addition to the belief in karma of other religions. One participant stated: ‘We believe in karma: If you take good care of sick people, God will bless you’ (P12 DIA). Another added:

> ‘I feel pain from the inside for them […] we are human beings with feelings not rocks; he stands on his feet, I imagine myself in his situation, thus I give the maximum care I can to relieve him or make him smile. You have to consider him as your father or someone you love. Regardless of anything, we are human. Also, it is encouraged by our religion to care of Muslims and non-Muslims as humans, with mercy.’
>
> **(P04 INT)**

Hence, all eleven participants mentioned above believed that caring for people with dementia was rewarding, along with one more participant finding it rewarding but not from a religious perspective.

Nurses working in emergency departments and outpatient departments observed that whenever they encountered an older adult with suspected dementia in the department, they needed to provide nursing care to them—even when the person did not have an appointment or if he/she simply looked lost. This was due to the culture of Eastern-Mediterranean countries that tends to value older adults and cares for them with gratitude and respect. The Filipino and Indian nurses also held similar beliefs. ‘In my country it is our norm to look after our elders as a sign of love, respect, and gratitude’ (P13 DIA). Yet, non-Arab participants admitted that cultural restrictions negatively impacted the nursing care: ‘Cultural differences negatively affect the provision of care. Since mine is completely opposite to Arab culture’ (P24 DIA).

All non-Saudi participants (n=7) also acknowledged that cultural differences negatively impacted the care they provided most of the time, especially when those differences were regarding gender segregation and touching a person of a different gender. These were in addition to the language barrier:

> ‘Usually, we have restrictions for the male and for the female; especially if you are a male providing care to a female. So, that greatly affects the care because for these people, you need to assist them and when you speak to them, there are some restrictions on discussing a lot of things here in Saudi Arabia; so, it affects the care that can be provided.’
>
> **(P25 INT)**

It was reported that there were not only cultural restrictions but also many organisational restrictions that had distressed the participants, such as walking a patient outside the ward and issues with diagnosing dementia (see Theme Three: Nurses’ perceptions towards living with and caring for people with dementia, P 148).

### *Theme Five: Nurses' ideas for enhancing dementia care*

This theme corresponds to the questions put forward within the diary booklet, and further discussed during the interview, about nurses' recommendations and suggestions to enhance dementia care practice. Considering that all the participants included recommendations, this theme identifies three key concepts that interpret participants' ideas for enhancing dementia care, as shown in Figure 6.7. The first key concept is raising awareness regarding dementia and dementia care. One participant wrote: '… training courses for all nurses about how to treat people with or with suspected dementia' (P21 DIA). The second key concept is developing nursing policies that support caring for a person with dementia. In this regard, one participant said, 'They should make one policy, like, for each patient there should be one family member to contact. So, they will listen more from the family member, and they will not feel loneliness' (P12 INT). The third key concept is nurses' calls for organisational changes; for example, one participant said:

> '[…] increasing the number of staff nurses, providing equipment, providing at least a specialised ward for them. If they cannot provide a specialised hospice for them, as it may cost a lot, at least a specialised ward or department, and adding entertainment to the ward and providing them with entertainment stuff.'
>
> **(P16 INT)**

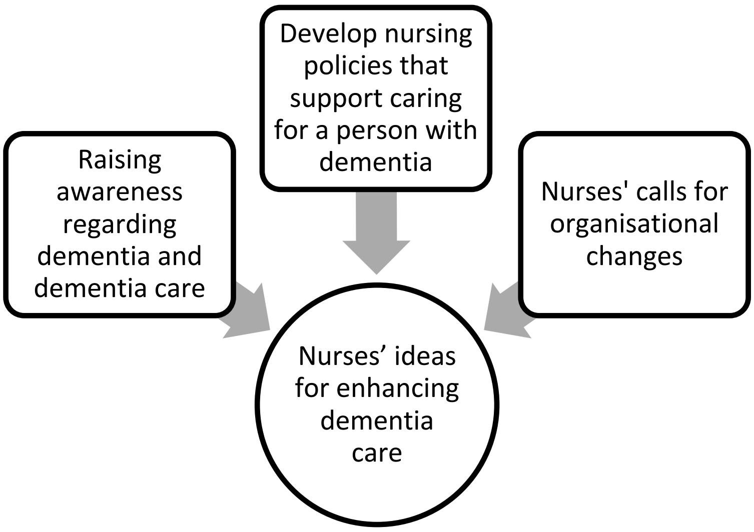

Figure 6.7 Theme five sub-themes

### *Raising awareness regarding dementia and dementia care*

All the participants acknowledged that they lacked knowledge about people with dementia, the condition itself, and their families and how best to care for those affected. This was in addition to the lack of research conducted in the country and the availability of training courses in Saudi Arabia. For example, one participant said, ‘I feel that what I know is still a drop in the ocean. Dementia is a huge subject. I would like to know more about it’ (P08 INT). One participant added, ‘Dementia patients need a well-trained nurse with high compassion’ (P05 INT). Moreover, three of the participants asked about recent numbers and statistics regarding people with dementia and specialised nurses, to better know about the care system and available resources.

Participants acknowledged that core knowledge about dementia is much needed since the number of people with dementia admitted in the previous few months was higher than last year. During the interview, eleven of the participants were keen to improve their knowledge and asked to know the symptoms of dementia, its causes, types, and the descriptions of each stage. Most importantly, all participants agreed that they wanted to know about the ways to treat people with dementia and communicate with them. They wanted to know what actual nursing care for people with dementia looks like:

> ‘Still we do not have sufficient information and acquired knowledge to help us provide care for them. We really need courses and awareness in each hospital. It will be better to have an intensive training for it.’
>
> **(P15 INT)**

Additionally, all participants who had relatives with dementia were concerned about the risk factors and causes of the disease and wanted to know about the available treatments and interventions to stop or slow down the disease’s progression.

Moreover, nurses wanted to ensure that they adhere to certain ethical behaviours and characteristics when caring for people with dementia, and most (n=10) felt that self-awareness, dedication, and patience were the most important characteristics nurses caring for people with dementia should possess:

> ‘A nurse is caring, loving, and, regardless of how hard it is, we need to do it; we need to be patient because they are patients. They came here in the hospital because they need us […]. If you love your work, regardless of how difficult it is, it seems ... it will be ... it's just not easy, regardless of how stressful it is, especially in this hospital. But, if you love your work, and you love what you are doing, you will be successful.’
>
> **(P25 INT)**

### *Develop nursing policies that support caring for a person with dementia*

It was clear from the analysis of the interview data that no policies were available regarding care for people with dementia. Although administrative nurses argued about the importance of reviewing hospital policies annually, there is nothing that pertains to caring for people with dementia. One head nurse said, ‘Most of our policies should be reviewed again and developed. I think we should review yearly. Because these policies are defining our institution. With these policies… our work depends on these policies’ (P23 INT). Despite bedside and community care nurses’ acknowledging the need for developing policies, they were more concerned about paperwork, as they stated that they had too much paperwork to fill out, such as risk assessment forms:

> ‘Extreme routine in the documentation. As nurses, we have to fill up a lot of forms, which becomes a load for us, and we find it useless for the patient and a waste of time for us. But if we have something that is really beneficial for the patient, why not?’
>
> **(P04 INT)**

Hence, participants suggested four important policies that needed to be formulated to care for persons with dementia: self-introductions, nurse-to-patient ratio and specialist nurses, maintaining safety, and the mandatory and constant presence of a family member for patients with dementia.

The available policies are general about introducing oneself during the first meeting with a patient and explaining the procedures and treatments that would be given. However, for a person with dementia it was suggested by five participants—working at extended medical, surgical, and emergency wards—that nurses should introduce themselves every time they approach a patient with dementia. ‘To an Alzheimer's patient, I must introduce myself not every day, but every time I enter her room, and sometimes I even do it a few times in the same meeting’ (P03 INT). A person with dementia was perceived by most study participants (n=16) as a critical patient who required close observation, was always to be accompanied, and needed more time to properly communicate with. Therefore, all the participants agreed that nurse-to-patient ratios must decrease to a maximum of 1:3 when there is a case with dementia. A few participants (n=4) suggested having a primary care nurse or a dementia specialist nurse who would be responsible for a person with dementia in acute care settings. Ten participants, across all included wards, suggested at least one trained nurse to care for people with dementia in each ward and to assist other nurses and raise their awareness regarding the required nursing care.

All participants working at the central and psychiatric hospitals doubted the appropriateness of admitting a person with dementia in their ward because of a failure to maintain a safe environment for them. Hence, maintaining a safe environment was suggested as one of the policies that needed to be implemented as well within the organisation. The last policy suggested by all the participants was that a person with dementia must be accompanied by a family member during their hospitalisation. ‘They should make one policy: like for each patient, there should be one family member. So, they will listen more to the family member, and they will not feel loneliness’ (P12 INT).

### *Nurses’ calls for organisational changes*

Starting with the admission into a care facility, crucial changes were suggested to achieve a more positive hospitalisation experience for people with dementia. First, a patient should have some sort of identification; there should be a specialised area in a hospital or a clinic strictly for people with dementia; and a multidisciplinary team ought to care for them. One participant commented:

> ‘[…] increasing the number of staff nurses, providing equipment, providing at least a specialised ward for them. If they cannot provide a specialised hospice for them, as it may cost a lot, at least a specialised ward or department, adding entertainment to the ward and providing them with entertainment stuff.’
>
> **(P16 INT)**

Emergency ward and clinic nurses believed that having some sort of identification for people with dementia that showed their condition would make the work smoother and enhance the care provided. Some participants suggested patients wear bracelets or hold a note that their family could keep in the patient’s wallet. Other participants recommended using colour-coded files or laminated cards that would be attached to their hospital files when persons were suspected to have or had been diagnosed with dementia. Hence, all hospital employees, including administrative and secretarial staff, would know such patients’ special needs. An emergency department head nurse said:

> ‘Maybe we can provide a card pinned to the patient file that he has got dementia. Maybe have the files in certain colours, similar to sorting cases during triage, like colour coding, red or yellow. So, we can add a different colour for the special needs’ cases. These cards will make us differentiate patients and know that this patient has dementia, even if it was not the main complaint that caused his hospital visit.’
>
> **(P19 INT)**

Another participant agreed, saying, ‘I recommend that every patient admitted to the hospital MUST have a card or something to prove that he has Alkharaf so that he can receive special care’ (P15 INT).

All nurses suggested that having a specialised ward or even a clinic just for people with dementia was most needed so that patients could receive high quality care from qualified and specialised nurses. It was suggested that such specialised wards would have to have home-like bedrooms, living areas, dining areas, and flexible rules such as walking outside the ward and various meal options: ‘A good long-term facility should feel comfortable and homelike’ (P24 DIA). Most participants commented similarly:

> ‘The care differs. Their needs are different […] with his personal care […] we need to trick them to give it (medication and eating) unlike other regular patients […] The patient with dementia, I need to trick him to give him his medication, trick him to eat, trick him to clean and shower, and so on. He needs special care [….] They should be admitted in specialised areas for dementia.’
>
> **(P21 INT)**

The emergency care and clinic nurses (n=6) suggested having a clinic within each hospital run by a specialist in dementia care to assist in the care provided to people with dementia, their families and caregivers, similar to those in diabetes and violent services clinics:

> ‘Opening a clinic […] will make the sorting easier and save time for doctors and minimise the load on us. At the same time, it will make them special [….] At least if the patient does not have a significant illness and does not require immediate intervention, he can be transferred to this clinic. Then, at this clinic, they will educate the family and close relations of the patient.’
>
> **(P20 INT)**

Significantly, all the female participants considered a multidisciplinary team to be of fundamental significance in order to deliver quality care for people with dementia: ‘In order to deliver high-quality care, all the members in healthcare must co-operate well’ (P14 DIA). The team would include nurses, physicians, social workers, psychiatrists, occupational and recreational therapists, translators, dieticians and religious representatives[3]. The importance of the role of social workers to aid in communicating with persons with dementia and their families and educate them about the condition was acknowledged by most participants (n=15). Then, the need for psychiatrists in the team to help enhance the psychological well-being of patients was suggested by ten participants. Additionally, all the non-Arabic-speaking participants (n=6) acknowledged the importance of having a translator amongst the care team. For occupational and recreational activities, such as crafts, crochet, yoga, meditation and music sessions, occupational and recreational therapists were suggested by some participants. In fact, the psychiatric hospital participants (n=2) confirmed that the recreation area they had in the hospital had a positive influence on the care provided. Both participants advocated for it as it reduced the load for nurses and allowed other team members to provide specialised service. This, in turn, entertained a person with dementia and improved his/her psychological status.

## 6.3 Key points from the diary-interviews

These data extracts show that nurses are aware of their lack of knowledge, but they are nevertheless able to draw on their personal experiences and cultural beliefs to provide appropriate support for people with dementia. Moreover, all three aspects of attitudes – affective, behavioural and cognitive – inform nurses’ behaviours and their knowledge, as well as their perceptions towards caring for people with dementia. Socio-cultural factors, such as society and social norms, negatively impact nurses’ perceptions and dementia nursing care. Lastly, all nurses called for organisational changes and for actions aimed at meeting the healthcare requirements for people with dementia, as well as to enhance their well-being and improve nursing care practices within KSA hospitals.

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[3] A religious member is a person who works within the hospital and meets and talks to patients about Islamic religion, end-of-life and the later life after death on a regular basis.

More specifically, participants seemed acutely aware of the lack of training opportunities, particularly in the KSA. This lack of knowledge may be connected to the idea that dementia is a disease caused by *Gadar* (fate), a test from God for the person with dementia and his/her family, and is therefore a natural means to atone for one's sins (Khan, 1994); this idea is confirmed in the published literature review, which suggests that this is the case among other Eastern-Mediterranean people as well (Yaghmour, Bartlett and Brannelly, 2019).

Another significant finding from the diary-interviews data was that nurses' emotions, notably sadness, love and anger, were influential factors in the care they provided. These emotions are of particular note since participants had had negative experiences and were not confident about the care they provided. For instance, participants from all wards have expressed anger as a result of patients' aggressive behaviour towards them, as well as the shortage of and inaccessibility to healthcare facilities. These mostly negative feelings were echoed in the literature review, wherein nurses working at psychiatric wards and community care facilities in Australia, Canada, Japan and the Netherlands have noted similar negative correlations between a person's cognitive status and aggressive behaviour and nurses' perceptions that drive their anger (Eritz *et al.*, 2016; Van Hoof *et al.*, 2016; Kang *et al.*, 2017). This is suggested to be linked to communication difficulties and a patient's inability to make decisions for him/herself. While the literature review does mention love and compassion, psychological stress was more commonly noted in most of the literature (Yada *et al.*, 2014; McPherson, Hiskey and Alderson, 2016; Monthaisong, 2018; Yaghmour, 2021) refer to3.3. Researchers have claimed that although emotional work is a part of many different occupations, it is the *hallmark* of nursing and of providing proper care (Ruckdeschel and Haitsma, 2004, p. 43); as nurses are more emotionally involved with patients' conditions, this work renders nurses' feelings more prone to volatility, wherein nurses must learn to express only the appropriate ones yet manage all their emotions in order to maintain professional nurse-patient relationships (Bolton, 2000; Delgado *et al.*, 2017). In other words, they cannot sympathise too deeply or show their grief as they must always uphold a professional face (Bolton, 2000). Thus, it is evident that understanding nurses' emotions while at work in a care environment is essential in helping them assess their own emotional intelligence (Bolton, 2000; Delgado *et al.*, 2017).

As participants in this study were self-aware, motivated and had the capacity to process information and analyse the causes of their emotional states, it was evident that their emotional intelligence should contribute to forming a clearer picture of the complex nature of nursing care required for dementia patients. Thus, administrative nurses and organisational development personnel should henceforth consider emotional intelligence skills and cognitive capacities and be responsible for the development of policies to demonstrate appropriate emotional work practices.

Another finding relates to patients' behaviours and participants' perceptions, which were found to affect care practices. Nurses perceived a person with dementia as neither alive nor dead, a stranger to oneself and being in a place that cannot accommodate them. Therefore, participants viewed the care for people with dementia as being difficult and challenging, consequently affecting their stability and mood swings, which were exacerbated by patients' inabilities to express their feelings or needs and being demanding of others. Moreover, some patients' aggressive behaviours caused added stress among some nurses, indicating that extra care and special ways of communication were needed to deliver the care. However, workplace routines and policies, along with staff shortages, were considered barriers to providing this proper nursing care.

Societal and cultural norms are other factors that impacted the participants' knowledge, attitudes and perceptions. For instance, nursing care is performed much more easily when family members show high levels of awareness about people with dementia. Unfortunately, from the participants' diaries it could be seen that families in the KSA actually had a negative impact on the nurses and patients, especially due to their low awareness levels and negative attitudes. Some Saudi participants reported that families were increasingly tending to abandon their relatives in hospitals for days, sometimes months, without taking them home or answering their phones, particularly when the person with dementia had neither a spouse nor children. A participant said:

> 'They [the family] are not even answering their phones. They know the hospital numbers and they are not answering […] their families are refusing to take them out because they are difficult to deal with at home, so they prefer to leave them here to be taking care of'
>
> **(P21 INT)**

Another participant added: ‘when they do not have the strong family-bond, they will just leave the patient for the care of the rehabilitation’ (P23 INT). All extended convalescence medical wards and psychiatric wards nurses contend that the presence of a person with dementia or with suspected dementia at these wards was likely an indicator of abandonment by their families. Of course, this not only adds to the emotional challenges of caring for people with dementia, but it also adds increased administrative burdens.

With this in mind, the last finding has to do with organisational pressures. In addition to communication challenges, the nurse-to-patient ratio was seen by all participants as a main reason for their stress and inability to provide good nursing care. Bedside nurses, in particular, claim that they care for seven to ten patients, including one or two with dementia, which has negatively impacted overall care. This of course leads to further increases in stress levels, burnout and emotional strains. In fact, a recent scoping review claims that many studies exposed unfortunate patient outcomes as adverse effects of low staffing of nurses (Griffiths *et al.*, 2020). Despite a nursing supervisor’s claim that when a person with dementia is admitted the ratio changes to one nurse to three patients, all the other participants stated that they never cared for fewer than six patients at a time, even with the presence of a person with dementia. Hence, participants universally called for action, with some recommending having a primary nurse or nursing assistant to deal with people with dementia. However, a retrospective longitudinal observational study in the UK found that having a temporary nursing assistant who is not properly trained actually increases the threat of death (Dall’Ora, Maruotti and Griffiths, 2020). Thus, it is important to have knowledgeable nurses with higher degrees while at the same time increasing staff sizes to enhance patients’ well-being and maintain healthy care environments for both nurses and patients.

Hopefully, all of these insights will be useful in developing a theoretical framework for dementia nursing practices and emerging future projects from the present study.

## 6.4 Summary of this chapter

This chapter provides an in-depth overview of the key findings from the diary-interviews data. Five main themes and their sub-themes are identified and summarised, with support from direct quotations from diary entries and interview transcripts. The five themes are (1) acquisition of knowledge and belief systems of nurses, (2) attitudes informing nurses' behaviours, (3) nurses' perceptions towards living with and caring for dementia, (4) socio-cultural factors affecting nursing practices and (5) nurses' ideas for enhancing dementia care.

Interviews were found to support information entered in the diaries, which aided in detecting the actual experiences of the participants. This in turn assist the triangulation by observing different points using different methods (Jupp, 2006). Diary entries reflected participants' care, emotions and personal wisdoms and insights, while the interviews aided in understanding nurses' knowledge acquisition and their belief systems and explored their attitudes and perceptions towards people with dementia and dementia care. The subsequent chapter presents the data integration process and its findings from the surveys, diaries and interviews. Using the Pillar Integration Process further analysis was undertaken to gain more insights into nurses' knowledge, attitudes and perceptions.

# Chapter 7 Dataset and Pillar Integration

This chapter presents and explains the dataset, which represents the findings from the Survey and Diary-Interviews data analysis. It then outlines the four stages of pillar integration using tables to show the integration process and building of themes. Each pillar (which can also be understood as a 'finding') is then presented and explained in greater detail before the study findings are summarised and reflected upon.

Analysing the data in an integrated way ensured that the data generated was valid and reliable and could be generalised (Gibbs, 2018). The extensive explanation of nurses' experiences and perceptions was made to ensure a valid outcome. Moreover, research validity is required to minimise error and produce deeper clarification of the dataset (Gibbs, 2018). In the present study, the data triangulation was based on the questionnaire and diary-interviews data, with incorporation of the reflexive diary of the study researcher who used mixed methodologies to investigate the nurses' knowledge, attitudes and perceptions. The validation process included transcriptions of the interviews and translations of the diary-interviews entries. To ensure the validity and reliability of the translation process, transcripts from the diary-interviews were translated from Arabic to English and were sent to the participants for their feedback on the accuracy of the translation. In addition, two thirds of coding were applied to the data during the analysis process, as well as code cross checking to maintain validity and reliability (Gibbs, 2018). The findings were reported with constant comparisons between participants, different datasets and settings with quotations sustaining the analysis process. Furthermore, consistency between the questionnaire data and diary-interviews respondents' findings confirmed the reliability of the research results

The survey data identified five central areas of focus: (1) a positive association between knowledge and attitudes, (2) the impacts of work environment on nurses' knowledge and attitudes, (3) the influence of educational and cultural backgrounds on nurses' knowledge levels and attitudes, (4) nurses' low self-confidence, which further affects their comfort level when caring for people with dementia, and (5) nurses' basic knowledge about dementia. The in-depth analysis of the diary-interviews data identified five areas of focus: (1) the acquisition of knowledge and the belief systems of nurses, (2) the attitudes informing nurses' behaviours, (3) nurses' perceptions towards living with and caring for people with dementia, (4) socio-cultural factors affecting nursing practices and, finally, (5) nurses' ideas for enhancing dementia care. These findings have been highlighted and summarised, including the sub-themes associated with these.

## 7.1 The datasets

To begin the pillar integration process, it is important to manage the dataset. Considering that one of the reasons for using NVivo was to integrate the data, the quantitative data were exported to NVivo as case classifications along with the audio files and transcripts. Case classification is the collection of code ‘nodes’ that have multiple variables, or ‘attributes’, which represent participants.

The data were analysed abductively using all the datasets from surveys, diaries and interviews. In addition, a categorical pattern approach, implied by the survey’s quantitative analysis and applied within the existing literature by implementing a dialectical view, was used to identify patterns and meaningful themes among the participants. An overarching question was raised by the study researcher from the datasets of the survey and diary-interviews: what recommendations can be developed to inform policy and/or practice development and to improve nursing care for people with dementia in the KSA? In order to answer this question, a further analysis of the results was applied to gain better insights into current nursing practices and to identify the barriers and obstacles nurses face. To do this, the data were integrated with the mixed method, which formed the dissemination part, to develop recommendations for nursing practices and future implementation within the KSA’s nursing environment. The integration process of the survey and diary-interviews data follows.

## 7.2 Pillar integration process

To review, the data integration techniques that were used in this study are transformation and cross-case matrix in two stages (for further discussion, refer to sections 4.2.3 and 4.8.3). Firstly, the data transformation technique was applied when the questionnaire statements were interpreted and analysed qualitatively—i.e. when the questionnaire data were analysed using a qualifying technique (see section 4.2.3 for details). The cross-case matrix technique was used to visualise the study’s findings and to help in the dissemination of the results.

The visualised cross-case matrix used in this study is the pillar integration process guidance, which incorporates four stages: listing, matching, checking and pillars building. This is a type of joint display for integrating quantitative and qualitative findings that is rigorous and transparent (Johnson, Grove and Clarke, 2019; Younas, Pedersen and Durante, 2020). The integration process involves merging the findings across datasets throughout the transformation technique and joint display (Creswell and Clark, 2011; Fetters , Curry  and Creswell, 2013; Johnson, Grove and Clarke, 2019). The joint display aids in creating a structure of the integrated results by having columns for both quantitative and qualitative data that are presented at opposing sides, and then moving to the centre to focus on themes. The headings of the columns were established while listing, matching, checking and later pillars building from the data to direct the integration process to reach a conclusion (as shown in Figure 4.3). The application of this methodological integration is meant to maximise the data contents of the current knowledge, attitudes and perceptions of nurses caring for people with dementia. It also extends synthesis prospects and reduces the researcher's bias (Johnson, Grove and Clarke, 2019). Henceforth, the pillar integration process is a systematic four-stage technique that aids in the integration of multiple data sources using a cross-case matrix.

### 7.2.1 Pillars listing

In the first stage of the integration process, data were listed in a blank table, starting with the survey findings, including percentages, scores and findings. This information is listed under the 'Survey data/list' and 'Survey category/themes' columns. The listing was done selectively based on the survey's findings identified from the earlier analysis to meet the study's aim and objectives (Chapter 5). By the end of this phase, two columns out of five were completed on one side of the integration template. The findings from the quantitative data were listed in the 'Survey data/list' column. Then these data were listed, abstracted and transformed in the 'Survey category/theme' column (see Table 7.1 below). Firstly, all key points from the survey data were listed, then, similar topics were grouped together and abstracted under a broader heading, and, finally, transformed into themes. The survey categories/themes identified include scores, nurses' low self-confidence that alters their comfort level, basic knowledge nurses possess about dementia with minimal resources available, and what they have learned about dementia. The cognitive aspect of attitude statements had the most positive responses. Negative responses were accredited to the affective and behavioural aspects of attitudes, family with dementia, how educational and cultural backgrounds influence nurses' knowledge levels and attitudes and work environment implications on nurses' knowledge and attitudes.

The table below presents the quantitative data. This was an extensive list, but through the integration process the data was streamlined.

Table 7.1 Pillars listing

**Survey (SUR= 710)**

| **Data/ list** | **Category/ themes** |
|---|---|
| - Participants scored between 0–38 in a 0–42 scale with a mean of 24.15 for their knowledge about dementia.<br>- Diary-interviews participants' scores vary between 12 and 34 with a mean of 25.89.<br>- Participants scored 53–129 in a 20–140 scale with a mean of 93.92 for their attitudes towards dementia.<br>- Diary-interviews participants' scores vary between 64 and 129 with a mean of 103.<br>- A positive and linear association between knowledge and attitudes scores is presented ($R^2$ 0.1116). | Low to moderate scores noted with a positive association between knowledge and attitude scores |
| Within the knowledge questionnaire, the comfort category had the most undecided statements and participants had the least knowledge on this point. | Nurses' low self-rated confidence associated with their comfort level |
| - A significant low level of knowledge about dementia has been noted.<br>- Most participants stated that dementia occurs in the brain, that it is progressive and that Alzheimer's disease is one of its main causes (90.3%; 83.8% and 63.2%, respectively).<br>- Access to evidence-based resources at work relates to holding more positive attitudes. | Nurses' basic knowledge about dementia with minimal resources available |
| - In a scale of 1 to 5, the mean of survey participants who are willing to learn about dementia is 3.1 and the diary-interviews participants' mean was a bit higher, 3.4.<br>- 124 (17.5%) participants provided contact details to participate in the study. | Nurses own rating of their willingness to learn about dementia |
| - 79% of participants acknowledged that a person with dementia has different needs.<br>- 76.6% of participants believed that they can do a lot to improve the lives of people with dementia.<br>- Almost 70% of participants acknowledged that difficult behaviour is a form of communication for people with ADRD. | The cognitive aspect of attitude statements had the most positive responses |
| - 51% admitted that they are not very familiar with dementia.<br>- 41.3% feel frustrated, as they are not confident about the care they provide to people with dementia.<br>- 40.8% 'I would avoid an agitated person with ADRD.' | The affective and behavioural aspects of attitude statements had the most negative responses |

| **Survey**<br>**(SUR= 710)** | |
|---|---|
| **Data/ list** | **Category/ themes** |
| 124 of the study participants 17.5% had a family member with dementia. | Study participants' experiences with having a family member with dementia |
| - A statistically significant link was found between positive attitudes and high dementia knowledge among Filipino (25.8%) and Indian (26.8%) nurses.<br>- Most diploma holding participants are Saudi with fewer Saudi nurses holding bachelors and masters degrees<br>- A statistically significant link found between participants having bachelors and masters degrees with more positive attitudes and higher knowledge. | Educational and cultural backgrounds influence nurses' knowledge levels and attitudes |
| - Working at emergency departments (14.5%) and surgical wards (12.8%) significantly leads to more negative attitudes and lower knowledge among participants.<br>- The availability of evidence-based resources at work (27.6%) is associated with positive attitudes and significantly related to lower knowledge.<br>- Working in wards admitting different diagnoses is associated with positive attitudes, but also with lower knowledge | Work environment implications on nurses' knowledge and attitudes |
| - Spending more than six years in a dementia ward (28.6%) was found to be strongly associated with the lowest knowledge and the forming of the most negative attitudes.<br>- Lower knowledge was found to be linked to nurses providing care for people with dementia at hospitals (42.1%) even when having a family member with dementia (17.5%). | Nurses' experience influences their knowledge and attitudes |

### 7.2.2 Pillars matching

After completing the first stage of the integration process, the relevant data of the diary-interviews, such as selected quotations and abstracted categories and themes, were listed in the 'Diary-Interviews codes/quotes' and the 'Diary-Interviews categories/themes' columns (see the Table 7.2 below). While this process may seem straightforward and iterative, it in fact requires a lot of concentrated effort and plotting. An extensive list of qualitative data from data excerpts and codes was developed, after which both columns—a quantitative list and a qualitative list—were matched and presented accordingly. This was done to match the findings from the different methods used in this study. During this stage, the data in the opposing columns were matched to reflect content related to the raw listed data and to align with similar data in the corresponding column. The listed data were then refined and organised accordingly. By the end of this stage, four columns were completed. The findings from the qualitative data were listed in the 'Diary-Interviews codes/quotes' column. Then these data were listed, abstracted and transformed in the ‘Diary-Interviews category/theme’ column. The Diary-Interviews categories/themes include knowledge about dementia, confidence level and comfort, desire to know about dementia and dementia care, nurses’ acknowledgement of the need for training and for raising awareness about dementia and dementia care, communication difficulties and personal care, frustrations and feelings associated with providing nursing care for people with dementia, nurses’ shame of a diagnosis in one’s own family, social stigmas and cultural norms, societal implications stemming from the care provided and workplace issues perceived as deterring dementia nursing care.

Table 7.2 Pillars matching

| | **Diary-Interviews (DIA= 17, INT= 18)** |
|---|---|
| **Category/ themes** | **Codes/ quotes** |
| Dementia knowledge acquisition and current nurses’ cognition about dementia | - ‘My source of information regarding dementia is this orientation of this hospital.’ (P08 INT).<br>- ‘We studied about it; however, it was just an idea; a dementia and that’s it. When we started working, we were supposed to forget about it and start all over again to gain knowledge with experience.’ (P03 INT). |
| Confident feeling and the link with nurses’ comfort level | - Three participants expressed uncomfortable feelings when talking about caring for people with dementia during interviews.<br>- Three participants wrote about comfort levels in their diary entries.<br>- In the diaries, participants rated their confidence as confident to very confident and further claimed during the interviews that the more they know the patient the more confident they become. |
| Nurses are keen to learn about dementia and dementia care | - Fifteen participants during the interviews said that they wanted to know about the disease itself, its stages and complications and, most importantly, nursing care and ways of approaching the patients and providing them nursing care.<br>- ‘If there is any cure, I would like to know. Support system, environment, that long-term ... I do not know whether this kingdom has, like a facility.’ (P24 INT) |
| All nurses acknowledged the need for training and for raising awareness about dementia and dementia care | - Recommendations and ideas regarding improving dementia nursing practices (DIA/INT), including training, research, and education (DIA/INT) were collected from 25 files and 70 references. Also, areas participants need to know more about were spotted (INT) from 15 files and 25 references.<br>- ‘To be honest they were not teaching us these things; unfortunately, nothing was given […] No one motivated us to learn, or called to train us, unless you had the courage yourself.’ (P04 INT)<br>- ‘I feel that what I know is still a drop in the ocean. Dementia is a huge subject. I would like to know more about it.’ (P08 INT) |

| | **Diary-Interviews (DIA= 17, INT= 18)** |
|---|---|
| **Category/ themes** | **Codes/ quotes** |
| Difficulties faced by nurses when communicating with people with dementia and providing them personal care | - Communication is perceived as a main barrier in providing dementia nursing care.<br>- 'Never disregard the psychological status of the patient or his ability to boost his contribution to his own care and communicate properly with him.' (P04 DIA) |
| Frustrations and feelings associated with providing nursing care for people with dementia | - 'Alzheimer's patients are very sensitive as everything around them is different; the disease hinders social relationships that causes their sensitivity. From my observation, they struggle to perform the easy tasks they used to do before and as a result they become so nervous.' (P22 DIA)<br>- 'At the time we needed them, they did not let us down. I hope this time we will pay them back—their standing next to us in our ups and downs; they were with us every step.' (P20 INT) |
| Nurses' shame of a diagnosis in their own families | - Eight of the participants (44%) had a family member with dementia, four preferred not to report that in the survey.<br>- When the family member with dementia was from the mother's side, they were found to have more regret.<br>-'Because the patient's daughter has no idea of her mother's disease, there is no knowledge and no cooperation at all.' (P03 DIA)<br>- '[...] though her son and daughter were hiding this (dementia diagnosis) and we had not been told this clearly.' (P19 INT) |
| Stigma and cultural norms: societal implications on the care provided | - 'Usually we have restrictions for the male and for the female; especially if you are a male providing care to a female. So, that greatly affects them because for these people, you need to assist them and when you speak to them, there are some restrictions on discussing a lot of things here in Saudi Arabia; so, it affects the care that can be provided.' (P25 INT) |
| Organisational roles and work environment impact nurses' perceptions of nursing care for people with dementia | - 'They should make one policy: like for each patient, there should be one family member. So, they will listen more from the family member, and they will not feel loneliness.' (P12 INT)<br>- 'If you admitted him (patient with dementia) in a general area with other patients, the nursing staff have a lot of responsibilities. So, I think there should be special nurses for them.' P17 INT |
| Workforce issues perceived as deterring the nursing care for people with dementia | - 'Care for this patient needs a single nurse, which means a 1:1 ratio one. The patient should be handled by one nurse.' (P12 DIA)<br>- 'Of course, the years of experience has a positive impact on you and the patient in terms of how we deliver the medical care to the patient. The more experience you have, the more cases you care for. Normally, this will be better for you and the patient.' (P04 INT) |

### 7.2.3 Pillars checking

The third stage of the integration process involves checking the previous stages for quality purposes. During this stage, all data that were listed and matched were closely investigated. Also, it was ensured by the study author that all data listed and categorised met the aim and objectives of this study. Therefore, lists and their matches were checked and discussed during the supervisory meetings prior to building the pillars and finalising the integrated findings.

### 7.2.4 Pillars building

In this stage, the central column was filled out with the pillars identified by synthesising the themes noted. The researcher's conceptualised insight is illustrated by integrating and connecting survey and diary-interviews data. Each identified pillar holds the integrated themes from each row. After all the pillars were presented in the table, the researcher was able to weave pillars together into more meaningful descriptions from the survey and diary-interviews integration (see the Table 7.3 below).

Table 7.3 Overview of the pillars

| **Survey (SUR= 710)** | | **Pillar building** | | **Diary-Interviews (DIA= 17, INT= 18)** |
|---|---|---|---|---|
| **Data/ list** | **Category/ themes** | **Themes** | **Category/ themes** | **Codes/ quotes** |
| - Participants scored between 0–38 in a 0–42 scale with a mean of 24.15 for their knowledge about dementia.<br>- Diary-interviews participants' scores vary between 12 and 34 with a mean of 25.89.<br>- Participants' scored 53–129 in a 20–140 scale with a mean of 93.92 for their attitudes towards dementia.<br>- Diary-interviews participants' scores vary between 64 and 129 with a mean of 103.<br>- A positive and linear association between knowledge and attitudes scores is presented ($R^2$ 0.1116). | Low to moderate scores noted with a positive association between knowledge and attitude scores | **Pillar one: A lack of knowledge is associated with a lack of confidence when providing nursing care for people with dementia** | Dementia knowledge acquisition and current nurses' cognition about dementia | - 'My source of information regarding dementia is this orientation of this hospital.' (P08 INT).<br>'We studied about it; however, it was just an idea; a dementia and that's it. When we started working, we were supposed to forget about it and start all over again to gain knowledge with experience.' (P03 INT). |

| Survey (SUR= 710) | | Pillar building | Diary-Interviews (DIA= 17, INT= 18) | |
|---|---|---|---|---|
| **Data/ list** | **Category/ themes** | **Themes** | **Category/ themes** | **Codes/ quotes** |
| Within the knowledge questionnaire, the comfort category had the most undecided statements and participants had the least knowledge on this point. | Nurses’ low self-confidence associated with their comfort level | | Confident feeling and the link with nurses’ comfort level | - Three participants expressed uncomfortable feelings when talking about caring for people with dementia during interviews.<br>- Three participants wrote about comfort levels in their diary entries.<br>- In the diaries, participants rated their confidence as confident to very confident and further claimed during the interviews that the more they know the patient the more confident they become. |
| - A significant basic knowledge about dementia has been noted.<br>- Most participants stated that dementia occurs in the brain, that it is progressive and that Alzheimer’s disease is one of its main causes (90.3%; 83.8% and 63.2%, respectively).<br>- Access to evidence-based resources at work relates to holding more positive attitudes. | Nurses’ basic knowledge about dementia with minimal resources available | **Pillar two: Nurses are willing to learn about nursing care for people with dementia but information and resources are not always available** | Nurses are keen to learn about dementia and dementia care | - Fifteen participants during the interviews said that they want to know about the disease itself, its stages and complications and, most importantly, nursing care and ways of approaching the patients and providing them nursing care.<br>- ‘If there is any cure, I would like to know. Support system, environment, that long-term ... I do not know whether this kingdom has, like a facility.’ (P24 INT) |
| - In a scale of 1 to 5, the mean of survey participants who are willing to learn about dementia is 3.1 and the diary-interviews participants’ mean was a bit higher, 3.4.<br>- 124 (17.5%) participants provided contact details to participate in the study. | Nurses’ own rating of their willingness to learn about dementia | | All nurses acknowledged the need for training and for raising awareness about dementia and dementia care | - Recommendations and ideas regarding improving dementia nursing practice (DIA/INT), including training, research, and education (DIA/INT) were collected from 25 files and 70 references. Also, areas participants need to know more about were spotted (INT) from 15 files and 25 references.<br>- ‘I feel that what I know is still a drop in the ocean. Dementia is a huge subject. I would like to know more about it.’ (P08 INT) |

| Survey (SUR= 710) | | Pillar building | Diary-Interviews (DIA= 17, INT= 18) | |
|---|---|---|---|---|
| **Data/ list** | **Category/ themes** | **Themes** | **Category/ themes** | **Codes/ quotes** |
| - 79% of participants acknowledged that a person with dementia has different needs.<br>- 76.6% of participants believed that they can do a lot to improve the lives of people with dementia.<br>- Almost 70% of participants acknowledged that difficult behaviour is a form of communication for people with ADRD'. | The cognitive aspect of attitude statements had the most positive responses | **Pillar three: Nurses' attitudes, emotions and perceived communication difficulties affect their delivery of dementia care** | Difficulties faced by nurses when communicating with people with dementia and providing them personal care | - Communication is perceived as a main barrier in providing dementia nursing care.<br>- 'Never disregard the psychological status of the patient or his ability to boost his contribution to his own care and communicate properly with him.' (P04 DIA) |
| - 51% admitted that they are not very familiar with dementia.<br>- 41.3% feel frustrated, as they are not confident about the care they are providing to people with dementia.<br>- 40.8% 'I would avoid an agitated person with ADRD'. | The affective and behavioural aspects of attitude statements had the most negative responses | | Frustrations and feelings associated with providing nursing care for people with dementia | - 'Alzheimer's patients are very sensitive as everything around them is different; the disease hinders social relationships that causes their sensitivity. From my observation, they struggle to perform the easy tasks they used to do before and as a result they become so nervous.' (P22 DIA)<br>- 'At the time we needed them, they did not let us down. I hope this time we will pay them back—their standing next to us in our ups and downs; they were with us every step.' (P20 INT) |
| 124 of the study participants (17.5%) had a family member with dementia. | Study participant had a family member with dementia | **Pillar four: The stigma associated with a dementia diagnosis, as well as cultural norms and perceptions of dementia can have a negative impact on nursing care for people with dementia** | Nurses' shame of a diagnosis in their own families | - Eight of the participants (44%) had a family member with dementia, four preferred not to report that in the survey.<br>- When the family member with dementia was from the mother's side, they were found to have more regret.<br>-'Because the patient's daughter has no idea of her mother's disease, there is no knowledge and no cooperation at all.' (P03 DIA)<br>- '[…] Though her son and daughter were hiding this (dementia diagnosis) and we had not been told this clearly.' (P19 INT) |

| **Survey (SUR= 710)** | | **Pillar building** | | **Diary-Interviews (DIA= 17, INT= 18)** |
|---|---|---|---|---|
| **Data/ list** | **Category/ themes** | **Themes** | **Category/ themes** | **Codes/ quotes** |
| - A statistically significant link was found between positive attitudes and high dementia knowledge in Filipino (25.8%) and Indian (26.8%) nurses.<br>- Most diploma holding participants are Saudi with fewer Saudi nurses holding bachelors and masters degrees<br>- A statistically significant link found between participants having bachelors and masters degrees with more positive attitudes and higher knowledge. | Educational and cultural backgrounds influence nurses' knowledge level and attitudes | | Stigmas and cultural norms: societal implications on the care provided | - 'Usually we have restrictions for the male and for the female; especially if you are a male providing care to a female. So, that greatly affects them because for these people, you need to assist them and when you speak to them, there are some restrictions on discussing a lot of things here in Saudi Arabia; so, it affects the care that can be provided.' (P25 INT) |
| - Working at emergency departments (14.5%) and surgical wards (12.8%) significantly leads to more negative attitudes and lower knowledge among participants.<br>- The availability of evidence-based resources at work (27.6%) is associated with positive attitudes and significantly to lower knowledge.<br>- Working in wards that admit different diagnosis is associated with positive attitudes but lower knowledge | Work environment implications on nurses' knowledge and attitudes | **Pillar five: Organisational factors can negatively impact the nursing care for people with dementia** | Organisational roles and work environment impact nurses' perceptions of nursing care for people with dementia | - 'They should make one policy: like for each patient, there should be one family member. So, they will listen more from the family member, and they will not feel loneliness.' (P12 INT)<br>- 'If you admitted him (patient with dementia) in a general area with other patients, the nursing staff have a lot of responsibilities. So, I think there should be special nurses for them.' P17 INT |
| - Spending more than six years in a dementia ward (28.6%) was found to be strongly associated with the lowest knowledge and the forming of the most negative attitudes.<br>- Lower knowledge was found to be linked to nurses providing care for people with dementia at hospitals (42.1%) even when having a family member with dementia (17.5%). | Nurses' experiences influence their knowledge and attitudes | | Workforce issues perceived as deterring nursing care for people with dementia | - 'Care for this patient needs a single nurse, which means a 1:1 ratio one. The patient should be handled by one nurse.' (P12 DIA)<br>- 'Of course, the years of experience has a positive impact on you and the patient in terms of how we deliver the medical care to the patient. The more experience you have, the more cases you care for. Normally this will be better for you and the patient.' (P04 INT) |

## 7.3 The findings of this study

In this study, a pillar is a ‘finding’; therefore, the five main pillars identified through the integration process are discussed in this section. These are shown in Table 7.3, and are (1) a lack of knowledge is associated with a lack of confidence when providing nursing care for people with dementia, (2) nurses are willing to learn about nursing care for people with dementia but information and resources are not always available, (3) nurses’ attitudes, perceived emotions and communication difficulties affect the delivery of dementia nursing care, (4) the stigma, cultural norms and perceptions associated with a dementia diagnosis can have a negative impact on nursing care for people with dementia, and (5) organisational factors can negatively impact the nursing care for people with dementia. Together, these pillars inform the discussion and recommendations.

The five pillars are discussed next and each pillar has a figure that summarises the quantitative and qualitative findings and the link between the findings is shown in arrows within each of the five figures Figure 7.1; Figure 7.2; Figure 7.3; Figure 7.4; Figure 7.5). The quantitative findings in this study were either expanded by the qualitative data or confirmed by them.

### 7.3.1 Pillar one: A lack of knowledge is associated with a lack of confidence when providing nursing care for people with dementia

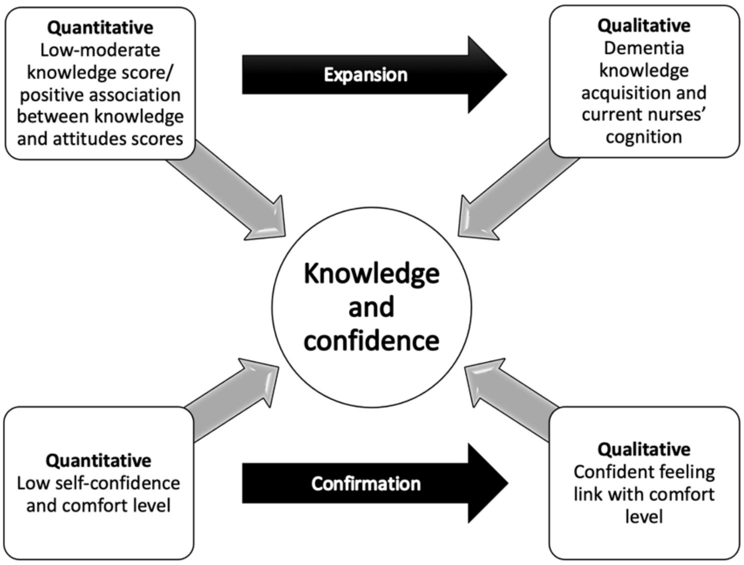


Figure 7.1 The link between quantitative data and qualitative data in pillar one

The survey found low-moderate knowledge scores among the study's participants with an overall mean of 24 in a 42-point scale. A positive association between their knowledge and attitudes scores was also noted. This was further confirmed by the qualitative strand, the diary entries and interviews, which find that the acquisition of dementia knowledge plays an important role in obtaining high scores and enhancing nurses' cognition about dementia (as shown in the above Figure 7.1).

The process of nurses' knowledge acquisition was also found to play a significant role in their confidence levels when caring for people with dementia. Nurses' present knowledge and their cognition about dementia is altered by motivation and resource availability, such as training and reading groups. One participant said: 'To be honest, they were not teaching us these things (caring for people with dementia); unfortunately, nothing was given […] No one motivated us to learn, or called to train us, unless you had the courage to do it yourself.' (P04 INT).

A survey finding shows that low self-confidence about nurses' own cognition about dementia is associated with their comfort level when providing nursing care for people with dementia. Since nurses often do not have the necessary knowledge, they experience a lack of confidence when caring for people with dementia. It is indicated that nurses' age, experience within a specific ward, years of experience as a nurse, as well as the nursing degree they have obtained have an impact on this theme. Around 15% of the study participants were undecided about survey statements in the comfort category, while only a quarter of the study participants agreed that they feel relaxed and confident around people with dementia and admire the coping skills of people with dementia who can be creative.

Younger nurses who had never had any contact with people with dementia and had limited knowledge on their care needs felt a lack of confidence when caring for such patients. Due to the significant rise in the number of people with dementia, a much higher number of both newly graduated and more experienced nurses has to come into direct contact with these patients (particularly during student clinical placements or training) as more rotations are needed between wards every few years. This issue was further expanded on in the diary-interviews, wherein one participant noted in the diary entries that more confidence was gained in day-after-day rating scales. Despite nurses trying their best to provide nursing care for people with dementia, one participant said, 'We studied about it; however, it was just an idea, a dementia and that's it. When we started working, we were supposed to forget about it and start all over again to gain knowledge with experience.’ (P03 INT). Another participant added:

> I feel that I became more curious about this subject. I was looking for these patients to investigate the differences and to know how they behave. I mentioned that I was not focusing on this matter before. But now I would like to know ways of treating them. Are their needs similar to other patients with dementia? Why does this patient need somebody always around while that patient does not? What are the differences between them? This is what I was trying to know—definitely I benefited from writing diaries.
>
> **(P19 INT)**

This finding led to the next pillar: nurses are willing to learn about nursing care for people with dementia but information and resources are not always available.

### 7.3.2 Pillar two: Nurses are willing to learn about nursing care for people with dementia but information and resources are not always available

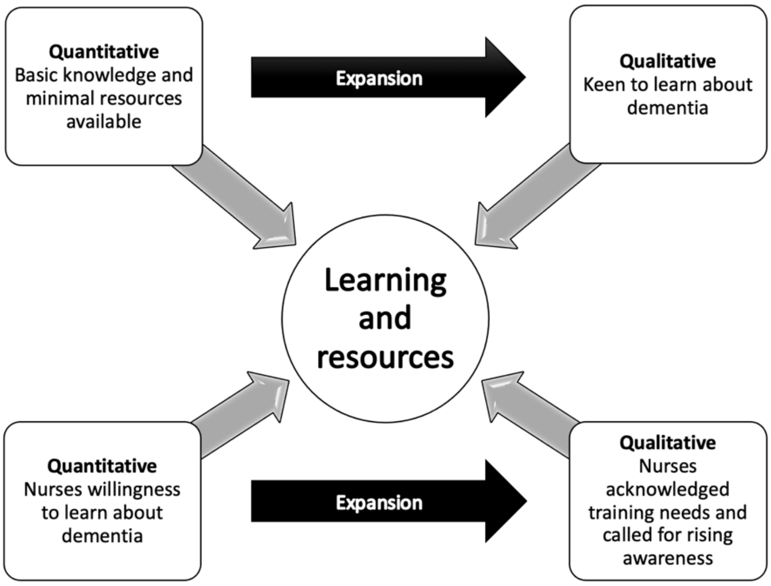


Figure 7.2 The link between quantitative data and qualitative data in pillar two

The significance of having basic knowledge about dementia has been noted from the survey data and then expanded by the diary-interviews data (Figure 7.2). Most participants understand that dementia occurs in the brain, that it is progressive and that Alzheimer's disease is one of its main causes (90.3%, 83.8% and 63.2%, respectively). Yet, around half of the study participants knew less about dementia complications. Fifteen participants during the interviews said that they want to know about the disease itself, its stages and complications and, most importantly, the nursing care and ways of approaching the patients and providing the nursing care. As one participant said:

> As you have seen, what I am doing is similar to all patients. We need to know the different actions that could be done, how to change and ways of communicating and providing care. Knowing ways to treat people with dementia will make things easier. When the patient is admitted, how can we deal or treat him?
>
> **(P03 INT)**

Another participant, when asked about what they want to know about dementia, added: 'If there is any cure, I would like to know. Support systems, environment, that long-term ... I do not know whether this kingdom has, like a facility.' (P24 INT). Another participant added: 'About dementia! Honestly, everything. If you asked me before the study, it was not making any difference. But now I would like to know and am keen to know everything about dementia.' (P19 INT).

Despite participants' willingness to learn about dementia, resource availability seems to be scarce and forms an obstacle to gaining the required knowledge. The survey has indicated that higher knowledge scores were noted when reading groups (5.2%) and computers (37.2%) were accessible at nurses' workplaces. Lower knowledge scores were found among participants who have access to evidence-based resources but more than a quarter of the study participants also hold more positive attitudes. These findings were further expanded during the interviews that show many participants referred to reading (using internet search engines such as Google but not an evidence-based search) as their source of information, in addition to personal experience. Many participants indicated that using search engines is easier than exploring the evidence-based materials as they are not trained to use these even if they have the access to them. One participant said:

> I believe that if a person is well educated, reads a lot, looks for information and gains knowledge […] it may minimise or reduce the occurrence […] of using Google. I found most risk factors that may cause Alkharaf are hard life events, genetics, and sometimes doing physical jobs rather than cognitive ones such as journalists or teachers.
>
> **(P05 INT)**

Participants' own rating of their knowledge about dementia and readiness to learn about dementia with confidence when providing care correlates positively with their knowledge and attitude scores. However, it was noted that nurses' who rated their knowledge high, tended to have more negative attitudes. These quantitative findings show the nurses' willingness to gain knowledge about nursing care for people with dementia. This was further expanded in the diary and interviews. Study participants provided recommendations and ideas regarding improving dementia nursing practice, including training, research, and education (DIA/INT) from 25 files and 70 references, and spotting what areas participants need to know more about (INT) from 15 files and 25 references.

One participant said: 'I feel that what I know is still a drop in the ocean. Dementia is a huge subject. I would like to know more about it.' (P08 INT) Amongst the nursing staff interviewed, nurses are willing to learn about dementia but information is not always available. The nursing staff has indicated their willingness to gain more knowledge of nursing care for people with dementia, particularly hands-on information on correct handling of patients as well as caring for the specific needs of people with dementia. However, such hands-on, experience-based knowledge is not readily available for nursing staff. Despite study participants' having basic knowledge of dementia care, nurses seem to require more information on which hands-on skills are to be used in efficiently providing nursing care for people with dementia to meet their needs as well as effectively carrying out their regular care protocols.

### 7.3.3 Pillar three: Nurses' attitudes, emotions and perceived communication difficulties affect their delivery of dementia care

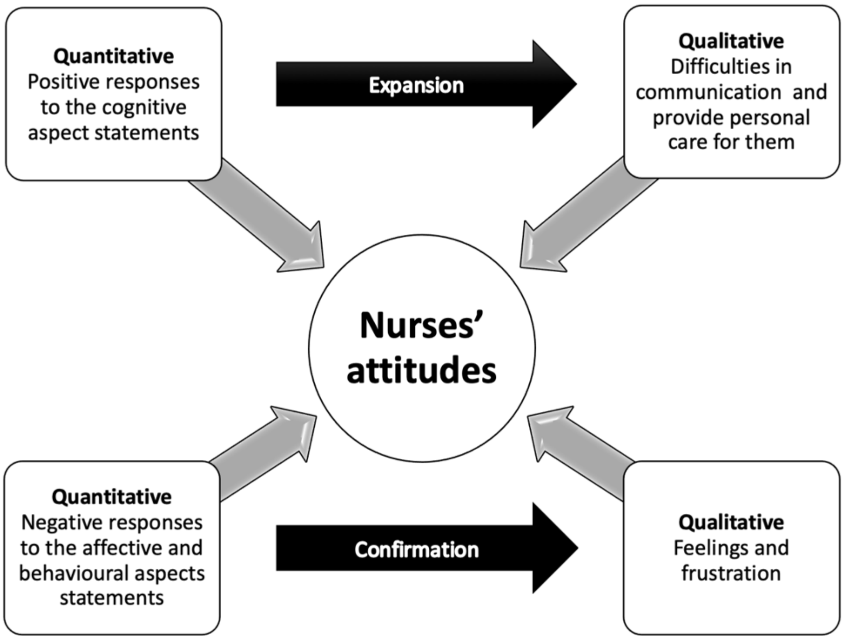


Figure 7.3 The link between quantitative data and qualitative data in pillar three

From the dataset, it was evident that nurses' attitudes towards people with dementia across three aspects—cognitive, affective and behavioural—have an impact on providing nursing care for people with dementia. On the one hand, the cognitive aspect of attitude statements had the most positive responses, being agreeable by more than half of the study participants. Eighty percent of the study participants acknowledged the importance of knowing the past history of the person with dementia and agreed that the person with dementia has different needs. Almost 70% acknowledged difficult behaviours as a form of communication for people with dementia, which was further expanded by the diary-interviews data analysis (Figure 7.3). Participants, in their diaries, had touched on communication challenges and the ways patients communicate. One participant said: 'Never disregard the psychological status of the patient to boost his own contribution to the care and communicate properly with him.' (P04 DIA). While nurses' cognitive attitudes were positive among the survey and diary-interviews data, they face difficulties when communicating with people with dementia and providing nursing care for them. Hence, communication is perceived as a main barrier in providing dementia nursing care. Another participant said: 'Because you cannot understand sometimes what they are telling you, you need to guess. You need to… investigate what they are really saying; so, I think that is one of the barriers.' (P23 INT). Another added: 'Treating Alzheimer's patients is very difficult as I don't know exactly what their needs are, and I am afraid to abuse them.' (P02 DIA).

On the other hand, the affective and behavioural aspects of attitude had the most negative responses, with over half of the study participants agreeing that they are not very familiar with dementia. Approximately 41% feel frustrated, as they are not confident about the care they provide to people with dementia and would avoid an agitated person with dementia. These were confirmed by the diary-interviews data as frustration and feelings of sadness were associated with the nursing care provided to people with dementia.

Again, nurses' comfort and confidence levels are altered by their knowledge level and is reflected in their emotions and the way they provide nursing care for people with dementia. Most diary-interviews participants claimed they experience fear when treating patients. Hence, it was found that nurses' lack of time and patients' comorbidities—in addition to their knowledge level about dementia—play an important role in developing nurses' frustrations and emotions such as fear, sadness and anger. This finding was detected in most nurses' diaries as well as during interviews. One participant wrote: 'There are aspects of daily routines for dementia patients that I will never get used to and it will always irritate you from time to time.' (P13 DIA). Another participant said:

> I hated her because she was aggressive. She slaps my face. She is ... It is understandable, but like I said, your patience will be challenged and you will be like, 'I hate her. I do not want to work with this kind of patient,' like this.
>
> **(P24 INT)**

Another added:

> Sometimes this is exhausting because I have limited time as I care for 6–7 patients besides this case. I would lose my temper if I did not have patience. The situation is not easy and varies according to the work pressure of that day.
>
> **(P03 INT)**

Another participant added:

> It is not their fault and you have to help them even if you have no time and are stressed. One day we may be like them! So, how you care and how you treat them will come back to you DOUBLE. Honestly, it is sad. I feel that the people who are going to value those Alkharaf patients are the Muslim group not like the foreign worker who is not valuing or appreciating the person with Alkharaf. The religious reason affects the impact on this.
>
> **(P15 INT)**

It is shown that nurses' attitudes play a significant role in managing communication barriers and emotional challenges when dealing with people with dementia. Moreover, these difficulties involve the three aspects of attitude and are caused by the nurses' own knowledge levels. These difficulties are in addition to the cultural beliefs and organisational roles that affect care and which make up the next two pillars.

### 7.3.4 Pillar four: Stigmas, cultural norms and perceptions associated with a dementia can have a negative impact on the nursing care for people with dementia

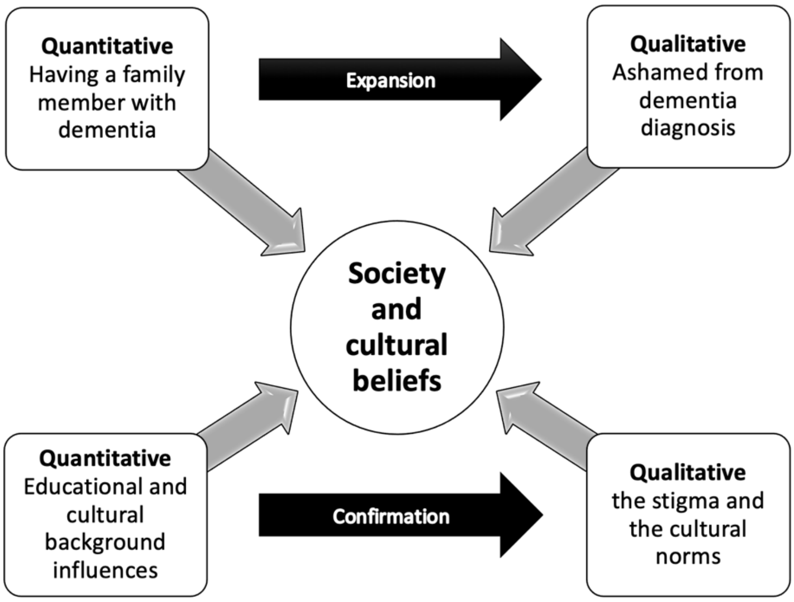


Figure 7.4 The link between quantitative data and qualitative data in pillar four

The survey data was expanded and confirmed by the diary-interviews data (Figure 7.4). Almost 18% of the survey participants indicated that they had a family member with dementia; of those, 44% who participated (n=8) in the diary-interviews had a family member with dementia. Half of them chose not to say, when asked, that they had a family member with dementia when they were recruited for the study. During the interview, the study researcher asked study participants if they had a family member with dementia when they referred to their families. One participant said: ‘She is my grandmother from my mother’s side, not my father's. She is in Ta'ef (a city in south-east Jeddah).’ (P04 INT). When the family member with dementia was from the mother’s side, there was more regret. All eight participants felt ashamed of the diagnoses and isolated their family members from their extended families. Some participants were reluctant to disclose a diagnosis of dementia to nurses, probably because of the social stigma associated with this condition. One said that ‘though her son and daughter were hiding this (dementia diagnosis) we had not been told (by administrative/education nurses) this clearly.’ (P19 INT).

Educational and cultural backgrounds also influence nurses’ knowledge level and attitudes. A statistically significant link was found between positive attitudes and high dementia knowledge in Filipino (25.8%) and Indian (26.8%) nurses. Additionally, other Eastern-Mediterranean participants (2.3%) scored higher in their knowledge and attitudes than Saudi nurses. A statistically significant relationship was found between participants having Bachelors and Masters degrees and their having more positive attitudes and higher knowledge. It is worth mentioning that most diploma holders are Saudi, with fewer Saudi nurses holding bachelors and master degrees. These survey findings were confirmed by the diary-interviews (Figure 7.3). As noted earlier in the background chapter, there is a slow recognition in the KSA of the need to train nurses in dementia care. The nursing curricula in the KSA seems to be different than it is in India and Philippine. Therefore, the differences in knowledge scores is suggested to be related to the nursing curricula.

It was also acknowledged that the stigma and cultural norms associated with dementia impact nursing care for people with dementia, and that these mainly impact Eastern-Mediterranean nurses, including Saudis. Hence, cultural beliefs have an impact on the care provided for people with dementia. One participant said: ‘The term is hard for some families and they never believe it even if the doctors tell them that he has dementia, Alzheimer’s, Kharaf, or whatever the word is. They don’t believe in the disease.’ (P15 INT). Another participant added: ‘Because the patient’s daughter has no idea of her mother's disease, there is no knowledge and no cooperation at all.’ (P03 DIA). Another participant said:

> Usually we have restrictions for the male and for the female; especially, if you are a male providing care to a female. So, this greatly affects care because for these people, you need to assist them and when you speak to them, there are some restrictions on discussing a lot of things here in Saudi Arabia, which affects the care that can be provided.
>
> **(P25 INT)**

### 7.3.5 Pillar five: Organisational factors can negatively impact the nursing care for people with dementia

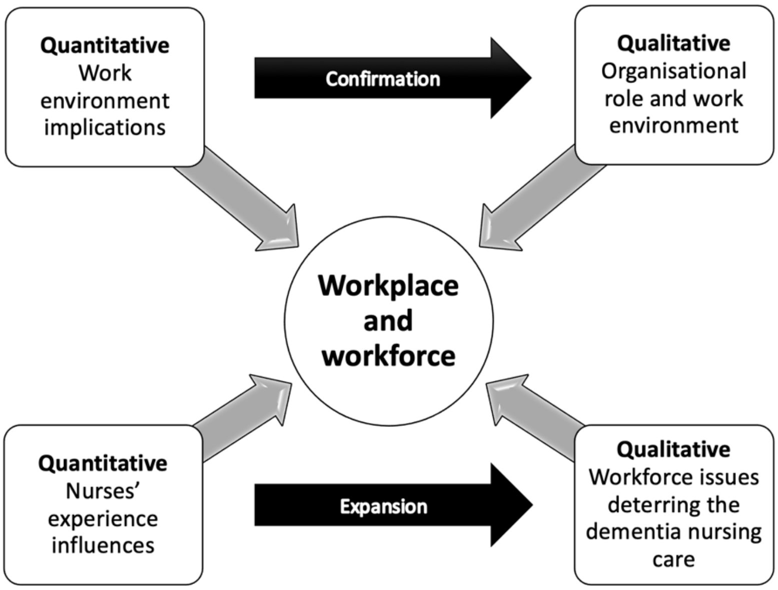


Figure 7.5 The link between quantitative data and qualitative data in pillar five

As shown in the above figure, several factors, such as workforce issues and organisational roles, have been noted by the study researcher to have negative implications on nurses while providing care for people with dementia (Figure 7.5). On the one hand, nurses who work in speciality and other particular wards who also spend time with people with dementia and have a high nurse-to-patient ratio are perceived as being most affected by organisational roles when caring for people with dementia. This was evident from the survey and further confirmed by the diary-interviews data. In terms of wards, working in emergency departments (14.5%) and surgical wards (12.8%)

significantly leads to more negative attitudes and lower knowledge among participants. It is suggested that the acute nature of the emergency departments and surgical wards could lead to more negative attitudes towards patients who require more attention. The availability of evidence-based resources at work (27.6%) is associated with positive attitudes and significantly related to lower knowledge. Higher knowledge is noted when reading groups (5.2%) and computers (37.2%) are accessible at nurses' workplaces, but internet access (36.5%) is linked to lower knowledge and more negative attitudes. Working in psychiatric wards (4.4%) is associated with higher knowledge about dementia but with more negative attitudes. Being in mixed wards (15.1%), convalescence departments (9.3%) and clinics (18.2%) leads to more positive attitudes with lower knowledge. Working in wards that admit different diagnoses is associated with positive attitudes but lower knowledge. One participant said:

> They need to increase the number of staff nurses, provide equipment, at least provide a specialised ward for them. If they cannot provide a specialised hospice for them as it may cost a lot, at least a specialised ward or department, adding entertainment to the ward and providing them with entertainment stuff.
>
> **(P16 INT)**

In term of nurses' time for providing nursing care for people with dementia, one participant wrote: 'We need to spend more time on such patients as compared to the other, regular patients.' (P14 DIA). Another added: 'Care for this patient needs a single nurse, which means a 1:1 ratio one. The patient should be handled by one nurse.' (P12 DIA). Also, during the interviews, almost all participants agreed with the following: 'If it is time to give medicine to the patient, sometimes it will take time, too much time for them to receive the medicine. Then, after that, the care you will give to other patients will also be delayed.' (P13 INT). One participant said:

> They should increase the nurse-to-patient ratio. I would feel better because sometimes the staff is not enough. We cannot care for the patient, we cannot assist them in every.... Sometimes they're neglected. So, they should increase the nurse-to-patient ratio. It's a main condition.
>
> **(P12 INT)**

Hence, participants indicated the importance of spending more time with patients with dementia. Yet, one participant indicated that it is important to have the same gender nurse involved in the care:

> Oooooh, in the morning, there are approximately six nurses, the majority are females not males. This is a problem as the ward is a male ward. The female nurse is not going close to the patient; they care from a distance!! When a patient is hurt, falls or any there is an incident, they call a male colleague from the office to assist.
>
> **(P05 INT)**

On the other hand, the most important workforce issues that were indicated by all study participants are nurses' experience and teamwork. Survey findings indicate that nurses' experiences influence their knowledge and attitudes, which is further expanded in the diary-interviews to workforce issues perceived as deterring the nursing care for people with dementia. One participant said:

> Of course, the years of experience has a positive impact on you and the patient in terms of how we deliver the medical care to the patient. The more experience you have, the more cases you care for. Normally this will be better for you and the patient.
>
> **(P04 INT)**

Even though participants acknowledged that nurses with more chances have to care for people with dementia the more positive the experiences and the better the care they can provide to patients. It is indicated that spending a maximum of five years working within the same ward (65.8%) results in a significantly higher knowledge level and more positive attitudes. Spending more than six years (28.6%) is found to be strongly associated with lower knowledge and the formation of the most negative attitudes. Administrative nurses (6%) have the most knowledge and most positive attitudes, unlike community nurses (18.3). Lower knowledge was found to be linked with nurses experiencing providing care for people with dementia at hospitals (42.1%) and/or when having a family member with dementia (17.5%). The nurses who had provided professional dementia care hold more positive attitudes. Nurses with family members with dementia are noted to have more negative attitudes. Knowledge is found to be elevated and attitudes enhanced when participants indicated that they had a formal dementia education (11.8%).

Also, teamwork and having a multidisciplinary team was desired by all nurses as a shared experience was found to be effective when providing nursing care for people with dementia. One participant wrote: ‘In order to deliver high-quality care, all members of healthcare must co-operate well.’ (P14 DIA). Another participant said: ‘They should make one policy: like, for each patient there should be one family member. So, they will listen more to the family member, and they will not feel loneliness.’ (P12 INT). In further discussions with nurses during the interviews, many had indicated that it is recommended to assign a particular trained nurse who had previously treated patients with dementia upon admission. One participant explained:

> If you admitted him (patient with dementia) into a general area with other patients, the nursing staff have a lot of responsibilities. So, I think having special nurses for them…, no need to have high degree of nursing but need to have good care for our patients and know how to take care of them. Like nursing aides and assistant nurses […] to assist in hygiene and feeding the patient.
>
> **(P17 INT)**

## 7.4 Summary of this chapter

In addition to the descriptive and statistical analysis of the survey and the thematic analysis of the diary-interviews that were conducted in Chapter 5 and Chapter 6, the Pillar Integration Process has added yielded five overarching findings. The aim of this integration process is to strengthen the datasets related to nurses’ knowledge of, attitudes towards and perceptions of people with dementia in the KSA. The five findings lend a comprehensive view of the current nursing practices in the KSA, as well as the actual personal experiences of nurses.

Thus, by forming a holistic view of the collected data, the researcher is able to relate the findings to the research questions in order to identify recommendations to inform policy and/or practice development and to improve nursing care for people with dementia in the KSA. These findings are the basis of the discussion in the next chapter.

# Chapter 8 Discussion

This chapter discusses the study findings in relation to the original research questions and existing knowledge on nursing care for people with dementia. The purpose of this study was to explore nurses' knowledge of, attitudes towards and perceptions of the care of people with dementia in KSA hospitals. Of particular significance, this discussion will focus on the factors that most impact nurses and nursing in Ministry of Health (MOH) hospitals in the Kingdom of Saudi Arabia (KSA), particularly socio-cultural influences and demographic changes, the role of emotional work and its influence on nurses, and nurses' working environments. In addition, the discussion will use relevant literature to relate these factors to the key findings outlined in the previous chapter, which are 1) that a lack of knowledge is associated with a lack of confidence when providing nursing care for people with dementia; 2) that nurses are willing to learn about nursing care for people with dementia but information and resources are not always available; 3) that nurses' attitudes, emotions and perceived communication difficulties affect their delivery of dementia care; 4) that stigmas, cultural norms and perceptions associated with dementia can have a negative impact on the nursing care for people with dementia; and 5) that organisational factors can negatively impact the nursing care for people with dementia. Lastly, the discussion will focus on this study's contribution to the wider literature in relation to the findings from the earlier literature review, primarily as it affects dementia studies in the Eastern-Mediterranean region.

## 8.1 Overview

It is of primary importance to note the fact that the current study is localised and personalised, wherein it provides insights specific to MOH nurses working in the KSA and can offer policy-makers a tool to improve delivery of quality care in these settings. It has been found that knowledge of cultural factors is essential to an understanding not only of ageing and dementia, but of the approaches taken to caring for people with dementia. Unlike most global studies researching dementia, which historically have been dominated by biomedical models that consider dementia solely as a pathological entity caused by neuronal and neurotransmitter loss (Mountford and Dening, 2019), this study supports the notion that neglecting the cultural, social, religious, and educational differences among study participants, that is, those caring for people with dementia, can have a profoundly negative impact on people with dementia, their families and the country as a whole (Annear *et al.*, 2015b).

Consequently, the study focuses on nurses working with people with dementia. Most Eastern-Mediterranean studies are cross-sectional in terms of their focus, notably in that they looked at issues surrounding dementia care, including types of care, cultural influences, comorbidities and other issues but did not explore issues central to nurses in these settings, including questions of their attitudes and perceptions of this type of work. Adding to this feature, and an important aspect of this study, is that it utilises a mixed-methods, pragmatic approach to data collection. The lack of these types of studies in the region can be considered a limitation on the research into dementia care.

One notable benefit of this pragmatic approach to data collection is the fact that it allowed for a certain circumvention of cultural limitations present in the KSA, whereby participants were presented a greater opportunity to express themselves freely and openly. Moreover, by utilising both a general survey questionnaire, followed by a diary-interview, participants were free to make personal adjustments to facilitate the researcher's needs. For example, participants could adhere to their own schedule and pace and in some instances were not faced with the problem of gender separation or the need for a chaperone.

From a research perspective, the pragmatic mixed-methods approach provided both qualitative and quantitative data sets to satisfy concept and process domains while focusing on both the purposes, objectives and questions of the study and the experiential aspect of the data. Moreover, this approach provided greater flexibility, a validation process, and a broader range of research questions to propose, including how nurses rate their own knowledge regarding dementia versus DKAT2 scores and their DAS scores of attitudes. Of especial significance, the interviews provided the researcher with deeper insights into how nurses' perceive people with dementia and dementia care as well as these nurses' cultural, emotional, and intellectual influences.

## 8.2 Discussion of the findings

Before discussing the main findings in the context of the wider literature on the nursing care of people with dementia it is important to focus first on the role of knowledge in caring for people with dementia. As has been found in most studies about dementia care, knowledge is the one factor that underscores all others. In other words, knowledge affects the attitudes and perceptions of nurses. Just as important, knowledge informs the biases and approaches of society at large and the healthcare policy decisions and organisational designs made by those in charge.

### 8.2.1 Knowledge

Findings from the datasets indicate that nurses hold limited knowledge about caring for people with dementia and their attitudes positively correlate with their level of knowledge. According to previous research, nurses worldwide have low to basic knowledge about dementia (Ross, Tod and Clarke, 2015; Unroe *et al.*, 2015; Nakanishi and Miyamoto, 2016; Yaghmour, Gholizadeh and Alsenany, 2016; Lin *et al.*, 2018; Midtbust *et al.*, 2018a; Wang *et al.*, 2018b; Yaghmour, 2021). In the UK, the USA and Japan, authors have suggested that higher knowledge and positive attitudes are associated with nurses' qualification levels (Ross, Tod and Clarke, 2015; Unroe *et al.*, 2015) and with their clinical experience (Nakanishi and Miyamoto, 2016). Furthermore, the knowledge acquisition process among this study's participants suggests that there is a lack of training and availability of resources such as training courses and seminars about dementia and nursing care for people with dementia in the KSA. This was evident in similar studies conducted in the USA and UK that used quantitative elements to evaluate nurses' knowledge about dementia (Ross, Tod and Clarke, 2015; Unroe *et al.*, 2015). Moreover, as the literature review confirms, there is also a lack of recognition and tools with concerns regarding the Mini-Mental State Examination's cultural appropriateness, particularly for people who have low literacy levels. As such, it was found that diagnosis is a significant challenge due to a gap in culturally-appropriate diagnostic tools that address barriers such as language and low literacy levels (Yaghmour, Bartlett and Brannelly, 2019). Despite this absence, however, this study found that participants were motivated to learn more about dementia, which they suggest would be helpful to ease their fears and improve their comfort levels when providing nursing care for people with dementia. Yet, nurses' motivation is not enough to enhance knowledge and improve attitudes. Studies were conducted regarding training programmes (Bolmsjö, Edberg and Andersson, 2012; Krumm *et al.*, 2014; Smythe *et al.*, 2014;

Conway and Chenery, 2016; Eritz *et al.*, 2016; De Witt Jansen *et al.*, 2017; Fry, Arendts and Chenoweth, 2017; Karlin, Young and Dash, 2017) and educational interventions (Pellfolk *et al.*, 2010; Brody *et al.*, 2016; de Witt and Ploeg, 2016; Kohler *et al.*, 2016; Kang *et al.*, 2017; Wang *et al.*, 2017b; Wang *et al.*, 2017a), which made evident the significance of enhancing nurses' knowledge and attitudes towards people with dementia (see literature review 3.2.1; (Yaghmour, 2021)) and meeting patients' needs (Pinkert *et al.*, 2018). A lack of knowledge, as well as an absence of training in the nursing curriculum, can generally be seen as attributing to a lack of nursing practice and quality care provisions specific to people with dementia (Yaghmour and Gholizadeh, 2016). Hence, various interventions were recommended to address this gap in knowledge and attitudes.

This study found that nurses in MOH facilities mainly acquired their knowledge about dementia and dementia care from their experiences as a nurse or carer for a family member with dementia. In this study, unlike previous studies, nurses' experiences were explored from two perspectives: the years of experience as a nurse and the experience working within the current wards. The significant differences between the two suggests that rotation between wards and exposure to different cases is crucial in enhancing nurses' ability to provide appropriate care delivery. A recent study found a weak association between years of experience and the knowledge level of nurses caring for people with dementia (Annear, 2020). Another study found no association between knowledge and experience (Blaser and Berset, 2019). The same study found that nurses' attitudes were significantly positive when they worked in dementia-related wards (Blaser and Berset, 2019). Hence, it is suggested that the care setting (ward) has a strong association with attitude scores. This study suggests that when nurses have some sort of experience in dementia care, they tend to have more knowledge and hold more positive attitudes. Hence, working in dementia-related wards such as medical, extended medical, psychiatric or neurology is considered an important factor in this context, unlike acute care wards. In contrast, emergency care nurses reported significantly lower knowledge about dementia care than ward nurses (Lin *et al.*, 2018), which concurs with this study's findings. In addition, several studies suggest that acute care nurses are not prepared to take care of people with dementia and they are found to have difficulties in applying person-centred care (Smythe *et al.*, 2014; Wang *et al.*, 2018a).

Lastly, researchers suggest that even with an increased prevalence of dementia, there is little awareness of the disease (Stephan *et al.*, 2018). The symptoms are often misjudged, neglected or misinterpreted. This results in late diagnoses, which thereby reduces the choice of future treatment. It can thus be claimed that most nurses who care for older people are unlikely to want to work with people with dementia in the future, which is a significant point of concern as meeting the needs of patients requires that nurses maintain positive attitudes and acquire the necessary knowledge in treating them. To illustrate, in one study most nurses interviewed stated that Alzheimer's disease is incurable, that half of those with Alzheimer's have dementia and that only in rare cases does recovery from the disease occur (Lorenz *et al.*, 2019). Respondents in this study also suggest that people with dementia have a sense of understanding, for example, when people are kind to them; however, they are unable to enjoy life. This reveals that nursing staffs have limited understanding of dementia and attitudes toward people with dementia tend to be positive in nature.

This lack of extensive training needs to be addressed at governmental level. In the KSA specifically, while nursing training and public awareness programmes are improving, there is still scope for improvement. Of particular issue is the lack of a national scope of nursing practice, wherein nursing schools are adopting different international syllabi, which may lead to variations in learning outcomes. Also, the lack of established guidelines in various care facilities suggests that nursing graduates may not be able to practice what they have learned and trained for during their studies. These issues also work against Saudi nurses who graduate from international nursing schools, including advanced nursing practitioners who are not guided by clear nursing practice regulations when returning to work in the KSA. Thus, it is imperative for politicians and planners to participate efficiently in supporting the development of nursing as a mature and independent profession (Aljohani, 2020).

### 8.2.2 The impact of emotional work on attitude

Emotional nursing work involves managing the emotional demands of relating with patients, families and colleagues (Delgado *et al.*, 2017). It is influenced by knowledge and the ability to communicate effectively, which is essential to success in managing one's emotions as it facilitates better interactions with patients. It is argued that communication difficulties disrupt the provision of person-centred care for people with dementia and causes frustration and agitation for nurses (Fazio *et al.*, 2020). Therefore, researchers recommend skills-based training to increase knowledge and enhance attitudes by improving communication and problem-solving skills of staffs working with people with dementia in acute settings (Smythe *et al.*, 2014; de Witt and Ploeg, 2016; Yaghmour, 2021). Furthermore, the application of communication skills training in community-based aged care practice can contribute to quality dementia care (Conway and Chenery, 2016) and is necessary to minimise nurses' "burnout" (Moonga and Likupe, 2016). Many of this study's participants agreed that knowing the past history of the person with dementia is vital, as every person with dementia is different and has unique needs. One way to do this is to follow models of dementia care used in other countries. For example, Person-Centred Care and Continuum of Care models stress gaining and sharing information about individual patients and prioritising person-centred interactions above the completion of tasks and acquiring theoretical knowledge about dementia (Saxell, Ingvert and Lethin, 2019). As KSA care settings do not distinguish dementia as its own condition, this lack of focused patient information only adds to the stress and burnout mentioned above as nurses have neither the time not the ability to gain personalised knowledge of each patient and therefore attend to their specific needs. Thus, by implementing regimens that include regular nursing rotations, having patient's relatives around, assigning nurses who speak the same language as the people with dementia and scheduling regular social worker visits, nurses can feel they are being supported, which will enhance not only the care given but the nurses' own attitudes towards and perceptions of people with dementia. Another vital tool that can help achieve this is documentation, whereby nurses keep records of interactions with people with dementia and leave these notes for the subsequent shift's nurse to add to. Of course, nurses need to be trained in this aspect; this study's use of diaries and interviews may have contributed to helping implement this tool in some contexts by keeping a diary and/or reflexive notes.

In addition, this study confirms that emotional intelligence and self-understanding are required skills that nurses should have when providing dementia nursing care. In terms of interpersonal communications, nurses are required to have emotional intelligence, which allows them to interpret their feelings and manage their own emotions when providing nursing care for people with dementia. In fact, nurses' own levels of emotional intelligence dictate the way they manage emotional work (Delgado *et al.*, 2017), which, as in many disciplines, is the hallmark of the nursing occupation and is necessary to assess and provide proper care (Ruckdeschel and Haitsma, 2004, p. 43; Delgado *et al.*, 2017). However, this work renders nurses' feelings more prone to volatility, wherein they must learn to express only appropriate feelings yet manage all their emotions in order to maintain professional nurse-patient relationships (Bolton, 2000). In other words, they cannot sympathise too deeply or show their grief as they must always uphold a professional face (Bolton, 2000). Thus, understanding nurses' emotions while at work in a care environment is essential in helping them assess their own emotional intelligence (Bolton, 2000). The complex nature of dementia nursing care requires nurses to be self-aware and motivated and to have the capacity to process information and identify the causes of their emotional states. This was evident among study participants.

This study also found that that when nurses show positive emotional behaviour and confidence, people with dementia become more responsive to the treatment. Nurses can use their emotional intelligence to provide better care for the person with dementia as this can be reflected in their attitude. The study also demonstrates a correlation between nurses' confidence levels and their comfort in delivering care that is driven by their perceptions about people with dementia and dementia care. In previous studies, the negative attitudes of nurses towards people with dementia was found to be associated with high levels of perceived patient dependency (Deasey, Kable and Jeong, 2014), with some nurses in acute care settings reporting feeling hesitant to attend to cases related to old age (Deasey, Kable and Jeong, 2014; Digby, Lee and Williams, 2018). From the findings, it is apparent that nurses' knowledge and positive attitudes facilitate the efficient delivery of quality care for dementia patients (Krumm *et al.*, 2014; Conway and Chenery, 2016). This is line with the literature review's evidence-based findings that the creation of awareness about dementia and experience in dealing with people with dementia improves both knowledge and the general skill sets that are relevant to people with dementia (Wang *et al.*, 2017a; Wang *et al.*, 2017b; Yaghmour, 2021).

As well as managing their own emotions, nurses need to understand and manage the emotions of people with dementia. The latter have less or no control over their feelings and ways of expressing these emotions (Mason and Tofthagen, 2019). For instance, in cases in which people are irritated or tend to rapidly change moods or overact, they appear to be aggressive or hyper-reactive in nature. In some cases, they appear to be uninterested in a person or thing or are distant. These changes were found to be difficult for the participants of this study to deal with. It can be useful for the care provider to know that the situation is partly caused by damage in the brain function of the person. Researchers claim that there is evidence that some people with dementia react in a more emotional manner to a particular situation than expected, such as being agitated or tearful, and this is due to factual memories or the ability to comprehend in a clear manner (Khalaf *et al.*, 2018). Therefore, it is vital to observe far beyond words or actions by seeking to understand the feelings that the person with dementia is trying to express. In most cases, strong emotions are a result of unmet needs. Therefore, nurses need to try to evaluate the needs and preferences of people with dementia and address them in a proper manner.

### *Emotions involved in dementia care*

This study found that sadness and love were strong emotions influencing nursing care. The patients are treated with honesty and love and their families are always told about their health condition and are treated accordingly. The patients are considered as a part of the extended family and they receive care according to the collective decisions of the patients' close family members. It has been noted from the participants that feelings of love, including showing mercy and empathy, and being comfortable around the person with dementia were the most common emotions. Sadness was also a common emotion that participants have when they provide nursing care for people with dementia and is commonly interpreted as having feelings of empathy towards the mental health condition of the person with dementia. What may be unique to this study, however, is that these emotions were found to be heavily influenced by cultural biases and do not seem reflective of studies of nurses' emotions based in healthcare settings in other countries and their respective cultures. Thus, this cultural influence, which is specific to the KSA, is discussed in greater detail later on in this chapter.

Conversely, Anger and frustration were found to be emotions negatively influencing nursing care. This anger is felt by nurses when they cannot express themselves and inform the patients about their conditions completely and honestly or cannot support them emotionally to a large extent. Researchers suggest that handling anger exhibited by people with dementia is one of the more challenging tasks while caring for these people (Wallace *et al.*, 2020). Although it is natural to show some form of aggression now and then, authors found that people with dementia and Alzheimer's tend to have much worse anger issues, even if these were previously not present (Betriana and Kongsuwan, 2019). Moreover, the study found that these anger issues worsen over time as the person's condition becomes more severe, and the issues become more complicated. The first step in dealing with anger in people with dementia involves understanding the cause of the anger, as understanding the causes and triggers of anger could be useful in preventing them and defusing problematic situations in the care setting. The aggressive behaviour is suggested to be caused by many factors, including physical discomfort, poor communication and environmental factors. Participants' anger, on the other hand, often 'varies according to the work pressure of that day' (P03 INT), suggesting that there are several factors that trigger these emotions, even beyond the direct interactions with patients. These include barriers in communication, a lack of knowledge about dementia and external barriers such as the work environment. Thus, this study found that a look beyond the care given by nurses is vital to understanding the role of attitudes about caring for people with dementia as the care itself is not the sole influence.

### ***Managing emotional work***

This study supports the notion that in order to maintain a positive emotional environment, it is important to implement approaches that focus on treating people with dementia with dignity and assisting them in contributing actively to their own self-care. These approaches may include Kitwood's Flower of Emotional Needs person-centred care and compassionate care (Mitchell and Agnelli, 2015). It is also important to note that nurses also need to consider the emotions of family members and caregivers and show empathy while involving them in planning for a patient's future care and applying their knowledge of dementia (Walsh *et al.*, 2017). Thus, it is the responsibility of professional nurses to have a deeper understanding about the disease and to show positive attitudes that help mitigate challenges and to adopt good skills and elements related to passionate caregiving (Fazio *et al.*, 2020). That being said, cultural barriers can often stand in the way of this.

Thus, nurses' ability to build resilience (the capacity to positively and successfully adapt to challenging circumstances or adversity) relies on overcoming barriers to engaging in emotional work such as socio-cultural expectations, gender aspects, management of emotions (intrapersonal), conflicts with colleagues (collegial), and the organisation (Saxell, Ingvert and Lethin, 2019). This is especially relevant in settings such as MOH facilities in the KSA where nurses have limited influence over these barriers.

Thus, as the needs of patients and their caregivers add to nurses' responsibilities, it is fair to say that it also adds to their stress levels. This study's diary-interviews process uniquely demonstrated that providing a forum to nurses to express pent-up feelings is one way to alleviate some of that stress. It is therefore suggested (by this researcher as well as several participants in this study) that care facilities implement similar means of expression and assign a nurse to deal directly with families. For example, nurses can be asked and/or encouraged to maintain their own reflexive diaries. In addition, a trained nurse or therapist should be regularly accessible for one-on-one discussions with nurses who have no other source of emotional support. Where viable, support groups for nurses working with people with dementia can also be organised to provide a forum for these types of discussions. It is vital, however, that privacy be assured, meaning diaries do not need to be seen by supervisors and discussions not shared, in order to allay fears and prejudices that nurses may have regarding reaching out. This study also discovered that when nurses suspected that their contributions would be viewed by others, they were less forthcoming with their answers. With the above in mind, it should be noted that these suggestions for support can be a subject for further research. More specifically, future interventions could be developed to include components that focus on emotional regulation to address nurses' emotional labour, and build nurses' emotional intelligence and resilience (Delgado *et al.*, 2017).

### 8.2.3 Socio-cultural influences on perception

Apart from the emotional factors that impact nurses’ ability and motivation to provide essential care, nurses also need to gain knowledge of and the ability to navigate the stigmas, cultural norms and perceptions associated with a dementia diagnosis and the negative impacts on nursing care for people with dementia these may bring.

An important cultural element that was found to be unique to this study is that some participants believe that dementia is a disease caused by *Gadar* (fate), which is a test from God for the person with dementia and his/her family. In the early nineties, a researcher claimed that people in the KSA perceived diseases to be caused by fate, which manifests as a means to atone for one’s sins (Khan, 1994). Additionally, in the published literature review, this was also the case among other Eastern-Mediterranean people (Yaghmour, Bartlett and Brannelly, 2019). Hence, this perception of the disease from a cultural perspective can be considered a barrier in providing dementia nursing care, as it leads to not treating the dementia condition well and not treating the cause of the dementia. In addition, Arab people are often ashamed of a dementia diagnosis (Rizzi, Rosset and Roriz-Cruz, 2014; Høgsnes *et al.*, 2016; Parlevliet *et al.*, 2016), meaning a dementia diagnosis and knowledge of the condition issues remain problematic in the KSA as in the general Eastern-Mediterranean region. This finding will need to be taken into consideration when developing dementia nursing care in the KSA, as nurses approach this care with the attached social stigmas that work against both the people with dementia and the nurses themselves. This will also have an impact on dementia nursing education in the future that will need to overcome this hindrance to learning.

It should be noted that the surveys conducted for this study did not specifically ask about *Gadar*. In fact, these responses were volunteered during the diary-interviews and were expressed by Saudi nurses only. This suggests that even with the training these participants did receive, they were unable to dispel these prior convictions, further suggesting that not only do nursing training programmes in the KSA need to work harder to dispel these beliefs, a focused public awareness campaign needs to change public opinion about this disease. As a point of special interest, this study was the first opportunity for some participants to have their voices heard without fear of repercussions. This ability to express themselves may be a crucial tool to be aware of in future studies as this freedom to express one’s thoughts in a safe environment not only influences nurses’ perceptions of their patients and their work, but it can also influence others’ perceptions as well.

In addition, this freedom of expression may be used as a tool in managing emotional work, as mentioned in the previous section.

Another cultural aspect that negatively affects delivery of nursing care is the stigma associated with dementia. Several participants only hesitantly admitted that they had family members with dementia and had actively hid the diagnosis from extended family. In fact, people in the KSA will either ignore or simply disbelieve the diagnosis, leading to delayed treatment or none at all. Further aggravating the situation is the relation of the family member, with matriarchal members receiving more compassion than those on the father's side of the family. On the other hand, if the disease can be linked to a medical treatment for something else, then they will seek assistance. Researchers suggest that stigma and stereotyping can alter dementia care and treatment. Therefore, they recommend not to use the Arabic translation of dementia 'Kharaf' nor Alzheimer to avoid Alzheimersation of the dementia and the stigma around the translation. Rather, it is suggested to study the diagnostic term and use more cultural acceptable diagnostic (Yaghmour, Bartlett and Brannelly, 2019).

Thus, this study uncovered a paradox among Saudi nurses as these perceptions of the disease as something shameful seem to be opposed to the idea of respecting one's elders. A positive cultural aspect of Eastern-Mediterranean cultures, as outlined in Chapter 1 (section 1.2), is that people tend to value older adults and care for them with gratitude and respect. The common policy then is generally to introduce oneself on the first meeting with a person with dementia and/or a family member and explain the procedures and treatments that would be given.

However, as also highlighted in Chapter 1, there is a shift in these traditions. As people move to cities and focus shifts to nuclear rather than extended families, economic and social burdens are forcing more people to send their older adults' relations to care facilities. As per the opinion of Wang et al. (2018a), dementia care is stated to be a long and challenging journey due to significant economic burdens, increasing service demands and caregiver distress. These challenges are stated to have a significant impact on the healthcare system that aims to offer a continuum of services. More specifically, there is a severe shortage of nurses in the KSA and a consequent need for increased recruitment of foreign nurses.

This leads to other cultural issues, such as lack of a common language (and hence increased communication barriers) as well as a lack of cultural awareness among staffs. For example, as Indian and Filipino nurses do not speak Arabic in many cases, they face additional barriers interacting with fellow nurses. This is compounded by religious and customs differences that can affect the general feeling of unity, or collegiality, in a care area. While this study did not look at collegiality specifically, it certainly did enter the data sets as a factor influencing delivery of care, namely in terms of workplace environment issues.

Another impact of increased recruitment of non-Saudi nurses is the level of knowledge and positive attitude scores among nurses. Indian and Filipino nurses have higher levels of knowledge, as do other regional nurses who are non-Saudi. This may explain the public's preference for non-Saudi nurses mentioned in Chapter 1 and the dire need for improved training in KSA nursing programmes.

Lastly, following the Arab Spring revolutions of 2014, the number of Arab immigrants has increased worldwide, adding unforeseen challenges to those countries' health care systems. The workforce in England, for instance, includes 13 nationalities out of the 22 Eastern-Mediterranean countries in 2020. In addition, Asian nurses, mainly Filipino and Indian, make up 8.7% of the nursing workforce in England and African nurses make up 2.5% (Baker, 2020). Many researchers claim there are no available diagnostic tools for dementia that can be used by nurses for illiterate people and older Arab immigrants (Goudsmit *et al.*, 2016; Parlevliet *et al.*, 2016; Yaghmour, Bartlett and Brannelly, 2019; Yaghmour, 2021); yet, understanding the Arab community, family structures and cultural issues concerning people with dementia is considered important to aid in care delivery when providing support for people with dementia and their families. This study aims to support that knowledge base.

### 8.2.4 Work environments' influence on nurses' attitudes and perceptions

A final aspect of knowledge affecting nursing care is nurses' willingness to learn about nursing care for people with dementia; however, information and resources are not always available.

Most studies, including this one, acknowledge the benefits of training and knowledge acquisition. Most studies also view person-centred care as the gold standard for nursing people with dementia (Yaghmour, Bartlett and Brannelly, 2019; Yaghmour, 2021). However, two studies published in 2020 that focus on dementia care, one on meta-synthesis (Saxell, Ingvert and Lethin, 2019) and the other a qualitative systematic review (Gwernan-Jones *et al.*, 2020), argue that most nurses fail to provide person-centred care as a result of a busy work environment and unidentified approaches to applying holistic nursing care (which involves physical, social, psychological and spiritual care.)(See best nursing practices for dementia nursing care in Chapter 2 section 2.2).

Needless to say, work environment and work culture play important roles in shaping nurses' attitudes towards people with dementia and their care. When the dementia progresses and care demands increase, admission to a long-term care facility often becomes inevitable. A study aimed at exploring the associations between ward and nurses' stress, found that caring for people with dementia in nursing homes is associated with various stressors for healthcare workers. The role of the unit type, and particularly the proportion of residents with dementia, remains unclear (Vogel *et al.*, 2017). Busy work environments and under-staffing were obstacles highlighted by the nurses (Smythe *et al.*, 2014). In support of this research, qualitative studies from Australia, Canada and the UK, found that nurses are always under pressure and lack of time causes their added stress (Ervin, Cross and Koschel, 2014; McPherson, Hiskey and Alderson, 2016; Hunter *et al.*, 2017). Work pressure affects nurses' perceptions of people with dementia and these affects are varied; while some show compassionate care, others lead to burnout and physiological stress (McPherson, Hiskey and Alderson, 2016). Organisational changes are suggested in terms of staffing to minimise nurse's burnout (Midtbust *et al.*, 2018b).

This study found that of prime concern for nurses were nurse-to-patient ratios, time in a rotation (i.e., spending too long in one area), access to resources, gender issues (namely, not enough male staff to assist with male patients), and demands in too many areas. As with the findings of many studies, this study also concluded that a prime commodity lacking in hospital settings and one that affects all the issues just mentioned is time. People with dementia require a lot of time and as nurses in the KSA are not designated as dementia nurses, they are responsible for a variety of patients. Many participants complained that they did not have the time to adequately care for people with dementia, which not only affected the emotional aspect of their work, but led to further challenges in delivering quality care to other patients. The Royal College of Psychiatrists presented a similar observation in a report on in-hospital dementia care, namely, that successful delivery of person-centred care was arbitrarily the result of individual RNs' competency, as opposed to systematic consistency in the organisation. Such responsibility may place considerable pressure on RNs, and recent research suggests that RNs suffer distress in the workplace due to organisational limitations affecting their ability to deliver adequate care to patients in need (Saxell, Ingvert and Lethin, 2019).

This is further supported by a study in Norway that found conflicting feelings among nurses result from wanting to spend more time with people with dementia to provide care but this makes nurses feel the pressure to help everyone and causes their added stress (Midtbust *et al.*, 2018b; Yaghmour, 2021). Also, quantitative studies from Japan and the UK found that nurses working with dementia patients have high stress levels and burnout (Yada *et al.*, 2014; Moonga and Likupe, 2016).

Thus, without institutional-level changes in hospitals, nursing staffs would be unable to provide proper care to people with dementia. Key components of this change include having dedicated nurses to deal only with people with dementia and their caregivers, lower nurse-to-patient ratios, increased diagnoses of dementia, among others. (See section 9.5 in the next chapter for further recommendations).

## 8.3 Summary of the findings

Below is a visual summary of the study findings:

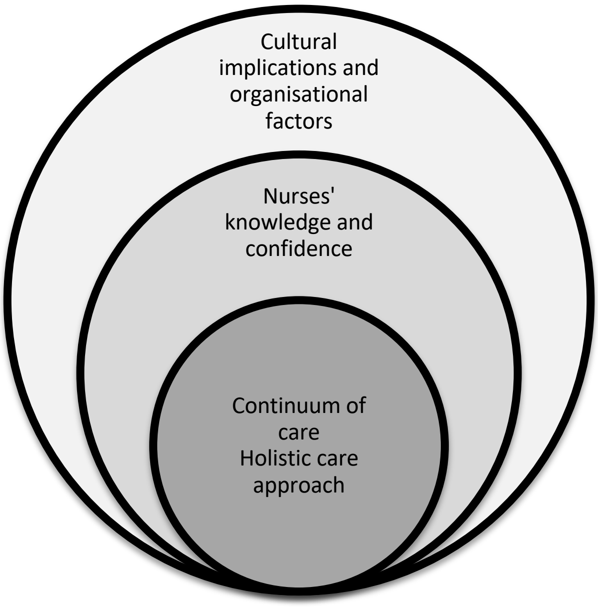


Figure 8.1 Visual summary of the study findings

Taking all the findings and their discussions into account, this study concludes that both nurses and institutions would benefit greatly by ensuring that continuum of care and the training required to implement it are achievable goals when designing policy for nursing care for people with dementia (see the visual summary in the above Figure 8.1). Continuum of care and holistic care approaches can be met by considering nurses' knowledge and confidence about the nursing care they provide for people with dementia, their attitudes towards providing that care and their learning and resources availability. Also, these care types can be met by nurses' perceptions of cultural implications and organisational factors when providing nursing care for people with dementia. It is crucial to consider certain nurses' characteristics, such as patience, confidence, communication skills, keenness to learn about dementia, previous knowledge and experience related to dementia, as well as previous experience with and attitudes towards nursing people with dementia when keeping organisational policies in mind. Conflicts in care, communication barriers, organisational restrictions and ward business are deemed to be barriers in achieving the continuum of care and providing the holistic nursing care that causes nurses' moral distress and added stress, then failure in care delivery. Moral distress is suggested to lead to frustration and added stress among nurses; therefore, this needs to be addressed by the general nursing profession and other employers within the organisation (Corley, 2002). However, moral distress could have a constructive effect: it could facilitate the development of both personal and professional attitudes that lead nurses to acquire more skills in providing compassionate care.

In terms of effective change in a KSA setting, findings from this study suggest that change must begin at the top, that is, with the government policy-makers. As dementia care is not merely a matter of better training for nurses and hospital managers, it is up to the government to raise public awareness of dementia, dispel beliefs that inhibit action, and provide financial support to those that need it to provide care for the older people of the nation. As the population of older adults increases, failure to address these issues will result in a growing problem in hospital settings for all patients.

## 8.4 Contribution to wider literature (study's significance)

This study has made an original contribution to the scholarship on dementia nursing care by investigating the knowledge, attitudes and perceptions of nurses working in KSA, namely by exploring the factors contributing to achieving and enhancing the continuum of dementia nursing care experiences in Jeddah, Saudi Arabia. The key contributions that this research has made to the existing knowledge and evidence base are summarised in this section. Specifically, it considers contributions to research of nursing, dementia care, research methodologies (mixed-methods and diary methodology in particular), and key messages for nursing care practice.

The thesis introduces a new understanding of dementia care from a non-Western context. Although there is considerable research on nursing people with dementia in the UK and other Western countries, a thorough search of the literature on nursing for people with dementia in the specific context of the KSA found four studies (see section 3.1). Issues relating to nursing education in the KSA in general have received little attention in academia. However, nursing in the KSA presents some different issues that might not be found in the Western world. One such issue found by the researcher was the cultural difficulties and communication barriers between nurses and people with dementia. A high number of registered nurses in Jeddah's healthcare facilities are from the Philippines and/or India (Tumulty, 2001) and are not native speakers of either English or Arabic, the two main languages spoken in hospitals in Jeddah. This problem would not be as significant in a country where most healthcare providers and patients are native speakers of the same language.

This study is the first to investigate in depth the nursing care for people with dementia in the KSA in relation to the concepts of knowledge, attitudes, and perceptions when caring for people with dementia. This study has generated new knowledge showing that knowledge is directly linked to nurses' attitudes and perceptions, and that this knowledge is influenced by and influences cultural, emotional, and environmental factors. Thus, understanding emotional work and its development is considered important to enhance the dementia nursing care practice as well as to develop nursing policies that contribute to achieving the continuum of care. Also, understanding Eastern-Mediterranean culture and acceptance of dementia diagnoses needs to be enhanced by more training and raising awareness about people with dementia. Crucially, the evidence contributes to an explanation of nurses' experiences over the factors of their knowledge and cognitive attitudes. It is mostly important in that it supports their attitudes and forms their perceptions towards people with dementia. The data also stresses the importance of understanding the nursing experience for people with dementia with comorbidities and acknowledging and respecting their differences.

The thesis will benefit nursing practice education by increasing the understanding of issues related to nurses' knowledge acquisition and factors for enhancing nurses' attitudes that form their perceptions towards people with dementia. It also offers strategies to enhance the dementia nursing care process and inform organisational policy. Such strategies could include clarifying nurses' roles and expectations in dementia care. This could be achieved by offering training programmes, rotation between wards and the development of multidisciplinary teams to assist in providing dementia nursing care. Another feasible strategy is encouraging nurses to keep nurse-patient diaries as a reflection exercise in order to encourage the continuum of care and maintain a holistic care approach when nurses give constructive feedback about the care process. Such feedback is needed, as evidenced by the need to increase recognition of nurses' emotions and emotional work.

The study design (mixed-methods research design) used in this research supported a greater understanding of the phenomenon. This study illustrated how a mixed-methods study approach was used and data were integrated from several aspects: participants' groups, methods, wards and perspectives. A major strength of this research is the representation of the findings from the nurses' perspectives, notably the inclusion of nurses working in different care areas through the implementation of methods that assisted accounting for their voice in a convenient way. Furthermore, participation was not restricted to specific wards; it enabled the inclusion of all nurses who cared for at least one person with dementia per month.

It is worth mentioning that diary entries were made during participants' own time and facilitated the data collection process while securing ethical approval. This is particularly important to consider for research studies with busy populations. This method has not been used before in the KSA. This thesis sets out clearly how it can be used for such situations taking into consideration the participants' abilities, ages and languages, and cross-cultural aspects.

The findings of this research have significant implications for the development of a nationwide standard framework for nursing care for people with dementia, specifically the proposed recommendations outlined in the above section (please see Appendix K for developing guidelines to measure the appropriateness of dementia nursing care in the KSA).

It is hoped that this research influences and enhances nursing practices for people with dementia in the KSA. The findings and recommendations will be shared with the sponsored institutions and the Saudi MOH in order to gain their support in increasing the quality and status of nursing care for people with dementia in the Kingdom. Finally, the researcher hopes to encourage the MOH to publish appropriate national guidelines for nursing care for people with dementia in the KSA, shaped by the national culture and setting and influenced by the standards of Western countries. This study will inform future research on nursing care for people with dementia in Eastern-Mediterranean countries and the wider population that has roles to play in this process.

It is planned to use the visual summary of this study's findings as a roadmap for dementia nursing care in the KSA. It is highly recommended to use the RAND/UCLA Appropriateness Method, which is a process of investigating the appropriateness of proposed guidelines (see Appendix K). The appropriateness methods allow better implications of the study's findings to take this knowledge further; however, this must be undertaken with caution. Crucially, there is a need to undertake several stages before applying the findings to create opportunities for better dementia care experiences utilising the continuum of care and holistic care approaches. Nevertheless, in using the findings of this study, future research should extend the understanding of the relationship between nurses' knowledge, attitudes and perceptions of people with dementia as well as that of their families. This is in addition to evaluating the appropriateness of policies for dementia nursing care on people's well-being. It is also important to understand the organisational culture as well as to investigate the care barriers. In addition, it is crucial to understand nurses' experiences in order to be able to support their holistic care needs. This is for the purpose of ensuring the continuum of care and achieving holistic care experiences for people with dementia.

## 8.5 Summary of this chapter

Studies about nursing care in the Eastern-Mediterranean countries including in the KSA, are scarce. The present study is the first to specifically address nurses’ knowledge, attitudes and perceptions as they relate to people with dementia in MOH hospitals and observe that knowledge and attitudes are inseparable and that knowledge, attitudes and perceptions of nurses are solid and interconnected. Of significance to the general study of dementia care, this study highlights the importance of considering factors other than medical considerations when preparing a care plan for people with dementia. These include social and cultural influences, emotional work demands and work environments.

The study findings indicate that nurses hold limited knowledge about people with dementia and their attitudes positively correlate with their level of knowledge. Additionally, the study found that certain aspects of attitude have a huge impact on delivering nursing dementia care, including emotions and communication. The study also demonstrates a correlation between nurses’ confidence levels and comfort that drives their perceptions about people with dementia and dementia care. The analysis confirms that the available resources and policies about dementia training are lacking in most wards, hence nurses’ calls for organisational changes, as work environment is perceived as deterring dementia nursing care. The data suggests that societal and cultural aspects also greatly impact dementia nursing care.

# Chapter 9 Conclusion

This chapter offers the conclusion of the study and the implications of the research. It includes a discussion of the study's limitations, recommendations for dementia nursing practice and suggestions for future research. To organise the evidence discussed and presented, this chapter has been divided into the following subsections: summary of the study, quality issues, reflections, limitations, implication for nursing practice, and final remarks/ concluding thoughts.

## 9.1 Summary of the study

In this thesis, nurses' knowledge, attitudes, and perceptions were explored when caring for people with dementia in hospital care settings in Jeddah, Kingdom of Saudi Arabia (KSA). The study's aim was addressed by exploring the current nursing care practices in Jeddah hospitals. The four objectives were met and the knowledge will be used to inform policy and practice development across Eastern-Mediterranean countries.

The first objective was to gather data regarding nurses' knowledge of and attitudes about dementia in the KSA. This was met by using questionnaire surveys, the Dementia Knowledge Assessment Tool version 2 (DKAT2) and the Dementia Attitude Scale (DAS). The questionnaire shows that nurses' knowledge was low-moderate with a positive association between knowledge and attitudes scores. Also, the knowledge level and attitude scores were impacted by the nurses' work environment, including availability of resources, as well as their educational and cultural backgrounds, their self-confidence level and the effects on their comfort level when caring for people with dementia.

The second objective was to explore the current practices of nursing care for people with dementia to gain greater insight into nurses' attitudes and perceptions regarding dementia and the care they provide to people with dementia using diaries and interviews. The dementia nursing practice was altered by nurses' acquisition of knowledge and their belief systems, nurses' perceptions towards living with and caring for people with dementia and socio-cultural factors affecting nursing practice. Also, it is evident that attitudes informing nurses' behaviours include patience, communication and emotions.

The third objective was to identify the learning needs of registered nurses when caring for people with dementia. This was met by finding the associations between the scores obtained in the survey and nurses' qualifications, educational backgrounds, experiences and resources available at work, as well as data from the diary-interviews, wherein nurses expressed their ideas for enhancing dementia nursing care.

The fourth objective was to identify the barriers and obstacles faced by nurses when caring for people with dementia in Ministry of Health facilities using diaries and interviews. The study discovered that knowledge acquisition, emotional work performance, organisational policies and cultural understanding are important factors to achieve the holistic care approach and, in turn, ensure the continuum of care.

The study found that by combining survey and diary-interviews data using the integration process, key concepts could be collected to form a foundation for a future discussion of a roadmap/framework for changes to dementia nursing care in the KSA. These concepts have the potential to support dementia nursing care in hospital settings by providing a practical application for both individual and organisational improvements in providing that care.

The study also provides a roadmap for other Eastern-Mediterranean countries to develop strategies to advance a dementia research agenda, including understanding strengths, opportunities, weaknesses and threats, and prioritising research questions. It is designed around a set of principles to guide work and research collaborations. The concepts mentioned above should act as a basis for developing dementia research collaborations nationally and internationally, and provides direction for research activity.

It is worth mentioning that this study supports the growing body of evidence that nurses' knowledge and attitudes are correlated and form nurses' perceptions on dementia nursing care that alters the delivery of that care. The five pillars were discussed under sub-headings that will enable the continuum of care and the holistic care approaches, including knowledge, emotional work, socio-cultural influences, and work environment impacts. It is also important to consider certain characteristics of nurses, such as patience, confidence, communication skills, keenness to learn about dementia, previous knowledge and experience related to dementia, as well as previous experience with and attitudes towards nursing people with dementia and organisational policies. Moreover, the policies that need to be addressed are nurses' rotation between wards, time spent with people with dementia, nurse-patient ratio when having a person with dementia admitted to the ward and keeping a diary and/or reflexive notes. Nurses are encouraged to illuminate any conflicts in care, communication barriers, organisational restrictions and ward business as these are believed to be barriers to achieving the continuum of care and providing the holistic nursing care, which further causes nurses moral distress and added stress and failure in care delivery.

Development of nursing practices and policies are worthy of further study with this client group. This study appears to be the first among Eastern-Mediterranean countries to observe that knowledge and attitudes are inseparable and that knowledge, attitudes and perceptions of nurses are solid and interconnected. It also makes an original contribution by finding that cultural factors inherent in this region directly influence the continuum of nursing care, suggesting that like studies in other regions will provide similar discoveries. Hence, by exploring the knowledge, attitudes and perceptions using the sequential explanatory mixed-methods design this study has strengthened the findings and makes an original contribution to the body of knowledge.

Analysis of the data from the diary-interviews also uncovered unexpected viewpoints and insights that either would have been difficult or impossible to obtain via the survey alone. The opposite is true as well, with some research needed to explore existing knowledge and attitudes using validated psychometric tools to gain insight into current nursing practices.

Despite nurses having limited knowledge, resource scarcity, communication barriers and organisational restrictions, they are keen to learn about dementia and tend to improve their dementia nursing practices. These findings were supported by findings from previous studies. However, this study found that in performing emotional work, cultural understanding and organisational policies are of equal importance. Thus, dementia nursing care practice is suggested to be improved by integrating emotional work with reading and searching websites using the Google search engine and, most importantly, writing diaries and/or reflexive notes that were shown in this study to have a knowledge raising affect. This also makes an original contribution to the body of knowledge.

## 9.2 Quality issues

In mixed-methods research, it is vital to consider quality criteria as a useful overarching term when referring to strategies for defending the study's outcomes and for building the credibility of the researcher's implications through transparency (Poth, 2018). Quality issues in this study are broken down in this section according to each stage in the study: literature review, survey data collection and analysis, diary-interviews data collection and analysis and integration and implication process.

### 9.2.1 Literature review

In both literature reviews that were conducted in the current study – Review #1 and Review #2 – the international protocol for reporting systematically reviewed papers, also known as the Preferred Items for Reporting Systematic Reviews and Meta-analyses (PRISMA) was followed. The study's author followed the guidelines that includes the use of critical appraisal tools for every study included in the literature review. Review #1 has already been published in Dementia Journal (Yaghmour, Bartlett and Brannelly, 2019) and Review #2 has been accepted for publication in the Nursing Open Journal (one of Willey Online Library that consider a high standard and rigorous peer-review journal; see Appendix D; (Yaghmour, 2021)).

### 9.2.2 Validity and reliability of survey data

This study used two validated tools for knowledge and attitudes and its acceptable reliability estimations have been well reported (O'Connor and McFadden, 2010; Annear *et al.*, 2015b). Additionally, the validity of these tools was recognised by the original authors of the scales (O'Connor and McFadden, 2010; Annear *et al.*, 2015b). Also, before the actual data collection took place, the study author did a pilot for the study. This was to give the study researcher a valuable insight of data and responses. The reliability was suggested to be estimated by comparing the different responses from piloted participants using the same questionnaire. While admitting that validity is harder to assess, it was estimated by comparing the respondent data to the available evident that used similar research tools. Finally, checking the eight assumptions of linear regression added credibility to this study’s quality, including its validity and reliability as well as the objectivity of the concluded findings.

### 9.2.3 Dependability and credibility of the diary-interviews and integration process

The application of rigorous data collection procedures and data analysis strategies occurred in order to ensure dependable and credible findings and to increase the study’s trustworthiness (Lincoln and Guba, 1985 ). Data source triangulation was also implemented to gain multiple perspectives and ensure the credibility of the data (Denzin, 1978; Patton, 1999). In addition, a thorough, coherent, and transparent research process was delineated: first, the use of diary data, followed by interviews, strengthened the study’s findings as it provided more understanding of the study’s context and the phenomena explored. Then, following the six steps of thematic analysis in analysing the qualitative data encouraged a rigorous finding that can be dependable and credible and increases the study’s trustworthiness. Additionally, the four-step technique of the pillar integration process used a matrix (pillar integration process table) to present data from different datasets to increase the rigours and maintain the researcher’s positionality. It also aids in minimising the researcher’s bias and maintains the confirmability of the concluded findings. It can be concluded that all these elements assisted in maintaining the quality of this study’s findings.

## 9.3 Reflection about this study

My reflection about the study's development and exploration in the field of dementia and nursing research is provided in this section, including my skills and knowledge development while conducting my PhD study. This assisted in conceptualising, designing and implementing this study for the generation of new knowledge, applications or understanding at the forefront of the discipline, and to adjust the project design in the light of unforeseen problems.

First of all, I would like to acknowledge that I undertook a complicated study. This allowed me to acquire advanced personal research skills that were enhanced by extensive reading and learning and attending seminars and training sessions. It is worth mentioning that undertaking a mixed-methods postgraduate award from the University of Warwick while my PhD study is ongoing had a considerable advantage in developing such knowledge. When I return to work in the KSA, I will use my knowledge and research skills, especially using mixed-methods designs, to assist my lecturing at my workplace, which sponsored my pursuit of a PhD degree. Also, the applicability of my research findings and the study's recommendations are mentioned in the implication of nursing practices section 9.5.

During the data collection, I was surprised by the study participants' resilience and commitment, regardless of their professional level or roles they have. The nurses' views about research have positively changed from what I experienced while conducting my Master's degree thesis in 2015. Nurses were more open and they appreciated the importance of conducting such a study to explore dementia and nursing. Most gatekeepers have contacted me even after the data collection stage was completed and asked for the results. They especially asked for the study's conclusions and recommendations to be emailed to them after completion.

Also, the chosen methodology was successful in generating sufficiently rich data, and this study has added to what is already known about nursing care for people with dementia in the KSA. Participants reported that the survey had refreshed their knowledge about dementia and made them think about and investigate dementia care. Also, the diary entries made most participants appreciate their own care that they provide and reflect on their work by expressing themselves freely. In addition, diaries have had a knowledge raising affect (See quotes about the study in the appendix J.4).

Some of the challenges faced while conducting the study included facing the scabies disease epidemic that was rampant in Jeddah’s healthcare facilities during the data collection stage. In response to this matter, and after receiving prior approval by the ethics committee, I made minor changes to the data collection protocol that involved gatekeepers to be the only contact with the survey participants. Lately, the COVID-19 pandemic was a challenge and causes social and psychological stress while finalising my findings and writing my thesis.

## 9.4 Limitations of the study

As a result of the nature of doctoral studies, one person mostly collected, analysed and interpreted the data, and then discussed these with the supervisors. The consistency of the method used is maintained but it fails to form multiple perspectives from different areas of expertise. When using such methods in future studies, it is highly recommended to involve more than one person in the collecting, entering, coding and interpreting of the data.

The undertook study to present this thesis has produced valuable findings, however, there are some limitations to be acknowledged. These are pointed below first is the sampling strategy and bias, then data analysis, and finally the social considerations.

Collecting data using purposive sampling strategy initiated a bias in choosing the hospitals and conducting study in one city. However, I am confident about the level of generalisability across Saudi because of variety of hospitals I sampled and diversity of workforce. Hence, findings are applicable in Gulf countries as the nursing workforce are similar and most hold similar beliefs and education, as well as Pilipino and Indian nurses. The unequal sample size (in term of hospital distribution, included wards and also the days that diary participant was in the study). Also, conducting the study in one health region in Jeddah city; yet the findings might be relevant to most clinical settings in the KSA as most sittings share similar personal and educational demographics as well as experiences and workforce distribution. With the above in mind, a large amount of (survey) data was collected and had to be limited for inclusion in the study by applying the adjusted, partially adjusted and not adjusted model in linear regression as it is worth considering what is happening moving from the fully adjusted model. Linear regression is bit difficult with so many variables. Trying to make everything fit is a risk with the pillar integration process; therefore, survey questionnaires statements were qualified to assist in mixing and matching and overcome this risk. This is a long and time-consuming process. The limitations of the survey itself as well as it might not captured the nature of these wards and the differences that imposes of the nurses. however, supplement the study with diary-interview data overcome this limitation.

In terms of social considerations, diaries do not align with cultural values, which meant taking a calculated risk by approaching nurses in the KSA. Also, information about having access to evidence-based, internet and computer used at work impact the nurses' knowledge and attitudes cannot be reliable; as presence of the materials themselves does not mean the nurses will have the time to access them, or that they would use them with the intention to access them relating to dementia.

During interviews, participants' reactions might have been affected by the presence of the researcher. The researcher took care not to influence the participants or share similar ideas and perceptions and did not agree or disagree with participants during the interview in order to avoid false perceptions expressed by participants trying to provide the answers they thought were desired. The researcher was aware that some participants, specifically, non-Saudi nurses, might have feared that providing honest answers would give their clinical setting a bad reputation. To avoid this problem, the researcher assured participants that their data would be kept confidential and used only for research purposes only and no one except the researcher would have access to it. The researcher also stressed the importance of honest and genuine responses. Confident that people were not just choosing to represent themselves in best light.

Another issue was coding my own experiences and thoughts as this information is collected over time to detach myself from the study. While it helped me to form some semblance of objectivity, maintaining objectivity by separate myself from the study was found to be nearly impossible.

Additionally, the study could have been affected by a different ratio of Saudi to non-Saudi participants. As the nursing shortage continues to be a problem in the KSA and with the proportion of non-Saudi nurses growing yearly, especially in urban areas (see section 1.2.2), this may affect the impacts of factors such socio-cultural influences on dementia nurses. This, however can also be a source for a further research looking at the impact of collegiality that a mixed ward of nurses has in KSA hospital settings.

## 9.5 Implication for nursing practice

This thesis makes a number of original contributions to knowledge in the field of dementia and nursing care. The following points are recommended as a result of this research:

### 9.5.1 Recommendations for nurses and nursing people with dementia

1. Make sure nurses:
    a. upon admission, arrange for a multidisciplinary team visit and not wait for a crisis or major issue.
    b. do a complete assessment, not only physical but also psychological, social and spiritual.
    c. have comprehensive history from a family member/relative.
    d. introduce themselves every time they approach a person with dementia.
    e. are assigned to a patient who can understand them (linguistically and culturally).

2. Nurses should keep diaries about their own care and perceptions towards themselves and people with dementia. This was found to be a beneficial tool in the study as it helped participants be more aware of the care they provided.

### 9.5.2 Recommendations for organisations that care for people with dementia

1. Based on the findings of this study, it is recommended that training programmes be aligned nationwide, with an added focus on dementia as a neurological condition (as opposed to fate) and a de-emphasis of cultural biases affecting dementia diagnoses.

2. To increase continuum of care and reduce emotional burdens on nurses who lack certain knowledge of dementia, have at least one nurse trained in dementia care for each working shift.

3. Although nurse-to-patient ratios vary according to setting, an ideal nurse-to-patient ratio, based on all interview participants' suggestions, is one nurse to three patients when a patient with dementia is present.

4. Care facilities should have a system of identification for people with dementia or suspected dementia. This system must be adaptable so as to consider illiterate people or those hesitant to admit to dementia. It must also consider family members' sensitivities whenever possible.

5. Develop extended medical wards and have specialised facilities wherein people with dementia do not interfere in the care of other patients and can be cared for in a focused and compassionate way.

## 9.6 Concluding thoughts

It is everyone’s right to have positive experiences and receive the right support when admitted to a healthcare facility. This study contributed to the current body of knowledge on the topic and suggested possible ways to enhance the nursing care for people with dementia and ensure the continuum of care for them, which, in-turn, can influence their well-being. It is our professional responsibility to create positive nursing care experiences for people with dementia and their loved ones no matter what stage of dementia they are in or if they can recognise us or if we are forgotten.

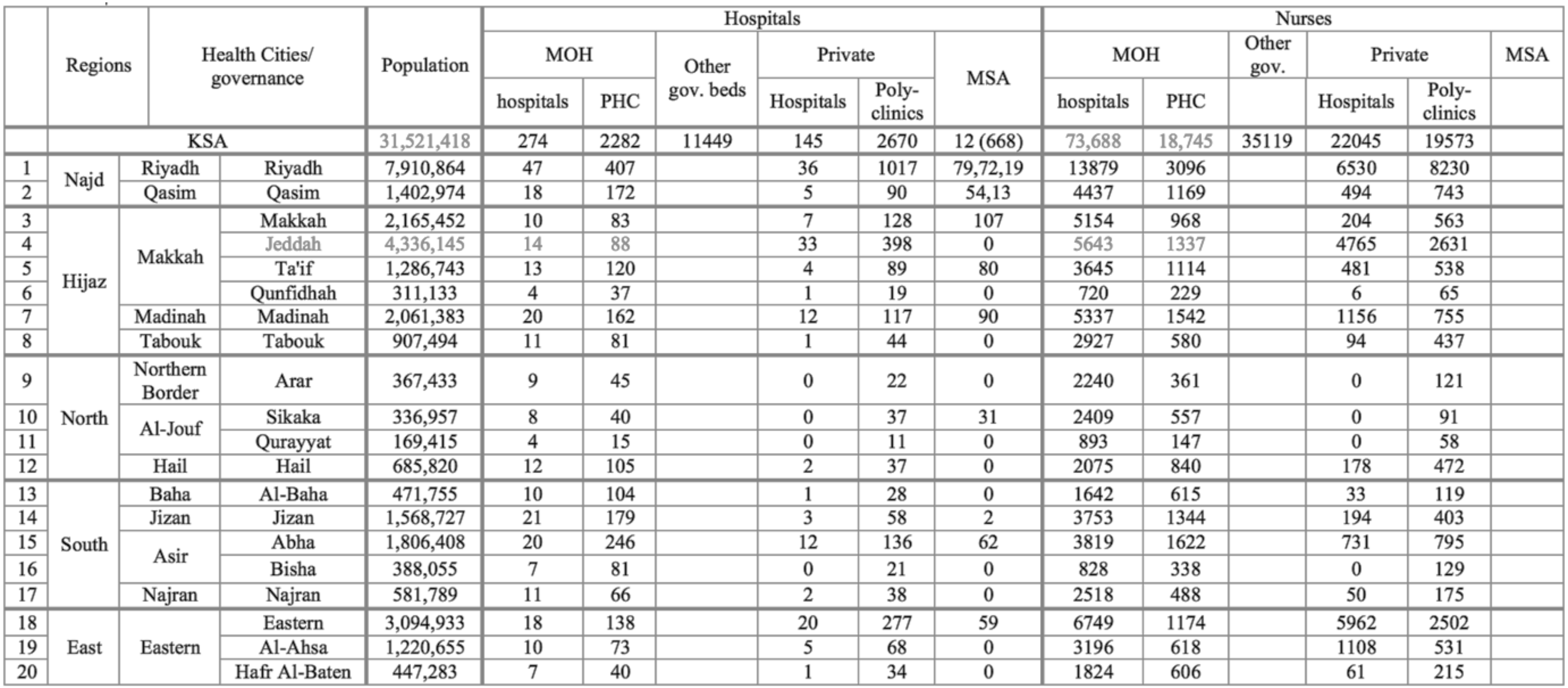
# Appendix A Overview of the study

| Task | Aim | Design | Guidelines | Method | Participants / Materials | Inclusion criteria | Data analysis |
|---|---|---|---|---|---|---|---|
| Literature Review #1 | Explore what is known about dementia in Eastern-Mediterranean countries | Systematic review | The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA) | Systematic search on data bases between Feb-Jul 2017 (updated March 2020) | N=33 studies<br>Added 15 studies when updated | All evidence available about dementia in Eastern-Mediterranean countries between 2007-2017 in peer-reviewed journals | Thematic analysis using NVivo software |
| Literature Review #2 | Explore nurses' knowledge, attitudes and perceptions toward people with dementia in acute and community care settings | Integrated Systematic review | The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA) | Systematic search on data bases between Nov 2017-Jun 2018 (updated March 2020) | N=72 studies | All evidence available between 2010-2020.<br>Registered nurses working in Healthcare facilities that involved caring of people with dementia.<br>Clearly indicated or discussed nurses' knowledge, attitudes or perceptions toward caring for a person with dementia. | Thematic analysis using NVivo software |
| Survey | to identify nurses' attitudes and knowledge concerning people with dementia in hospital settings | Quantitative cross-sectional survey questionnaire (section 1: Demographical data, section 2: Dementia Attitude Scale, and section 3: Dementia Knowledge Assessment Tool version 2) | The Consolidated Standards of Reporting Trials for RCTs of non-pharmacologic treatments (CONSORT) | Printed paper questionnaire collected between Mar-Jul 2018 | N=710 surveyed nurses using purposive sampling strategy | Registered nurses working in Ministry of Health (MOH) facilities in areas involved caring for people with dementia at least once a month with minimum one year of experience | Regression analysis, correlations and descriptive statistics using SPSS software |

Appendix A

| Task | Aim | Design | Guidelines | Method | Participants / Materials | Inclusion criteria | Data analysis |
|---|---|---|---|---|---|---|---|
| Diary | to gather a deeper understanding of nurses' perceptions and attitudes toward people with dementia | Qualitative written diary (participants to Record/write perceptions, experience, obstacles as a carer) | Standards for Reporting Qualitative Research (SRQR) | Printed diary booklet for 10 working days collected between Apr-Aug 2018 | N=17 diaries using purposive event sampling strategy | Agreed registered nurses from survey part who are working in different positions and areas who currently caring for person with dementia | Thematic analysis using NVivo software |
| Interviews | | Qualitative semi-structured face-to-face interviews | Standards for Reporting Qualitative Research (SRQR) | Face-to-face interviews conducted between Apr-Aug 2018 | N=18 nurses (post-diary interview) | Registered nurses who completed their diary entries | Thematic analysis using NVivo software |
| Integration | Suggest practice guidance and/or policies to improve the nursing care for people with dementia in the KSA | Intuitive merging, and transformation | Pillar integration process | Data triangulation | N=710 surveyed nurses & N=18 diary-interviewed | All study participants | meta-matrixes during the merging process (parallel/ separate) using NVivo software |
| Dissemination | Develop recommendations about improving care for people with dementia | discussion | - | - | - | - | - |

# Appendix B Hospital and Nurses in the KSA



| | Regions | Health Cities/ governance | | Population | Hospitals | | | | | | Nurses | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | MOH | | Other gov. beds | Private | | MSA | MOH | | Other gov. | Private | | MSA |
| | | | | | hospitals | PHC | | Hospitals | Poly-clinics | | hospitals | PHC | | Hospitals | Poly-clinics | |
| | KSA | | | 31,521,418 | 274 | 2282 | 11449 | 145 | 2670 | 12 (668) | 73,688 | 18,745 | 35119 | 22045 | 19573 | |
| 1 | Najd | Riyadh | Riyadh | 7,910,864 | 47 | 407 | | 36 | 1017 | 79,72,19 | 13879 | 3096 | | 6530 | 8230 | |
| 2 | | Qasim | Qasim | 1,402,974 | 18 | 172 | | 5 | 90 | 54,13 | 4437 | 1169 | | 494 | 743 | |
| 3 | Hijaz | Makkah | Makkah | 2,165,452 | 10 | 83 | | 7 | 128 | 107 | 5154 | 968 | | 204 | 563 | |
| 4 | | | Jeddah | 4,336,145 | 14 | 88 | | 33 | 398 | 0 | 5643 | 1337 | | 4765 | 2631 | |
| 5 | | | Ta'if | 1,286,743 | 13 | 120 | | 4 | 89 | 80 | 3645 | 1114 | | 481 | 538 | |
| 6 | | | Qunfidhah | 311,133 | 4 | 37 | | 1 | 19 | 0 | 720 | 229 | | 6 | 65 | |
| 7 | | Madinah | Madinah | 2,061,383 | 20 | 162 | | 12 | 117 | 90 | 5337 | 1542 | | 1156 | 755 | |
| 8 | | Tabouk | Tabouk | 907,494 | 11 | 81 | | 1 | 44 | 0 | 2927 | 580 | | 94 | 437 | |
| 9 | North | Northern Border | Arar | 367,433 | 9 | 45 | | 0 | 22 | 0 | 2240 | 361 | | 0 | 121 | |
| 10 | | Al-Jouf | Sikaka | 336,957 | 8 | 40 | | 0 | 37 | 31 | 2409 | 557 | | 0 | 91 | |
| 11 | | | Qurayyat | 169,415 | 4 | 15 | | 0 | 11 | 0 | 893 | 147 | | 0 | 58 | |
| 12 | | Hail | Hail | 685,820 | 12 | 105 | | 2 | 37 | 0 | 2075 | 840 | | 178 | 472 | |
| 13 | South | Baha | Al-Baha | 471,755 | 10 | 104 | | 1 | 28 | 0 | 1642 | 615 | | 33 | 119 | |
| 14 | | Jizan | Jizan | 1,568,727 | 21 | 179 | | 3 | 58 | 2 | 3753 | 1344 | | 194 | 403 | |
| 15 | | Asir | Abha | 1,806,408 | 20 | 246 | | 12 | 136 | 62 | 3819 | 1622 | | 731 | 795 | |
| 16 | | | Bisha | 388,055 | 7 | 81 | | 0 | 21 | 0 | 828 | 338 | | 0 | 129 | |
| 17 | | Najran | Najran | 581,789 | 11 | 66 | | 2 | 38 | 0 | 2518 | 488 | | 50 | 175 | |
| 18 | East | Eastern | Eastern | 3,094,933 | 18 | 138 | | 20 | 277 | 59 | 6749 | 1174 | | 5962 | 2502 | |
| 19 | | | Al-Ahsa | 1,220,655 | 10 | 73 | | 5 | 68 | 0 | 3196 | 618 | | 1108 | 531 | |
| 20 | | | Hafr Al-Baten | 447,283 | 7 | 40 | | 1 | 34 | 0 | 1824 | 606 | | 61 | 215 | |

Key: KSA Kingdom of Saudi Arabia / MOH Ministry of Health / PHC Primary Health Centre / MSA Ministry of Social Affairs data from (Ministry of Social Affairs, 2016; Ministry of Health, 2018)

# Appendix C First Literature reviews

## C.1 Published review #1

Article

Dementia
2019, Vol. 18(7–8) 2635–2661
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### Dementia in Eastern Mediterranean countries: A systematic review

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**Abstract**

Globally, there is an increase in the older population, whose lives are affected by local cultural norms. In Eastern Mediterranean countries, dementia is conventionally hidden from view with few dedicated services or recognition for diagnosis. The aim of this systematic review is to explore the limited literature on dementia and cognitive impairment among older people in Eastern Mediterranean countries to present an evaluation of current practices and to consolidate knowledge for future planning. Thirty-three studies were identified for inclusion in the review, and four themes were apparent. Firstly, prevalence, comorbidity and gender: In Eastern Mediterranean countries, many studies identify that the prevalence of dementia is high. As is the case elsewhere, many older adults in Eastern Mediterranean countries have at least one coexisting long-term condition, and some experience low life-satisfaction. Secondly, culture: In Eastern Mediterranean countries, the older adult is highly respected, and placement outside of the family home is considered an abandonment of family duty. The term dementia carries stigma, and it is widely believed that dementia is caused by 'fate'. Thirdly, recognition and tools: There is a lack of verified assessment instruments to assess for dementia. Despite concerns about the cultural appropriateness of the Mini-Mental State Exam, particularly for people who have low literacy levels, and low literacy being the norm in Eastern Mediterranean countries, the Mini-Mental State Examination is the main assessment instrument. Translation and transition of non-

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Arabic assessment instruments and tools with psychometric properties presents a challenge for clinicians. Finally, workforce issues: health care workers lack knowledge about dementia, as dementia care is a relatively recent addition to the nursing and medical syllabi. While there were some inconsistencies in the papers published, many of the articles call for increasing educational programmes and health and social care policies to promote improved and practical gerontological nursing and medicine. Health care professionals need education about sociocultural, religious, and language needs to deliver improved culturally sensitive care.

**Keywords**
dementia, cognitive impairment, Eastern Mediterranean, culture, Alzheimer's disease, health care

## Introduction

This paper aims to explore what is currently known about dementia and cognitive impairment among the older population in Eastern Mediterranean (EM) countries to identify current practices and identify needs for future development. It is estimated that in 2016, 47 million people around the world live with dementia; 2.3 million of whom live in EM countries (Schillings & Wahnsiedler, 2016). By 2030, this number is expected to increase to 4.4 million people living with dementia in EM countries (Schillings & Wahnsiedler, 2016). The increase in the older population in EM is consistent with growth globally (World Health Organisation [WHO], 2006).

The EM consists of 22 countries: Afghanistan, Bahrain, Djibouti, Egypt, Iran, Iraq, Jordan, Kingdom of Saudi Arabia (KSA), Kuwait, Lebanon, Libya, Morocco, Oman, Pakistan, Palestine, Qatar, Somalia, Sudan, Syria, Tunisia, United Arab Emirates (UAE), and Yemen, grouped for representation with bodies such as the World Health Organisation. The EM has 670 million people, with populations ranging from 196.7 million in Pakistan and 95.2 million in Egypt to 2.6 million in Qatar (The International Agency for the Prevention of Blindness, 2014; Cent, 2015; Cipriani & Borin, 2015; Ministry of Health [MOH], 2016; Okasha & Boutros, 2010; Worldometers, 2017). Global life expectancy is 71 years, and the average life expectancy in EM countries is 68.8 years. Life expectancy, however, varies in the EM from 78.2 years in Qatar; to 77.9 in Iran; 77.1 in UAE; 74.5 in KSA, Jordan, Kuwait, Lebanon, Morocco; 70.9 in Egypt; and at its lowest in Afghanistan at 60.5 years (MOH, 2016; WHO, 2015, 2017). This compares with a life expectancy of 76 years for a boy born in a high-income nation in, 2012 (WHO, 2015). With an increase in life expectancy and in the older population, dementia has become one of the most prevalent public health issues.

## Method

In February 2017, a systematic search was conducted in scientific databases, including DelphiS, CINAHL, MEDLINE, OVID, ProQuest, Embase and PsychINFO, using the following keywords: *older adult, old*, elder*, geriatric,* and *senior*, in combination with *dementia, Alzheimer's*, cognitive impairment, cognitive decline, memory loss, Lewy Body, Parkinson*, Vascular dementia*. These terms were then combined with the names of relevant

22 EM countries that is *Saudi, Arabia**, *Egypt, Emirate, Kuwait, Middle East**, or *Eastern Mediterranean* and studies in both English and Arabic (Table 1). In total, 1740 articles were found that were then limited to peer-reviewed articles published from 2007 to 2017, leaving $n = 687$ articles. Duplicate and irrelevant articles were excluded based on title and abstract, leaving $n = 99$ articles. Further research conducted using Google Scholar added $n = 11$ articles. However, considering the search limitations in the current study, finding recent data from the EM region from the past few years was challenging. Hence, searching for articles from the last 10 years proved more worthwhile. English and Arabic articles are the most accessible and most frequently used languages within the EM region. A limitation to peer-reviewed articles with the full-text available was applied as well to find best available evidence. The exclusion and inclusion criteria are outlined in Table 2.

Thirty-three articles were found using the search terms and search strategy (Figure 1, Table 3). The quality of the 33 studies was checked using the Joanna Briggs Institute (JBI) checklist, the Critical Appraisal Skills Programme (CASP) and the Mixed Method Appraisal Tool. Twenty-seven studies were assessed to be of ‘good quality’, and six were ‘average’ (Aromataris et al., 2015; CASP, 2017a, 2017b, 2017c; JBI, 2016; Lockwood, Munn, & Porritt 2015; Pluye et al., 2011). However, studies having an average quality were included in this review due to the limited number of studies available and due to their valuable contributions to the field.

There were 11 cross-sectional studies; 4 of these estimated the prevalence of Alzheimer’s disease, Parkinson’s disorder and mild cognitive impairment, and discussed the risks associated with sociodemographic factors; $n = 944$ Palestinian, in addition to $n = 200$ and $n = 44$ Egyptian from two studies, and, $n = 221$ Jordanian (Afgin et al., 2012; Almomani,

**Table 1.** Search terms and alternative terms/synonyms.

| Main term | Older adult | Dementia | Arab |
|---|---|---|---|
| Alternate terms | ‘old*’,<br>‘*older adult*’<br>‘elder*’,<br>‘geriatric’, or<br>‘senior’ | ‘*dementia*’, ‘Alzheimer*’,<br>‘cognitive impairment’,<br>‘cognitive decline’,<br>‘memory loss’,<br>‘*Lewy Body*’,<br>‘*Parkinson**’, or<br>‘*Vascular dementia*’ | ‘Arab*’,<br>‘middle east*’,<br>‘Eastern-Mediterranean’, ‘Afghanistan’,<br>‘Bahrain’, ‘Djibouti’, ‘Egypt’, ‘Emirate’,<br>‘Iran’, ‘Iraq’, ‘Jordan’, ‘Kuwait’, ‘Lebanon’,<br>‘Libya’, ‘Morocco’, ‘Oman’, ‘Pakistan’,<br>‘Palestine’, ‘Qatar’, ‘Saudi’, ‘Somalia’,<br>‘Sudan’, ‘Syria’, ‘Tunisia’, or ‘Yemen’ |

**Table 2.** Inclusion criteria to pertain search.

| | Limitation | Reason |
|---|---|---|
| Years | 2007–2017 | Finding recent data in EM region for the past few years is challenging, hence, searching articles of the past decade will be worthwhile |
| Language | English and Arabic | English and Arabic articles are more accessible and understandable, as well as the most frequently used within the EM region |
| Other | Peer-reviewed available texts | Looking at evidence based journals with best available evidence |

# Appendix C

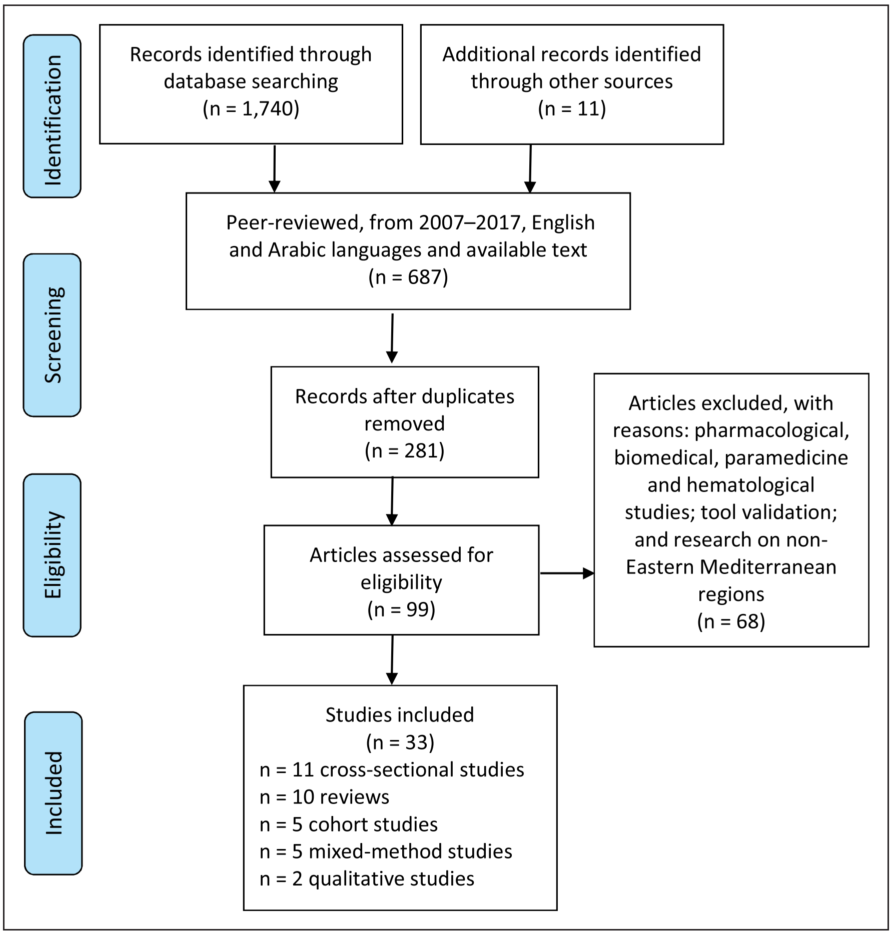

**Figure 1.** Study PRISMA chart.

Almomani, Alghadir, Alharethy, & Gabr, 2016; Esmayel, Eldarawy, Hassan, Mahmoud, & Mohamed, 2013; Khedr et al., 2015). A cross-sectional study in the Netherlands (Parlevliet et al., 2016) determined the prevalence of dementia and mild cognitive impairment across cultures, based on Arab participants (*n* = 1625), and assessed the validity of the Cross-Cultural Dementia Screening tool (Goudsmit et al., 2016). Two cross-sectional studies that used hospital-based data to assess morbidities and risk factors among older people were included in the review; *n* = 880 Saudis and *n* = 5399 Arab Americans (Almodeer, Hassanien, & Jabloun, 2013; Dallo, Ruterbusch, Kirma, Schwartz, & Fakhouri, 2016). In Saudi Arabia, Alaama (2016) assessed 70 medical students' knowledge of geriatrics, and Yaghmour, Gholizadeh, and Alsenany (2016) explored 265 nurses' knowledge of dementia. Alsenany and Alsaif (2012) conducted a comparison study that explored the intentions of

**Table 3.** Summary of studies included in the review.

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| **Culture** | | | | | | | |
| 1 | Abyad (2015) | Review | — | — | Explore Alzheimer's disease among Eastern Mediterranean people | – EM population is aging<br>– Older adults are source of high spiritual blessing, faith and wisdom within the community<br>– Strong family relations<br>– High illiteracy among EM older adults and low technology oriented<br>– Limited recourses and facilities available in the region to people with dementia | Good |
| 2 | Afgin et al. (2012) Wadi-Ara, Palestinian Occupied Territory | Quantitative observational study | – Clinical Dementia Rating Scale<br>– Dementia: DSM-IV, ICD-10<br>– Alzheimer: NINCDS-ADRDA<br>– Parkinson's: Gelb's | $N = 944$, age 65+ | Estimated the prevalence of AD, MCI and the risk of conversion to AD | – Arab shows significant higher prevalence of AD and MCI<br>– Females' prevalence of AD and MCI is higher than males<br>– High illiteracy rate among study sample<br>– The MCI epidemiology with high illiteracy rates are rarely reported<br>– Confirm literature scars in Arab world<br>– Recommend not to use MMSE<br>– MCI is more common than AD | Good |
| 3 | Alaama (2016) Jeddah, KSA | Quantitative descriptive study | Self-developed questionnaire: geriatric knowledge assessment questionnaire | $N = 70$ medical students | Assess the basic knowledge of medical trainees, in the absence of a structured geriatrics curriculum | – Dementia knowledge lacking among medical trainees<br>– Introducing geriatric medicine into residency programme in early 2016<br>– Older adults are expected to experience cognitive decline with normal aging, but not dementia as it is deemed to be pathological | Average |
| 4 | Alabed et al. (2014) Arab Australia | Systematic literature review | — | $N = 8$ studies | Explore health care needs of older Arab migrants in Australia | – Arab do not visit hospitals as preventive care; Exclusively in hypertension, diabetes and hyperlipidaemia or other subtle conditions<br>– Family members are discouraged in term of respecting, valuing, honouring and caring for older family members<br>– Limited facilities were available in UAE and Egypt | Good |

(continued)

# Appendix C

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | | – Receiving care from a nonfamily member is shameful<br>– The care is a family member's duty<br>– Usually older adults attend medical appointments with family member<br>– families do not openly discuss end-of-life care and death issues<br>– EM older adults' views obtained by Islamic religion, faiths and traditional culture<br>– EM attitude affected by cultural values when receiving care from nonfamily basis<br>– Caring for a mental health family member experienced with anxiety, loss, fear, shame and ignominy of family character | |
| 5 | Alsenany and Alsaif (2012) Jeddah, KSA | Quantitative descriptive study | The intent to work with older people questionnaire | $N = 566$ Saudi; $N = 718$ British | Explore the intentions of Saudi nursing students toward working with older people as baseline data for Saudi nursing students' perspectives | – Older adults are taken care of in Saudi Arabia by their families<br>– Saudi Arabia has few care facilities<br>– Using nursing homes facilities are not accepted in the Saudi culture<br>– Older adults care obtains in acute care settings when they need a nursing care<br>– Nursing students assumed that caring for older adults is similar to the prominence of general nursing from acute care setting<br>– Saudi students: establishing a nurse–client relationship with older adults is easier<br>– Shortage in nursing specialist in SA and limited research and high demand in develop education<br>– Increase health care professionals awareness of different sociocultural, religious and linguistic backgrounds while delivering culturally sensitive health care<br>– Nursing in SA was only established in 1960s | Good |
| 6 | Alsenany and AlSaif (2014) Jeddah, KSA | Mixed-method study | 5 focused groups and survey | $N = 132$ faculty members from 3 nursing schools | Explores nursing faculty members' attitudes towards older people, | – More gerontological content and clinical experience should applied to the nursing curriculum<br>– Nursing students are deemed to deal with older | Good |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | and their thoughts about gerontological nursing education | adults with gratitude and respect<br>– Older adults are spoken to with soft tune and not called by their names<br>– Respect and restrict behaviours are encouraged when dealing with an older adult | |
| 7 | Amr et al. (2014) Hufof, KSA | Quantitative population-based study | Clinical Dementia Rating scale, MMSE, Neuropsychiatric Inventory NPI, ADLs scoring. The Lawton IADL and DSM4 | $N = 53$ people with dementia<br>(39 male, 14 female) age 60+ | Evaluate the clinical and demographic profile among people with dementia in hospital setting | – 96.2% illiterate<br>– 12.9% the prevalence of dementia in the study<br>– The co-morbidity rate is high 52.8% (hypertension 45.3%, cardiac problem 30.2%, diabetes 23.7%)<br>– Female in eastern culture not attending hospitals frequently as men<br>– Females are totally dependent on male and thought to be more tolerant of psychological and physical pain than western females<br>– High respecting of elderly and extended family<br>– Only a few are living alone<br>– Recommended to use MMSE and NPI to early detect dementia and neurocognitive impairment | Good |
| 8 | Bentwich et al. (2018) Galilee, Palestinian Occupied Territories | Mixed method study | Semi-structured interviews<br>Self-developed questionnaire | $N = 20$<br>Sabra $n = 7$, Arab $n = 7$ and Russian $n = 6$ caretaker | Explore the gap existence among caretakers from different ethno-cultural groups regarding their perceptions of autonomy and human dignity of patients with dementia | – Attitude toward dementia clients' dignity and autonomy were differ significantly between Arabs and Russians<br>– Arab caretakers raise covering conceptions of self-respect and independence, provides better grounds for person-cantered care in health care setting<br>– Person-centred care for treating dementia clients consider the gold standard<br>– Dementia awareness starts in 1980s<br>– Older adults' dependency increases and their complexity rises as a result in deteriorating their autonomy and capability gradually | Good |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | | – Conserve valuing older adults' autonomy and human dignity | |
| 9 | Cipriani and Borin (2015)<br>Arab | Literature review | — | — | Explore dementia phenomena in ethnically diverse groups and cultures | – EM community have difficulty to admit dementia<br>– Stigma related to Arabic translation of dementia word<br>– In Arabic dementia called 'Kharaf' which means 'unravelled', 'lost the mind' that led to negative connotation in its understanding<br>– The Oldest member is the heart of wisdom, love, and blessing<br>– Fate 'Qadar' assumed to be the cause of illnesses in EM believes | Average |
| 10 | Eltallawy et al. (2013a)<br>El-Qaseir, Egypt | Sociodemographic study | Self-developed questionnaire Diagnosed by neurologists WHO criteria | $N = 33{,}285$ (Parkinson's 8183 age 40+) | Study the prevalence of aged-related neurological disorders in AlQuseir City | – 3.83% among participants aged 60+ are experiencing dementia as a most common neurological disorder<br>– Parkinson's disorder prevalence was higher in comparison to worldwide cities<br>– Cultural and social norms were affected on neurological disorders<br>– Evil attach<br>– Dementia in part of normal aging process<br>– High demand on concrete projects and framework to illuminate and shed the light on the nature of these disorders and their suitability of treatment | Good |
| 11 | Eltallawy et al. (2013a)<br>El-Qaseir, Egypt | Epidemiological study | Not hospital-based | $N = 33{,}285$<br>Age 40+ | Discover the prevalence of neurological disorders including dementia | – Females 5.2% higher than females<br>– 15 neurological disorders were identified | Average |
| 12 | Esmayel et al. (2013)<br>Egypt | A cross-sectional study | Geriatric Depression Scale (GDS)<br>MMSE | $N = 200$<br>Hospitalised aged 60+ | Determined the prevalence of these problems and their associations with sociodemographic | – Depression and cognitive impairment are the most common mental health problems among geriatrics<br>– 72% prevalence rate of depressive symptoms<br>– 30% of cognitive impairment among medical inpatients | Good |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | | – Conserve valuing older adults' autonomy and human dignity | |
| 9 | Cipriani and Borin (2015)<br>Arab | Literature review | — | — | Explore dementia phenomena in ethnically diverse groups and cultures | – EM community have difficulty to admit dementia<br>– Stigma related to Arabic translation of dementia word<br>– In Arabic dementia called 'Kharaf' which means 'unravelled', 'lost the mind' that led to negative connotation in its understanding<br>– The Oldest member is the heart of wisdom, love, and blessing<br>– Fate 'Qadar' assumed to be the cause of illnesses in EM believes | Average |
| 10 | Eltallawy et al. (2013a)<br>El-Qaseir, Egypt | Sociodemographic study | Self-developed questionnaire Diagnosed by neurologists WHO criteria | $N = 33{,}285$ (Parkinson's 8183 age 40+) | Study the prevalence of aged-related neurological disorders in AlQuseir City | – 3.83% among participants aged 60+ are experiencing dementia as a most common neurological disorder<br>– Parkinson's disorder prevalence was higher in comparison to worldwide cities<br>– Cultural and social norms were affected on neurological disorders<br>– Evil attach<br>– Dementia in part of normal aging process<br>– High demand on concrete projects and framework to illuminate and shed the light on the nature of these disorders and their suitability of treatment | Good |
| 11 | Eltallawy et al. (2013a)<br>El-Qaseir, Egypt | Epidemiological study | Not hospital-based | $N = 33{,}285$<br>Age 40+ | Discover the prevalence of neurological disorders including dementia | – Females 5.2% higher than females<br>– 15 neurological disorders were identified | Average |
| 12 | Esmayel et al. (2013)<br>Egypt | A cross-sectional study | Geriatric Depression Scale (GDS)<br>MMSE | $N = 200$<br>Hospitalised aged 60+ | Determined the prevalence of these problems and their associations with sociodemographic | – Depression and cognitive impairment are the most common mental health problems among geriatrics<br>– 72% prevalence rate of depressive symptoms<br>– 30% of cognitive impairment among medical inpatients | Good |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | factors among hospitalized elderly in Egypt | – Significant relation between cognitive impairment and each depressive symptom were detected<br>– Education level and low MMSE result are correlated | |
| 13 | Halabi and Zafar (2010) UAE | Literature review | — | — | Review the care provided to older adults in UAE | – Disabled and vulnerable elderly cared by extended family<br>– Geriatrics often surrounded by strong family relations; tribal<br>– In case older adult need assistance families hire a caregiver<br>– Inappropriate to refer a family member to a care facility<br>– A stigma related to using a care home<br>– Low number of gerontologists, while geriatric psychiatry almost not-exist<br>– Lack of trained personnel in dementia care<br>– No validated instruments available<br>– MMSE not appropriate to the population<br>– Dementia were determining on late stage and cared by a general practitioner<br>– Consider culture and social norms before introducing a new system or services | Good |
| 14 | Okasha and Boutros (2010) Arab | Literature review | — | N= 6 papers | Study papers published in Arab world concerning mental health and psychiatry | – The stigma associated to mental health is decreasing<br>– More psychiatric units were integrated to the hospitals and care facilities<br>– Mental health treatment gap is high as most Arab population are dependence on traditional and religious healers, which form obstacles to | Average |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | | pursue a medical treatment<br>– Caused by evil eye | |
| 15 | Sayegh et al. (2013) South Asian & Middle Eastern Americans, USA | Literature review | — | — | Discuss topics associated with dementia and mood and anxiety disorders among South Asian and Middle Eastern American older adults | – Noted the gap in researches conducted in EM community that investigate the prevalence of dementia, mood and anxiety disorders among older adults<br>– Language barriers and lack of verified assessment instrument consider issues in recognising and treating dementia<br>– A problem in translating and uses of culturally accepted terminology<br>– Older adults supported emotionally and socially by their families<br>– Seeking advice from outside the family boarder consider is untrustworthiness<br>– Evil spirit was attributed these illnesses<br>– EM health professionals are including Arabic versions of the shortened Geriatric Mental State Interview as assessment of dementia<br>– Validity of MMSE and the Informant Questionnaire on Cognitive Decline in Elderly<br>– In gulf region people are seeking medical support rather late as commonly acknowledged that forming a cognitive deficit is a part of normal aging<br>– EMs are seeking help in the moderate and sever stages as they tend to report emotional and behavioural problems rather than memory<br>– Recommended to use MMSE for educated older adults<br>– It is highly recommended to understand EM culture to help in dementia care | Good |
| 16 | Spalter et al. (2014) Palestinian | | Survey of Health and Retirement (SHARE) | $N = 982$<br>Age 60+ | Examine the functional changes in late life in | – Older adults living with other than spouse having higher number of diseases and comorbidity | Good |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | Occupied Territories | Longitudinal study 2005–2010 | | | mobility, movement, activities of daily living | – Physical functioning can improve and decline with ageing<br>– ADLs is a key indicator of QoL and wellbeing<br>– Educate homecare workers and families to enhance the QoL of the elderly | |
| **Prevalence, comorbidity and gender** | | | | | | | |
| 17 | Alhawiti et al. (2016) Tabuk, KSA | Historical cohort longitudinal study | Patients' records | $N = 313$<br>Age 50+ | Identify the specific risk factors of dementia and Alzheimer's disease | – Diabetes, hypertension, vascular disorders as a risk factor as these chronic illnesses plays a significant role in dementia development and prognosis, that maximise the risk of earlier onset dementia<br>– Participants with multiple risk factors are experiencing earlier onset dementia<br>– Include Alzheimer's disease, dementia with Lewy bodies, fronto-temporal dementia, and vascular dementia<br>– Females more than males in term of risk factors | Average |
| 18 | Almodeer et al. (2013) Southern, KSA | Quantitative descriptive study | Hospital-based data | $N = 880$<br>Age 60+ | Determine the morbidity profile in home health care among older adults registered at one hospital in KSA | – Comorbidity is common in the study's sample<br>– 16.5% of older adults have two chronic illnesses<br>– 22% are experiencing three chronic illnesses<br>– 51% have four or more illnesses<br>– Hypertension (59.1%), diabetes mellitus (57.3%), stroke (34.9%), dementia (28.5%), osteoarthritis (24.2%) and Alzheimer (21.4%)<br>– Females are at higher risks of having many types elderly diseases<br>– The highest risk was for obesity, then osteoporosis and fracture neck. In addition, females were also at higher risks of having osteoarthritis and thyroid disorder, males are more susceptible to hypertension, stroke and renal diseases<br>– No baseline data available on elderly's chronic diseases<br>– There is a need for developing a beneficial preventing and rehabilitating programme toward improving the quality of life among older adults | Average |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| 19 | Almomani et al. (2016)<br>Jordan | Quantitative study | The Arabic versions of the Tinetti assessment battery (TAB) for gait and balance, mini-mental state examination, and disability of arm, shoulder and hand assessment test | $N = 221$ nursing home residents in Jordan<br>Age 18–100 | Investigate the effects of physical, mental, and cognitive disabilities on gait and balance deficits among nursing home residents with different diseases in Jordan and also to find the risk of fall associated with or without these diseases | – Sever demented clients were excluded (11.7% from $n = 290$)<br>– Severe gait and balance deficits were found in younger adults (55 years) who had mental or physical health problems<br>– Psychiatric disorders (including dementia) and cognitive impairments are related to fall risk balance and gait deficit<br>– Cognitive impairment, dementia and Alzheimer are prevalent in older adults (70+) | Good |
| 20 | Ayalon et al. (2010)<br>Palestinian Occupied Territories | Mixed-method cross-sectional study | SHARE<br>Face-to-face interviews | $N = 2492$ (8.7% Arab)<br>Age 50+ | Evaluates population group differences in the cognitive functioning of Israelis 50 years and older | – A little less than the half have shown impaired performance on the task of word learning<br>– More than half of participates have shown impairment on the mathematic tasks, verbal recall task and word fluency task<br>– Approximately half of the study sample experience impaired reading and writing abilities<br>– More education in Arab population is needed | Good |
| 21 | Boulos et al. (2013)<br>Lebanon | Mixed-method cross-sectional study | MMSE, GDS-5 | $N = 1200$<br>Age 65+<br>Cluster sampling in rural setting | Assess the nutritional status of community dwelling elderly people living in a rural settings in Lebanon, in line of socioeconomic factors, health and living conditions | – Significant differences between gender<br>– Females are significantly higher than males in illiteracy level and poor income, which are associated with chronic illnesses, poor self-perceived health, fragility and functional disability<br>– Females are higher than males in the prevalence of depressive symptoms and cognitive impairment | Average |
| 22 | Dallo et al. (2016)<br>Michigan, USA | Quantitative descriptive study | Hospital-based data | $N = 68{,}047$ (5399 Arab American)<br>Age 18+<br>Attending a large, metropolitan hospital system | Estimate and compare Alzheimer's disease and other disorders prevalence between Arab Americans and white Americans | – A comparison between Arab Americans and white Americans in the study but shows no significant differences in experiencing Alzheimer's disease<br>– Men: Arab American have higher prevalence rate of diabetes, hypertension and lower chronic | Good |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | | lower respiratory disease than white Americans significantly<br>– Women: were higher prevalence of experiencing chronic lower respiratory disease, diabetes, influenza/pneumonia and hypertension than men<br>– Arab are under-studied group in the USA and international | |
| 23 | Elshahidi et al. (2017) | Systematic review | Databases | $N = 6$ studies | Summarise the current evidence available regarding dementia prevalence in Egypt | – Prevalence of dementia was vary among studies (2.01–5.07%)<br>– Dementia is increased with age<br>– Females were affected with dementia more than males<br>– Males 80+ are higher than females<br>– Dementia is higher prevalence among illiterate older adults | Good |
| 24 | Ghubach et al. (2010)<br>UAE | Qualitative | Interviews using Geriatric Mental State Interview (GMS-A3) | $N = 610$<br>Age 60+ | Examine the relationships of psychiatric disorders and physical disorders on life satisfaction among Arab older adults in general population | – 20.2% were diagnosed with depression, 5.6% have anxiety, 4.4% hypochondriasis and 3.6% have organic brain syndrome with or without dementia<br>– Having depressive disorder significantly associated with less life satisfaction<br>– Decreased life satisfaction was significantly accompanying with anxiety, hypochondriacal disorders and organic brain syndrome<br>– 48% of older adults in the study were not satisfied with their lives<br>– Amongst participants above 85, the level of life satisfaction was significantly low, as well as with the participants who are living alone or with only spouse | Good |
| 25 | Khan et al. (2013)<br>Riyadh, KSA | Mixed-method study | Interviews, BMI, mini-nutritional assessment<br>Study investigate the BMI and nutrition status and its relation to psychological problems in AD's clients | $N = 63$ Saudis above 60-year-old | Assess the nutritional status of a small number of Alzheimer's patients living in Saudi Arabia and evaluate the risk of malnutrition | – 38% of participant with good nutrition are less likely to develop ADs<br>– Almost all participant with ADs have malnutrition or risk of malnutrition<br>– Scar in data regarding dementia in Saudi Arabia in particular, and in the Middle East in general | Good |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | associated with this disease | – Disease recognition plays an important role in slowing its progression | |
| 26 | Khedr et al. (2015) Qena, Egypt | Quantitative cross-sectional study | The unified Parkinson disease rating scale (UPDRS), mini-mental state examination (MMSE) and the non-motor symptoms scale (NMSS) | $N = 44$ with Parkinson's disease | Provide evidence for the prevalence rate of PD in Egypt | – High PD prevalence in north Egypt<br>– 14.3% of participants had mild dementia<br>– Environmental risk factors; air and water pollution and genetic susceptibility<br>– Promote longitudinal studies and risk factors investigation are needed in future studies | Good |
| 27 | Parlevliet et al. (2016) Netherland | Quantitative cross-sectional study | Population-based Systematic Memory Testing Beholding Other Languages study, comprehensive geriatric assessment and cognitive testing using the CCD screening, EuroQoL, Informant Questionnaire for Cognitive Decline | Age 55+ | Determine the MCI and dementia prevalence in older community-dwelling adults from the largest non-western immigrant groups in the Netherland | – Higher prevalence in compression with western citizens in MCI and dementia (3 or 4 times more than native Dutch (14.8% in Turkish, 12.2% in Moroccan Arabic, 11.3% in Moroccan Berber and 12.6% in Surinamese–Hindustani participants, compared to 4.0% in Surinamese–Creoles and 3.5% in native Dutch)<br>– In immigrants, the higher prevalence of dementia was associated with higher prevalence of vascular risk factors and psychiatric disorders such depression | Good |
| 28 | Werner et al. (2015) Palestinian occupied territories | Literature review | Ethnic differences in epidemiologic and risk factors for Alzheimer's disease, including genetic differences as well as disparities in health access and quality of health services. | — | Describe ethnic differences in prevalence and risk factors for Alzheimer's disease. | – Participant with age 60+ have four times higher prevalence than non-Arab who are 75+ living in the same area using similar diagnostic tools<br>– Illiteracy and education are strongly associated with prevalence of AD<br>– Arab population is higher than in population with similar literacy and educational profile<br>– Few studies strong association between education and prevalence of dementia<br>– High prevalence of cognitive impairment<br>– Differences in testing methods may be responsible for the variable results<br>– Dementia is associated with older-age, female gender, lower education | Good |
| **Recognition and tools** | | | | | | | |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| 29 | Goudsmit et al. (2016) Netherland | Quantitative cross-sectional study | Cross-cultural dementia screening CCD | $N = 1625$ (173 Moroccan-Arabic)<br>55+ old | Test the validity of newly developed Cross-Cultural Dementia Screening (CCD) | – A cross-cultural dementia screening test is a neuropsychological instrument for dementia screening for low-educated immigrant population that is sensitive and culture-fair tool<br>– It is valid tool to predict dementia among 1625 participants in Netherland who are illiterate, low-educated, different culture or have languages barriers<br>– Immigrants are minor ethnicity in host countries, with limited knowledge regarding host country culture and language, as well as many were illiterate or have low education level, which result lower MMSE score<br>– Recommended tool to use in memory clinics with standard multidisciplinary diagnostic checks | Good |
| 30 | Uysal-Bozkir et al. (2013) Arab, Turkish, Surinamese | Systematic literature review | — | $N = 68$ articles (31 cognition, 24 mood, 23 QoL, 1 loneliness, 21 ADL) 65+ | Assess the quality of the cross-cultural adaptations and the psychometric properties of health assessment scales measuring cognition, mood, activities of daily living, health-related quality of life and loneliness | – Insufficient cross-cultural versions with unknown psychometric properties for several converted health assessment instruments<br>– Most frequent used assessments were:<br>* Cognition: Some studies used dementia diagnosis according to (DSM-IV) classification as their gold standard. The Mini-Mental State Examination (MMSE) and Alzheimer's Disease Assessment Scale been used more frequently<br>* Mood: the Geriatric Depression Scale (GDS), Hamilton Depression Rating Scale (HDRS), Centre for Epidemiologic Depression Scale (CES-D), and Hospital Anxiety and Depression Scale (HADS)<br>* Loneliness the self-report University of California, Los Angeles, Loneliness Scale<br>* ADL: the Barthel index (BI) and Functional Independence Measure (FIM).<br>* QoL: Short Form 36 Health Survey (SF-36)<br>– EM countries faces a challenge to evaluate the psychometric properties as a result of lacking in cross-cultural high-standard adapted | Good |

(continued)

**Table 3.** Continued

| No. | Study | Design | Tool | Sample | Aim/question | Key findings | Quality rating |
|---|---|---|---|---|---|---|---|
| | | | | | | assessment instruments while the using instruments consider a mediocre in most cases | |
| **Health care workers** | | | | | | | |
| 31 | Boughtwood et al. (2011)<br>Arab, Australia | Qualitative study—grounded theory | Focused group | $N = 121$ family carers (19 Arab) | Examining family caregiving for dementia in CALD communities in Australia | – All communities were heavily involved in the care<br>– EM families were the most sensitive, while much emotions showed along with grief and anxiety about living with dementia person<br>– EM carers were the least concerned about dementia-related behaviours amongst other group<br>– Arabic-speaking carers were less encouragement role in hospitals<br>– Arabic-speaking and Chinese-speaking carers may not have discussed gender as impacting care-giving, but this may have been due to an uncritical acceptance that family members of a certain gender provide care | Good |
| 32 | Sharifi et al. (2014)<br>Iran | Review | Estimate dementia burden over 24 years<br>Estimate dementia prevalence by age and sex (from literature and dementia drug sale, inpatients). calculating the dementia burden using DALYS, YLL, YLD | — | Explain the systematic approach, data sources, research methodology and statistical analysis that will be used to quantify the prevalence and burden of dementia at national and sub-national levels | – Lack of published data of dementia incidence and prevalence<br>– Inconsistency in published studies in term of dementia prevalence and burden around Iran<br>– Indicate the important of periodic burden of dementia estimation nationally and regionally that help in making better decisions by policymakers | Good |
| 33 | Yaghmour et al. (2016)<br>Jeddah, KSA | Quantitative cross-sectional study | Dementia Knowledge Assessment questionnaire | $N = 265$ Registered nurses | Explore nurses' dementia depression and delirium knowledge in Saudi Arabia | – Nurses acknowledge the need of increasing dementia's training to enhance their knowledge<br>– Dementia and delirium knowledge lacking among Saudi nurses | Good |

Saudi ($n = 566$) and British ($n = 718$) nursing students regarding working with older people.

Among the articles there were 10 reviews, of which two were systematic reviews. Okasha and Boutros (2010) reviewed influential papers about psychiatry from Arab countries. Halabi and Zafar (2010) explored care of the elderly in UAE, while Alabed, Davidson, and Hickman (2014) systematically reviewed eight studies that explored the health care needs of immigrant Arab older people in Australia. Furthermore, Cipriani and Borin (2015) explored the phenomena of dementia across cultures, and Abyad (2015) in Lebanon focussed on the EM population. Sayegh, Kellough, Otilingam, and Poon (2013) discussed the issues associated with dementia and mood and anxiety disorders among older Arab Americans. Werner, Friedland, and Inzelberg (2015) studied the prevalence of Alzheimer's disease with respect to ethnic differences. Regarding prevalence of dementia, two reviews intended to explore the systematic approaches used in Iran and Egypt (Sharifi et al., 2014; Elshahidi, Elhadidi, Sharaqi, Mostafa, & Elzhery, 2017). Meanwhile, Uysal-Bozkir, Parlevliet, and Rooij (2013) assessed the quality of cross-cultural adaptation of psychometric tools including assessment of cognition.

Five cohort studies focused on the prevalence of neurocognitive disorders, including dementia, and they explored the relation between these disorders and risk factors and morbidities; $n = 33{,}285$ Egyptians, $n = 982$ Palestinians, $n = 53$ and $n = 313$ Saudis in different studies (Eltallawy et al., 2013a, 2013b; Spalter, Brodsky, & Shnoor, 2014; Amr, Elgilany, Sallam, & Shams, 2014; Alhawiti, Alfaer, Altuwaylie, & Elbadawi, 2016). Two mixed method studies out of these five explored attitudes of health care workers and caretakers towards older people with dementia; $n = 132$ Saudi nursing faculty members and $n = 20$ Palestinian caretakers (Alsenany & AlSaif, 2014; Bentwich, Dickman, & Oberman, 2018). Meanwhile, Ayalon, Heinik, and Litwin (2010) explored the cross-cultural differences of Palestinian older adults ($n = 2492$). In 2013, Khan et al., in Saudi Arabia and Boulos, Salameh and Barberger-Gateau in Lebanon used the mixed method study design to assess and evaluate the nutritional status of older people with dementia ($n = 63$, $n = 1200$, respectively). Finally, two qualitative studies from UAE were included which examined the effects of psychiatric and physical disorders on life satisfaction among 610 older people (Ghubach et al., 2010). Furthermore, another qualitative study was included that was conducted with 121 Arab immigrants in Australia which examined the care provided by family members (Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos, 2011).

## Findings

The data were analysed using NVivo 11. The 33 articles were read and coded for themes. Four themes were identified in the articles that are presented below. They are Prevalence, comorbidities and gender, Culture and religion, Recognition and assessment procedures, and Workforce issues.

### *Prevalence, comorbidity, and gender*

In the EM region, awareness has increased of the prevalence of dementia in general and particularly Alzheimer's disease (Elshahidi et al., 2017; Werner et al., 2015). It is generally agreed that dementia, cognitive impairment and Alzheimer's disease are more common in the over 70s (Almomani et al., 2016; Elshahidi et al., 2017). However, there were a number of conflicting findings among the studies. In one study among Palestinian was found to demonstrate a higher prevalence of Alzheimer's Disease compared to western countries (Afgin et al., 2012). In contrast to this research, Ayalon et al. (2010) found lower levels of dementia among Palestinian. In an epidemiological study in Egypt, the prevalence of neurological disorders, including dementia, was higher than the global data (Eltallawy et al., 2013a, 2013b). The study included 8183 people over the age of 40, and found that nearly 4% of participants above 60 years experienced dementia as a common neurological disorder (Eltallawy et al., 2013a). Additionally, a study conducted in North Egypt that included participants with Parkinson's disease found a high prevalence of Parkinson's disease, with 14.3% of participants exhibiting mild dementia (Elshahidi et al., 2017; Khedr et al., 2015), and the authors indicated that the prevalence of Parkinson's disease was higher than in other cities worldwide (Elshahidi et al., 2017; Eltallawy et al., 2013a). A lack of health professionals and the absence of neurologists and gerontologists in the area meant that prevalence was under-reported, and increased pollution was identified as a contributing factor for higher prevalence (Elshahidi et al., 2017; Eltallawy et al., 2013a). Another two Egyptian studies suggested that the high prevalence of Parkinson's disease was possibly associated with air and water pollution and genetic susceptibility (Elshahidi et al., 2017; Khedr et al., 2015).

In the Netherlands, a cross-sectional study with immigrant younger adult participants ($n = 2254$), of whom 31% were from the EM, showed there was a higher prevalence of mild cognitive impairment and dementia at three to four times greater than that among native Dutch. Higher prevalence of dementia among immigrants was associated with a higher incidence of vascular risk factors and psychiatric disorders, such as depression (Parlevliet et al., 2016). Similarly, a study found that Arab participants above 60 years demonstrated a prevalence of Alzheimer's disease four times greater than that of non-Arabs 75 years and older in the same area when tested with a similar diagnostic tool (Werner et al., 2015) attributed to genetic aspects and high illiteracy rates among Arabs. Overall, the EM community has a high prevalence of cognitive impairment (Cent, 2015; Werner et al., 2015).

Bentwich et al. (2018) in Palestine found that the attitudes towards the dignity and autonomy of people with dementia differed significantly between Arabs and Russians. Arab people were brought up to respect the concepts of self-respect and independence, and thus demonstrated better grounds for person-centred care in a health care setting. However, Arab Americans and white Americans were compared in a study that showed no significant differences in their experiences of Alzheimer's disease (Dallo et al., 2016).

Older age is the main risk factor for dementia (Elshahidi et al., 2017; Werner et al., 2015). The prevalence of Alzheimer's disease and mild cognitive impairment is higher in women than in men; this is typically attributed to the fact that women live longer than men. However, this review found that a high rate of illiteracy was found among one study sample (Afgin et al., 2012) which influences assessment scoring. While illiteracy and education were strongly associated with the prevalence of Alzheimer's disease, higher levels of education among participants resulted in less impairment in tests (Ayalon et al., 2010; Werner et al., 2015) highlighting how tests are biased towards educated people. Yet, the authors indicated that the incidence of Alzheimer's disease in the Arab population is greater than that in a population with a similar literacy and educational profile (Eltallawy et al., 2013a, 2013b).

Women in this region are not seen in hospitals as frequently as men. Women are dependent on men, and they are thought to be more tolerant of psychological and physical pain than western women (Amr et al., 2014; Dallo et al., 2016; Eltallawy et al., 2013a, 2013b). A mixed-method, cross-sectional study conducted in a rural setting in Lebanon found significant differences between genders (Boulos et al., 2013). Women demonstrated significantly higher rates of illiteracy and lower income than men, risks associated with chronic illness, poor self-perceived health, fragility and functional disability. Additionally, women also showed higher prevalence levels than men of depressive symptoms and cognitive impairment (Alhawiti et al., 2016; Boulos et al., 2013; Eltallawy et al., 2013b).

A descriptive study conducted in KSA that reviewed the morbidity profile at hospitals found that co-existing conditions were common among the sample. While 16.5% of older adults had two long-term conditions, almost 22% experienced three and approximately 51% had four or more illnesses, leading to challenges for health care providers (Almodeer et al., 2013). These were hypertension, diabetes mellitus, stroke, dementia, osteoarthritis, and Alzheimer's disease (Almodeer et al., 2013), and women were at higher risks of developing these conditions.

A population-based study conducted in KSA, found a 13% prevalence of dementia among older adult participants. The comorbidity rate was high at 52.8%, while the rates of hypertension, cardiac problems and diabetes were 45.3%, 30.2% and 23.7%, respectively (Amr et al., 2014). Furthermore, a retrospective study conducted in KSA of individuals with Alzheimer's disease, dementia with Lewy bodies, frontotemporal dementia and vascular dementia, acknowledged diabetes, hypertension and vascular disorders as risk factors. It was found that these illnesses maximise the risk of earlier-onset dementia (Alhawiti et al., 2016), and participants with multiple risk factors experience earlier-onset dementia (Alhawiti et al., 2016; Amr et al., 2014). In addition, Spalter et al. (2014) found that older adults who live with someone other than a spouse have a higher number of diseases and comorbidity factors.

In a cross-sectional study conducted in Egypt of older adults, depression and cognitive impairment were identified as the most common mental health problems among older participants, with a 30% prevalence of cognitive impairment among medical inpatients (Esmayel et al., 2013). In addition, the study detected a significant relationship between cognitive impairment and each depressive symptom (Esmayel et al., 2013). Likewise, in the UAE, among older adults who were interviewed, nearly 25% were diagnosed with depression, while almost 6% have anxiety, approximately 4% have hypochondriasis and 4% have organic brain syndrome with or without dementia (Ghubach et al., 2010). Additionally, decreased life satisfaction was markedly accompanied by anxiety, hypochondriacal disorders and organic brain syndrome. Nearly half of the study sample was dissatisfied with their lives, and among the older adults aged above 85, the level of life satisfaction was low, particularly among those participants who live alone or only with a spouse (Ghubach et al., 2010).

## Culture and religion

In the EM region, older adults are highly respected within the family (Amr et al., 2014; Cipriani & Borin, 2015; Halabi & Zafar, 2010; Spalter et al., 2014), and family members are discouraged from institutionalising older adults. In general, emphasis has been placed on respecting, valuing, honouring and caring for older family members driven by Islamic values (Alabed et al., 2014), that call for collective care towards vulnerable people. The oldest members of EM families represent wisdom, love, blessings and faith, and their opinions are usually predominant within the family as their opinions are held in the highest regard (Alabed et al., 2014; Alsenany & Alsaif, 2014; Cipriani & Borin, 2015) that is features in the religious instruction to care for elders. In addition, in the EM, older adults are treated with gratitude and respect, spoken to in soft voices and referred to as mother/father of the oldest son or as the father's name (Alsenany & Alsaif, 2014).

Disabled and vulnerable older adults are often cared for by family (Abyad, 2015; Halabi & Zafar, 2010), as it is important to value older adults' autonomy and dignity (Bentwich et al., 2018). Commonly, older adults in the EM region are primarily supported emotionally and socially by their families, often tribal, and few live alone (Amr et al., 2014; Halabi & Zafar, 2010; Sayegh et al., 2013). If an older adult needs assistance, the family will typically hire a caregiver or a nurse at home; if the family cannot afford a caregiver or nurse, the older adult must remain in the care of his or her relatives (Abyad, 2015; Alabed et al., 2014; Halabi & Zafar, 2010). Introducing the older person to a care facility is considered abandonment of a family duty, which is unacceptable. Consequently, the EM region has few care facilities (Abyad, 2015; Alsenany & Alsaif, 2012; Amr et al., 2014; Halabi & Zafar, 2010; Sayegh et al., 2013).

In the EM, caring for a family member with a cognitive impairment can lead to anxiety, loss, fear, shame and ignominy of the family character. Regardless of global changes in terms of perceptions of mental illness, EM families remain influenced by restrictive social beliefs and cultural norms (Alabed et al., 2014). Even with limited facilities available within the region, people feel ashamed to receive care from a non-family member, and they believe that providing this care is the duty of relatives (Alabed et al., 2014; Alsenany & Alsaif, 2012; Amr et al., 2014; Halabi & Zafar, 2010; Sayegh et al., 2013).

As a person ages, levels of dependency and care complexity increase due to deteriorating autonomy and capabilities (Bentwich et al., 2018). Therefore, older adult care is provided in acute settings when medical evaluations and nursing care are needed. Older people do not seek preventive care but will access medical treatment if they have a recognisable illness, such as hypertension, diabetes or hyperlipidaemia, or help for behavioural problems associated with moderate and severe stages of cognitive impairment (Alsenany & Alsaif, 2012; Sayegh et al., 2013). Dementia is viewed as a normal part of ageing and people are less likely to seek medical support for memory issues (Esmayel et al., 2013; Okasha & Boutros, 2010; Sayegh et al., 2013). Fate, *Qadar* (God's will), evil spirits and the evil eye are cited as causes of illness by many in the EM (Alabed et al., 2014; Amr et al., 2014; Cipriani & Borin, 2015; Eltallawy et al., 2013a; Okasha & Boutros, 2010; Sayegh et al., 2013).

Sometimes, dementia is deemed pathological (Alaama, 2016; Alsenany & Alsaif, 2012). Cipriani and Borin (2015) claim that members of the EM community find it difficult to recognise dementia as an illness, and are reluctant to accept a diagnosis. It has been suggested that this stigma is due to the Arabic translation of the word *dementia* and its relation to mental illness. In Arabic, dementia is called *Kharaf*, meaning 'unravelled' or 'lost the mind', which leads to negative connotations in understanding the word (Cipriani & Borin, 2015). Researchers suggest that stigma and stereotyping can alter dementia care and treatment (Alaama, 2016; Alabed et al., 2014; Okasha & Boutros, 2010). Therefore, they recommend the term *mild cognitive impairment* be used for diagnoses other than Alzheimer's disease (Afgin et al., 2012), as it is considered more acceptable (Afgin et al., 2012; Okasha & Boutros, 2010).

Palliative care decisions such as artificial feeding and resuscitation are viewed as purely medical decisions and are not openly discussed by families (Alabed et al., 2014; Halabi &

Zafar, 2010). Most of the Arab population depend on traditional and religious healers (Alabed et al., 2014; Okasha & Boutros, 2010), which creates obstacles to pursuing medical care when it may be beneficial.

### *Recognition and assessment procedures*

Recognition of dementia through assessment is instrumental in slowing disease progression by introducing treatments (Halabi & Zafar, 2010; Khan et al., 2013; Sayegh et al., 2013). A study found that older adults of the EM community were insufficiently studied (Sayegh et al., 2013), as language barriers and a lack of verified assessment instruments are considered obstacles in recognising and treating dementia. A problem was identified regarding translation and the use of culturally accepted terminology in the participants' native language to describe separately mental and physical distress (Sayegh et al., 2013). Dementia was determined at a late stage and cared for by general practitioners because of the low number of gerontologists (Alsenany & Alsaif, 2012; Esmayel et al., 2013; Halabi & Zafar, 2010). Most clinics and hospitals use the Mini-Mental State Examination (MMSE), despite many researchers having claimed that this tool is inaccurate in its scoring and that it is unsuitable for the EM's high number of illiterate older adults (Afgin et al., 2012). Hence, education level and low MMSE score are correlated. Conversely, a study recommended that almost all physicians should use the MMSE and Neuropsychiatric Inventory for the early detection of dementia and neurocognitive impairment (Amr et al., 2014).

EM countries face a challenge in evaluating psychometric properties because of a lack of high standard, cross-cultural, adapted assessment instruments. In most cases, use of the instruments is considered mediocre (Uysal-Bozkir et al., 2013). For example, EM immigrants form minority ethnicities in host countries, with limited knowledge regarding the host country's culture and language, and many are illiterate or they have low education levels. Hence, a cross-cultural dementia-screening test was used in the Netherlands as an appropriate, culturally sensitive neuropsychological instrument for dementia screening of a low-educated immigrant population (Goudsmit et al., 2016). It showed validity in predicting dementia among the 1625 participants in the Netherlands who were illiterate, had lower education or were culturally different or who had language barriers. The test results showed lower MMSE scores, and the recommendation was to use this instrument in memory clinics along with a standard multidisciplinary diagnostic check-up (Goudsmit et al., 2016).

### *Workforce issues*

Numerous studies aimed to investigate health professionals' knowledge and perceptions regarding geriatric peoples and some neurological problems, such as dementia, where several reviews reported a lack of personnel trained in dementia care (Alaama, 2016; Alsenany & Alsaif, 2014; Halabi & Zafar, 2010; Yaghmour et al., 2016). In the KSA, a study found a knowledge deficit among medical students, despite geriatric medicine being introduced into a residency programme in early 2016 (Alaama, 2016). The results of focus groups and nursing faculty member surveys suggested that more gerontological content and clinical experiences are needed in the nursing curriculum (Alsenany & Alsaif, 2014). Another study investigated that nurses' knowledge of dementia, depression and delirium found the need for increased dementia training, as insufficient dementia knowledge was detected among the study's participants (Yaghmour et al., 2016).

In a comparative quantitative study of Saudi and British nursing students, the students assumed that caring for older adults was similar to general nursing in an acute care setting (Alsenany & Alsaif, 2012). Saudi students found that establishing a nurse–client relationship with older adults was easy because older adults in Eastern cultures are talkative and easy to communicate with (Alsenany & Alsaif, 2012). A qualitative study conducted in Australia found that EM families were the most sensitive amongst the study sample, with participants reporting many emotions, including grief and anxiety, associated with living with a person with dementia (Boughtwood et al., 2011). Regarding dementia-related behaviours, EM carers were the least concerned, whereas families were heavily involved in care (Boughtwood et al., 2011).

## Discussion and recommendation for future studies

While there are cultural differences and variations in state care provision, EM countries share many values and cultural beliefs, and common history and heritage (Cipriani & Borin, 2015; Okasha & Boutros, 2010). Throughout the world, there are differences in the way that dementia is assessed and treated and how care is provided for people with dementia and their families. Cultural norms affect how older people are subjected to stigma, and whether there are obstacles related to getting help with diagnosis and treatment of dementia (Faisal, 2014). Dementia is conventionally overlooked in EM countries, as its diagnosis, treatment and management are not widely available to the general population (Almodeer et al., 2013; Okasha & Boutros, 2010; Schillings & Wahnsiedler, 2016). For example, in KSA, accessing such services must be done through private geriatric and memory clinics that are available only in major KSA cities, a fact that consequently affects health and wellbeing (Almodeer et al., 2013; Alsenany & Alsaif, 2012; Amr et al., 2014).

In the EM region, the term *dementia* first appeared in the literature in the early 1990s, and in the late 1990s, researchers first recognised dementia as a cause of death (Alansary & Alrajeh, 1994; Alrajeh et al., 1993; Loza & Milad, 1990; Ogunniyi et al., 1998; Ozand, Gascon, & Dhalla, 1990). The most prevalent dementias are Alzheimer's disease, vascular dementia and Parkinson's disease (Benamer, de Silva, Siddiqui, & Grosset, 2008; Ogunniyi et al., 1998). At present, there are few geriatric specialists available in the region and there are limited facilities specialising in geriatric care (Alrajeh et al., 1993; Benamer et al., 2008; Eltallawy et al., 2013a; MOH, 2016; Ogunniyi et al., 1998).

While there has been recent increased focus on dementia in the EM region, significant steps are needed to provide people with dementia the care needed to improve their wellbeing. There is a lack of public awareness about and organised efforts to mobilise resources and deal with dementia and the provision of proper care. How older people view and experience their health has a significant impact on wellbeing (Benamer et al., 2008; Qannam & Bello, 2016), which includes perceived health and especially psychological wellbeing, the impacts of long term conditions and functional impacts of impairments (Almodeer et al., 2013; Amr et al., 2014; Benamer et al., 2008; Ullah, Qamar, Qureshi, & Niaz, 2016). To promote wellbeing, people need to be able to access the right support. Furthermore, in EM countries, the placement of older adults' relatives in care facilities is considered abandonment of a family duty (Andrews, 2014). Consequently, the care provided to people with dementia depends on the family carer's own knowledge and skills (Alabed et al., 2014; Ghubach et al., 2010), which varies.

Over the last few decades, several studies have called for epidemiological data, as data regarding dementia in the EM region are scarce. Studies indicated a lack of published data on dementia incidence and prevalence, as well as inconsistencies among published studies regarding dementia prevalence in the EM region (Sharifi et al., 2014). Older adults in the EM are insufficiently studied, and no baseline data are available for dementia (Abyad, 2015; Afgin et al., 2012; Alaama, 2016; Almodeer et al., 2013; Werner et al., 2015).

It is essential that health care professionals become aware of the health intentions shared by people from different sociocultural, religious and linguistic backgrounds to deliver culturally sensitive care (Alsenany & Alsaif, 2012; Boughtwood et al., 2011; Yaghmour et al., 2016). There is a need for research on caregivers of people with dementia in the EM that uses qualitative methods to explore ethnic and cultural values and norms related to caring for people with dementia (Alsenany & Alsaif, 2014; Werner et al., 2015). In addition, it has been suggested that EM communities should work towards reducing illiteracy, raising awareness and developing and evaluating the education of health professionals and the community (Werner et al., 2015; Yaghmour et al., 2016). Many highlighted the demand for shedding light on the nature of dementia and its treatment and for the mobilisation of decision-makers to prioritise dementia awareness among the EM population (Eltallawy et al., 2013a; Werner et al., 2015).

As this review has shown, understanding the EM culture is highly recommended to help improve dementia care and to enhance older adults' wellbeing (Alabed et al., 2014; Sayegh et al., 2013), and it is crucial to consider culture and social norms before introducing a new system or services (Almodeer et al., 2013). However, there is a high demand for the creation of an educational programme and policies to promote practical gerontological nursing and medicine (Alaama, 2016; Alsenany & Alsaif, 2012; Sharifi et al., 2014; Yaghmour et al., 2016).

## Conclusion

Numerous studies indicated that dementia prevalence was higher amongst EM community, however, it is suggested that the prevalence was under-reported due to the absence of neurologists and gerontologists and lack of health professionals. While women show higher prevalence than men in experiencing dementia, however, high illiteracy with low-income was found among women in the region. Dementia among EM older adults was associated with at least two to four comorbidities such hypertension, cardiac problems and diabetes. That conversely accounted as risk factors for dementia along with stress, air and water pollution and genetic susceptibility. Additionally, older adult in EM community were cared by family members as introducing them to a care facility consider abandonment of a family duty. Restrictive social behaviours and cultural norms are influencing the care provided to people with dementia within the EM community. Therefore, people with dementia are not seeking for medical treatment from care facilities unless they have a recognisable physical illness. However, they are highly respected within the family and this is driven by Islamic values and believes. Nevertheless, dementia believed to be caused by fate, *Qadar* (God's will), evil spirits and evil eye and sometimes deemed to be pathological. Furthermore, Authors declared that there is an issue in recognising dementia across EM region, many referred that to the lack of health professional personnel's awareness, as well as, inadequate use of psychometric properties. Language barriers, high illiteracy rates amongst older adults and lack of training are considered obstacles in providing adequate care for people with dementia and treatment.

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**Ruth Bartlett** is an associate professor at the Faculty of Health Sciences, University of Southampton. Ruth's research interests are cross-disciplinary and related to people with dementia, health activism, ageing, disability and participatory methods, especially use of diaries. She has led several social research studies involving people with dementia living in the community and published widely on the topic of citizenship and participatory/visual methods. Her next book entitled *Life at Home for People with Dementia* (co-authored with Tula Brannelly) is due to be published by Routledge in 2018.

**Tula Brannelly** is a lecturer in mental health at Bournemouth University, with a longstanding interest in the experiences of dementia that are shaped by health and social care policy. Tula's research area is the ethics of care which has a focus on marginalisation and equality, improving access to the seldom heard voices of people with dementia.

**Sara Mahmoud Yaghmour** is a psychogeriatric nursing lecturer at King Abdulaziz University and now a PhD candidate at the University of Southampton. Currently, she is working on a project to investigate nurses' perception and learning needs when caring for people with dementia using a diary-interview method. Her research interests include nursing education, psychogeriatric nursing care and people with dementia care.

## C.2 Updated literature search

| # | Author & country | Aim | Tool | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| 1 | El-Metwally et al. 2019.<br>Egypt, Saudi Arabia, Jordan, Tunis, Lebanon, Qatar and United Arab of Emirates. | Evaluating the dementia epidemiology in Arab countries that focused on its prevalence, distribution and risk factors. | N/A | N = 16 studies included. | Systematic literature review. | - Dementia prevalence data was detected from studies published inconsistently between 1990 and 2018 from heterogeneous cross-sectional studies.<br>- Risk factors identified was the age, literacy, gender, comorbidities and heredity.<br>- Age was significantly associated dementia as found in Egypt and Lebanese studies but was not significant among Tunisian residents.<br>- Developing dementia found to be significantly associated with illiterate people (level of literacy).<br>- A study found that females developing dementia two times higher than males, however, this is not the case when considering other factors such age, marital status, education and income.<br>- In Lebanon and Saudi Arabia, it was found that hypertension and diabetes (especially uncontrolled blood sugar) was significantly associated with dementia. but not in Jordan.<br>- Dementia believed to be a part of normal ageing.<br>- The person with dementia is taken care after by their family members; their children and grandchildren. | High |

Appendix C

| # | Author & country | Aim | Tool | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| 2 | Bhalla et al. 2018.<br>Egypt, Lebanon and Palestinian occupied territory. | Assess the risk of dementia in Eastern-Mediterranean countries. | N/A | N = 6 studies included. | Systematic literature review. | - A considerable insufficiency of dementia awareness in the region.<br>- Reviewer suggested as Eastern-Mediterranean populated with youth, therefore dementia is neither likely to be an epidemic nor threatening the future.<br>- The migration of aged people to other than Eastern-Mediterranean countries resulted in lack of evidence about dementia prevalence and lack of support.<br>- Also, the low life-expectancy rate may result in that too.<br>- Risk factors of dementia were smoking, hypertension and diabetes | Average |
| 3 | Albugami et al. 2018.<br>Saudi Arabia. | Explain the demographical information and dementia risk factors, as well as the prevalence of dementia types and explore the current clinical practice of dementia at tertiary care hospital. | Chart review of<br>patients have dementia in one hospital from 1995 -2010. | N = 418 people with dementia. | retrospective cohort study. | - Mixed dementia (Alzheimer's disease and vascular dementia) is the most common dementia in the kingdom.<br>- High prevalence of mixed dementia suggested to be associated with cardiovascular risk factors, such as hypertension, diabetes and dyslipidaemia among Saudis.<br>- High prevalence of depression among people with dementia.<br>- People with moderate to severe dementia needs hospitalisation for long-term, which result in a financial burden to them.<br>- Lack of strategies that support people with dementia in Saudi Arabia with lack of trained personnel. | Average |
| 4 | Abd Elaaty et al. 2019.<br>Egypt | Investigate the prevalence of comorbid dementia and depression in patients with Type 2 diabetes. | - Hospital Anxiety and Depression Scale (HADS)<br>- The Montreal Cognitive Assessment (MoCA). | N = 400 participants. | Cross-sectional. | - There is an association between diabetes and dementia which increases the prevalence of the comorbidity of dementia in later life.<br>- Older people with diabetes has a higher risk of developing dementia.<br>- Diabetes associated with vascular dementia as well as Alzheimer's disease. | Average |

| # | Author & country | Aim | Tool | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| 5 | Karam et al. 2019<br>Arab in UK and USA | Assess the validity of Arabic versions of the eight-item Alzheimer's Dementia, Alzheimer Questionnaire, and Clinical Dementia Rating scales, also the Katz Activities of Daily Living and Neuropsychiatric Inventory. | - Eight-item Alzheimer's Dementia. - Alzheimer Questionnaire.<br>- Clinical Dementia Rating scales.<br>- the Katz Activities of Daily Living.<br>- Neuropsychiatric Inventory. | N = 150 Arabic speaking participants in different care settings. | Cross-sectional. | - The Arabic tools showed strong validity and internal consistency.<br>- These Arabic versions of the tools will benefit to facilitate dementia diagnosis by the healthcare workers and assist people with dementia. | High |
| 6 | Werner and AboJabel 2019a.<br>Palestinian occupied territory | Develop knowledge about Alzheimer's disease and family stigma. | Focused group | N = 20 family caregivers. | Qualitative; focused group | - Caregivers faced stigma perceived by people in their community (neighbours) due to their caring for a person with dementia.<br>- The main stereotypes reported is the perception of others of being<br>'crazy' and 'filthy', which largely based on beliefs of being 'contaminated' by the person with Alzheimer's disease through the caregiver.<br>- People labelled most caregivers as 'neglectful caregiver', which cause emotional distress to the caregiver.<br>Caregivers trying their best to provide the person with dementia with love and support they need.<br>- Most participants referred to the lack of public knowledge about dementia.<br>- Some found that caring for people with dementia is God punishment. | High |

Appendix C

| # | Author & country | Aim | Tool | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| 7 | Werner and AboJabel 2019b.<br>Palestinian occupied territory | Assess the family of persons with dementia characteristics who affect with stigma, and investigate care process. | Interviews. | N = 175 family caregivers. | Qualitative; face-to-face interviews. | - Stigma was experienced by half of the caregiver as a result of caring of people with dementia.<br>- Stigma was associated with the lower educational level of the caregiver.<br>- The main predictor of stigma among the caregivers was the low social support level.<br>- Caregivers hold negative public stereotypes towards themselves.<br>- Awareness suggested to be raised and more recognition of the family caregiver role is needed. | High |
| 8 | Manee et al. 2019<br>Kuwait | Assess understanding level about dementia among to be able to better plan for future intervention. | An Arabic version of the Dementia Knowledge Assessment Scale | N = 1350 students in a university | Cross-sectional | - A significant difference in the dementia total score across all five campuses.<br>- Low knowledge were noted in all departments, however, health care departments illustrated moderate knowledge about dementia.<br>- All students need to boost their knowledge about dementia.<br>- Students with family member diagnosed with dementia had higher knowledge. They show more understanding about the dementia symptoms.<br>- Attending conferences and presentations about dementia made no different in dementia knowledge scores.<br>- Students with willingness to learn about dementia were significantly differ that who did not. | Average |

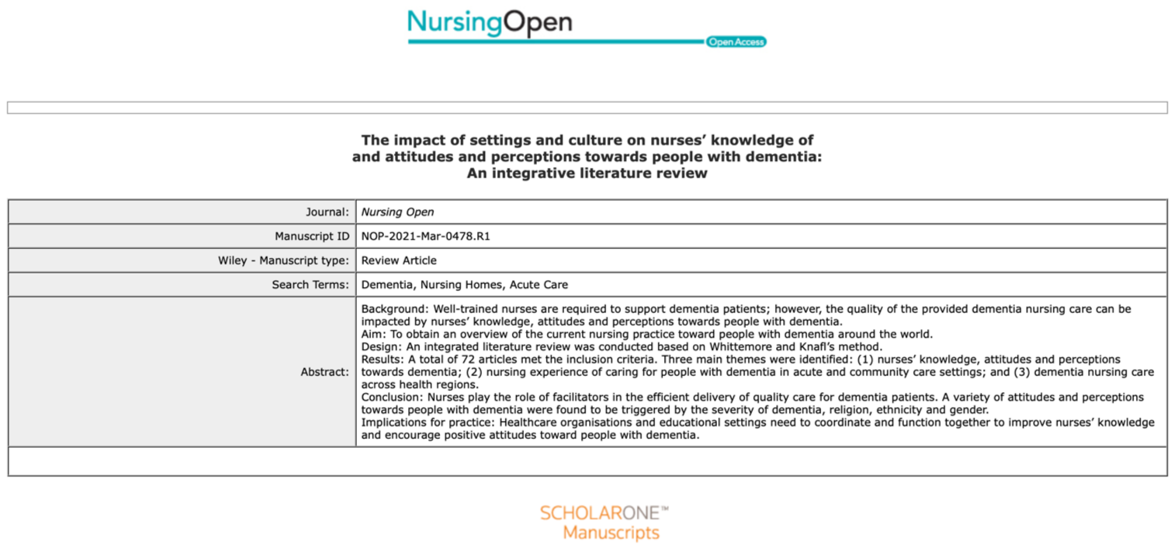
| # | Author & country | Aim | Tool | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| 9 | Elmahdy et al. 2020<br>KSA | Assess knowledge and attitudes among medical students | A knowledge and attitudes questionnaire (by authors) | N = 241 medical students | Cross-sectional | - Poor knowledge were noted especially the aetiology of dementia, diagnosis confirmation and the role of anti-dementia medications.<br>- There is a clear gap in the education system and training.<br>- more than 80% of the participants denied having any dementia care training with another 93% denied having any extracurricular courses in the subject.<br>- Participant mostly showed positive attitudes towards people with dementia.<br>- Almost 25% of participants agreed that treating dementia is frustrating than gratifying. | Average |
| 10 | Feghali et al. 2019<br>Lebanon | Test the psychometric properties of an Arabic version of the Neuropsychiatric Inventory Questionnaire | Arabic version of the Neuropsychiatric Inventory Questionnaire | N = 136 dementia patients | Cross-sectional | - Most participants (85%) were diagnosed with Alzheimer's disease then 5% with vascular dementia, 1.5% with frontotemporal dementia, 1.5% Parkinson disease and the rest were diagnosed with other types of dementia.<br>- Over 77% of patients had moderate to severe dementia which significantly associated with the age and gender but not the types of dementia.<br>- The Arabic version of the Neuropsychiatric Inventory Questionnaire shows its validity and reliability for assessing neuropsychiatric symptoms among Lebanese patients having dementia. | Good |

| # | Author & country | Aim | Tool | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| 11 | Konda et al. 2019<br>India | Understand the dementia prevalence among urban elderlies | Mini Mental State Examination, depression assessment using Geriatric Depression Scale, blood pressure measurement and anthropometry | N = 100 urban older adults | Cross-sectional | - Prevalence of dementia and mild cognitive impairment among older adults is 10%. Females had a higher prevalence than males.<br>- Several factors were found that it is significantly associated with cognitive impairment among older adult which are: ageing, illiteracy, being single, under-weight, lower waist and hip ratios, difficulty in performing the activities of daily living, poor self-reported health, being bedridden and having depression. | Average |
| 12 | Alamri 2020<br>KSA | Identify all studies conducted in the geriatric field in KSA and understand the research trends for future directions | N/A | N = 38 studies included | Observational review | - It is evident that geriatric research in Saudi Arabia is increased over the last decade.<br>- Still the research output and quality of publications were low and did not address commonly seen geriatrics health conditions such as dementia, delirium and polypharmacy. | Average |
| 13 | Algethami et al. 2019<br>KSA | Explore the knowledge and attitude of the general population about dementia and identify the associated factors that affects knowledge and attitudes | A knowledge and attitudes questionnaire (by authors) | N = 400 participants from general population | Cross-sectional | - The majority of participants (67.5%) had low to no knowledge about dementia.<br>- Mostly negative attitudes were detected.<br>- Only 18% of participants finds that caring for dementia is rewarding.<br>- 47.5% of participants agreed that people with dementia can live alone in early stage of dementia and 75% of participants believed that the person with dementia can be managed by medication.<br>- Several factors significantly impact the level of knowledge such as Gender, age, and education level. | Average |

| # | Author & country | Aim | Tool | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| 14 | EL Tallawy et al. 2019<br>Egypt | Determine the Alzheimer's disease prevalence and identify the risk factors. | Standardised questionnaire based on DSM-IV R | N = 12,508 people aged 50 and above | Cross-sectional (door to door survey) | - 1% is the prevalence of Alzheimer's disease that is increases with age. The percentage is 0.34% for people between 60-70 years old, it is 2.9% for people between 70-80 years old and jump to 9.74% for people above 80 years.<br>- Alzheimer's disease is more common among females than males in all ages.<br>- 85% of diagnosed patients are having it mild and moderate.<br>- The risk factors are: among Alzheimer's disease participants above 14% having Hypertension, more than 10% are smokers, approximately 9% had diabetes, while around 6% developed the disease prior to epilepsy, and almost 4% had a family history of the disease.<br>- The most symptoms faced the diagnosed people are: 88% had impaired self-care, 84% had memory loss, 77% had impaired social judgment, approximately 59% experienced agnosia, and around 49% had behavioural changes. | Good |
| 15 | Alkhunizan et al. 2018<br>KSA | Determine dementia prevalence among older adults in a community-based setting in Riyadh, Saudi Arabia. | the validated Arabic version of the Montreal Cognitive Assessment (MoCA) test. | N = 171 older adults | Cross-sectional | - The identified prevalence of dementia was 6.4%.<br>- This high prevalence may relate to the high rate of risk factors associated with the disease.<br>- The risk factors noted are: age, illiteracy level, hypertension, and cardiovascular diseases. | Good |

# Appendix D Second Literature reviews

## D.1 Accepted integrated literature review #2



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**The impact of settings and culture on nurses' knowledge of and attitudes and perceptions towards people with dementia: An integrative literature review**

| | |
|---|---|
| Journal: | *Nursing Open* |
| Manuscript ID | NOP-2021-Mar-0478.R1 |
| Wiley - Manuscript type: | Review Article |
| Search Terms: | Dementia, Nursing Homes, Acute Care |
| Abstract: | Background: Well-trained nurses are required to support dementia patients; however, the quality of the provided dementia nursing care can be impacted by nurses' knowledge, attitudes and perceptions towards people with dementia.<br>Aim: To obtain an overview of the current nursing practice toward people with dementia around the world.<br>Design: An integrated literature review was conducted based on Whittemore and Knafl's method.<br>Results: A total of 72 articles met the inclusion criteria. Three main themes were identified: (1) nurses' knowledge, attitudes and perceptions towards dementia; (2) nursing experience of caring for people with dementia in acute and community care settings; and (3) dementia nursing care across health regions.<br>Conclusion: Nurses play the role of facilitators in the efficient delivery of quality care for dementia patients. A variety of attitudes and perceptions towards people with dementia were found to be triggered by the severity of dementia, religion, ethnicity and gender.<br>Implications for practice: Healthcare organisations and educational settings need to coordinate and function together to improve nurses' knowledge and encourage positive attitudes toward people with dementia. |

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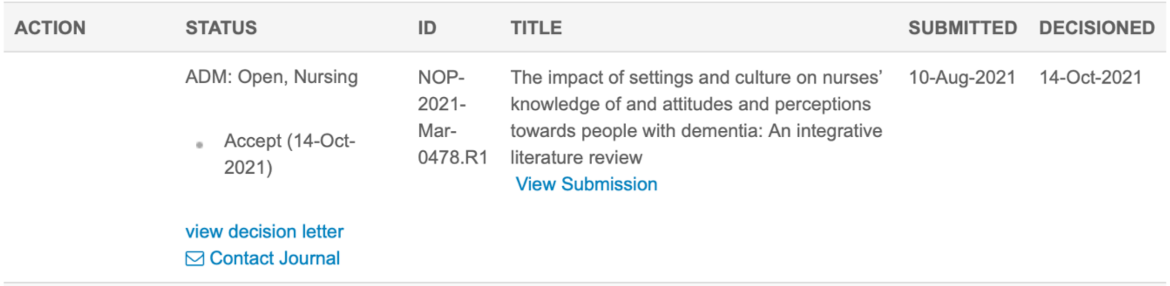

| ACTION | STATUS | ID | TITLE | SUBMITTED | DECISIONED |
|---|---|---|---|---|---|
| | ADM: Open, Nursing<br>• Accept (14-Oct-2021)<br>view decision letter<br>✉ Contact Journal | NOP-2021-Mar-0478.R1 | The impact of settings and culture on nurses' knowledge of and attitudes and perceptions towards people with dementia: An integrative literature review<br>View Submission | 10-Aug-2021 | 14-Oct-2021 |

# The impact of settings and culture on nurses' knowledge of and attitudes and perceptions towards people with dementia: An integrative literature review

**Abstract**

**Background:** Well-trained nurses are required to support dementia patients; however, the quality of the provided dementia nursing care can be impacted by nurses' knowledge, attitudes and perceptions towards people with dementia.
**Aim:** To obtain an overview of the current nursing practice toward people with dementia around the world.
**Design:** An integrated literature review was conducted based on Whittemore and Knafl's method.
**Results:** A total of 72 articles met the inclusion criteria. Three main themes were identified: (1) nurses' knowledge, attitudes and perceptions towards dementia; (2) nursing experience of caring for people with dementia in acute and community care settings; and (3) dementia nursing care across health regions.
**Conclusion:** Nurses play the role of facilitators in the efficient delivery of quality care for dementia patients. A variety of attitudes and perceptions towards people with dementia were found to be triggered by the severity of dementia, religion, ethnicity and gender.
**Implications for practice:** Healthcare organisations and educational settings need to coordinate and function together to improve nurses' knowledge and encourage positive attitudes toward people with dementia.

**KEYWORDS:** Dementia, nursing care, attitudes, perceptions, knowledge, integrative review, neurocognitive disorders, nursing homes, acute care in dementia.

**What does this research add to the existing knowledge in gerontology?**

- This review examined the different strategies used by nurses in caring for dementia patients and the measures that can be taken to improve their knowledge, attitudes and perceptions in both acute hospital and community care settings.
- Nurses' burnout, ward routine and work environment were found to have a negative impact on nurses' perceptions towards dementia patients.
- Nurses' perceptions towards end-of-life and holistic care are influenced by the religious and cultural practices of the person with dementia.

**What are the implications of this new knowledge for nursing care with older people?**

- It is suggested to include both theoretical and practical interventions to enhance nurses' knowledge and attitudes towards people with dementia.
- Nurses in administrative roles must acquire knowledge about skills to care for people with dementia, and they must support nurses in providing advanced and high-quality care.
- Communication competencies and strategies to care for dementia patients have to be defined and added to core nursing competencies for dementia care.
- Nurses must be aware of people with dementia actual condition and have the proper knowledge and skill set for managing people with dementia and their specific needs.

**How could the findings be used to influence policy, practice, research or education?**

- Healthcare organisations and educational settings should work together to enhance nurses' knowledge and encourage positive attitudes towards people with dementia.
- Furthermore, studies adapting mixed methodologies are needed to validate the best practices and generalise the findings in the context of nursing care for dementia across the world.
- The policies and practices within community care centres and acute care hospital settings require improvement to maintain patients' expectations about care.

## 1. Background

Dementia is one of the most prevalent health-related conditions across the globe, and it is estimated that around 35.6 million people are living with dementia worldwide (American Psychiatric Association (1, 2). Dementia is one of the most prevalent psychiatric conditions that affects the ageing population, mostly adults above the age of 65 (3). Dementia causes multiple symptoms that are characterised by memory impairment, language problems, motor speech disorder, sensory recognition problems and general body functioning disturbance (3). The nature of the disease dictates that advanced nursing care must be provided for the successful management of dementia. People with dementia need to receive care from well-trained nurses in both acute hospital and community care settings so that patients can receive around-the-clock care (4).

Despite the fact that nurses play a special role in attending to the special needs of dementia patients, in many cases, it has been found that dementia patients do not receive optimal care (5). It has been suggested that the provision of care for dementia patients extends beyond the confines of nursing education and overlaps with additional factors, such as attitudes and perceptions regarding this illness (6). In 2019, authors reported that nursing students have almost no knowledge about how to provide ideal care to patients with dementia; they often struggle in dealing with the behavioural problems of patients (4). Thus, because knowledge and attitude influence the quality of care provided, it is important to distinguish between nursing knowledge, attitudes and perceptions when considering the educational skills of nurses. Each of these three concepts has a different meaning and function. For example, knowledge is associated with cognitive expertise derived from learning, which outlines the role of modern nurses in healthcare (7). The attitude of a nursing professional relates to the individual's belief system, which may or may not be the same as widely accepted societal attitudes (8, 9). In addition, it is well-known that societal attitudes also vary depending on the country and culture. Perceptions, on the other hand, are associated with the views, concerns and interpretation of behaviours.

It has been noted that nursing care for people with dementia is different between organisations and it vary according to nursing experience, wards and its business, nurses' knowledge and their perceptions about the disease, as well as their attitudes towards people with dementia and dementia care (9-13). Therefore, exploring the current nursing practices for people with dementia from a global perspective was significant in order to provide policy-makers educational organisations and healthcare organisations with the best available evidence.

The main objective of the current paper is to carry out an integrated literature review of nurses' knowledge, attitudes and perceptions towards caring for dementia patients in different care settings, including acute care hospitals and community care settings. This to obtain an overview of the current nursing practice toward people with dementia around the world by exploring the cultural differences impact on nurses' knowledge, attitudes and perceptions. This will help in identifying any existing gaps in knowledge and opportunities for nursing practice development in the field of mental health. This could pave the way for new reforms in mental health nursing and geriatric educational programmes.

## 2. Methods

This integrative review was guided by Whittemore and Knafl's method. This method's guidelines were used to assist the data extract and analysis of the included papers (14). An integrative method involves the inclusion of both empirical and theoretical publications. This methodological approach consists of five stages to guide the review. This includes problem identification, literature search, data evaluation, data analysis and presentation. This section provides comprehensive details of stages two and three, which relate to the description of a comprehensive search strategy, explaining the methodological quality and representativeness of the primary studies (15).

## 2.1 Search strategy

A systematic search was conducted in March 2018 and updated in June 2021 using a number of scientific databases, including DelphiS, CINAHL, MEDLINE, OVID, ProQuest, Embase and PsychINFO, using keywords such as ‘nurses’, ‘staffing’, ‘knowledge’, ‘attitude’, ‘perception’ and ‘dementia’. Several truncations were used to further refine the key terms and ensure that all relevant articles related to the research question were taken. The key truncations used included ‘Nurs* staff’ OR ‘register* nurse*’ in combination with knowledge, educational, understand*, awareness, attitude, perception, opinion, thought, feeling, OR beliefs. Search terms like dementia, Alzheimer*, ‘Lewy body’, Parkinson*, ‘mild cognitive impairment’, ‘cognitive impairment’, ‘cognitive decline’, ‘memory loss’, ‘cognitive function’, OR ‘cognitive dysfunction’ were also used during the search process (Table 1).

Table 1: Search terms and alternative terms/synonyms

| **Main term** | **Nurse** | | **Learning** | | **Attitude** | | **Perception** | | **Dementia** |
|---|---|---|---|---|---|---|---|---|---|
| **Alternate terms** | ‘Nurs* staff’ OR ‘register* nurse*’ | AND | knowledge OR educational OR understand* OR awareness | AND | attitude OR thought OR feeling | AND | perception OR opinion OR Beliefs | AND | dementia OR Alzheimer* OR ‘Lewy body’ OR Parkinson* OR ‘mild cognitive impairment’ OR ‘cognitive impairment’ OR ‘cognitive decline’ OR ‘memory loss’ OR ‘cognitive function’ OR ‘cognitive dysfunction’ |

## 2.2 Eligibility criteria

The inclusion criteria focused on defining the target sample group who were registered nurses, research design, publication date, language and main outcome in the articles selected for review. A summary of the inclusion/exclusion criteria is presented in Table 2. The exclusion criteria for article selection were also defined. All nursing students were excluded from the review. In addition, studies investigating patients with mental disorders other than dementia were excluded.

Table 2: Inclusion and exclusion criteria

| Inclusion/exclusion criteria | | Justification |
|---|---|---|
| **Study participants** | **Registered nurses** | Papers were included if they indicated nurses were the study's participants and that these nurses directly cared for dementia patients. This reflects the objective of this review. When studies included other healthcare professionals, nurses must have to be more than 35% of the total study's participants. However, when studies included nurses among other healthcare professionals without mentioning the quantity, the study was excluded.<br>Nursing assistants and nursing students were excluded because they have not received full training and are often still in the process of gaining knowledge, so their knowledge may differ from that of a qualified nurse. |
| **Settings** | **Acute hospital settings or community-based practices** | Only residential, palliative care and/or primary health settings were included because these settings are involved in caring for dementia patients. |
| **Findings** | **Clearly indicated/discussed nurses' knowledge, attitudes or perceptions towards caring for a person with dementia** | Articles that sought views from nurses directly so that the analysis could frame what the nurses said rather than reporting what other people think about the nurses. |
| **Designs** | **All study designs were included** | Because this is an exploratory study to identify and analyse what is known about the topic. |
| **Study's quality** | **High to moderate** | Inclusion of low-quality studies would affect the overall review's findings and conclusion, which may lead to unreliable and inaccurate data. |
| **Date** | **2010–2021** | This allowed for a comprehensive review of development in dementia care over the past decade |
| **Language** | **English** | The study included English papers. It excluded studies in other languages. |

## 2.3 Selection of studies

The screening of the articles was done by looking at duplicate articles first and then removing them. Following the removal of duplicate articles, the titles of the returned articles were examined. All articles with irrelevant titles were excluded. After the title was reviewed, the abstract of each article was reviewed. This was followed by full-text screening of the articles by comparing them with the inclusion and exclusion criteria. Two researchers were involved in the screening process, and they finalised the studies after discussion and comparing all the results. The final list of articles was selected after any arguments were resolved through discussion. In case no agreement could be reached, a third expert member of the research team was consulted. The PRISMA flow chart was followed to summarise the screening process (Figure 1).

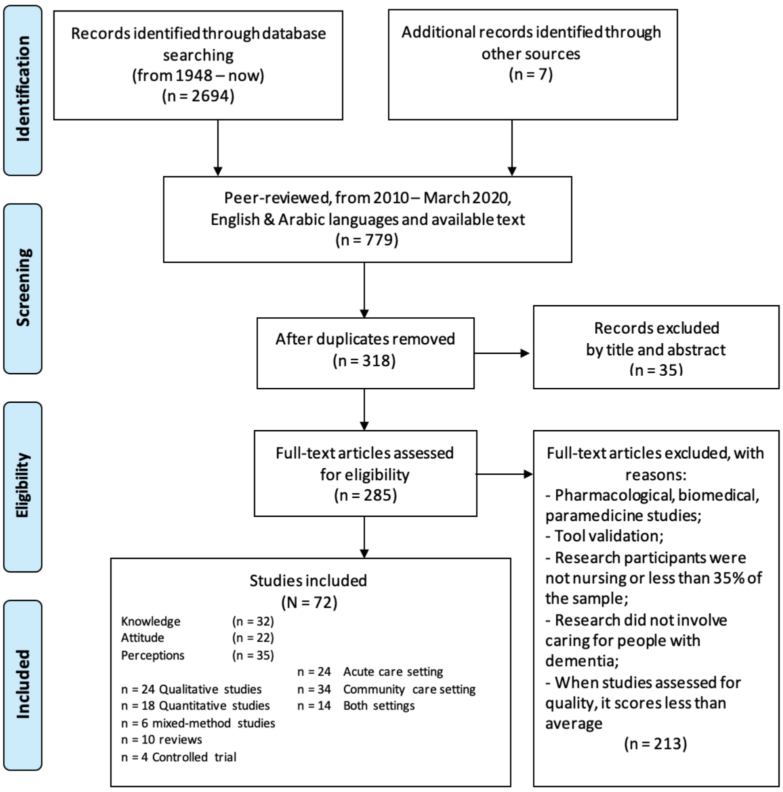

Figure 1: PRISMA chart with search results.

### 2.4 Methodological quality assessment

It is important to assess the quality of the papers to be included to ensure the integrity of the overall review's findings. The quality of research evidence was assessed using the Joanna Brigs Institute (JBI) appraisal tool for qualitative and quantitative studies, control trials and the mixed methods appraisal tool. The tool consists of 10 questions according to different research designs, and the answers need to be chosen from four options: yes, no, unclear and not applicable. This research aims to classify articles according to their quality because high-quality research papers will be reflective of the validity of the research papers. Studies were considered as having a good quality of research evidence if the score was between 50–84%. The papers were classified as very high-quality papers if the score was higher than 85%. In addition, papers scoring 50% or below were rated as low-quality research evidence. This percent was set by the study researcher to insure rigorous peer-reviewed studies were included. The quality appraisal of the articles will be given in the results section.

### 2.5 Data extraction

The data were extracted using a data extraction sheet. The key data extracted from the data include the following: a) author name, title and date of publication, b) setting, c) study design, d) outcome data and e) conclusion. The process of data extraction was completed by the study researcher.

### 2.6 Data analysis

Relevant articles were extracted using NVivo software, the articles were coded accordingly within the software. The extracted data were synthesised and analysed using a thematic analysis method. The main purpose of this form of data synthesis was to assess how the literature addresses the research question. Because the current review focused on the three outcomes of attitude, knowledge and perception, the findings related to these three areas were synthesised by looking at patterns within the dataset. According to authors, the significance of using the thematic analysis method is that it offers a flexible yet rigorous approach to establish links between the study question and test of primary studies (16). It involves the systematic coding of data and generating of analytical themes. In the present research, line-to-line coding was done, followed by grouping together codes based on the similarities and differences between the codes. In this review, the focus was to group together findings into knowledge, attitude and perceptions and to explore their experience when caring for people with dementia across different health regions. As a result of the thematic analysis from the coded studies, three themes were identified: (1) nurses’ knowledge, attitudes and perceptions towards dementia; (2) nursing experience of caring for people with dementia in acute and community care settings; and (3) dementia nursing care across health regions.

## 3. Findings

### 3.1 Included studies

Based on the database search process, a total of 777 articles published between 2010 and March 2021 were obtained. The articles were further screened by looking at duplicate papers. A total of 318 papers were obtained after removing duplicates. After this, the articles were assessed by reviewing the title and abstract. A total of 35 articles were excluded by title and abstract. The remaining 283 articles were reviewed based on inclusion and exclusion criteria. Finally, a total of 72 articles were included in the review. The PRISMA flowchart for the search result is given in Figure 1 above. The list of articles, along with numbering for the selected articles, is provided in Table 3 in the appendix.

The studies were presented in a summary table ordered my World Health Organization regions and countries. From Europe (17-51), Americas (6, 10-12, 52-57), the Western Pacific region (58-71), South East Asia (72) and finally, Eastern Mediterranean countries (73, 74). Then the reviews were summarised too (75-83).

### 3.2 Results of the critical appraisal

Using the JBI appraisal tool for quantitative studies (84), 14 studies were found to rank as high quality and six good (refer to table 3 for details). When the qualitative studies were critically appraised using the JBI checklist (85), 30 studies were found to be high quality and two were good quality papers. Regarding the systematic reviews that were included, the JBI checklist (86) found six articles were of high quality, while two were good. The mixed methods appraisal tool (87) found that all eight studies that used a mixed method design were of a high quality. Additionally, control trials were assessed using the JBI critical appraisal tool (88), which found three good quality studies and one high-quality study. The rationale behind the inclusion of only good-quality and high-quality papers is to increase the reliability and validity of these integrated reviews' findings and the study's rigour.

### 3.3 Characteristics of the studies

The characteristics of selected studies and its context, such as scope, setting and participants' numbers are presented in table 3.

# Appendix D

Table 3: Summary of included studies

| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(17)* | Beck, et al. (2017) UK | Examine nursing home managers' attitudes, beliefs, knowledge and current practice regarding advance dementia care planning. | Community care setting | N=116 nursing managers | Quantitative; Cross-sectional | - Nursing homes managers have lack of knowledge toward planning advanced care for dementia patients. Also, they hold negative attitude regarding the dementia patient's capacity.<br>- Nurse-patient with dementia communication is playing important role in changing work environment and care provided to them. | 100% |
| *(18)* | Burns and McIlfatrick (2015a) UK | Assess nurses' attitudes and knowledge towards pain assessment in dementia patients. | Community care setting n=17 | N=33 nurses | Quantitative; Cross-sectional | - Study found that nurses had good knowledge about pain management of dementia patients, but they were uncertain regarding the safe use of analgesic. | 83% |
| *(19)* | Cooper, et al. (2016) UK | Ascertain the consensus in the professional development and care requirements for RNs in UK home care facilities. | Community care setting | N=352 nurses | Quantitative; Cross-sectional, Delphi survey | - Delphi study on nurses working at nursing homes in England, Wales, Scotland & Northern Ireland.<br>- Nurses working in nursing homes acquired specific skills, knowledge and experiences.<br>- key areas identified for continuous nursing practice development were dementia care, personal care, end-of-life care, falls prevention and medication management.<br>- Barriers of dementia practice development identified were lack of opportunity for awareness, limited access to training, staff shortage, and lack of management support, besides time and fund burden. | 65% |
| *(20)* | de Witt, et al. (2017) UK | Explore hospice, acute care and nursing home nurses' experiences of pain management for advanced dementia patients in the end-of-life settings | Both settings; n=13 Community n= 2 Acute | N=24 nurses | Qualitative; semi-structured interviews and thematic analysis | - Nurses were struggling in administer medication to facilitate pain management to dementia patients.<br>- Communication and nurse-physician relationship are important to enhance the care provided to dementia patients.<br>- Also, nurses declared that accessing recourses and educational session is important to empower them to learn more and to become more confident in care delivery. | 100% |
| *(21)* | Kupeli, et al. (2016) UK | Explore the circumstance approaches as well as the outcomes for providing good palliative care to people living with advanced dementia in nursing home settings | Community care setting | n=5 nurses (among N=14 health professionals) | Qualitative; interviews | - Prioritisation of psychosocial and spiritual care leads to good palliative care.<br>- Person-centred care and end-of-life.<br>- Poor staff condition, undertrained and negative image of care homes.<br>- Negative perception toward work environment with lack of confidence.<br>- However, nurses were compassionate toward dementia patients, initiative and find the care is rewarding. | 100% |

| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(22)* | Lee, et al. (2017)<br>UK | Explore the perspective of service managers and frontline care staff on dementia patients. | Both settings | n=19 nurses (among N=54 health professionals) | Qualitative; interviews and focus groups | - The staff recognises the important of end of life; however, they mostly face a significant challenge in providing good end-of-life care. | 80% |
| *(23)* | McPherson, et al. (2016)<br>UK | Explore the experiences of managing Occupational pressures in front-line NHS workers attending to geriatric patients living with dementia. | Acute care settings- n=3 Dementia | N=10 nurses | Qualitative; interviews | - Work pressure effect the nurses' perception toward dementia patients; it is varied, some show compassionate care and others being burnout and have physiological stress.<br>- However, Staff possessing compassion and training may not alter the outcome of care for dementia patients in challenging and demanding work environment. | 100% |
| *(24)* | Naughton, et al. (2016)<br>UK | Investigate the development, delivery and early evaluation of the Older Person's Nurse Fellowship program among senior nurses. | Both settings | N=11 nurses (survey)<br>N=9 nurses (focus group) | Mixed-method; online post-survey and focus group interview | - Topics such as pharmacology, comprehensive geriatric assessment, frailty and cognitive assessment were regarded as highly relevant and most likely to result in a change to clinical practice.<br>- This educational program focuses on the population rather than the disease.<br>- Geriatric nurses contribute in developing a health and social care workforce that is built based on the population needs. | 80% |
| *(25)* | Ross, et al. (2015)<br>UK | Investigate nurses' insight and assistance of patient-centered care in an acute setting. | Acute care setting- Medical | N=14 nurses | Qualitative; semi-structured interviews | - Investigating nursing knowledge & attitude in long-term facilities in Japan.<br>- Dementia knowledge and attitude scores were significantly higher among nurses with experience and higher educational level.<br>- Palliative care facilities that had developed manual for end-of-life care were scored higher in knowledge and attitude. | 100% |
| *(26)* | Smythe, et al. (2014)<br>UK | Assess a brief psychosocial training intervention for healthcare workers working with dementia patients. | Acute care setting | N=81 nurses pre,<br>N=66 post,<br>n=15 interviews | Mixed methods; pre-post training questionnaire and focus group | - Skills-based training increases knowledge by improving communication and problem-solving skills of staff working with dementia patients in acute settings.<br>- Acute care settings not ideal for dementia patients.<br>- Busy work environment and understaffing were obstacles underpinned by the nurses. | 85% |
| *(27)* | Smythe, et al. (2017)<br>UK | Explore the training requirements of nurses working with dementia patients | Community care setting | N= 11 nurses | Qualitative; Focus groups | - Barriers to educational; time, training programs.<br>- Valued by residents but not by organisation or at home. | 90% |

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| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(28)* | Egede-Nissen, et al. (2017) Norway | Evaluate the minority nurses' experiences with challenges in caring for dementia patients. | Community care setting | N=5 nurses | Qualitative; interviews, narrative approach | - In a phenomenological-hermeneutical study, five nurses', from different cultural background, perceptions were structurally analysed.<br>- When dementia patients develop communication difficulties, nurses-patient relationship is affected and the challenge arises.<br>- these challenges comprise both ethical and cultural striving to understand persons with dementia to care for persons with dementia in an unfamiliar context may be understood as a striving for acting ethically, when at the same time striving to adapt and acculturate to new cultural norms, in order to practice good dementia care. | 80% |
| *(29)* | Hansen, et al. (2017) Norway | Explore the psychosocial needs of persons with dementia | Community care setting | N=24 nurses | Qualitative; semi-structured focus group interviews | - Study highlighted the importance of including the psychological and spiritual care alongside with the physical care.<br>- providing holistic care for dementia patients is enabling them to live at their own place as long as possible. This by raising the awareness of nurses to meet their psychological need. | 80% |
| *(30)* | Jakobsen and Sørlie (2016) Norway | Explore the caregiver's experiences with ethical challenges in dementia care settings and the importance of professional leadership | Community care setting | n=19 nurses (among N=23 health professionals) | Qualitative; narrative interviews. a phenomenological-hermeneutical | - The concept of trust and mistrust were discussed. As leadership influencing the attitude toward caring for dementia patients.<br>- Most nurses act negatively toward their work as a result of the negative work atmosphere and leaders' perspectives toward their staff. | 70% |
| *(31)* | Lillekroken, et al. (2015) Norway | Explore nurses' approaches that may support the sense of coherence in dementia patients. | Community care setting n=2 | N=16 nurses | Qualitative; focus group interviews | - The sense of coherence can be developed. More awareness needed.<br>- Caring, finding creative solutions and meaningful activities enhance the person's with dementia sense of coherence. | 90% |
| *(33)* | Midtbust, et al. (2018a) Norway | Explore the barriers of healthcare professionals when caring for people with dementia in palliative care settings | Community care settings- n=4 nursing homes | Four focus groups and N=20 in-depth interviews | Qualitative; focused group and interviews | - Lack of communication was experienced as the main barrier to facilitating dementia care.<br>- Work and pressure impact negatively on caring for people with dementia, especially on the weakest and bedridden patients with dementia.<br>- Conflict feelings were found among nurses as a result of wanting to spend more time with every patient to provide their care and the burnout and feeling pressure to help everyone.<br>- Priority were always given to dying residents.<br>- Organisational changes is suggested in term of staffing to minimize nurse's burnout | 80% |

| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(32)* | Midtbust, et al. (2018b). Norway | Explore healthcare professionals experience when caring for patients with severe dementia | Community care settings | N=20 Nurses | Qualitative; interviews | - Nurses' with limited knowledge about dementia increase their frustration and caring difficulties.<br>- Nurses are unable to provide care for patients with severe dementia as result of their *suffering*.<br>- Most challenges were attributed to the behavioural symptoms of dementia, like agitation, irritability, physical aggression and rejection of care.<br>- Nurses described their experience as painful and distressing as they found themselves helpless.<br>- Getting to know patients more is one of the successful approaches in providing care and minimising patients irritations.<br>- The important of having close relative around to aid the care process. | 80% |
| *(34)* | Skomakerstuen Ødbehr, et al. (2015) Norway | Analyse nurses' attitudes in regard to accommodations of patients' religious inclinations and practice in dementia care. | Community care setting n=4 | N=16 nurses | Qualitative; Eight focus group interviews | - Embarrassment versus comfort toward resident's religiosity private matters.<br>- Difficult discussing death and End-of-life issues.<br>- focus on life and quality of life. | 90% |
| *(35)* | Solli, et al. (2015) Norway | Investigate the relationship between nurses and caregivers using a web camera and web forum as a communication strategy. | Community care setting Web | N=6 nurses | Qualitative; content analysis | - Nurses perception toward dementia patients affects the person-centred care.<br>- Perceive the dementia patients as demanded. | 100% |
| *(36)* | Bolmsjö, et al. (2012) Sweden | Investigate the application of drama as a tool to support rejection among workers in the nursing homes for dementia patients. | Community care setting | N=10 nurses | Qualitative; observations, focus group and reflexive diary | - Drama and theatrical training are useful in enhancing knowledge among nurses caring for dementia patients.<br>- Reflection on daily care practice is influenced by exercising. | 70% |
| *(37)* | Brorson, et al. (2014) Sweden | Explore nurses' experiences on end-of-life pain relief in dementia patients. | Community care setting | N=7 nurses | Qualitative; Semi-structured interview technique with open-ended questions | - The paper explored the end-of-life care for dementia patients in a palliative care centre and how is the pain management.<br>- Pain management perceived as difficult task for nurses providing care for a dementia patient. As nurses feels powerless and unable to communicate with them.<br>- Nurses concern about the recourses available such standardised pain management tools and medication. | 90% |

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| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(38)* | Ericson-Lidman, et al.<br>(2013)<br>Sweden | Investigate care providers' lived experiences in caring for dementia patients | Community care setting | N=12 nurses | Qualitative; semi-structured interviews | - Nurses struggled to perform person-centred care for dementia patients as most did not hold positive attitudes towards dementia patients.<br>- work environment impact on nurses' attitude toward dementia patients. | 90% |
| *(39)* | Høgsnes, et al.<br>(2016)<br>Sweden | Investigate the perception of end-of-life care by healthcare professionals in records of deceased dementia patients in Swedish nursing homes. | Both settings Databases | N=50 nursing records | Qualitative; retrospective approach | - Investigate end-of-life in nurses' documentation.<br>- The end-of-life care has been depicted in the healthcare records based on factors such as the participation and communication as well as decision-making, assessment and prevention of symptom and following up after the resident has died.<br>- Physical symptoms have been recorded and, to a lesser extent, psychological or existential/spiritual needs.<br>- Healthcare professionals must have a holistic approach to the dementia patient. | 100% |
| *(40)* | Krupić, et al.<br>(2018).<br>Sweden | Explore nurses' perspectives about pain management for people with dementia in postoperative setting | Acute care setting (operation) | N=51 nurses | Qualitative content analysis of self-administered questionnaire | - Nurses mostly rely on the facial expression as well as the body language of the person with dementia to recognise their pain, while they agreed that with the severity of dementia this become more challenging.<br>- Communication with the person with dementia difficult.<br>- Nurses acknowledge the lack of awareness in providing care for people with dementia | 90% |
| *(41)* | Nilsson, et al.<br>(2016)<br>Sweden | Illuminate the meanings of caring for geriatric patients with cognitive impairment in acute care settings. | Acute care setting-Medical, Oncology & Neurology | N=31 nurses | Qualitative; interviews. phenomenological-hermeneutic | - Caring for dementia patient is complicated.<br>- Gap between thoughts and perceptions. | 100% |
| *(42)* | Pellfolk, et al.<br>(2010)<br>Sweden | Effect on an educational program on nurses' knowledge, attitudes and practice | Community care settings-n=40 dementia wards | Pre-intervention (n=205, n= 188 staff)<br>Post-intervention (n=156, n=133) | Cluster-randomised controlled trial | - Nurses knowledge in intervention group was higher than the control group in follow-up but not in no different in their attitudes.<br>- Overall, knowledge and attitudes scores were significantly improved by the educational program.<br>- Nurses minimises the use of restrains after completing the education program. | 50% |

| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(43)* | Rosendahl, et al. (2016) Sweden | Evaluate the experiences of family caregivers and professionals on the care provided to immigrants with dementia | Community care setting | N=9 nurses | Qualitative study; semi-structured interviews | - Family members are playing a crucial role in facilitating communication of immigrants' dementia patients between the nursing staff and the dementia patients.<br>- Family also enable accessing the cultural activities that the dementia patients want, which professional caregivers were either not able to recognise as needed or could not deliver. | 80% |
| *(44)* | Adams, et al. (2017) Netherlands | Explore perceptions of the needed expertise and assess the variations in job satisfaction and motivation. | Community care setting | N=138 nurses | Quantitative; Cross-sectional | - Job satisfaction and motivation were different in nurses caring for dementia patients in different nursing homes types.<br>- Most significantly, correlate with higher job satisfaction and motivation is social support. | 100% |
| *(45)* | van Hoof, et al. (2016) Netherlands | Examine the factors determining the sense of home setting for geriatric patients in the nursing home from the perspective of professional caregivers including nurses. | Community care setting n=4 | N=26 nurses | Qualitative; photography, interviews and focus groups | - Communication.<br>- Empathy and aggression behaviour.<br>- Nurses exclude dementia patients from decision making. | 100% |
| *(46)* | Krumm, et al. (2014) Germany | Expound health professionals' experiences of assessing the symptoms dementia | Community care setting n=3 | N=13 nurses | Qualitative; semi-structured interviews | - Implementation of the Minimal Documentation system for Palliative care; the tool enhances the quality of care of dementia patients. | 90% |
| *(47)* | Kuehlmeyer, et al. (2015) Munich, Germany | Determine nurses' perceptions and assess the non-verbal behavior about feeding dementia patients. | Community care setting n=12 | N=131 nurses | Quantitative; Cross-sectional | - Nurses consider the nonverbal communication of the dementia patients as crucial in decision making process. | 71% |
| *(48)* | Pinkert, et al. (2018). Germany and Austria | Explain the experiences of nurses' caring for people with dementia. | Acute care settings-Mixed | Germany: n=22 nurses among N=42 healthcare professionals. Austria: N=57 nurses. | Quantitative; Focus group | - Training correlates with knowledge and meeting patients' needs.<br>- Nurses found that caring for people with dementia is rewarding.<br>- Nurses in both countries were greatly uncertain about the care and perceived a person with dementia.<br>- Having person with dementia disturbs the ward's routine.<br>- In order to perform person-centred care, organisations must minimise restrains on nurses.<br>- Application of dementia-friendly environment proves its benefit in minimise patient's confusion. | 100% |

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| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(49)* | Rantala, et al. (2014)<br>Finland | Explore perceptions of nurses on the barriers to postoperative pain management in hip fracture dementia patients | Acute care settings<br>n=7 | N=331 nurses | Quantitative; Cross-sectional | - Difficulty in assessing pain for dementia patients.<br>- There were statistically significant differences between the sufficiency of pain management and barriers. | 83% |
| *(50)* | Blaser and Berset (2018).<br>Switzerland | Investigate nurses' attitudes when caring for people with dementia | Both care settings | N=417 Nurses | Quantitative; cross-sectional | - Nurses attitudes were significantly positive with nurses working in dementia-related wards.<br>- The care setting (ward) has strong association with attitudes scores.<br>- All other factors– such as age, gender, years of experience, nursing degree and employment– were not found to be associated with the attitudes scores (no effect found). | 86% |
| *(51)* | Kohler, et al. (2016)<br>Switzerland | Explore the effectiveness of educational interventions on urinary incontinence and quality of life for dementia patients. | Community care setting<br>n=7 | N=140 nurses | Randomised control trial; stepped-wedge trial design | - an educational program and case conferences during 6 months proved to be elective in reducing urinary incontinence and improve the quality of life. | 69% |
| *(52)* | Brody, et al. (2016)<br>USA | Test the ability of the DSM-H Program to ameliorate the confidence, attitude and knowledge of nurses among other healthcare professionals in cognitive impairment pain management. | Community care setting | n=143 nurses from (among N=191 health professionals) | Quantitative; pre-post questionnaire | - Evaluating educational program (DSM-H).<br>- Significant improvement in pain knowledge and confidence, depression knowledge and confidence d neuropsychiatric symptom. Attitudes, Intervention knowledge and confidence. | 88% |
| *(6)* | Daniel, et al. (2014)<br>USA | Expound on nurses' practice and expertise level and comfort in the management of dementia patients | Both settings | N=114 nurses | Quantitative; Cross-sectional | - Wide diversity in practice and skill among nurses regarding dementia screening, evaluation and treatment.<br>- slightly over half of the nurses in this sample who care for adult patients were comfortable and familiar with the techniques for screening for dementia, diagnosing dementia, or managing patients with dementia. | 57% |
| *(53)* | Karlin, et al. (2016)<br>USA | assess the evolution of a training program, process and document its outcome | Both settings | N=32 nurses and care managers | Quantitative; pre-post intervention questionnaire | - a robust transformation in knowledge, attitudes and self-efficacy after training participants, with the greatest impact on knowledge and self-efficacy to manage behaviours. | 71% |

| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(54)* | Sharpp and Young (2016)<br>USA | Describe the healthcare occurrences and experiences of residents and caregivers transferred from assisted living to the emergency settings | Acute care settings | N=14 nurses | Mixed method study; quantitative demographic information, interviews and focus group | - Quantitative data and Focus group with an unspecified number of participants.<br>- Geriatric person claimed to be neglected by nurses in the acute hospital settings.<br>- Fall was the major problem faced the nurses that caused agitation and frustration for them. | 80% |
| *(55)* | Unroe, et al. (2015)<br>USA | Make comparison between palliative care knowledge and practices of staff. | Community care setting n=51 | N=1163 nurses | Quantitative; Cross-sectional | - Investigating the relationship between nursing homes and nurses' profile in a cross-sectional survey study using The Palliative Care Survey validated tool.<br>- Nursing assistants were significantly lower in knowledge and practice than practical nurses and registered nurses.<br>- Among all study participants, the physical symptoms and changes knowledge were high.<br>- The end-of-life knowledge was remark low in all study participants. However, nurses working in hospice scored higher. | 100% |
| *(56)* | Chaudhury, et al. (2017)<br>Canada | Analyse the effectiveness of settings alterations on residents' mealtime experience and staff practice in care units. | Community care setting n=2 | N=17 nurses | Qualitative; pre- and post-renovation ethnographic observations | - The physical environment plays a crucial role in enhancing dining experience for dementia patients<br>- Person-cantered care enhances the care. | 90% |
| *(10)* | de Witt and Ploeg (2016)<br>Canada | Expound on healthcare practitioners' experiences in caring for the geriatric dementia patients | Both settings | n=9 nurses (among N=15 health professionals) | Qualitative; Interviews | - The endings strongly supported providing healthcare educational programs and continuing professional development initiatives in the principles of person-centered approaches.<br>- Most participants declared that they are providing the best care as the can.<br>- Emotional struggles, cultural changes and holistic approaches were suggested by participants in community care settings. | 90% |
| *(11)* | Eritz, et al. (2016)<br>Canada | Analyse nurses' empathy, perceived patient-cantered approach as well as aggressive behaviours | Community care setting n=6 | N=99 nurses | Mixed method; controlled, parallel randomised groups design | - Negative correlation between nurses' perceptions toward personhood of residents and person's cognitive impairments.<br>- Communication and personal interactions positively changed after the intervention. | 80% |
| *(57)* | Hunter, et al. (2017)<br>Canada | Get insight on the safety in rural Emergency settings for transitional care for geriatric with dementia | Acute care settings N=2 | N=12 health professionals including nurses | Qualitative; interviews and field notes | - Safety and environment.<br>- Knowledge and process (practice).<br>- Pressure, cannot control and burnout (work). | 100% |

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| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(12)* | Martin, et al. (2016) Canada | Assess the influence of Gentle Persuasive Approaches (GPA) educational in the improvement of dementia care intervention | Acute care settings- Medical, Surgical, oncology, Orthopedic, Intensive, Cardiology & Emergency | N=468 nurses | mixed-methods; non-randomised controlled; a quasi-experimental design with repeated measures and a Focus groups | - Skills and knowledge.<br>- Experience. | 85% |
| *(58)* | Annear (2020) Australia | Explore the healthcare professional's knowledge about dementia | Both settings | n=99 Nurses (among N=234 healthcare professional) | Quantitative; cross-sectional | - Knowledge deficit observed for the risks and health promotion subscale and items addressing blood pressure, influence of lifestyle factors, prevalence of vascular dementia and differentiation of cognitive symptoms.<br>- Participants shows lack of understanding of the dementia risk factors.<br>- Participants who undertook educational program about dementia were more knowledgeable about it and the care process.<br>- Weak association between years of experience and knowledge level. | 100% |
| *(59)* | Conway and Chenery (2016) Australia | Evaluate the effectiveness of a communication skills training program on community nurses' knowledge. | Community care setting n=12 | N=38 nurses | Quantitative; Controlled pre–post-test | - Application of communication skills training in community-based aged care practice can contribute to quality dementia care. | 62% |
| *(60)* | Digby, et al. (2018) Australia | Explore nurses perspectives when caring for people with dementia in order to critically investigate the poor care received that reported widely by patients. by such patients. | Acute care settings- Geriatric rehabilitation | N=29 Nurses | Qualitative; interviews | - Nurses showed that they prioritised patients with rehabilitation goals who were returning to the community ahead of others who may be awaiting a bed in residential care.<br>- Patients with co-morbidities were the least concerned by nurses<br>- It was clear from the interviews that not all nurses perceived patients equally.<br>- Most nurses perceived the person with dementia as *unworthy* (lack of value, undeserving, not good enough, inappropriate) to the ward environment.<br>- Nurses professed that people with dementia as disturbance of the work routine and environment. | 80% |

| | **Author & country** | **Aim** | **Setting** | **Sample** | **Method** | **Relevant findings** | **Quality** |
|---|---|---|---|---|---|---|---|
| *(61)* | Ervin et al. (2014) Australia | Investigate nurses' perceptions of non-pharmacological and pharmacological approaches in dementia management. | Community care setting n=6 | N=130 nurses | Qualitative; questionnaire | - Non-pharmacological interventions are not nurses' role.<br>- Nurses are always under pressure and lack of time cause their burnout. | 100% |
| *(62)* | Fry, et al. (2017) Australia | Investigate emergency nurses' perceptions of the Pain Assessment in Advanced Dementia in geriatric with cognitive impairment. | Acute care setting- n=3 Emergency | n=36 nurses | Qualitative; Focus group interviews | - Challenge in identifying, managing and evaluating pain.<br>- Use of PAINAD was recommended by nurses than other similar tools available that ease the challenges. | 100% |
| *(63)* | Kable, et al. (2015) Australia | To expound health professionals' position on discharge planning and transitional care for dementia patients | Acute care setting- Medical | n=16 nurses (among N=33 health professionals) | Qualitative; focus groups | - Study claimed that nurses' perceptions greatly affect systems failures in transitional care for dementia patients.<br>- Nurses perceptions greatly affected among other issues, systems failures in transitional care for patients with dementia. | 100% |
| *(64)* | Shannon, et al. (2018) Australia | Explore nursing care for people with dementia | Acute care setting-Rural hospital | n=19 Nurses (Observations n=13 Nurses and interviews n=19 Nurses) | Qualitative; observations and interviews | - Nurses trying their best to make consistent ward routine to maintain calm atmosphere and allow focusing on maintaining patient's dignity.<br>- Nurses used physical and chemical restrains on patients with dementia to keep them safe and avoid their falling.<br>- Person-cantered care is challenging.<br>- Nurses referred to the important of having a family member to support the care and some seeks help from security personnel.<br>- Nurses main concern is the patient safety and minimise risks. | 80% |
| *(65)* | McCann, et al. (2014) Australia | Examine the attitudes of clinical staff towards the management of aggression in acute geriatric psychiatry inpatient environments. | Acute care settings- n=3 Psychiatry | N=75 nurses | Quantitative; Cross-sectional | - Aggressive behaviours of dementia patients cause difficulty in developing bonds and communication.<br>- Using medication useful for managing aggressive behaviours. | 100% |
| *(66)* | Nakanishi and Miyamoto (2016) Japan | Focus on the factors associated to attitudes and knowledge of nursing facility staff linked to palliative care of advanced dementia care. | Community care setting n=74 | n=121 nurses (among N=275 health professionals) | Quantitative; Cross-sectional | - Dementia knowledge and attitudes scores were found to be significantly higher among nurses that had more experience and possessed higher educational levels.<br>- Community care settings with nurses that have developed manual end-of-life care skills scored higher in terms of knowledge and attitudes. | 66% |

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| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(67)* | Yada, et al. (2014) Japan | Provide insight into the precise work-related stress in psychiatric dementia nurses care for geriatric patients demonstrating behavioral and psychological symptoms. | Acute care settings- n=2 Psychiatry | N=244 nurses | Quantitative; Cross-sectional | - If the workplace environment stressor were reduced for nurses, the cognitive health of the dementia patients is improved.<br>- Nurses working with dementia patients have high stress level and burnout.<br>- Shouting of the dementia patients is considered one of the environmental stressors that claimed by nurses.<br>- Shouting is common in such ward, in addition to the odour and noise. | 100% |
| *(69)* | Wang, et al. (2017a) China | Ascertain the effectiveness of a nurse-led dementia educational and knowledge and perception. | Community care setting n=14 | n=68 nurses (among N=170 health professionals) | Cluster randomised controlled trial | - Nurse-led dementia educational and knowledge translation program positively improve attitude and knowledge.<br>- Educational background impacts the dementia care practices. | 77% |
| *(68)* | Wang, et al. (2017b) China | Ascertain the effectiveness of dementia-septic educational program incorporating WeChat-based learning interactions could improve nurses' dementia attitudes, knowledge and intentions. | Community care setting | N=115 nurses | Randomised controlled trial | - demonstrated an educational program using WeChat application.<br>- Knowledge an attitude was positively improved.<br>- The program shows its acceptability and practicability in improving nurses' dementia attitudes as well as knowledge and intentions to achieve early detection of dementia. | 69% |
| *(70)* | Wang, et al. (2018). China | Assess healthcare professional knowledge and attitudes towards people with dementia in community care settings | Community care settings | n=178 Nurses (N=390 healthcare professionals) | Quantitative; cross-sectional | - Generally, positive attitudes towards dementia.<br>- Low dementia knowledge noted; especially in questions related to symptoms and caregiving.<br>- Failed to apply person-centred care. | 75% |
| *(71)* | Lin, et al. (2018). Taiwan | Examine dementia care knowledge, attitude and behavior among nurses regarding dementia care and self-education | Acute care settings- Emergency, psychiatry, and neurology | N=387 Nurses | Quantitative; cross-sectional | - Knowledge scores were significantly associated with age, nursing experience, accreditation as registered nurse, holding a bachelor's degree, work unit, training courses and learning behavior towards dementia care.<br>- Emergency nurses reported a significant low knowledge about dementia care that is significantly lower than the psychiatric and neurology ward nurses. | 75% |

| | **Author & country** | **Aim** | **Setting** | **Sample** | **Method** | **Relevant findings** | **Quality** |
|---|---|---|---|---|---|---|---|
| *(72)* | Kang, et al. (2017) South Korea | Investigate the impact of an educational program on acute care nurses in the aspect of dementia knowledge, their attitude and the role of caregivers. | Acute care settings - Medical | N=40 nurses' educational program<br>N=12 nurses' interviews | mixed-methods sequential explanatory design; single group, pre-post design and individual interviews | - Educational alter self-confidence lead to improve assessment for dementia patients.<br>- Improve knowledge and enhance positive attitude. | 75% |
| *(73)* | Bentwich, et al. (2017) Palestine | Explore the existing gaps between formal dementia careers and their perspective of dementia people dignity and autonomy. | Both settings n=3 Community n=1 Acute | N=196 nurses | Quantitative; Cross-sectional | - Significant variations in the attitudes to autonomy and human dignity patients living with dementia<br>- Nurses lacked positive perception and so did not maintain the dignity and autonomy of dementia patients in their care. | 50% |
| *(74)* | Yaghmour, et al. (2016) Saudi Arabia | Provide insight into the knowledge of nurses on dementia. | Acute care settings- n=2 Psychiatry & acute | N=265 nurses | Quantitative; Cross-sectional | - Poor understanding of dementia in Saudi Arabia is linked to nurses' unresponsiveness to geriatric patient with cognitive impairment such as depression and delirium.<br>- Nurses rated their knowledge low which significantly correlate with their knowledge score. | 85% |
| *(75)* | Burns and McIlfatrick (2015b) UK (Canada, Australia and US) | Explore the evidence on nurses' attitudes and knowledge in pain assessment in dementia geriatric patients. | Both settings | N=11 studies (7 to 244 nurses) | Systematic narrative review between 2000-2014 | - Nurses faced challenge in diagnosing pain for dementia patients.<br>- There are inadequate pain assessment tools available for nurses to use.<br>- Nurse-physician relationship is important to assist in communicating and investigating pain for dementia patients. | 73% |
| *(76)* | Deasey, et al. (2014) Australia | Explore nurses' attitude, knowledge of the ageing processes in geriatric patients in the emergency care. | Acute care setting- Emergency | N= 16 studies | Literature review Between 2004-2012 | - Lack of nurses' knowledge effect the care provided.<br>- The dementia patients become vulnerable as a result of lack of understanding of the disease process and skills.<br>- Negative attitude of nurses toward dementia patients associated with his level of dependency. | 91% |
| *(77)* | Digby, et al. (2017) Australia (UK, Sweden, Australia, Ireland, US, Japan, Finland and Malta) | Explore of literature regarding the perception of nurses and people living with dementia on acute hospital care | Acute care setting | N=24 qualitative studies; (n=270 nurses) | Integrative review between 2005-2015 | - Dementia patients treated in the acute hospital setting consider being a disturbance to the ward routine and mostly disregarded.<br>- Dementia patients are given low priority and have been regarded as an interruption to normal routine at the hospital.<br>- There is an absence of a patient-centred approach in caring for dementia patient.<br>- Inadequate nursing support leads to low job satisfaction of nurses caring for dementia patients. | 90% |

| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| *(78)* | Evripidou, et al. (2018) Cyprus (UK, Norway, Sweden, USA, Australia, Korea and Palestine) | Determine nurses understanding, knowledge and attitude toward dementia patients. | Both settings | N=19 studies | Systematic literature review | - A review published in 2018 found that nurses lack in their knowledge about dementia with negative attitude toward dementia patients that impact negatively on the care provided. | 82% |
| *(79)* | Gwernan-Jones, et al. (2020) UK | Review and synthesise qualitative data from studies exploring the experiences of hospital staff who care for people living with dementia | Acute care settings | N=58 qualitative studies | Qualitative systematic review | - Person-centered care improves experiences of care for people with dementia and their carers; also improve hospital staff experiences when caring for them.<br>- Person-centered care can reduce moral distress related to caring for people with dementia and improve job satisfaction for hospital staff.<br>- An important aspect of training involves attributing responsive behaviours to unmet needs. Time spent get- ting to know individual people with dementia is valuable because it can prevent or resolve responsive behaviour.<br>- Providing staff training may be inadequate to effectively enable person-centered care; hospital cultures that prioritise psychological well-being of people with dementia at the same level as physical health are needed to enable staff to spend time getting to know people with dementia. | 100% |
| *(80)* | Machiels, et al. (2017) Netherland | Provide a current update on communication interventions approaches in daily nursing care activities, in the home care setting and their outcomes in dementia care by nurse professionals | Community care setting | N=6 RCTs studies; (n=235 nurses) | Systematic literature review Between 2000-2016 | - All studies that measured non-verbal and verbal communication, found positive effects on at least some of the communication outcomes.<br>- Communication is important factor to establish patient-nurse relationship.<br>- Most PWD admitted in the long-term facilities have difficulties in communication. | 82% |
| *(81)* | Monthaisong (2018) USA (6 UK, 3 Sweden, 2 Norway, 2 Ireland, 2 | Investigate nurses' experiences toward caring for dementia patients | Both settings | N=19 studies | Integrated literature review | - looked at nurses' experiences and perception toward dementia patients.<br>- Nurses combating painful emotions when caring for dementia patients.<br>- Many nurses complain about working environment and the work pressure. | 60% |

| | Author & country | Aim | Setting | Sample | Method | Relevant findings | Quality |
|---|---|---|---|---|---|---|---|
| | Australia, Finland, Malta, France, Belgium) | | | | | - Nurses recognise the need of meeting the holistic care for dementia patients.<br>- They are experiencing inadequate knowledge and competence of dementia. These consider as barriers of caring for a dementia patient in any setting. | |
| *(82)* | Moonga and Likupe (2016) UK (8 UK, 4 Australia, 3 Sweden, 1 Ireland) | Probe the experiences of healthcare practitioners providing care to dementia patients in orthopaedic ward. | Acute care setting- Orthopaedic | N=14 studies | Systematic review Between 1998-2013 | - Educationally intervention improves nursing practice and coping mechanism.<br>- Person-cantered approached minimise nurses' burnout. Educational and practice together improve. | 80% |
| *(89)* | Saxell, et al. (2021) | Describe nurses experiences of facilitators for the delivery of person-centered care to inpatients with dementia | Acute care settings | N=19 studies | Systematic review | - Internal facilitators (experience and knowledge; values and beliefs; professional identity; empathy)<br>- External facilitators (physical environment; organisational culture and structure)<br>- Facilitating actions (forming a holistic picture; establishing trust; adjusting routines and interventions).<br>- While facilitators did exist in the hospital setting, the findings indicate that care received by inpatients with dementia is dependent on individual registered nurses knowledge, personal attitude and ability to compensate for structural flaws | 90% |
| *(83)* | Tomlinson and Stott (2015) UK | Investigate attitudes and factors involved in assisted dying of dementia. | Both settings | N=18 studies | Systematic literature review Between 1992-2013 | - Restricted views toward end-of-life.<br>- Opinion varies according to the severity of dementia, religion, ethnicity and gender. | 90% |

### 3.4 Review's findings

### Theme 1: Nurses' knowledge, attitudes and perceptions towards dementia

The review identified 72 studies that had investigated and explored nurses' *knowledge* (6, 10, 12, 18, 19, 24, 26, 27, 36, 42, 48, 51-53, 55, 58, 59, 66, 68-78, 81, 82, 89), *attitudes* (11, 18, 30, 38, 39, 41, 42, 47, 50, 52, 54, 60, 64-66, 68, 70, 72, 73, 76-81, 83, 89) and *perceptions* (10, 11, 20, 21, 23, 25, 28, 29, 31-35, 37, 40, 41, 43-46, 48, 49, 52, 56, 57, 60-64, 67, 73, 81, 82, 90).

Several studies reported that most nurses possessed the basic knowledge of dementia (6, 17-19, 24, 38, 55, 66, 73, 74, 76, 78), with a good understanding of effective screening and diagnosing of dementia and sufficient knowledge of general pain management (6, 18, 24, 55). However, there were also studies that highlighted significant deficiencies in nurses' knowledge regarding dementia; this was frequently highlighted within the literature (17, 38, 73, 74, 76, 78). Accurate knowledge of the disease spectrum from onset to end-of-life was found to be remarkably low (37, 55, 70). There was also a lack of knowledge regarding the specific safe use of certain pain management therapies (18, 49) and a lack of understanding of the disease process and skill set needed for the disease's management (18, 24, 55, 58, 71, 76).

The significance of these studies is that they revealed a positive relationship between knowledge and dementia care. For example, nurses with adequate knowledge of dementia were generally found to have a more positive attitude towards dementia and dementia care; however, this did not always translate into competency in the teams providing quality care for dementia patients (66, 76). Also, the negative attitudes of nurses towards dementia patients were found to be associated with high levels of perceived patient dependency (76, 78) with some nurses in acute care settings reporting feeling hesitant to attend to patient cases related to old age (76, 77). Dementia knowledge and attitudes scores were found to be significantly higher among nurses who had more experience and possessed higher educational levels (50, 66). This is consistent with the findings from Norway, which stated that licensed nurses with higher work experience had higher dementia care knowledge scores (30).

Studies also reported about an improvement in knowledge and attitude after the provision of training. To this end, nurses' knowledge and perceptions were significantly improved when educational interventions (10, 42, 51, 52, 68, 69, 72) and training programmes (11, 20, 26, 36, 46, 53, 59, 62) were implemented in both community and acute care settings in a number of different regions, including the Americas (Canada and USA), Europe (Germany, Sweden, Switzerland, UK, Austria, Finland, Italy and Norway), Western Pacific (Australia, China and Taiwan) and South East Asia (South Korea).

Hence, informed by these studies, researchers have recommended on-the-job training to increase the knowledge and attitudes of nurses. The literature review revealed positive benefits of educational programmes in improving knowledge. In the USA, an educational programme for community nurses provided significant improvements in levels of pain knowledge, neuropsychiatric symptom recognition and depression knowledge (52). In Canada, the Gentle Persuasive Approaches educational programme was carried out to educate nurses in acute care settings, including medical, surgical, oncology, orthopaedic, intensive, emergency wards and cardiology care units; this programme was found to significantly enhance nurses' knowledge, perceptions and practices regarding dementia (12). Similarly, studies done in Australia, South Korea and China also revealed an improvement in attitude and knowledge towards dementia patients (58, 68, 69, 72). Therefore, these approaches can be useful in maximising the advancement of interprofessional collaboration, thereby improving the overall dementia care for the patient.

### Theme 2: Nursing experience of the factors influencing dementia care in acute and community care settings

Work environment and care settings were believed to play a crucial role in the nurses' perceptions and in their dementia care delivery. A wide diversity in practices along with the skills of the nurses working in both community and acute care settings was evident with respect to dementia screening, evaluation and treatment (6, 45). In community care settings, researchers have suggested the application of effective communication skills at the time of training community-based caregivers, thereby contributing to the quality care of dementia-afflicted individuals (11, 26, 27, 59, 79). Additionally, community care settings with nurses who have developed manual end-of-life care skills scored higher in terms of knowledge and attitudes (66). Contextually, at the time of assessing the barriers with respect to the development of dementia care, it was found that the lack of educational opportunity, limited access to training, staff shortages, lack of management support, time constraints and lack of funding were among the most predominant and common barriers experienced by healthcare personnel (19, 27, 79, 81).

Nurses' experience of care was also found to be influenced by the staff's working condition. For example, in the UK, researchers found poor staff working conditions, undertrained nurses and a negative image of the work setting had a negative impact, but despite these factors, nurses were compassionate towards dementia patients (21, 60). A Swedish study found that nurses struggled to perform person-centred care for dementia patients, and most did not hold positive attitudes towards dementia patients (38) this is also confirmed by focused groups studied in Germany and Austria (48). While in China, authors claimed that nurses caring for people with dementia in community care settings failed to apply person-centred care. In Australia, nurses argued that nonpharmacological interventions were not the nurses' role, claiming that they always worked under pressure (60, 61, 64). Therefore, nurse–patient communication and a conducive environment played an important role in changing the nurses' perceptions towards patients with dementia (17, 40, 43).

In contrast, studies conducted in acute care settings revealed poor quality of services and a lack of knowledge about dementia. Issues like burnout and high stress levels were common in patients. Nurses' burnout and lack of essential knowledge of dementia incapacitates the delivery of quality services. In Japan, nurses within psychiatry wards who were working with aggressive dementia patients had high stress levels and experienced burnout (67). However, if workplace environment stressors were reduced for nurses, the cognitive health of patients with dementia improved (67). In the UK, work pressures on nurses were influenced by different perceptions of patients with dementia (31, 32); some indicted compassion and love while others experienced psychological stress (23, 67, 81). Thus, the work environment varied for nurses in different settings. A study evaluating dementia care experience from the perspective of nurses reported that inadequate staffing, along with few educational training opportunities, undermines the quality of care (91).

Job satisfaction was also linked to dementia care experience in both acute care settings and community care settings. Community care setting nurses from the Netherlands found that the level of nurses' job satisfaction, motivation and social support were different among those taking care of dementia patients (44). The most significant factor that was correlated with higher job satisfaction and motivation was social support (44). Inadequate nursing support leads to low job satisfaction in nurses taking care of dementia patients (44, 77). In both acute and community care settings, nurses may have to strive to understand the conditions of dementia patients and even struggle to adapt to the new cultural norms of offering quality care to these patients (28, 78). The nurses' perceptions towards dementia patients may vary depending the severity of the dementia and even based on the patient's religion, ethnicity and gender (83).

### Theme 3: Dementia nursing care across health regions

In the UK, the six qualitative studies mostly focused on investigating nurses' perceptions of dementia patients in both acute and community care settings (20-23, 25, 27). Despite the nurses acknowledging the importance of end-of-life care, they struggled to administer good end-of-life care to dementia patients (22, 23). In Norway, six qualitative studies were conducted in community care settings to investigate nurses' perceptions towards dementia patients and the nurses' care giving (20, 29-31, 34, 35). Work pressure and nurses' burnout can be perceived by nurses to be the most significant reasons behind the mismanagement of dementia-afflicted patients (33, 56, 57). In addition, these nurses also expressed that they felt that it is regular practice, which can assist in enhancing their knowledge together with educational interventions. This can further contribute to encouraging a positive attitude with respect to communication, as well as personal interaction (10, 11, 80). In the USA, four quantitative studies were conducted in both settings (6, 52, 53, 55), along with one mixed method study (54) in an acute care setting (dementia wards at the hospital), to gather a clear inference of the nurses' knowledge; this was done by investigating the nurses' attitudes towards dementia patients and towards dementia care. The diversities in the practice and skill of the nurses led to an increase in the level of risks over time (10, 55).

A few mixed methods studies have been conducted within community and acute care settings to investigate nurses' knowledge of providing the required care to dementia-affected people (19, 24, 26). However, considering the concept of communication, it can be inferred that a lack of empathy along with the aggressive behaviour of dementia patients tends to hamper the proper decision making of nurses. One qualitative and one quantitative study in community care contributed to inferring the importance of nonverbal communication in decision making (40, 46, 47, 89). A control trial study in Switzerland community care focused on nurses' knowledge (51) and concluded that educational programmes improve the quality of care provided and could further reduce urinary incontinence issues in dementia patients. In Southeast Asia, a mixed method study was conducted in an acute care setting (medical ward) in South Korea (72), and there was a review that included South Korean nurses

(78). It was declared that educational strategies alter self-confidence, which further leads towards improving the assessment of dementia patients (72). In Palestine, within community care settings, a significant variation in attitudes towards the autonomy and dignity of patients with dementia has been noted among 196 nurses (73). The researchers suggested that the nurses lacked positive perceptions of dementia patients, which further resulted in a failure to maintain autonomy and/or dignity in their care. This explains how nursing competency and the care environment can contribute to the dignity and quality of life of dementia patients (92).

## 4. Discussion

The main objective of the current study was to synthesise a comprehensive body of evidence regarding nurses' knowledge, attitudes and practices towards dementia care. Another objective was to explore experience of care in acute care hospitals and community care settings and evaluate experience by different regions across the world. A total of 72 articles were identified from the literature search, and these were classified into three themes. The majority of the reviews included qualitative or quantitative papers, but there were a few trials.

The first theme reported on the knowledge, perceptions and attitudes of nurses towards dementia care. A total of 72 studies explored this topic. The studies revealed that most nurses had basic knowledge about dementia. However, deficiencies in specific knowledge, such as onset to end-of-life care and pain management, were frequently reported (17, 18, 24, 41, 55, 76). Handling the aggressive behaviour of dementia patients was challenging for many nurses, and they reported poor therapeutic relationships with staff because of this issue. The studies also revealed the role of inadequate training and the absence of lessons on dementia management in the nursing curriculum. Most of the studies were of a high or good quality. However, the gaps that remained in addressing the first theme were that most of the studies were done using convenience sampling or purposive sampling methods. In addition, for end-of-life care, it remains to be seen how new service initiatives may help nurses support patients during end-of-life care. In the case of studies that reported concerns related to the management of aggressive behaviour, the findings were restricted to studies done in two or three inpatient units. Thus, recruiting samples from a broader range of services can help to generalise these findings. Despite this limitation, the findings are consistent with a recent research evidence, who argue that care delivery for dementia is challenging for nurses because they often navigate through patients' various feelings and emotions (91). They often experienced the ethical dilemma of feelings of anger when met patients who shows aggressive behaviour (91).

In response to the low knowledge and skill level of nurses, many countries have implemented educational programmes to increase competency in dementia care for health staff. These studies highlighted the benefits of educational programmes in improving nurses' confidence, knowledge and attitudes towards dementia patients. This signifies the role of education in boosting confidence in care delivery for this health issue (11, 12, 20). The evidence-based findings from the current review study give a clear indication that the creation of awareness about dementia and experience in dealing with dementia patients improves both knowledge and the general skill sets that are relevant to dementia patients (68, 69). Therefore, educational interventions and training programmes are an important resource for future improvement of the competency levels of dementia in nursing care. This helps to enhance nurses' ability to manage pain issues that are often not verbally expressed by patients. However, there were some quantitative surveys that used questionnaires lacking content validity. This limitation is addressed later.

The second theme was concerned with evaluating nurses' experiences in acute and community care settings. A wide diversity in practice was found. However, each of the settings had different limitations, and different actions were taken to enhance care. For instance, continuous professional development initiatives were evident in many community care settings (10, 11, 28). In contrast, there were many studies that were affected by a poor leadership style. A UK-based study focused on the fact that most nursing managers lacked proper knowledge of managing dementia patients; they even possessed negative attitudes towards planning for advanced care of dementia patients (17). A researchers also claimed that leadership style influences the attitudes towards caring, thus negatively affecting the nurses' working atmosphere, ultimately creating a somewhat negative impact on their work experiences (30). Thus, studies reported under this theme highlight the role of working environment and leadership style in dementia care. Job satisfaction and other forms of social motivation also greatly influenced the nature of the services offered by nurses to dementia patients. However, the gap that remains in addressing this theme is that the theme does discuss the role of community services in improving the care experience of these people. Thus, future research could evaluate how nurses' knowledge and access to community services can broaden their understanding of safety (63). This will help in finding out how a care transition takes place from acute care to community care settings.

The third theme was related to experience of dementia care in different regions across the world. It has been found that the issue of burnout and work pressure is not limited to one setting. Studies done in Europe, the USA, and Eastern Mediterranean countries reported these issues. Poor patient autonomy and violation of dignity in care was a major concern. For this reason, nurses are recommended to engage family members in the care to ensure that information about the patient's premorbid function and their likes/dislikes could be obtained (93).

Overall, the present review contributes to more knowledge regarding the current knowledge and attitude of nurses and how their knowledge, attitudes and perceptions is enhanced or reduced by different factors in care; it gives guidance regarding the areas that need more work.

### 4.1 Strengths and weaknesses of the review

This review mainly aims to uncover the knowledge, attitudes and practices of nurses in dementia care. The strength of the review is that it includes 72 articles from diverse settings. In addition, not limiting the research to any specific research design was also a strength because it ensured that diverse types of papers were reviewed. However, one major limitation of the review is that it lacked the inclusion of many randomised control trials. Because randomised control trials studies come under top quality in evidence hierarchy, including a few randomised control trials studies was important. The lack of these studies leaves a gap in the integrated review process. Second, the review focused on the quality of each article. Hence, most of the studies were high-quality or good-quality papers, which were mostly evaluated using the JBI critical appraisal tools. The strength of the review is that no studies were found that had a quality appraisal score of less than 50%.

### 4.3 Limitations of the studies

The main limitation of this study is it has been conducted by one researcher, however, all decisions and findings were discussed in supervisory meetings in order to reduce researcher's bias and maintain transparent findings and conclusion. Also, unequal data were found across the health regions and scarcity of literatures available in most developing countries in Eastern-Mediterranean and Asian region in particular.

## 5. Implications for policy or practice change

To achieve best nursing practices and enhance dementia nursing care, researchers across the globe have acknowledged the importance of exploring and investigating nurses' knowledge, attitudes and perceptions towards people with dementia. Researchers have used different research methodologies to achieve this aim; however, there is an absence of studies in particular areas, such as in the Eastern Mediterranean and Southeast Asia regions.

The current review's findings indicate that improving the practical experience of nurses enhances their knowledge of dementia, thereby leading to an improved quality of care. It found that skill-based training further increases knowledge by improving the communicate on and problem-solving skills of staff members working with dementia patients in acute settings. Also, a patient's inability to verbally communicate with nurses regarding their problems, including pain, makes them vulnerable and highly dependent on their caregivers. To improve pain relief during end-of-life care, professional experience, an understanding of the patient's background and the use of pain assessment tools are required. Developing a psychometric assessment tool for nurses to determine patients' requirements, such as pain assessment and the activities of daily living, can contribute to enhancing the person with dementia hospitalisation experience. Therefore, it can be concluded that the healthcare settings, as well as culture, along with the knowledge of the nurses, their attitudes and their perceptions, can have a tremendous impact on dementia-affected individuals.

This review also found that appropriate communication further plays a significant role in the development of a healthy environment between dementia patients and healthcare providers. The establishment of verbal and nonverbal communication protocols in nursing care for dementia is vital in providing dementia nursing care. In addition, nurse–physician relationships are vital for facilitating communication at the time of deciding the care plan of dementia patients. Also, the work environment and care settings play an important part in the nurses' perceptions, along with dementia care delivery. The burnout of nurses and lack of essential knowledge on dementia among them further incapacitates the delivery of quality services within acute or community care settings. If the workplace environment stressors were to be reduced for nurses, the cognitive health of patients with dementia would most likely be improved. Job satisfaction and other forms of social motivation greatly influence the nature of the services offered by nurses to dementia patients. Work pressure, as well as inadequate time and availability of training programmes, are noted to be the foremost barriers to educational improvement strategies as perceived by nursing professionals. Work pressure along with nurses' burnout can also be perceived as being the most significant reasons behind the mismanagement of dementia-afflicted patients.

Therefore, providing healthcare educational programmes and then setting up continuous professional development initiatives are the key principles of person-centred care approaches. The lack of educational opportunities, limited access to training, staff shortages, lack of management support, time constraints and lack of funding are the factors to be addressed for improving dementia care. Additionally, leadership style influences the attitudes towards caring, thus negatively affecting the nurses' working atmosphere, which ultimately creates a somewhat negative impact on their work experiences.

## 6. Conclusion

Overall, the present review contributes to the understanding of the current knowledge and attitude of nurses and how their knowledge, attitudes and perceptions are enhanced or reduced by different factors in care; it gives guidance regarding the areas that need more work.

In particular, the studies found that having samples from a broader range of services can help researchers draw a more generalised understanding of how nurses may navigate through the ethical dilemmas of dealing with patients' various emotions and aggressive behaviours. Moreover, the role of working environment and leadership style in dementia care is vital for job satisfaction, which influences the care offered by nurses to people with dementia. Lastly, the issue of burnout and work pressure resulting from poor patient autonomy and violation of dignity in care is a major concern that affects nurses in all regions of the world.

Thus, future research needs to focus on educational interventions and training programmes, as these are an essential component in raising nurses' competency levels in managing patients' pain issues. In addition, evaluating nurses' knowledge and access to community services can broaden their understanding of safety and help in transitioning patients from acute care to community care settings. Finally, nurses are advised to engage family members to ensure that the patient's care includes adjustments made for premorbid function and personal preferences.

This review mainly aims to synthesise the knowledge, attitudes and practices of nurses in dementia care. The strength of the review is that it includes 72 articles from diverse countries. In addition, not limiting the research to any specific research design was also a strength because it ensured that diverse types of studies were reviewed. This review focused on the quality of each article. Hence, most of the studies were high-quality or good-quality papers, which were mostly evaluated using the Joanna Briggs Institute critical appraisal tools. The strength of the review is that no studies were found that had a quality appraisal score of less than 50%.

It is everyone's right to have positive experiences and receive the right support when admitted to an acute or a community care facility. This study contributed to the current body of knowledge on the dementia nursing care and suggested possible ereas that need more development and concerns to enhance the nursing care for people with dementia, which, in-turn, can influence their well-being.

## 7. Conflicts of interest

The authors have no conflicts of interest that are directly relevant to the content of this review.

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# Appendix E Survey data collection

## E.1 Participant Information Sheet

### Participant Information Sheet (Survey)

نموذج معلومات المشارك (الاستبيان)

| | |
|---|---|
| **Study Title**:<br>Nurses' Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Methods Study | **عنوان البحث:**<br>مرئيات التمريض واحتياجات التعلم تجاه مرضى القصور الذهني (الخرف) في السعودية |
| **Researcher**:<br>Sara Mahmoud Yaghmour | **الباحث:**<br>سارة محمود يغمور |
| **ERGO number:** 29647 | رقم الموافقة: ٢٩٦٤٧ |

***Please read this information carefully before deciding whether or not to take part. If you are happy to participate you will be asked to complete a survey.***

**أرجو قراءة التعليمات بعناية قبل أن تقرر الموافقة أو الرفض للمشاركة، في حال رغبتكم بالمشاركة المطلوب منك استكمال الاستبيان.**

| | |
|---|---|
| **What is the research about?**<br>This research is about the care provided to people with dementia in Saudi Arabian Hospital. In particular, it looks at nurse's knowledge and learning needs in respect of caring for people with dementia in a general hospital. The research is sponsored by King Abdulaziz University and is being undertaken by Sara Yaghmour a mental health nursing lecturer at the university and Ph.D. student at University of Southampton. | **عن ماذا البحث؟**<br>البحث عن العناية المقدمة للأشخاص المصابين بالقصور الذهني (الخرف) في المستشفيات السعودية، تحديدًا استقصاء عن معلومات طاقم التمريض ومعرفة الاحتياج العلمي للعناية بالأشخاص المصابين بالديمنشيا (القصور الذهني/الخرف) في المستشفيات العامة.<br>البحث تحت إشراف جامعة الملك عبدالعزيز بجدة وتتولاه سارة محمود يغمور المحاضِرة بجامعة الملك عبدالعزيز قسم تمريض الصحة النفسية والمبتعثة لدرجة الدكتوراة في جامعة ساوثهامبتون في بريطانيا. |
| **Why have I been asked to participate?**<br>Because you are a qualified nurse working in a Saudi Arabian Hospital that admits people with dementia with more than one year of experience. Your knowledge and experience can help inform the future of nursing in KSA. | **لماذا تم دعوتي للمشاركة؟**<br>لأنك تعملـ/ـي بالتمريض مع خبرة أكثر من سنة في أحد مستشفيات وزارة الصحة السعودية والتي تعتني بالأشخاص المصابون بالقصور الذهني، معلوماتك وخبرتك ستساعد على تشكيل وتطوير مستقبل التمريض في السعودية. |
| **What will happen to me if I take part?**<br>If you decide to take part of this study, you will be asked to complete a self-administered survey in English that consists of three parts and will take around 30 minutes of your time to complete. | **ماذا سيحدث لي في حالة شاركت بالبحث؟**<br>في حال موافقتكم على المشاركة في هذه الدراسة سيتم الطلب منك استكمال استبيان باللغة الإنجليزية والمُقسم إلى ثلاثة أجزاء، ولإكماله سيستغرق من وقتكم حوالي 30 دقيقة. |
| **Do I have to take part?**<br>No. You can ignore this invitation if you wish. You are also free to withdraw from taking part at any time, without giving a reason. | **هل يجب علي المشاركة؟**<br>لا، بإمكانك تجاهل هذه الدعوة إذا كنت ترغبـ/ـي في ذلك، وكذلك لك الحرية في الانسحاب من المشاركة في أي وقت دون إبداء سبب. |
| **Are there any benefits in my taking part?**<br>There are unlikely to be any direct benefits to you taking part in this study. However, the information you provide will help to improve the nurses' training when caring for people with dementia and understanding the care provided to this group of clients. | **هل هناك أي فوائد من مشاركتي؟**<br>إنّ المعلومات التي تقدمها/تقدميها لنا، سوف تساعد على تحسين تدريب الممرضين/الممرضات عند رعاية الأشخاص الذين يعانون من الدمنشيا (القصور الذهني/الخرف) وفهم الرعاية المقدمة لهذه الفئة. |
| **Are there any risks involved?**<br>There are no risks that attached to your participation in this study. | **هل هناك أي مخاطر مُحتملة؟**<br>لا توجد مخاطر مرتبطة بمشاركتك في هذه الدراسة. |

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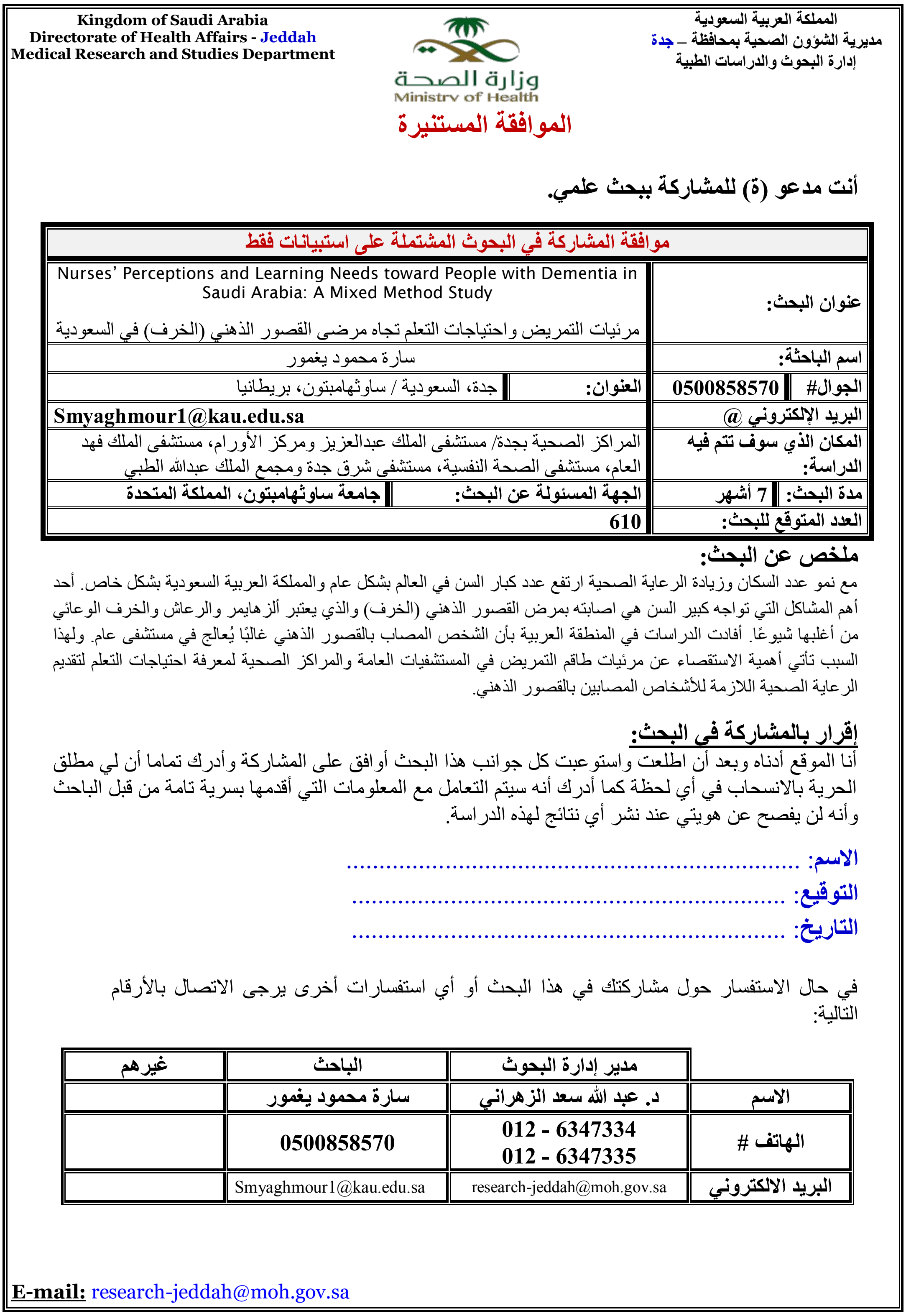
| | |
|---|---|
| **Will my participation be confidential?**<br>Yes. This project is committed to, and will abide by, the terms of the United Kingdom Data Protection Act. Survey information and participants' data are confidential and will be stored in accordance with strict privacy protection procedures. Additionally, confidentiality will be ensured, that means that study results will not contain a personal identifying information. While all papers will be stored in a locked cabinet in a locked room and during analysing the data using computer will be kept in a password-protected files, and only others who are involved in the data analysis will be eligible to access the data. The research data will be retained for a period of 10 years in accordance with the data protection policy at the Faculty of Health Sciences, University of Southampton. | **هل ستكون مشاركتي سرية؟**<br>نعم بالطبع، حيث أن هذه الدراسة تلتزم بشروط قانون حماية البيانات في بريطانيا، فتكون معلومات الاستبيان وبيانات المشاركين سرية وسيتم تخزينها وفقًا لإجراءات حماية الخصوصية الصارمة، بالإضافة إلى ذلك سيتم عدم الكشف عن هويتك وهذا يعني أن نتائج الدراسة لن تحتوي على معلومات خاصة بهوية وشخص المشترك، في حين سيتم تخزين جميع الأوراق في خزانة مقفلة في غرفة مغلقة وأثناء تحليل البيانات باستخدام الكمبيوتر سيتم الاحتفاظ بالملفات، المحمية بكلمة مرور، حيث المشرفون والمشاركون في تحليل البيانات هم فقط من سيكون لهم الأحقية في الوصول إلى البيانات، كذلك سيتم الاحتفاظ ببيانات البحث لمدة عشر سنوات وفقًا لسياسة حماية البيانات في كلية العلوم الصحية بجامعة ساوثهامبتون في بريطانيا. |
| **What happens if I change my mind?**<br>You have the right to withdraw from the study at any time without giving a reason. All the information and data collected from you will be destroyed and you name removed from all the study files. | **ماذا يحدث إذا غيرت رأيي؟**<br>لك كامل الحرية والحق في الانسحاب من الدراسة في أي وقت دون إبداء الأسباب، وسيتم حينها التخلص من كافة المعلومات والبيانات التي تم جمعها منك وسيتم إزالة معلوماتك من جميع ملفات الدراسة. |
| **What will happen to the results of the research?**<br>The study results will be written as a part of a Ph.D. thesis and will plan for its publication in international journals. In addition to use the information as a guidance for practice and policies development to care for people with dementia in Saudi Arabia.<br>If you would like to receive a copy of the results please provide your details at section one of the survey. | **ماذا سيحدث لنتائج البحث؟**<br>سيتم كتابة نتائج الدراسة كجزء من رسالة الدكتوراة والمُخطط نشرها في مجلات المحكمة الدولية، بالإضافة إلى استخدام المعلومات كدليل لتطوير ممارسة التمريض ووضع السياسات لرعاية الأشخاص المصابين بالدمنشيا (القصور الذهني/الخرف) في المملكة العربية السعودية.<br>في حال كنت ترغب في الحصول على نسخة من النتائج قم بتزويدنا بمعلومات التواصل بك في القسم الأول من الاستبيان. |
| **Where can I get more information?**<br>If you need more information and/or questions related the study please contact my supervisor Dr. Ruth Bartlett at R.L.Bartlett@soton.ac.uk or me Sara Mahmoud Yaghmour at smyaghmour1@kau.edu.sa or 0500858570 | **من أين أحصل على المزيد من المعلومات؟**<br>إذا كنت بحاجة إلى مزيد من المعلومات أو عندك أسئلة ذات صلة بالدراسة يرجى التواصل مع مشرفة الدراسة بالدكتورة روث بارتليت على R.L.Bartlett@soton.ac.uk أو الباحثة سارة محمود يغمور على smyaghmour1@kau.edu.sa أو 0500858570 |
| **What happens if something goes wrong?**<br>In the unlikely case of concern or complaint regarding any aspect of your participation, or if you feel that you have been placed at risk, please contact the Research Integrity and Governance Manager (rgoinf@soton.ac.uk, 044(0)2380595058). You may also contact the Chair of the Ethics Committee at the Faculty of Health Sciences, telephone 0044(0)2380595578, University of Southampton, Southampton, United Kingdom, SO17 1BJ. | **ماذا يحدث إذا حدث خطأ ما؟**<br>إذا كان عندك أي قلق أو شكوى بخصوص مشاركتك في هذه الدراسة أو إذا كنت تشعر بأنك قد تعرضت للخطر، يرجى الاتصال بمدير إدارة النزاهة وإدارة الحوكمة rgoinf@soton.ac.uk 00440238059058<br>يمكنك أيضا الاتصال برئيس لجنة الأخلاقيات في كلية العلوم الصحية، هاتف 00440238059557 8، جامعة ساوثهامبتون، المملكة المتحدة SO17 1BJ . |
| **Thank you for your time** | **شكرًا لوقتكم** |

## E.2 Arabic consent



المملكة العربية السعودية
مديرية الشؤون الصحية بمحافظة – جدة
إدارة البحوث والدراسات الطبية

Kingdom of Saudi Arabia
Directorate of Health Affairs - Jeddah
Medical Research and Studies Department

وزارة الصحة
Ministry of Health

### الموافقة المستنيرة

**أنت مدعو (ة) للمشاركة ببحث علمي.**

| | | | |
|---|---|---|---|
| **موافقة المشاركة في البحوث المشتملة على استبيانات فقط** | | | |
| **عنوان البحث:** | Nurses’ Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Method Study<br>مرئيات التمريض واحتياجات التعلم تجاه مرضى القصور الذهني (الخرف) في السعودية | | |
| **اسم الباحثة:** | سارة محمود يغمور | | |
| **الجوال#** | **0500858570** | **العنوان:** | جدة، السعودية / ساوثهامبتون، بريطانيا |
| **البريد الإلكتروني @** | **Smyaghmour1@kau.edu.sa** | | |
| **المكان الذي سوف تتم فيه الدراسة:** | المراكز الصحية بجدة/ مستشفى الملك عبدالعزيز ومركز الأورام، مستشفى الملك فهد العام، مستشفى الصحة النفسية، مستشفى شرق جدة ومجمع الملك عبدالله الطبي | | |
| **مدة البحث:** | 7 أشهر | **الجهة المسئولة عن البحث:** | **جامعة ساوثهامبتون، المملكة المتحدة** |
| **العدد المتوقع للبحث:** | **610** | | |

**ملخص عن البحث:**

مع نمو عدد السكان وزيادة الرعاية الصحية ارتفع عدد كبار السن في العالم بشكل عام والمملكة العربية السعودية بشكل خاص. أحد أهم المشاكل التي تواجه كبير السن هي اصابته بمرض القصور الذهني (الخرف) والذي يعتبر ألزهايمر والرعاش والخرف الوعائي من أغلبها شيوعًا. أفادت الدراسات في المنطقة العربية بأن الشخص المصاب بالقصور الذهني غالبًا يُعالج في مستشفى عام. ولهذا السبب تأتي أهمية الاستقصاء عن مرئيات طاقم التمريض في المستشفيات العامة والمراكز الصحية لمعرفة احتياجات التعلم لتقديم الرعاية الصحية اللازمة للأشخاص المصابين بالقصور الذهني.

**إقرار بالمشاركة في البحث:**

أنا الموقع أدناه وبعد أن اطلعت واستوعبت كل جوانب هذا البحث أوافق على المشاركة وأدرك تماما أن لي مطلق الحرية بالانسحاب في أي لحظة كما أدرك أنه سيتم التعامل مع المعلومات التي أقدمها بسرية تامة من قبل الباحث وأنه لن يفصح عن هويتي عند نشر أي نتائج لهذه الدراسة.

**الاسم:** ..........................................................................

**التوقيع:** ......................................................................

**التاريخ:** ......................................................................

في حال الاستفسار حول مشاركتك في هذا البحث أو أي استفسارات أخرى يرجى الاتصال بالأرقام التالية:

| | مدير إدارة البحوث | الباحث | غيرهم |
|---|---|---|---|
| **الاسم** | **د. عبد الله سعد الزهراني** | **سارة محمود يغمور** | |
| **الهاتف #** | **012 - 6347334<br>012 - 6347335** | **0500858570** | |
| **البريد الالكتروني** | research-jeddah@moh.gov.sa | Smyaghmour1@kau.edu.sa | |

**E-mail:** research-jeddah@moh.gov.sa

## E.3 Questionnaire

### SECTION (1)
### DEMOGRAPHIC AND PERSONAL information

you are asked to provide details of your background and **demographic information** (20 items). Please circle your response at all items (missing items will result in losing your contribution).

| # | *Personal information* | *Your responses* | | | | | |
|---|---|---|---|---|---|---|---|
| 1 | Age range | 21-25<br>26-30 | 31-35<br>36-40 | | 41-45<br>46-50 | | 51-55<br>56+ |
| 2 | Gender | Male | | | Female | | |
| 3 | Nationality | Saudi | Indian | Filipino | Other (please specify) | | |
| 4 | Job title | Nurse technician | Nurse specialist | Educator | Other (please specify) | | |
| # | *Work information* | *Your responses* | | | | | |
| 5 | Work at | Hospital | | | Primary Health Centre | | |
| 6 | Work in | Medical | Cardiology | Neurology | Psychiatry | Out-patient | |
| | | Surgical | ENT | Other (please specify) | | | |
| 7 | Work as | Bedside nurse | Clinic nurse | Charge nurse | Head nurse | Supervisor Educator | |
| 8 | Your contact with patients | Direct | | Indirect | | None | |
| 9 | Years of experience | | 1-3 | 4-5 | 6-10 | 11-20 | 20+ |
| 10 | Experience within the current area | <1 | 1-3 | 4-5 | 6-10 | 11-20 | 20+ |
| 11 | Please tick if you at workplace have access to | Evidence-based Databases | Internet | Computer | Reading groups | | |
| # | *Education information* | *Your responses* | | | | | |
| 12 | What is your highest educational degree | Diploma | Bachelor | Master | PhD | | |
| 13 | Did you complete this degree in Saudi | Yes | No | If no, please specify | | | |
| 14 | Have you ever completed a formal dementia education course or workshop | Yes | No | If yes, please specify | | | |
| # | *Other personal data* | *Your responses* | | | | | |
| 15 | Have any of your immediate family members, e.g. parents, grandparents, spouse, ever been diagnosed with dementia or Alzheimer's? | Yes | No | Please specify | | | |
| 16 | Have you ever provided professional health care for people experiencing dementia or Alzheimer's? | Yes | No | Please specify | | | |
| 17 | How do you rate your current knowledge of Dementia on a scale from 1 (no knowledge) to 5 (a high level of knowledge about it)? | 1<br>No knowledge | 2<br>Low knowledge | 3<br>Average | 4<br>High knowledge | 5<br>Expert knowledge | |
| 18 | How do you rate your confidence to care for people with Dementia 1 (not confident) to 5 (very confident)? | 1<br>Not confident | 2<br>Low confidence | 3<br>Average | 4<br>High confidence | 5<br>Very confident | |
| 19 | Rate your willingness to learn about Dementia; 1 (not willing) to 5 (very willing)? | 1<br>Not willing | 2<br>Low willing | 3<br>Average | 4<br>High willing | 5<br>Very willing | |
| 20 | Are you willing to participate in the phase 2 of this study that involve a Diary-interview*? | Yes | | | No | | |
| | If yes, please provide an email address | | | | | | |

*Diary-interview: is a qualitative methodology in research and participants will be asked to keep a diary (recorded/written) for ten working days and reflect their own care provided to people with dementia in a daily basis. Then the study researcher will conduct an interview for further discussion that help in developing policies and guidance for nursing practice in Saudi Arabia. *** You will be given a certificate of appreciation from University of Southampton, UK and King Abdulaziz University, KSA for your valuable participation.

## SECTION (2)
## ALZHEIMER'S DISEASE AND RELATED DISORDERS (DEMENTIA)

You are asked to choose from a ranging scale from 1 (strongly disagree) to 7 (strongly agree) (20 items). There are statements about Dementia: **Alzheimer's Disease and related Disorders (ADRD)** in older adult. Please complete all of the questions (missing items will result in losing your contribution).

| | *Statement* | ***1*** *strongly disagree* | ***2*** *disagree* | ***3*** *disagree somewhat* | ***4*** *undecided* | ***5*** *agree somewhat* | ***6*** *agree* | ***7*** *strongly agree* |
|---|---|---|---|---|---|---|---|---|
| *1* | It is rewarding to work with people who have ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *2* | I am afraid of people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *3* | People with ADRD can be creative | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *4* | I feel confident around people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *5* | I am comfortable touching people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *6* | I feel uncomfortable being around people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *7* | Every person with ADRD has different needs | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *8* | I am not very familiar with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *9* | I would avoid an agitated person with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *10* | People with ADRD like having familiar things nearby | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *11* | It is important to know the past history of people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *12* | It is possible to enjoy interacting with people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *13* | I feel relaxed around people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *14* | People with ADRD can enjoy life | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *15* | People with ADRD can feel when others are kind to them | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *16* | I feel frustrated because I do not know how to help people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *17* | I cannot imagine caring for someone with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *18* | I admire the coping skills of people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *19* | We can do a lot now to improve the lives of people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *20* | Difficult behaviours may be a form of communication for people with ADRD | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

* **ADRD=** Alzheimer's disease and related disorders (O'Connor & McFadden 2010)

## SECTION (3)
## DEMENTIA KNOWLEDGE ASSESSMENT SURVEY

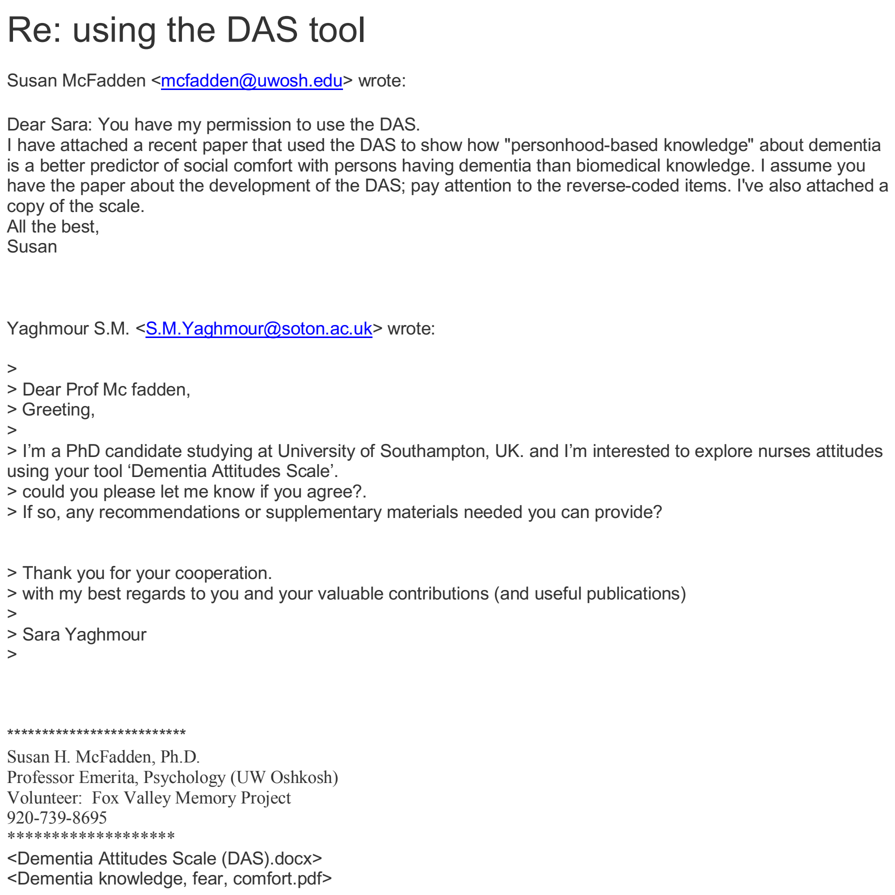
You are asked to indicate how true or false you believe each statement to be (21 Questions). There are statements about **dementia**. Please complete all of the questions (missing items will result in losing your contribution).

| | *Statement* | *Yes* | *No* | *Don't know* |
|---|---|---|---|---|
| *1* | Dementia occurs because of changes in the brain | ☐ | ☐ | ☐ |
| *2* | Brain changes causing dementia are often progressive | ☐ | ☐ | ☐ |
| *3* | Alzheimer's disease is the main cause of dementia | ☐ | ☐ | ☐ |
| *4* | Blood vessel disease can also cause dementia | ☐ | ☐ | ☐ |
| *5* | Confusion in an older person is almost always due to dementia | ☐ | ☐ | ☐ |
| *6* | Only older adults develop dementia | ☐ | ☐ | ☐ |
| *7* | Knowing the likely cause of dementia can help to predict its progression | ☐ | ☐ | ☐ |
| *8* | Incontinence always occurs in the early stages of dementia | ☐ | ☐ | ☐ |
| *9* | Dementia likely to limit life expectancy | ☐ | ☐ | ☐ |
| *10* | When a person has late stage dementia, families can help others to understand the person's needs | ☐ | ☐ | ☐ |
| *11* | People who have dementia may develop problems with visual perception (understanding or recognising what they see) | ☐ | ☐ | ☐ |
| *12* | Sudden increase in confusion are characteristic of dementia | ☐ | ☐ | ☐ |
| *13* | Uncharacteristic distressing behaviours may occur in people who have dementia (e.g., aggressive behaviour in a gentle person) | ☐ | ☐ | ☐ |
| *14* | Difficulty swallowing occurs in late stages dementia | ☐ | ☐ | ☐ |
| *15* | Movement (e.g., walking, moving in bed or chair) is limited in late stage dementia | ☐ | ☐ | ☐ |
| *16* | Changing the environment (e.g., putting on CD, opening or closing the blinds) will make no difference to person who has dementia | ☐ | ☐ | ☐ |
| *17* | When a person who has dementia is distressed, it may help to talk to them about their feelings | ☐ | ☐ | ☐ |
| *18* | It is important to always correct a person who has dementia when they are confused | ☐ | ☐ | ☐ |
| *19* | A person who has dementia can often be supported to make choices (e.g., what clothes to wear) | ☐ | ☐ | ☐ |
| *20* | It is impossible to tell if a person who is in the later stages of dementia is in pain | ☐ | ☐ | ☐ |
| *21* | Exercise can sometimes be of benefit to people who have dementia | ☐ | ☐ | ☐ |

The Dementia Knowledge Assessment Tool Version 2 was developed from Version 1 at Curtin University, Edith Cowan University, the Australian Catholic University, and the University of Tasmania by Toye, C., Lester, L., Popescu, A., McInerney, F., Andrews, S., and Pobinson, A. L. Version 1 was developed at Edith Cowan University with funding from the Australian Government Department of Health and Ageing and support from a dementia education consortium led by Alzheimer's Australia WA.

(Toye et al. 2014)

## E.4 Questionnaire authors' permission



# Re: using the DAS tool

Susan McFadden <mcfadden@uwosh.edu> wrote:

Dear Sara: You have my permission to use the DAS.
I have attached a recent paper that used the DAS to show how "personhood-based knowledge" about dementia is a better predictor of social comfort with persons having dementia than biomedical knowledge. I assume you have the paper about the development of the DAS; pay attention to the reverse-coded items. I've also attached a copy of the scale.
All the best,
Susan

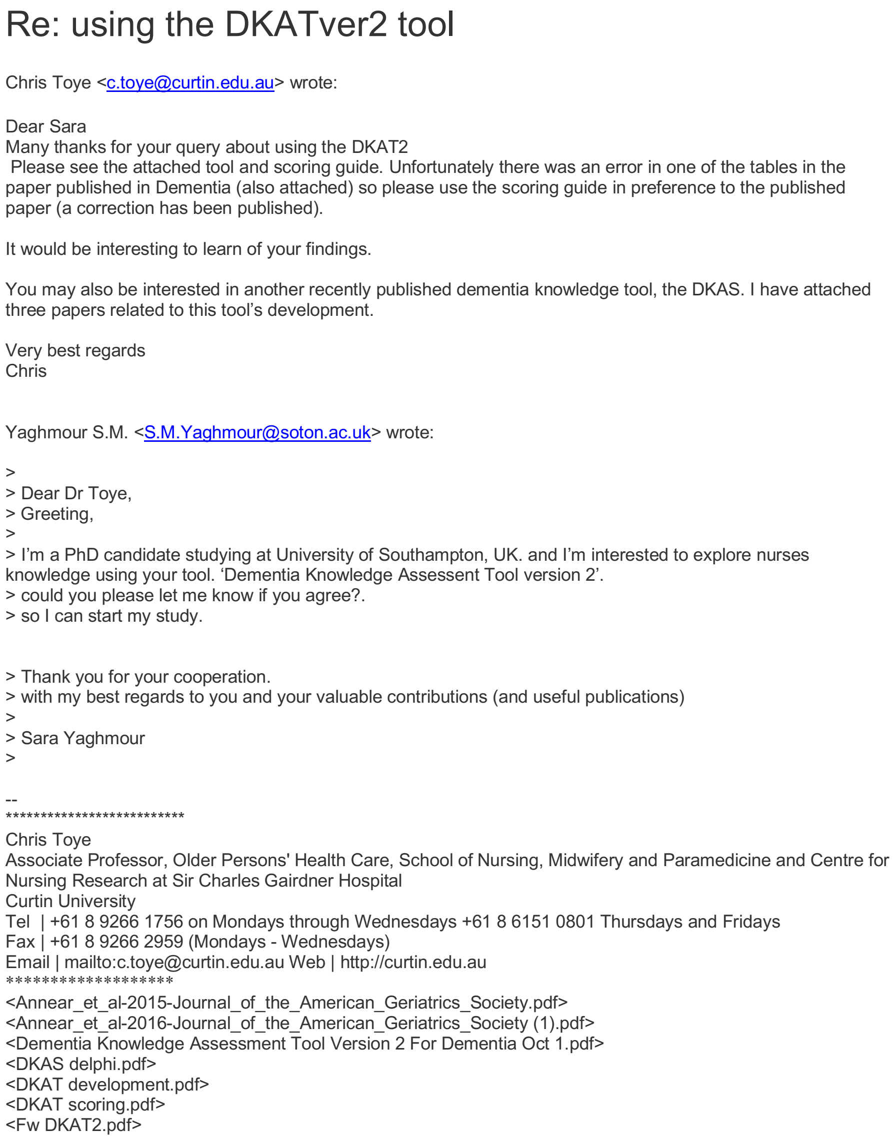
Yaghmour S.M. <S.M.Yaghmour@soton.ac.uk> wrote:

\>
\> Dear Prof Mc fadden,
\> Greeting,
\>
\> I'm a PhD candidate studying at University of Southampton, UK. and I'm interested to explore nurses attitudes using your tool 'Dementia Attitudes Scale'.
\> could you please let me know if you agree?.
\> If so, any recommendations or supplementary materials needed you can provide?

\> Thank you for your cooperation.
\> with my best regards to you and your valuable contributions (and useful publications)
\>
\> Sara Yaghmour
\>

**************************
Susan H. McFadden, Ph.D.
Professor Emerita, Psychology (UW Oshkosh)
Volunteer: Fox Valley Memory Project
920-739-8695
*******************
<Dementia Attitudes Scale (DAS).docx>
<Dementia knowledge, fear, comfort.pdf>

# Appendix E



## Re: using the DKATver2 tool

Chris Toye <c.toye@curtin.edu.au> wrote:

Dear Sara
Many thanks for your query about using the DKAT2
Please see the attached tool and scoring guide. Unfortunately there was an error in one of the tables in the paper published in Dementia (also attached) so please use the scoring guide in preference to the published paper (a correction has been published).

It would be interesting to learn of your findings.

You may also be interested in another recently published dementia knowledge tool, the DKAS. I have attached three papers related to this tool's development.

Very best regards
Chris

Yaghmour S.M. <S.M.Yaghmour@soton.ac.uk> wrote:

>
> Dear Dr Toye,
> Greeting,
>
> I'm a PhD candidate studying at University of Southampton, UK. and I'm interested to explore nurses knowledge using your tool. 'Dementia Knowledge Assesent Tool version 2'.
> could you please let me know if you agree?.
> so I can start my study.

> Thank you for your cooperation.
> with my best regards to you and your valuable contributions (and useful publications)
>
> Sara Yaghmour
>

--
**************************
Chris Toye
Associate Professor, Older Persons' Health Care, School of Nursing, Midwifery and Paramedicine and Centre for Nursing Research at Sir Charles Gairdner Hospital
Curtin University
Tel | +61 8 9266 1756 on Mondays through Wednesdays +61 8 6151 0801 Thursdays and Fridays
Fax | +61 8 9266 2959 (Mondays - Wednesdays)
Email | mailto:c.toye@curtin.edu.au Web | http://curtin.edu.au
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<Annear_et_al-2015-Journal_of_the_American_Geriatrics_Society.pdf>
<Annear_et_al-2016-Journal_of_the_American_Geriatrics_Society (1).pdf>
<Dementia Knowledge Assessment Tool Version 2 For Dementia Oct 1.pdf>
<DKAS delphi.pdf>
<DKAT development.pdf>
<DKAT scoring.pdf>
<Fw DKAT2.pdf>

# Appendix F Diary Interview

## F.1 Participant Information Sheet

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### Participant Information Sheet (Diary-interview)

### نموذج معلومات المشارك (مذكرات/مقابلة)

| | |
|---|---|
| **Study Title**:<br>Nurses’ Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Methods Study | **عنوان البحث:**<br>مرئيات التمريض واحتياجات التعلم تجاه مرضى القصور الذهني (الخرف) في السعودية |
| **Researcher**:<br>Sara Mahmoud Yaghmour | **الباحث:**<br>سارة محمود يغمور |
| **ERGO number:** 29647 | رقم الموافقة: ٢٩٦٤٧ |

***Please read this information carefully before deciding whether or not to take part. If you are happy to participate you will be asked to sign a consent form.***

**أرجو قراءة التعليمات بعناية قبل أن تقرر الموافقة أو الرفض للمشاركة، في حال رغبتكم بالمشاركة سيُطلب منك توقيع الموافقة المستنيرة.**

| | |
|---|---|
| **What is the research about?**<br>This research is about the care provided to people with dementia in Saudi Arabian Hospital. In particular, it looks at nurse’s knowledge and learning needs in respect of caring for people with dementia in a general hospital. The research is sponsored by King Abdulaziz University and is being undertaken by Sara Yaghmour a mental health nursing lecturer at the university and Ph.D. student at University of Southampton. | **عن ماذا البحث؟**<br>البحث عن العناية المقدمة للأشخاص المصابين بالقصور الذهني (الخرف) في المستشفيات السعودية، تحديدًا استقصاء عن معلومات طاقم التمريض ومعرفة الاحتياج العلمي للعناية بالأشخاص المصابين بالديمنشيا (القصور الذهني/الخرف) في المستشفيات العامة.<br>البحث تحت اشراف جامعة الملك عبدالعزيز بجدة وتتولاه سارة محمود يغمور المحاضرة بجامعة الملك عبدالعزيز قسم تمريض الصحة النفسية والمبتعثة لدرجة الدكتوراة إلى جامعة ساوثهامبتون في بريطانيا. |
| **Why have I been asked to participate?**<br>Because you are a nurse who has indicated that you care for people with dementia and agreed to be contacted by the researcher about participating in this diary-interview phase of the research. Your participation will enrich the study with evidence and guidance for practice development in term of care for people with dementia. | **لماذا تم دعوتي للمشاركة؟**<br>لأنك ممرضـ/ـة أشرت بأنك تقدم/ي الرعاية لمرضى القصور الذهني وأبديت رغبتك في التواصل للمشاركة في الطور الثاني من البحث الذي يتضمن تدوين مذكرات ومقابلة شخصية.<br>ومشاركتكم بدورها ستُغني الدراسة وستساعد على تشكيل وتطوير مستقبل التمريض في السعودية من حيث العناية بمن لديهم حالة الديمنشيا. |
| **What will happen to me if I take part?**<br>If you decide to take part of this study you will be given the diary instruction sheet, you will be asked to sign two consent forms to show you agreed to take part. (1) For participating in writing/recording diary for ten working days. (2) Consent to participate in a recorded interview at your workplace.<br>You are expected to provide the researcher with written/audio diary that is entered for 10 working days when you are taking care for a person with dementia; this could be done at the end of your shift using the handout given to you to guide you with your entries. In addition to have an audio-recorded interview with the researcher prior your completion of your diary entries that will last for approximately one hour. | **ماذا سيحدث لي في حالة شاركت بالبحث؟**<br>في حال موافقتكم على المشاركة في هذه الدراسة سيتم تزويدكم بتعليمات تدوين مذكراتكم وكذلك سيتم منك توقيع موافقتين للمشاركة: (١) كتابة/تسجيل مذكراتكم لمدة ١٠ أيام. (٢) تسجيل صوتي لمقابلة شخصية معكم.<br>مُتوقع منك تزويد الباحثة بمذكراتكم المدونة كتابة أو تسجيل والذي يتم إدخاله لمدة ١٠ أيام عمل اعتنيت فيها بمريض الديمنشيا، وذلك بتدوينكم للمذكرات بآخر المناوبة (الدوام) مستخدمـ/ـة المذكرة المقدمة لكم كدليل مساعد على التدوين. بالإضافة إلى تسجيل صوتي لمقابلة معك بعد الإنتهاء |
| **Do I have to take part?**<br>No. You are also free to withdraw from taking part at any time, without giving a reason. | **هل يجب علي المشاركة؟**<br>لا، بإمكانك تجاهل هذه الدعوة إذا كنت ترغب في ذلك، وكذلك لك الحرية في الانسحاب من المشاركة في أي وقت دون إبداء سبب. |
| **Are there any benefits in my taking part?**<br>There is no direct benefit for taking part in the study. However, the information we get from the study will help to improve the treatment of people with dementia and understanding the care is provided to them. Beside you will get a certificate of appreciation for your contribution in this study from University of Southampton UK and King Abdulaziz University KSA. | **هل هناك أي فوائد من مشاركتي؟**<br>لا يوجد فائدة مباشرة لك عند المشاركة في البحث لكن إنّ المعلومات التي تقدمها/تقدميها لنا، سوف تساعد على تحسين تدريب الممرضين/الممرضات عند رعاية الأشخاص الذين يعانون من الدمنشيا (القصور الذهني/الخرف) وفهم الرعاية المقدمة لهذه الفئة.<br>بالإضافة أنك ستحصل/ي على شهادة تقدير موقعة من جامعة ساوثهامبتون في بريطانيا وجامعة الملك عبدالعزيز. |

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**Are there any risks involved?**
Some people might experience keeping a diary as an additional burden; guidance and support will be provided by the researcher.

**هل هناك أي مخاطر مُحتملة؟**
قد يجد المشارك عند تدوين المذكرات عبء إضافي؛ لذلك فالباحثة ستوفر الدعم والتوجيه الدائم وقت الحاجة.

**Will my participation be confidential?**
This project is committed to, and will abide by, the terms of the United Kingdom Data Protection Act. Diary-interview information and participants' data are confidential and will be stored in accordance with strict privacy protection procedures. Additionally, confidentiality will be ensured, that means that study results will not contain a personal identifying information. While all papers will be stored in a locked cabinet in a locked room and during analysing the data using computer will be kept in a password-protected files, and only others who are involved in the data analysis will be eligible to access the data. The research data will be retained for a period of 10 years in accordance with the data protection policy at the Faculty of Health Sciences, University of Southampton.

**هل ستكون مشاركتي سرية؟**
نعم بالطبع، حيث أن هذه الدراسة تلتزم بشروط قانون حماية البيانات في بريطانيا، فتكون معلومات الاستبيان وبيانات المشاركين سرية وسيتم تخزينها وفقًا لإجراءات حماية الخصوصية الصارمة، بالإضافة إلى ذلك سيتم عدم الكشف عن هويتك وهذا يعني أن نتائج الدراسة لن تحتوي على معلومات خاصة بهوية وشخص المشترك، في حين سيتم تخزين جميع الأوراق في خزانة مقفلة في غرفة مغلقة وأثناء تحليل البيانات باستخدام الكمبيوتر سيتم الاحتفاظ بالملفات، المحمية بكلمة مرور، حيث المشرفون والمشاركون في تحليل البيانات هم فقط من سيكون لهم الأحقية في الوصول إلى البيانات، كذلك سيتم الاحتفاظ ببيانات البحث لمدة عشر سنوات وفقًا لسياسة حماية البيانات في كلية العلوم الصحية بجامعة ساوثهامبتون في بريطانيا.

**What happens if I change my mind?**
You have the right to withdraw from the study at any time without giving a reason. All the information and data collected from you will be used but you name will be removed from all the study files.

**ماذا يحدث إذا غيرت رأيي؟**
لك كامل الحرية والحق في الانسحاب من الدراسة في أي وقت دون إبداء الأسباب، كافة المعلومات والبيانات التي تم جمعها منك سيتم استخدامها ولكن معلوماتك الشخصية واسمك ستُمحى من جميع ملفات الدراسة.

**What will happen to the results of the research?**
The study results will be written as a part of a Ph.D. thesis and will plan for its publication in international journals. In addition to use the information as a guidance for practice and policies development to care for people with dementia in Saudi Arabia.
If you would like to receive a copy of the results please provide your details at the end of your interview.

**ماذا سيحدث لنتائج البحث؟**
سيتم كتابة نتائج الدراسة كجزء من رسالة الدكتوراة والمُخطط نشرها في المجلّات المحكمة الدولية، بالإضافة إلى استخدام المعلومات كدليل لتطوير ممارسة التمريض ووضع السياسات لرعاية الأشخاص المصابين بالدمنشيا (القصور الذهني/ الخرف) في المملكة العربية السعودية.

في حال كنت ترغب في الحصول على نسخة من النتائج نرجو تزويدنا بأرقام ومعلومات؛ للتواصل معك في نهاية المقابلة الشخصية.

**Where can I get more information?**
If you need more information and/or questions related the study please contact my supervisor Dr. Ruth Bartlett at R.L.Bartlett@soton.ac.uk or Sara Mahmoud Yaghmour at smyaghmour1@kau.edu.sa or 0500858570.

**من أين أحصل على المزيد من المعلومات؟**
إذا كنت بحاجة إلى مزيد من المعلومات أو عندك أسئلة ذات صلة بالدراسة يرجى التواصل مع مشرفة الدراسة الدكتورة روث بارتليت على R.L.Bartlett@soton.ac.ukأو سارة محمود يغمور على smyaghmour1@kau.edu.sa أو 0500858570

**What happens if something goes wrong?**
In the unlikely case of concern or complaint regarding any aspect of your participation, or if you feel that you have been placed at risk, please contact the Research Integrity and Governance Manager (rgoinf@soton.ac.uk, 044(0)2380595058). You may also contact the Chair of the Ethics Committee at the Faculty of Health Sciences, telephone 0044(0)2380595578, University of Southampton, Southampton, United Kingdom, SO17 1BJ.

**ماذا يحدث إذا حدث خطأ ما؟**
إذا كان عندك أي قلق أو شكوى بخصوص مشاركتك في هذه الدراسة أو إذا كنت تشعر بأنك قد تعرضت للخطر، يرجى الاتصال بمدير إدارة النزاهة وإدارة الحوكمة
rgoinf@soton.ac.uk 00440238059058
يمكنك أيضا الاتصال برئيس لجنة الأخلاقيات في كلية العلوم الصحية، هاتف 00440238059557‎8، جامعة ساوثهامبتون، المملكة المتحدة SO17 1BJ .

**Thank you for your time**

**شكرًا لوقتكم**

## F.2 Diary Consent Form

UNIVERSITY OF Southampton

### CONSENT FORM

**Study title**: (DIARY) Nurses' Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Methods Study

**Researcher name**: Sara Mahmoud Yaghmour
**ERGO number**: 29647

**Please initial the box(es) if you agree with the statement(s):**

| | |
|---|---|
| I have read and understood the information sheet (19/January/2018 /version no. 2.0 of participant information sheet) and have had the opportunity to ask questions about the study. | |
| I understand that I may be quoted directly in reports of the research but that my name will not be used. | |
| I understand my responses will be anonymised in reports of the research. | |
| I agree to take part in this research project and agree for my data to be used for the purpose of this study. | |
| I understand my participation is voluntary and I may withdraw at any time for any reason without my rights being affected. | |
| I understand that diaries and 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 ethically approved research studies. | |
| I understand that I can request my details be deleted at any time. | |

Name of participant ………………………………………………………………………………

Signature of participant………………………………………………………………………………

Date………………………………………………………………………………………………………

Name of researcher ………………………………………………………………………………

Signature of researcher ……………………………………………………………………………..

Date………………………………………………………………………………………………………

## F.3 Certificate of Appreciation

# Certificate of Appreciation

Faculty of Nursing, King Abdulaziz University, Jeddah, KSA and Faculty of Health Sciences, University of Southampton, Southampton, UK are wish to thank

For Her/his valuable contribution in the research ‘Nurses’ Perceptions and Learning Needs toward People with Dementia in Saudi Arabia’ and for sharing her/his experience with the study researcher.

| | | |
|---|---|---|
| Sara Yaghmour | Dr. Ruth Bartlett | Dr. Sean Ewings |

King Abdulaziz University,
Jeddah Saudi Arabia

University of Southampton,
Southampton, United Kingdom

## F.4 Diary Instructions and Template

UNIVERSITY OF Southampton

King Abdulaziz University
كلية التمريض
Faculty of Nursing

**Nurses' Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Methods Study**
**By:**
**Dr. Ruth Bartlett, Dr. Sean Ewings**
**and PhD candidate Sara Yaghmour**
**This Diary belong to:**

**Name:**

**Ward:**

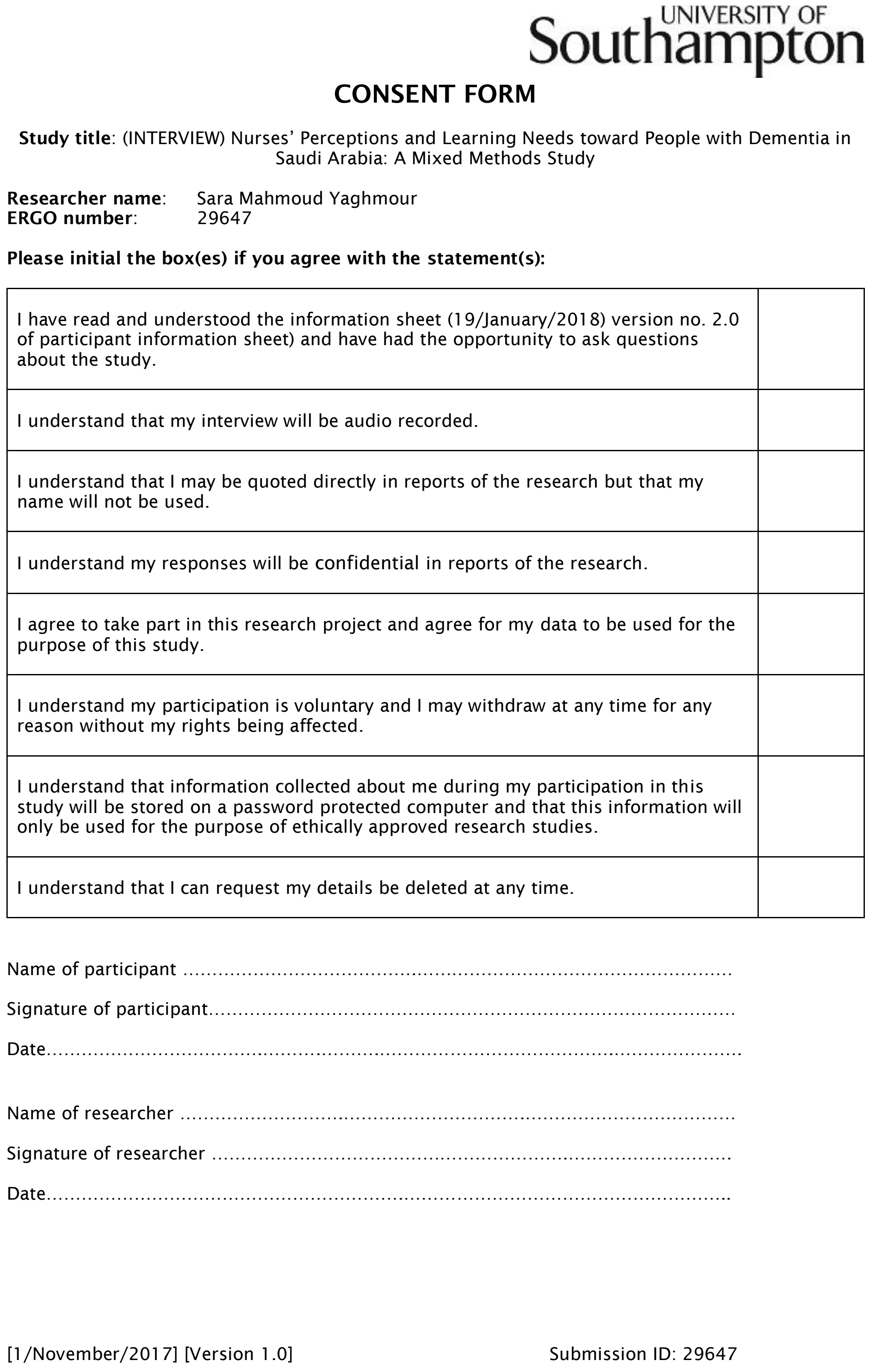
**Hospital:**

## Diary Entry Instruction تعليمات تدوين المذكرات

| | | |
|---|---|---|
| **Number of people with record diagnosis of dementia** | Here you state the number of people with dementia in your ward today (Alzheimer's disease, vascular dementia, Lewy bodies' dementia, Parkinson's disease, mild cognitive impairment, etc.).<br>هنا تكتبـ/ـي عدد الأشخاص المشخصين في قسمك اليوم بـ(الخرف، ديمنشيا، ألزهايمر، الخرف الوعائي، القصور الذهني، الرعاش،...إلخ) | **عدد الأشخاص المشخصين بالديمنشيا (حسب ملف المريض)** |
| **Number of patients with suspect dementia** | Here you state the number of people with suspected dementia in your ward today (Alzheimer's disease, vascular dementia, Lewy bodies' dementia, Parkinson's disease, mild cognitive impairment, etc.).<br>**هنا تكتبـ/ـي عدد الأشخاص المشتبه بتشخيصهم في قسمك اليوم بـ(الخرف، ديمنشيا، ألزهايمر، الخرف الوعائي، القصور الذهني، الرعاش،...إلخ)** | **عدد الأشخاص المشتبه بإصابتهم بالديمنشيا (حسب الأعراض وخبرتك)** |
| **How was your shift** | In general, how do you rate your shift while caring for a person with dementia or suspected dementia from 1 to 5 (1 in very bad and 5 is very good day).<br>**بصفة عامة، كيف كان دوامكم عند تقديم الرعاية للأشخاص المصابون أو المشتبه تشخيصهم بالديمنشيا، اختر/ي ١-٥ حيث ١ سيء جدًا و ٥ ممتاز جدًا** | **كيف كان دوامك** |
| **How confident you are today** | In general, how do you rate your confidence of your care provided to a person with dementia or suspected dementia (any kind of care or communication). **بصفة عامة، ماهو معدل ثقتك بالعناية والرعاية التي قدمتها/قدمتيها اليوم للمرضى (أي نوع من الرعاية، التواصل)** | **مدى ثقتك** |
| **Type of care** | State the care you provided to a person with dementia or suspected dementia today.<br>Any story to tell while providing that care?<br>**وضحـ/ـي الرعاية التي قدمتها اليوم للشخص المصاب بالدمنشيا أو المشتبه بتشخيصه. أي حكاية تود مشاركتها؟** | **نوع الرعاية المُقدمة** |
| **What influenced the care you provided? How?** | e.g. doctors, collogues, social workers, patient's family, friends, relatives... etc.<br>Please mention how your culture, knowledge, learning, experience influences the care you provided to a person with dementia or suspected dementia.<br>**مثال: الأطباء، الزملاء، الاخصائيين الاجتماعيين، أقارب المريض، الأصدقاء ... إلخ.**<br>**كذلك من فضلك، أذكر/ي مدى تأثير ثقافتك، عاداتك، تقاليدك، تعليمك وخبرتك على العناية والرعاية التي قدمتها اليوم؟ وكيف؟** | **ما العوامل التي تؤثر على العناية المُقدمة؟ وكيف؟** |
| **Feelings** | State your feelings in regard to: **وضحـ/ـي أحاسيسك تجاه:**<br>*Caring for a person with dementia* **رعاية بشخص مصاب الدمنشيا**<br>*Communication with a person with dementia* **التواصل مع شخص مصاب بالدمنشيا**<br>*Assisting in activity of daily livings* **المساعدة بالمهام اليومية لهم**<br>*Medication administration/ wound dressing* **إعطاء العلاج / تغيير الجروح**<br>*Providing nursing care (generally)* **تقديم الرعاية التمريضية بصفة عامة** | **أحاسيسك** |
| **Opinions** | Please state your beliefs toward people with dementia, the care you provided to them and the way you communicate with them. **وضحـ/ـي رأيك بخصوص مرضى الدمنشيا، العناية المُقدمة لهم، وطريقة التواصل معهم.** | **آراءك** |
| **Recommendations/ suggestions** | Mention any recommendations for your future implementation; such attending education program, reading more about particular issue etc. Changes you wish to see within your workplace, organisation and community. Suggestions to support people with dementia and to deliver a high-quality care.<br>**أي توصيات ترغبـ/ـي بتنفيذها مستقبلا؛ كحضور دورات تعليمية، قراءة المزيد عن المرض أو أعراضه، إلخ. التغييرات الترغبـ/ـي برؤيتها في دائرة عملك أو المنشأة أو مجتمعك. أي اقتراح لدعم ومساعدة الأشخاص المصابون بالدمنشيا لتقديم الرعاية بجودة عالية.** | **توصيات/ اقتراحات** |
| **Wisdom of the day, if applicable** | Indicate a lesson or wisdom you have learnt from the person of dementia and/or from your experience.<br>**حدد درسًا أو حكمة تعلمتها/تعلمتيها اليوم من مريض أو من خبرتكم** | **حكمة اليوم، إذا أمكن** |

| | |
|---|---|
| **Day # 1** | |
| **Number of people with record diagnosis of dementia** | |
| **Number of patients with suspect dementia** | |
| **How was your shift**<br>**Comments?** | Very bad 1 2 3 4 5 Very Good |
| **How confident you are today**<br>**Comments?** | Not confident 1 2 3 4 5 Very confident |
| **Type of care** | |
| **What influenced the care you provided? How?** | |
| **Feelings** | |
| **Opinions** | |
| **Recommendations/ suggestions** | |
| **Wisdom of the day, if applicable** | |

## F.5 Interview Consent form



UNIVERSITY OF Southampton

### CONSENT FORM

**Study title**: (INTERVIEW) Nurses' Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Methods Study

**Researcher name**: Sara Mahmoud Yaghmour
**ERGO number**: 29647

**Please initial the box(es) if you agree with the statement(s):**

| | |
|---|---|
| I have read and understood the information sheet (19/January/2018) version no. 2.0 of participant information sheet) and have had the opportunity to ask questions about the study. | |
| I understand that my interview will be audio recorded. | |
| I understand that I may be quoted directly in reports of the research but that my name will not be used. | |
| I understand my responses will be confidential in reports of the research. | |
| I agree to take part in this research project and agree for my data to be used for the purpose of this study. | |
| I understand my participation is voluntary and I may withdraw at any time for any reason without my rights being affected. | |
| 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 ethically approved research studies. | |
| I understand that I can request my details be deleted at any time. | |

Name of participant ..................................................................................................

Signature of participant..................................................................................................

Date..................................................................................................................

Name of researcher ..................................................................................................

Signature of researcher ..................................................................................................

Date..................................................................................................................

[1/November/2017] [Version 1.0] Submission ID: 29647

## F.6 Interview Schedule

### INTERVIEW SCHEDULE

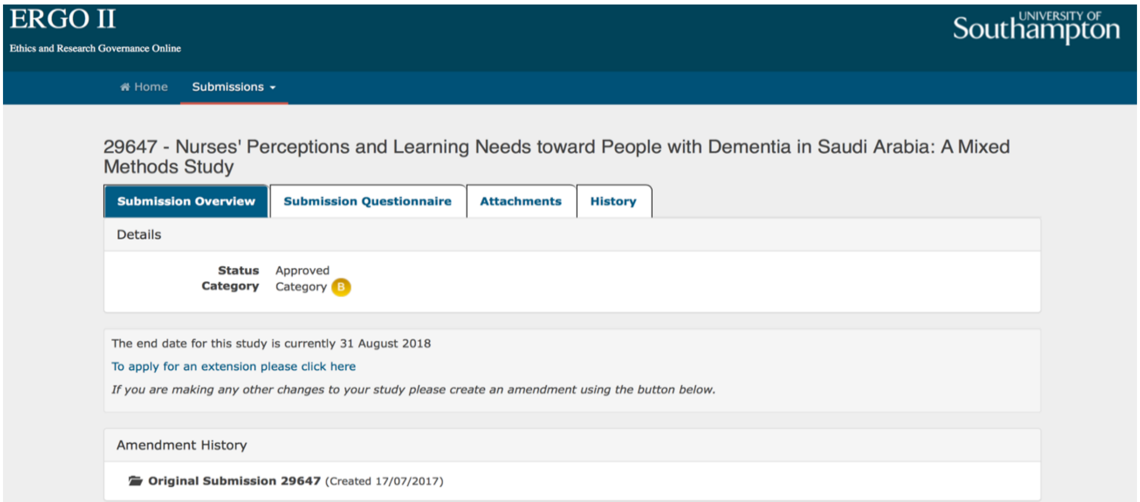
**Understanding nurses' perceptions and attitudes toward caring for people with dementia in Saudi Arabia: A Mixed Method Study**

| | | |
|---|---|---|
| ***Prior to interview*** | Sign informed consent / agreement to record / confidentiality of data and complete necessary forms | |
| ***The interview*** | | |
| **Before we start, I would like to remind you that there are no right or wrong answers in this discussion. I am interested in knowing what you think, so please feel free to be frank and to share your point of view. It is important that your opinion is heard.**<br>**At the beginning, I want to ask about keeping diary about your care provided to people with dementia** | | |
| **Theme** | **Sub-theme** | **Question** |
| **Background** | The survey and the diary | - How was the survey?<br>- How did you find keeping the diary? |
| **The first main area I would like to ask you about is your knowledge and experience about dementia** | | |
| **Theme** | **Sub-theme** | **Question** |
| **Knowledge** | Education | - Tell me about dementia?<br>- What training have you done about dementia?<br>(Before and after conducting the survey and during making your diary)<br>- From the survey I detected that your knowledge is … can you explain how do you enhance your knowledge in regard to dementia? |
| | Experience | - How your experience influences your care? (excerpt from their diaries)<br>- How frequent you care for people with dementia?<br>- How do you know that the person had dementia? examples? |
| | The routine | - How the routine in the word affect the care? |
| **Now I would like to ask more about the attitudes: feelings and opinions** | | |
| **Theme** | **Sub-theme** | **Question** |
| **Attitudes** | Feeling | - Can you recall your feeling while you care for people with dementia?<br>- How having your diary affect your feeling and practice?<br>- What made you feel that way? |
| | Opinion | - Describe a person with dementia life?<br>- How do you explain dementia to a person with dementia and to a carer? |
| **And now I would like to ask questions about your perceptions: belief, culture and judgment** | | |
| **Theme** | **Sub-theme** | **Question** |
| **Perception** | Believes | - What do you believe about caring for people with dementia?<br>- How this affect your care? |
| | Culture<br>Judgment | - What can alter the care provided for people with dementia?<br>- To what extent people with dementia can learn, communicate, behave…? |
| **I would like to discuss about the care provided to people with dementia and how they can handle it?** | | |
| **Theme** | **Sub-theme** | **Question** |
| **Attitudes and perception** | Care | - Activity of daily living, communication, medication, fall prevention, appointments and follow-up<br>- How you involve a person with dementia in their own care?<br>- What do you remember about nursing people with dementia?<br>What more you would like to learn/know? |
| **Now I would like to move to talk about the barriers of care from your point of view** | | |
| **Theme** | **Sub-theme** | **Question** |
| **Barriers** | Culture, attitudes, knowledge, perception | - What are the barriers to caring from your point of view? |
| **Finally, I would like to ask about your recommendations and suggestion to enhance the care that is provided to people with dementia** | | |
| **Theme** | **Sub-theme** | **Question** |
| **Recommendation** | Recommendations | - How to enhance the nursing care for people with dementia?<br>- What makes people with dementia experience positive?<br>- What change you want to see at your workplace |
| | Suggestions<br>Policies | - What do you suggest to make this change?<br>- What policies need to be developed? Give examples<br>- How |
| **Future implementation** | | - Any action you are going to take? What and why? |
| **Thank you for your contribution and your valuable time to talk to me!** | | |

# Appendix G Ethics

## G.1 University of Southampton

### G.1.1 ERGO2



29647 - Nurses' Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Methods Study

Details

**Status** Approved
**Category** Category B

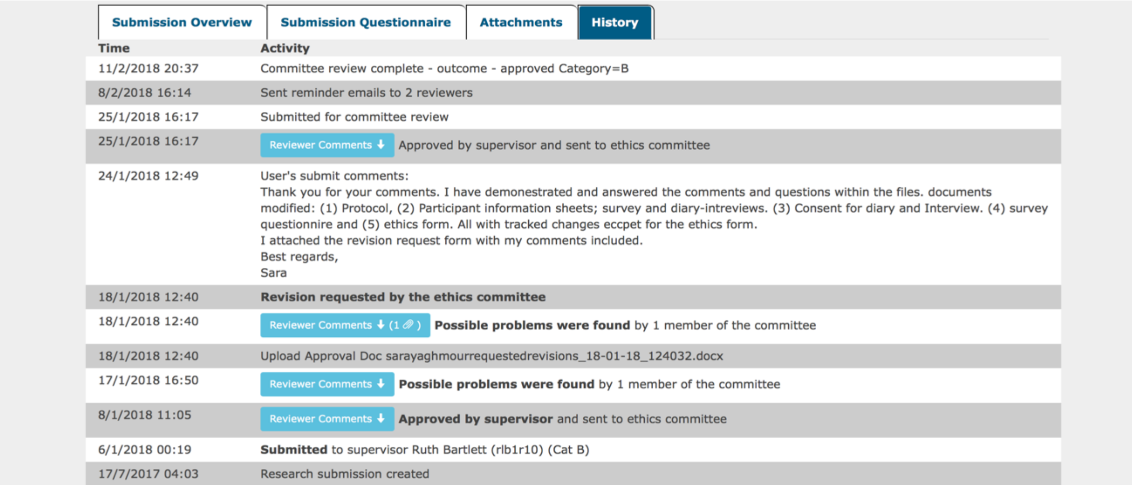
The end date for this study is currently 31 August 2018

To apply for an extension please click here

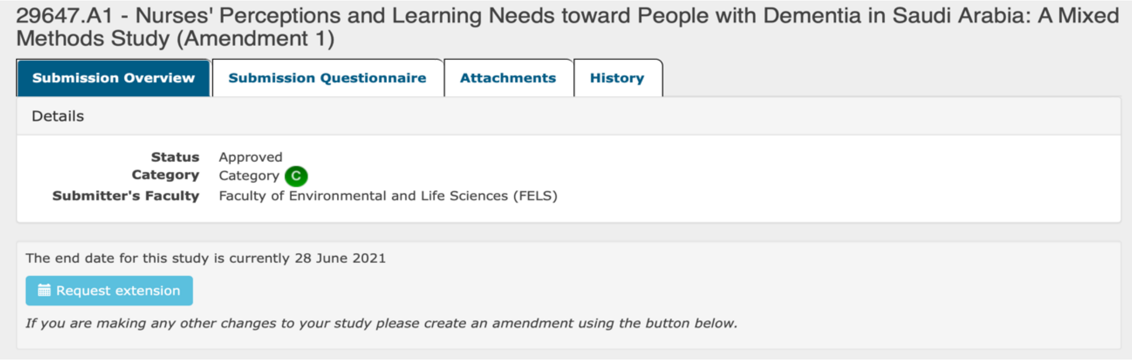
*If you are making any other changes to your study please create an amendment using the button below.*

Amendment History

**Original Submission 29647** (Created 17/07/2017)



| Time | Activity |
|---|---|
| 11/2/2018 20:37 | Committee review complete - outcome - approved Category=B |
| 8/2/2018 16:14 | Sent reminder emails to 2 reviewers |
| 25/1/2018 16:17 | Submitted for committee review |
| 25/1/2018 16:17 | Reviewer Comments ↓ Approved by supervisor and sent to ethics committee |
| 24/1/2018 12:49 | User's submit comments:<br>Thank you for your comments. I have demonestrated and answered the comments and questions within the files. documents modified: (1) Protocol, (2) Participant information sheets; survey and diary-intreviews. (3) Consent for diary and Interview. (4) survey questionnire and (5) ethics form. All with tracked changes eccpet for the ethics form.<br>I attached the revision request form with my comments included.<br>Best regards,<br>Sara |
| 18/1/2018 12:40 | **Revision requested by the ethics committee** |
| 18/1/2018 12:40 | Reviewer Comments ↓ (1 ) **Possible problems were found** by 1 member of the committee |
| 18/1/2018 12:40 | Upload Approval Doc sarayaghmourrequestedrevisions_18-01-18_124032.docx |
| 17/1/2018 16:50 | Reviewer Comments ↓ **Possible problems were found** by 1 member of the committee |
| 8/1/2018 11:05 | Reviewer Comments ↓ **Approved by supervisor** and sent to ethics committee |
| 6/1/2018 00:19 | **Submitted** to supervisor Ruth Bartlett (rlb1r10) (Cat B) |
| 17/7/2017 04:03 | Research submission created |



29647.A1 - Nurses' Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Methods Study (Amendment 1)

Details

**Status** Approved
**Category** Category C
**Submitter's Faculty** Faculty of Environmental and Life Sciences (FELS)

The end date for this study is currently 28 June 2021

*If you are making any other changes to your study please create an amendment using the button below.*

## G.1.2 Off-Site Risk Assessment

| | | | | | |
|---|---|---|---|---|---|
| **Title of off-site activity** | Data collection (Survey questionnaire and Diary-interviews) | | | **Proposed start date** | 05/March/2018 |
| **Type** **(research, teaching, etc)** | Research | | | **Proposed end date** | 05/June/2018 |
| **Brief description of off-site activity** | Collecting data for from registered nurses who are working in Jeddah, Saudi Arabia hospitals and primary health centres | | | | |
| **Number of trips** | 1 | **Duration of each trip** | 3 months | | |
| **Number of staff per trip** | 1 | **Number and type of non-staff per trip** **(UG, PGT, PGR, visitor)** | NA | | |
| **Location of off-site activity** | **Country** | Saudi Arabia | **Region / City / Town** | Jeddah, Hijaz region | |
| | **Address** **(if known)** | Jeddah, Saudi Arabia | | | |
| **Details of any other organisations involved** | Ministry of Health, Saudi Arabia | | | | |
| **Describe their involvement** | Collecting the data from their organisations | | | | |

| | | | | | |
|---|---|---|---|---|---|
| **Person directing work** **(Leader, Manager, etc)** | Sara Yaghmour | | **Position** | PhD Student | |
| **Person conducting assessment** | Dr. Ruth Bartlett / Dr. Sean Ewings | | **Position** | Supervisors | |
| **Academic unit / Team** | | **Faculty / Service** | | **Date of assessment** | |

| | | | |
|---|---|---|---|
| **Modes of travel to and during activity** (air, sea, rail, road, waterway, etc) | Air | **Types of travel** (car, 4x4, light aircraft, dinghy, etc) | Aircraft |
| **Commercial carrier or private hire?** | Via Saudi Arabian Airlines | **If commercial carrier, how will they be selected?** | - |
| **If private hire, who will be driving / in control?** | - | **How frequently and at what stage of the activity will these be used?** | - |

| Travel hazards | Yes/No/NA | Control measures |
|---|---|---|
| **Navigation in remote areas** | No | |
| **Unsafe or insecure regions** | No | |
| **Off road or poor road conditions** | Yes | A private family driver |
| **Lack of training in use of vehicle or equipment** | NA | |
| **Lone Travel** | NA | |
| **Other (specify)** | NA | |

| Type of accommodation | Details | When to be used | Reliable information on suitability of accommodation |
|---|---|---|---|
| **Private** | Own home<br>Almuhammadia 5 Dis., Jeddah, KSA | All the time | |
| **Hotel/Motel** | - | - | - |
| **Camping** | - | - | - |
| **Other** | - | - | - |

| Accommodation hazards | Yes/No/NA | Control measures |
|---|---|---|
| **Security** | No | |
| **Fire** | No | |
| **Food / water quality** | No | |
| **Other (specify)** | - | |

| For destinations outside the UK | Yes/No/NA | Details and control measures |
|---|---|---|
| **Foreign & Commonwealth Office (FCO) country advice checked?**<br>**Identify suitable controls** | NA | |
| **Does the FCO advise against travel to this country or regions within it?**<br>**If Yes, then detail senior manager approval** | - | |
| **Could the activity cause offence to or upset the local populace?**<br>**If Yes, then describe measures to mitigate** | No | |
| **Vaccinations required for this country or region?**<br>**If Yes, detail and confirm carried out** | No | |
| **Malaria prophylaxis required?**<br>**If Yes, confirm drugs have been obtained** | No | |
| **Significant security or accident risks with this country or region, eg, kidnap, poor roads, lack of emergency services, etc?**<br>**If Yes, identify suitable controls** | NA | |
| **Are personnel able to speak the local language?**<br>**If No, describe how will they communicate** | Yes | |

| Terrain (all destinations) | Yes/No/NA | Details and control measures |
|---|---|---|
| **Areas of high relief, altitude, mountains and cliffs** | No | |
| **Agricultural land** | No | |
| **Railways, motorways and roads** | No | |
| **Woods and forests** | No | |
| **Coastlines, estuaries, mudflats and salt marshes** | Yes | |
| **Tropical or hot climates** | Yes | |
| **Deserts, uplands and arid zones** | No | |
| **Cold climates** | No | |
| **Other (specify)** | - | |

| Other factors (all destinations) | Yes/No/NA | Details and control measures |
|---|---|---|
| **Will anyone be climbing, caving or diving?**<br>**If Yes, identify suitable controls** | No | |
| **Will there be unlimited supply of safe drinking water?**<br>**If No, describe how safe drinking water will be obtained?** | Yes | |
| **Where will food be sourced?**<br>**Describe how food will be prepared and outline any restrictions on what can be eaten** | Yes | |
| **Is vector-borne or parasitic disease a hazard in the country or region?**<br>**If Yes, identify suitable controls** | No | |
| **Are there adequate hygiene facilities?**<br>**If No, describe how this will be mitigated** | Yes | |
| **Will the group split up at any stage?**<br>**If Yes, identify suitable controls** | No | |
| **How will communications be maintained in the field, back to base, and back to the University?** | | Emails, Skype |

| Activity hazards | Yes/No/NA | Details and control measures |
|---|---|---|
| **Hazardous chemicals**<br>If Yes, then a further chemical (COSHH) risk assessment is required | No | |
| **Biological agents, human blood, body fluids, clinical samples, or GM**<br>If Yes, then a biological risk assessment is required, and possible HBV immunisation | No | |
| **Wild or domestic animals, or materials from these**<br>If Yes, consider zoonosis and injury risks | No | |
| **Sources of ionising radiation**<br>If yes, then contact University RPO or authorisation and assistance | No | |
| **Hazardous equipment**<br>If Yes, identify suitable controls | No | |
| **Lone working**<br>If Yes, identify suitable controls | No | |
| **Work in areas more than 24 hours travel from medical assistance**<br>If Yes, identify suitable controls | No | |
| **Work requiring a high standard of physical fitness**<br>If Yes, identify measures to address this | No | |
| **Chemical, biological, clinical, plant or food samples**<br>If Yes, consider transport of dangerous goods requirements and import permissions | No | |
| **Other (specify)** | - | |

| Emergency Provision | Details and control measures |
|---|---|
| **First aid kits and similar equipment** | Available on the data-collection site (hospitals) |
| **First aiders** | Sara Yaghmour |
| **Getting suitable help in an emergency** | Call the charged nurse on-site |
| **Evacuation arrangements** | Activate the code for evacuation through calling the security at 997 and follow the signs to assembly points |

**NB Report all incidents via the University incident report online form on the SOH website**

| Training | Details and control measures |
|---|---|
| **Personnel First Aid** | The researcher is holding Basic Life Support provider certificate |
| **Fieldwork First Aid** | Available |
| **Off-site activity safety management** | Available |
| **Off-road driving** | NA |

| **Inherent overall risk (ie, with no controls) using University Health & Safety risk matrix (mark with x)** | **High** | **Medium** | **Low** |
|---|---|---|---|
| | | | **X** |

| **Residual overall risk (ie, with all of the above controls applied) using University Health & Safety risk matrix (mark with x)** | **High** | **Medium** | **Low** |
|---|---|---|---|
| | | | **X** |

**Personnel conducting the fieldwork**

| Family name | Initials | Position | Email | Telephone (work) | Telephone (off-site activity) |
|---|---|---|---|---|---|
| Sara Yaghmour | SMY | Researcher | s.m.yaghmour@soton.ac.uk | 07767863352 | 00966500858570 |
| | | | | | |
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| | | | | | |

| **Declaration by person directing work (Leader, Manager, etc)**<br>I confirm that this is a suitable & sufficient risk assessment for the above off-site working. | | | | | |
|---|---|---|---|---|---|
| **Signed** | | **Print name** | Sara Yaghmour | **Date** | 21/12/2017 |

| | |
|---|---|
| **Approval for off-site working should be obtained from the senior manager in the Faculty/Service identified as responsible for such approvals.** | |

| | |
|---|---|
| **The Dean/Director must also give approval to any off-site working that involves work in a country or region to which the FCO advises no travel or essential travel only; or any unsupervised undergraduate off-site working; or any work excluded from cover by the University Insurance Office** | |

## G.2 Ministry of Health

### G.2.1 NIH Certificate

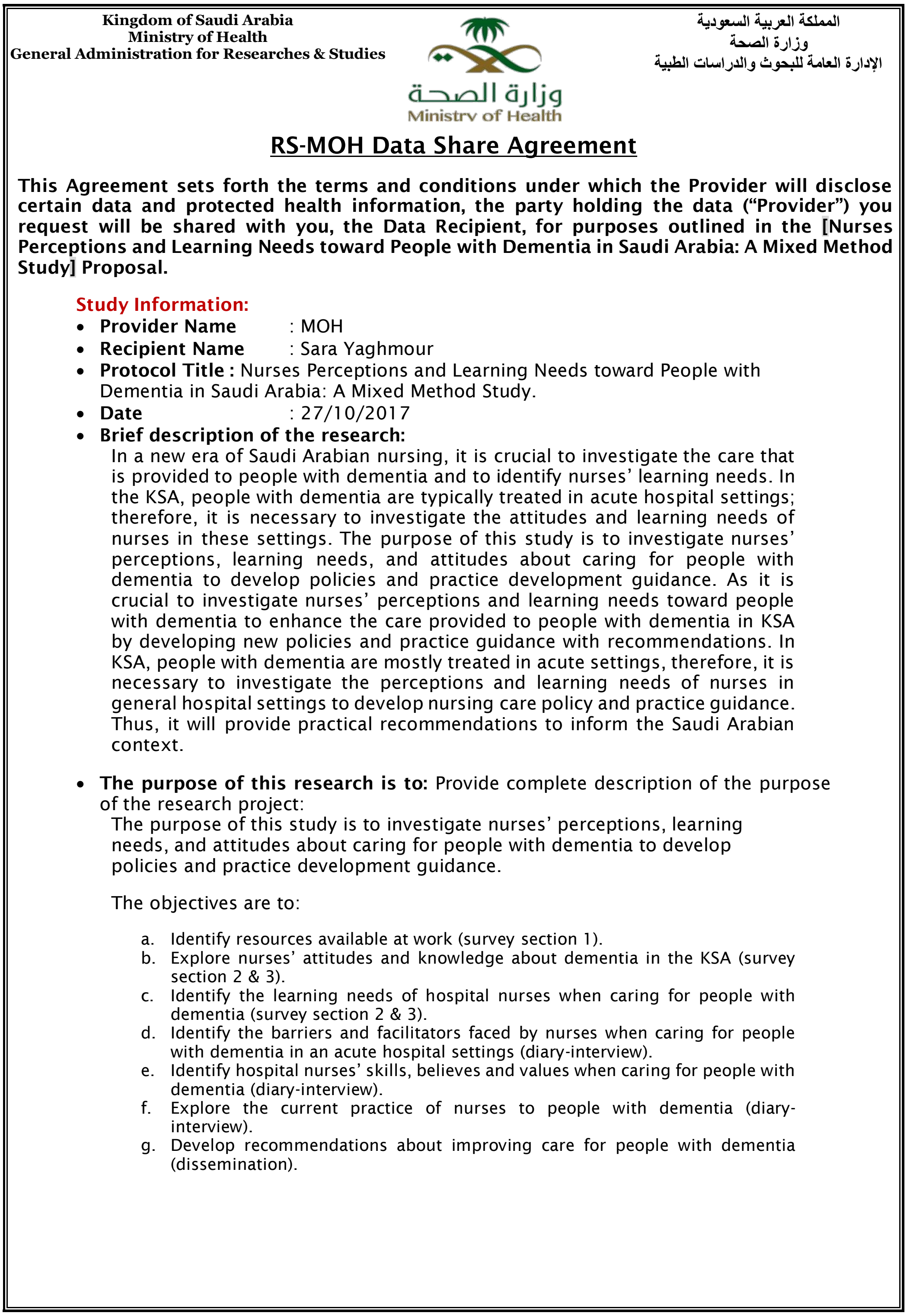
**Certificate of Completion**

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Sara Yaghmour** successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 07/01/2017.

Certification Number: 2384986.

## G.2.2 Data Sharing Agreement



Kingdom of Saudi Arabia
Ministry of Health
General Administration for Researches & Studies

المملكة العربية السعودية
وزارة الصحة
الإدارة العامة للبحوث والدراسات الطبية

### RS-MOH Data Share Agreement

**This Agreement sets forth the terms and conditions under which the Provider will disclose certain data and protected health information, the party holding the data ("Provider") you request will be shared with you, the Data Recipient, for purposes outlined in the [Nurses Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Method Study] Proposal.**

**Study Information:**

- **Provider Name** : MOH
- **Recipient Name** : Sara Yaghmour
- **Protocol Title :** Nurses Perceptions and Learning Needs toward People with Dementia in Saudi Arabia: A Mixed Method Study.
- **Date** : 27/10/2017
- **Brief description of the research:**
  In a new era of Saudi Arabian nursing, it is crucial to investigate the care that is provided to people with dementia and to identify nurses' learning needs. In the KSA, people with dementia are typically treated in acute hospital settings; therefore, it is necessary to investigate the attitudes and learning needs of nurses in these settings. The purpose of this study is to investigate nurses' perceptions, learning needs, and attitudes about caring for people with dementia to develop policies and practice development guidance. As it is crucial to investigate nurses' perceptions and learning needs toward people with dementia to enhance the care provided to people with dementia in KSA by developing new policies and practice guidance with recommendations. In KSA, people with dementia are mostly treated in acute settings, therefore, it is necessary to investigate the perceptions and learning needs of nurses in general hospital settings to develop nursing care policy and practice guidance. Thus, it will provide practical recommendations to inform the Saudi Arabian context.

- **The purpose of this research is to:** Provide complete description of the purpose of the research project:
  The purpose of this study is to investigate nurses' perceptions, learning needs, and attitudes about caring for people with dementia to develop policies and practice development guidance.

  The objectives are to:

  a. Identify resources available at work (survey section 1).
  b. Explore nurses' attitudes and knowledge about dementia in the KSA (survey section 2 & 3).
  c. Identify the learning needs of hospital nurses when caring for people with dementia (survey section 2 & 3).
  d. Identify the barriers and facilitators faced by nurses when caring for people with dementia in an acute hospital settings (diary-interview).
  e. Identify hospital nurses' skills, believes and values when caring for people with dementia (diary-interview).
  f. Explore the current practice of nurses to people with dementia (diary-interview).
  g. Develop recommendations about improving care for people with dementia (dissemination).

**Kingdom of Saudi Arabia**
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**General Administration for Researches & Studies**

**المملكة العربية السعودية**
**وزارة الصحة**
**الإدارة العامة للبحوث والدراسات الطبية**

- **Recipient agree to limit access to the information to the following individuals or classes of individuals:**
  Faculty of Health Sciences, University of Southampton

**Conditions and Stipulations:**

Recipient further agrees to the following conditions and stipulations:

1. The information will not be used or further disclosed other than as permitted by this agreement or as otherwise required by law.
2. Appropriate safeguards will be implemented as described above to prevent use or disclosure of information other than as provided for by this agreement.
3. Information set will not be re-identified.
4. Individuals whose information is contained in the information will not be contacted.
5. You will use the information only for the research purposes described above.
6. Recipient-investigator agrees to take the appropriate safeguards to prevent unauthorized use or disclosure of the information.
7. Upon learning of any use or disclosure of information not provided for by this agreement, such unauthorized use or disclosure will be reported to the holder within 15 days of becoming aware of such use a disclosure.
8. Any individuals or organizations, including subcontractors, to whom the information is provided, must first agree to the same restrictions and conditions set forth in this agreement.
9. The parties agree that they will not use or further disclose protected health information (PHI) other than as permitted by this agreement and the IRB or as otherwise required by law.
10. Recipient and Provider understand and agree that individuals who are the subject of PHI are not intended to be third party beneficiaries of this agreement.
11. Each party agrees that it will be responsible for its own acts and the results thereof to the extent authorized by law and shall not be responsible for the acts of the other party or the results thereof.

**Term and Termination:**

1. The term of this agreement shall be effective as of [1/1/2018], and shall remain in effect until the research proposed is completed, after which you agree to destroy or return safely and promptly to Provider all information.
2. Upon the Provider's knowledge of a material breach of this agreement by the Data Recipient, the Provider shall provide an opportunity for Data Recipient to cure the breach or end the violation. If efforts to cure the breach or end the violation are not successful within the 15 days period specified by the Provider, the Provider shall discontinue disclosure of PHI to the Data Recipient.
3. This agreement shall not be amended, altered, or changed except by written documentation agreed to and executed by both parties.

**Ownership of Data:**

All data shall remain exclusively owned by the disclosing party and its use by other parties shall be governed by the following:

1. Information may be disclosed to study sites provided solely as necessary to perform obligations in connection with the research project for which such data are provided under this agreement. Such uses and disclosures shall also be in compliance with applicable laws and regulations, protocols, consent forms, if any, IRB approvals.

2. No party shall use the names, logos, symbols or trademarks of another party or the other party's affiliates or related entities, without the express written permission of the other party, except that parties may identify each other in annual reports and like documents that generally describe or refer to the research project.

3. The Provider retains any and all tangible and intangible rights to the information.

4. The Products created by the Data Recipient shall be owned by the Data Recipient. Products jointly created by both the Data Recipient and the Holder shall be jointly owned.

5. The Data Recipient agrees not to use or disclose the Data Set for any purpose or secondary use other than the reporting purposes outlined above or as required by law.

**Kingdom of Saudi Arabia**
**Ministry of Health**
**General Administration for Researches & Studies**

المملكة العربية السعودية
وزارة الصحة
الإدارة العامة للبحوث والدراسات الطبية

6. The Data Recipient agrees to report to the Provider any use or disclosure of the Data Set not provided for by this agreement, of which it becomes aware, including without limitation, any disclosure of PHI to an unauthorized subcontractor, within ten (10) business days of its discovery.
7. The Data Recipient agrees not to identify the information contained in the Data Set, contact the individual, or publish or disclose publically any PHI.

## Security

The Data Recipient agrees to use appropriate administrative, physical, and technical safeguards to prevent use or disclosure of the Data Set other than as provided for by this agreement.

- All data will be stored in secure storage areas or on digital media that has been password protected, encrypted, or otherwise secured for storage and transfer.]

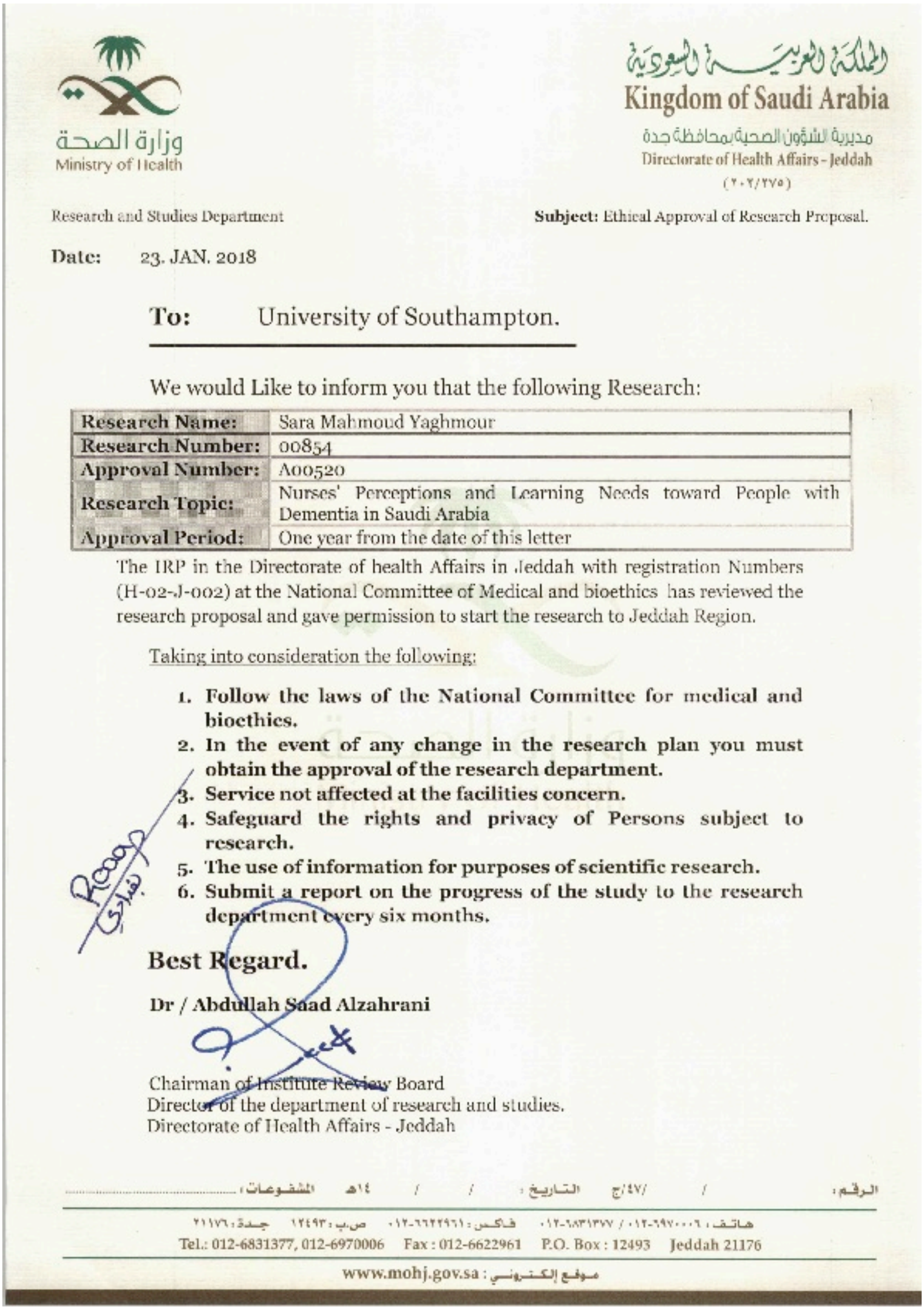
## Publications and Presentations

Organizations will work collaboratively to agree on the plan for analyses and drafting of reports and publications. The authorship and the dissemination of such documents will reflect the collaborative nature of the project between the two organizations, with authorship and acknowledgements following conventions of academic publication. Both the Provider and the Data Recipient will review and approve all information intended for public dissemination of any format prior to the dissemination of the information.

**The parties signing below agree to the conditions enumerated above.**

| | |
|---|---|
| **Authorized representative of the Provider or the facility releasing the data set:**<br>............................................................<br>Signature of authorized representative of the provider or the facility releasing the data set<br>Provider Name: Ministry of Health<br>Provider Institution:<br>Research and Studies Directorate (RS-MoH)<br>Address: Al Riyadh<br>Phone:011 4735038<br>e-mail: research@moh.gov.sa<br>Fax: 011 4735039 | Date |
| **Recipient of the limited data set:**<br>Signature of Recipient:<br>Name of authorized representative:<br>Sara Mahmoud Yaghmour<br>Title of authorized representative Recipient:<br>Ph.D. Candidate<br>Name of facility: Faculty of Health science<br>Address: University of Southampton, UK<br>Phone: +966-500858570<br>e-mail: smyaghmour1@kau.edu.sa | 27/Oct/2017<br>Date |

### G.2.3 Approval Letter



وزارة الصحة
Ministry of Health

المملكة العربية السعودية
Kingdom of Saudi Arabia
مديرية الشؤون الصحية بمحافظة جدة
Directorate of Health Affairs - Jeddah
(٢٠٢/٢٧٥)

Research and Studies Department

**Subject:** Ethical Approval of Research Proposal.

**Date:** 23. JAN. 2018

**To:** University of Southampton.

We would Like to inform you that the following Research:

| | |
|---|---|
| **Research Name:** | Sara Mahmoud Yaghmour |
| **Research Number:** | 00854 |
| **Approval Number:** | A00520 |
| **Research Topic:** | Nurses' Perceptions and Learning Needs toward People with Dementia in Saudi Arabia |
| **Approval Period:** | One year from the date of this letter |

The IRP in the Directorate of health Affairs in Jeddah with registration Numbers (H-02-J-002) at the National Committee of Medical and bioethics has reviewed the research proposal and gave permission to start the research to Jeddah Region.

Taking into consideration the following:

1. **Follow the laws of the National Committee for medical and bioethics.**
2. **In the event of any change in the research plan you must obtain the approval of the research department.**
3. **Service not affected at the facilities concern.**
4. **Safeguard the rights and privacy of Persons subject to research.**
5. **The use of information for purposes of scientific research.**
6. **Submit a report on the progress of the study to the research department every six months.**

**Best Regard.**

**Dr / Abdullah Saad Alzahrani**

Chairman of Institute Review Board
Director of the department of research and studies.
Directorate of Health Affairs - Jeddah

الرقم: / /٤٧/ج التاريخ: / / ١٤هـ المشفوعات: ..............................

# Appendix H Data Management

## H.1 Data management plan

UNIVERSITY OF
Southampton

# Explanatory Notes

**About your Research**

| | |
|---|---|
| **PhD title:** | Nurses’ Knowledge of, and Attitudes and Perceptions towards People with Dementia: A Mixed Method Study Saudi Arabia |
| **Student name:** | Yaghmour, Sara Mahmoud M. |
| **Supervis or(s):** | Prof Ruth Bartlett<br>Dr Sean Ewings |
| **Ethics No. (if appropriate)** | 29647 |

**About this plan**

| | | | |
|---|---|---|---|
| **Date of plan:** | 12/06/2021 | Frequency of reviews | 12m / **6m** / 3m |
| **Date of next review:** | 12/12/2021 | | |
| **Agreed actions to help you implement the plan** | *Have NVivo software and get to know the application.* | | |
| **Agreed equipment and/or resources required:** | *-N/A* | | |
| **Further information (as appropriate):** | Data is for both university of Southampton and Ministry of Health (MOH), Saudi Arabia. Any use after this study, further approval must be made by MOH. | | |

**Version Table**

| Version | Changes made | Date |
|---|---|---|
| 1 | Creating the plan using this template | 12/03/2019 |
| 2 | Updating the plan using this template | 12/12/2020 |
| 3 | Plan reviewed with no changes done | 12/06/2021 |
| | | |

## 1. Project Description:

This study adopted an embedded sequential mixed method design to achieve its aim. The first part had involved a survey and the second part diary-interviews. This design provided an understanding of nurses' attitudes towards people with dementia by incorporating some of the participants' perspectives. Hence, the study involves both quantitative and qualitative data; quantitative from the survey-questionnaire, and qualitative from the written diaries and interviews.

Data were managed, stored and analysed using two Computer Assisted Software Packages, SPSS and NVivo. SPSS version 25 has been used to enter all participants' data of the survey's first section and obtain scores for Dementia Attitude Scale and Dementia Knowledge Assessment Tool version 2. Additionally, NVivo version 12 have been used to store qualitative data collected from the diaries-interviews. While a thematic analysis and coding within NVivo analytical software were applied. Both quantitative and qualitative data were stored in the NVivo within a password protected document.

## 2. What policies will apply to your research?

This project is committed to, and abided by, the terms of the United Kingdom Data Protection Act. Survey information and participants' data are confidential and were stored in accordance with strict privacy protection procedures. Additionally, anonymity has been insured, that means that study results did not contain a personal identifying information. While all papers were stored in a locked cabinet in a locked room and during analysing the data using computer were kept in a password-protected files, and only others who are involved in the data analysis were eligible to access the data. The research data will be retained for a period of 10 years in accordance with the data protection policy at the Faculty of Health Sciences, University of Southampton.

Data will be shared with Research Department of MOH, Jeddah health directorate. From MOH agreement, we will need to get permission from the MOH about what we are publishing. This would include any research data that could be shared, in addition to the thesis and any articles I publish. If permission is not given, then I have a valid reason for not sharing.

## 3. What data/research material will you collect or create?

Data were collected in two attempts: (1) a convenient sampling method with N=710 registered nurses who are working in Ministry of Health facilities in the Hijaz region, Kingdom of Saudi Arabia (KSA) who were surveyed using a survey questionnaire that have three sections and has been collected in print. Its data were entered to SPSS v.25. software then all printed surveys were destroyed and participants' consents forms were scanned and then destroyed after uploading them in NVivo. (2) Using a purposive sampling strategy to choose deliberate sample of nurses to participate in structured solicited diaries and semi-structured interviews. The proposed and expected number of nurses who agreed to participate in the diary and interview stage was twenty-five nurses, however, n=17 had completed the diary-interviews in addition to one participant had completed only interview without having diary entries. This qualitative part involves having written/recorded data, which all been entered and saved within the NVIVO software.

Data have been stored in the format detailed in the below Table 1. During the study, the data were backed-up, managed and curated using a password-protected hard-drive with 2 Terabytes. Then it has been stored in a locked cabinet in locked office.

Data were stored in the format detailed in the below. During the study, the data were backed-up, managed and curated using a password-protected hard-drive with 2 Terabytes. Then it were stored in a locked cabinet in locked office.

| Type of data | | Sharing format |
|---|---|---|
| **Quantitative survey-questionnaire data with extensive metadata** | A data set with variable labels, code labels, and defined missing values, in addition to the matrix of data | proprietary formats of statistical packages<br>SPSS (.por), |
| **Qualitative diary-interview Data** | Textual<br>Transcripts and translated diaries and interviews | NVivo (nvp/ nvpx)<br>MS Word (.doc/.docx)<br>PDF/A or PDF (.pdf) |
| | Audio diary-interviews | NVivo (nvp/ nvpx)<br>MPEG-1 Audio Layer 3 (.mp3)<br>Waveform Audio Format (.wav) |

Table 1 Data storing format

### 4. How will your data/research material be documented and described?

| | File naming | Code |
|---|---|---|
| **Pilot study** | Participant number_ Pilot study_ Survey or Diary | 00_PIL_SUR<br>00_PIL_DIA |
| **Survey questionnaire** | Participant number_ Survey_ hospital_ ward or primary health centre | 000_SUR_HOS_WARD<br>000_SUR_PHC_WARD |
| **Diary** | Participant number_ Survey_ Diary_ consent, audio/scan, transcript | 000_SUR_DIA_CON,<br>000_SUR_DIA_AUD,<br>000_SUR_DIA_SCA,<br>000_SUR_DIA_TRA |
| **Interviews** | Participant number_ Survey_ Interview_ consent, audio/scan, transcript | 000_SUR_INT_CON,<br>000_SUR_INT_AUD,<br>000_SUR_INT_SCA,<br>000_SUR_INT_TRA |
| **Versions** | All dcuments and files will be stored with version ID | File_Name_ YYYY_MM_DD |

Table 2 File naming codes

### 5. How will you deal with any ethical and copyright issues?

I will share my data with my research group/supervisor using a shared folder Due to the sensitive nature of my data I encrypting my data and sending via Dropoff (dropoff.soton.ac.uk) to my collaborators. Also, my data will be pseudo-anonymised prior to sharing, with files encrypted.

**6. How will your data/research materials be stored, and backed up?**

The NVivo file is about 510MB of data, so over the course of my PhD I expect this to add up to about 5GB.

My primary copy of my bibliography is on my laptop. I make weekly back-ups of it to my University filestore H: drive every Friday afternoon

**7. What are your plans for the long-term preservation of data/research materials supporting your research?**

I am responsible for archiving data, and the archive service will maintain it for a minimum of 10 years as per the University RDM Policy.

All data, both raw and processed wil be retained. Spreadsheets will be saved as csv files.

Only simulation code and input parameters will be kept.

Transcripts of all interviews, but not recordings. Personal data and anonymisation key will need to be destroyed securely at the end of the project.

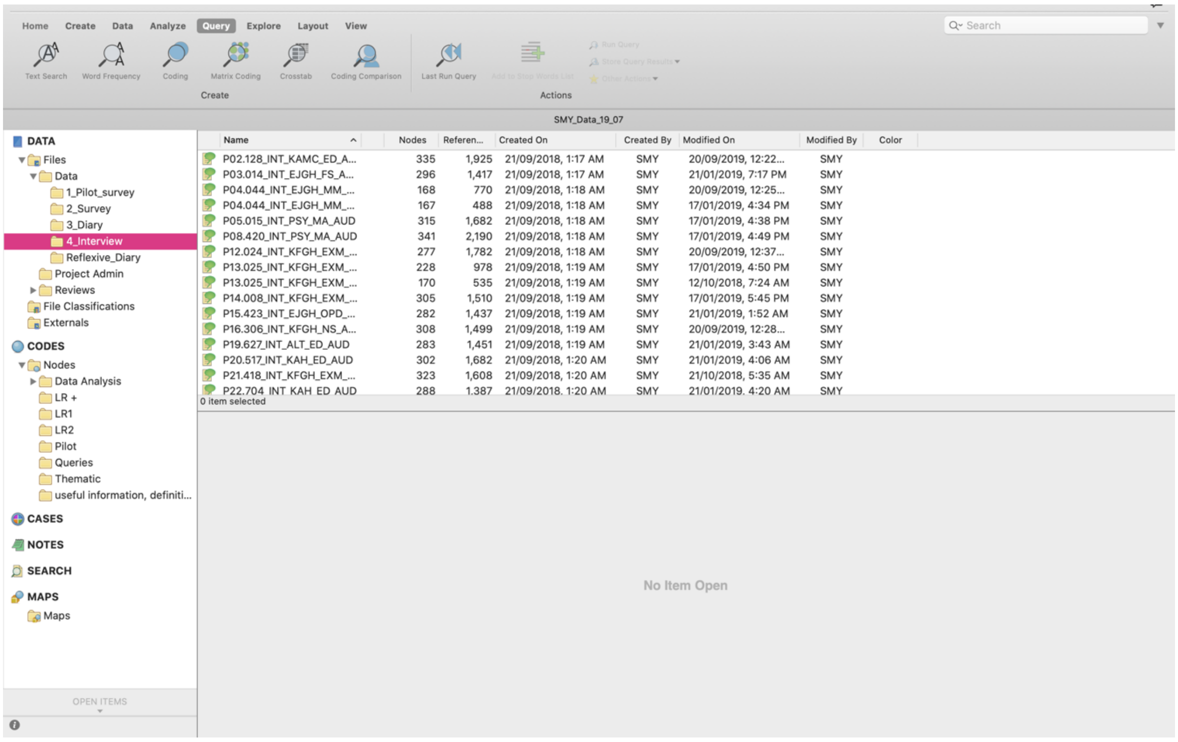
**8. What are your plans for sharing the data/research materials after the submission of your thesis?**

There will be no any digital data supporting the thesis.

Ministry of Health, Saudi Arabia consider a funding body that requires their permission to re-use of, or open-access to, the data.

All my data (within NVivo) will be made available on the institutional repository, accompanied by a readme file describing the data and the data linked back to the relevant part of my thesis. The data will only be made available after a three year embargo period as I plan to publish further articles from my thesis.

## H.2 Screenshot of the NVivo file



| Name | Nodes | Referen... | Created On | Created By | Modified On | Modified By | Color |
|---|---|---|---|---|---|---|---|
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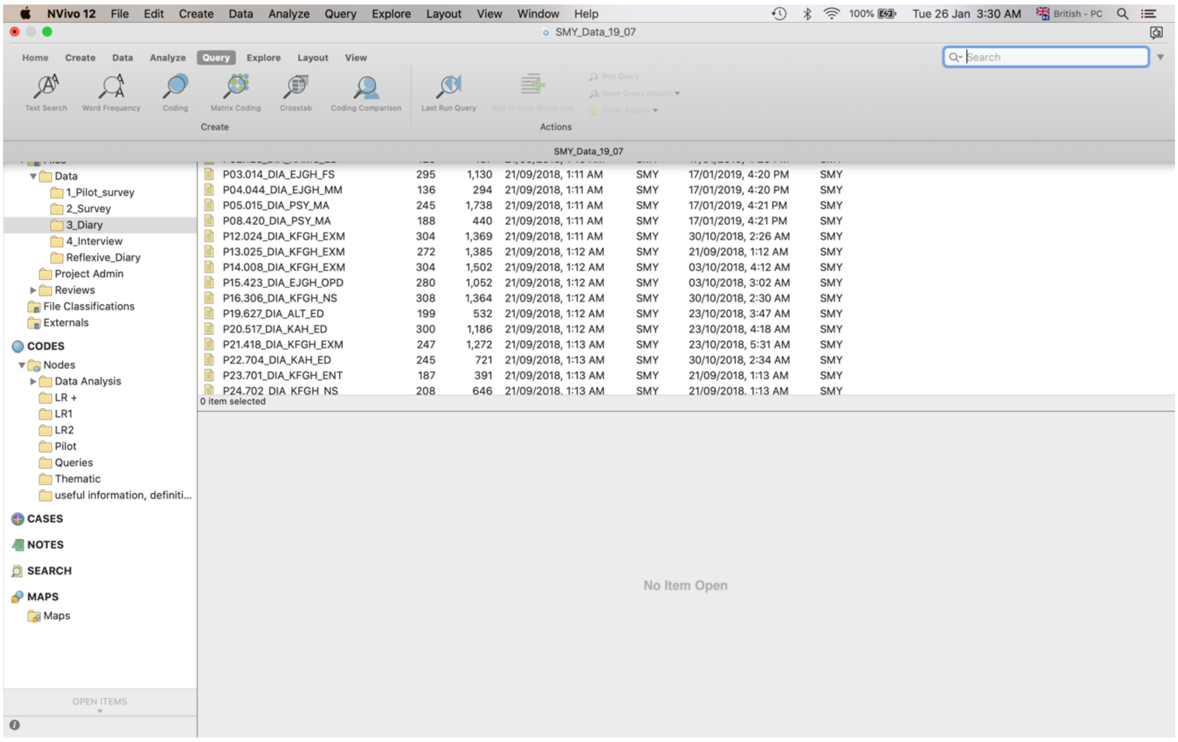
| P03.014_INT_EJGH_FS_A... | 296 | 1,417 | 21/09/2018, 1:17 AM | SMY | 21/01/2019, 7:17 PM | SMY | |
| P04.044_INT_EJGH_MM_... | 168 | 770 | 21/09/2018, 1:18 AM | SMY | 20/09/2019, 12:25... | SMY | |
| P04.044_INT_EJGH_MM_... | 167 | 488 | 21/09/2018, 1:18 AM | SMY | 17/01/2019, 4:34 PM | SMY | |
| P05.015_INT_PSY_MA_AUD | 315 | 1,682 | 21/09/2018, 1:18 AM | SMY | 17/01/2019, 4:38 PM | SMY | |
| P08.420_INT_PSY_MA_AUD | 341 | 2,190 | 21/09/2018, 1:18 AM | SMY | 17/01/2019, 4:49 PM | SMY | |
| P12.024_INT_KFGH_EXM_... | 277 | 1,782 | 21/09/2018, 1:18 AM | SMY | 20/09/2019, 12:37... | SMY | |
| P13.025_INT_KFGH_EXM_... | 228 | 978 | 21/09/2018, 1:19 AM | SMY | 17/01/2019, 4:50 PM | SMY | |
| P13.025_INT_KFGH_EXM_... | 170 | 535 | 21/09/2018, 1:19 AM | SMY | 12/10/2018, 7:24 AM | SMY | |
| P14.008_INT_KFGH_EXM_... | 305 | 1,510 | 21/09/2018, 1:19 AM | SMY | 17/01/2019, 5:45 PM | SMY | |
| P15.423_INT_EJGH_OPD_... | 282 | 1,437 | 21/09/2018, 1:19 AM | SMY | 21/01/2019, 1:52 AM | SMY | |
| P16.306_INT_KFGH_NS_A... | 308 | 1,499 | 21/09/2018, 1:19 AM | SMY | 20/09/2019, 12:28... | SMY | |
| P19.627_INT_ALT_ED_AUD | 283 | 1,451 | 21/09/2018, 1:19 AM | SMY | 21/01/2019, 3:43 AM | SMY | |
| P20.517_INT_KAH_ED_AUD | 302 | 1,682 | 21/09/2018, 1:20 AM | SMY | 21/01/2019, 4:06 AM | SMY | |
| P21.418_INT_KFGH_EXM_... | 323 | 1,608 | 21/09/2018, 1:20 AM | SMY | 21/10/2018, 5:35 AM | SMY | |
| P22.704_INT_KAH_ED_AUD | 288 | 1,387 | 21/09/2018, 1:20 AM | SMY | 21/01/2019, 4:20 AM | SMY | |

0 item selected



| | | | | | | |
|---|---|---|---|---|---|---|
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| P05.015_DIA_PSY_MA | 245 | 1,738 | 21/09/2018, 1:11 AM | SMY | 17/01/2019, 4:21 PM | SMY |
| P08.420_DIA_PSY_MA | 188 | 440 | 21/09/2018, 1:11 AM | SMY | 17/01/2019, 4:21 PM | SMY |
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| P14.008_DIA_KFGH_EXM | 304 | 1,502 | 21/09/2018, 1:12 AM | SMY | 03/10/2018, 4:12 AM | SMY |
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| P20.517_DIA_KAH_ED | 300 | 1,186 | 21/09/2018, 1:12 AM | SMY | 23/10/2018, 4:18 AM | SMY |
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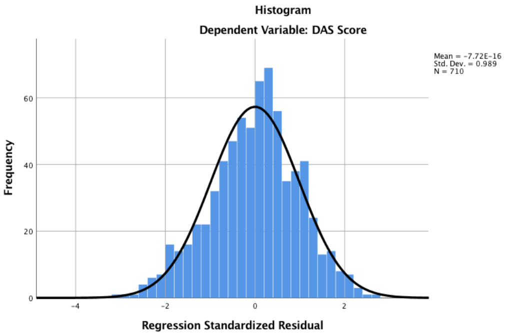
| P22.704_DIA_KAH_ED | 245 | 721 | 21/09/2018, 1:13 AM | SMY | 30/10/2018, 2:34 AM | SMY |
| P23.701_DIA_KFGH_ENT | 187 | 391 | 21/09/2018, 1:13 AM | SMY | 21/09/2018, 1:13 AM | SMY |
| P24.702_DIA_KFGH_NS | 208 | 646 | 21/09/2018, 1:13 AM | SMY | 21/09/2018, 1:13 AM | SMY |

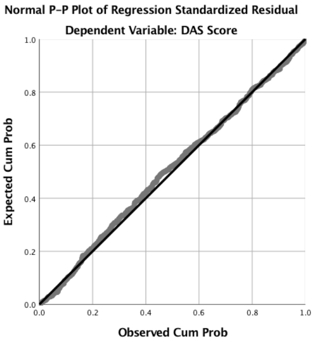
0 item selected

# Appendix I Survey Data Analysis

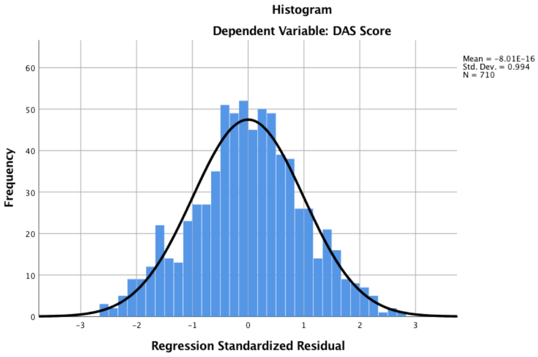
## I.1 standardised residual

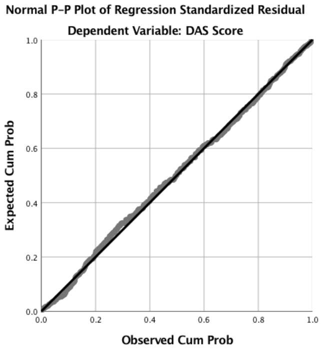
The Environmental Characteristics regression standardised residual with dementia attitude scores



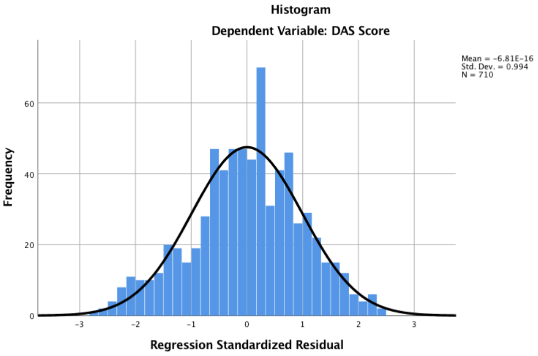


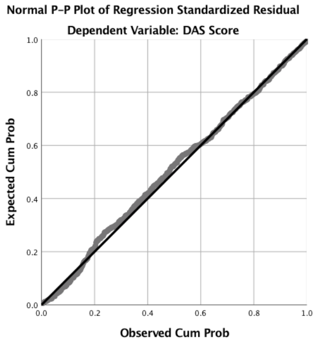
The Personal Demographics regression standardised residual with dementia attitude scores





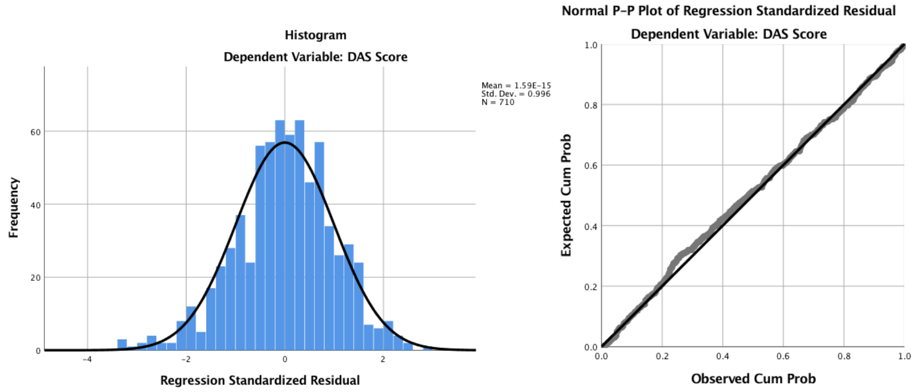
The Experience Characteristics regression standardised residual with dementia attitude scores



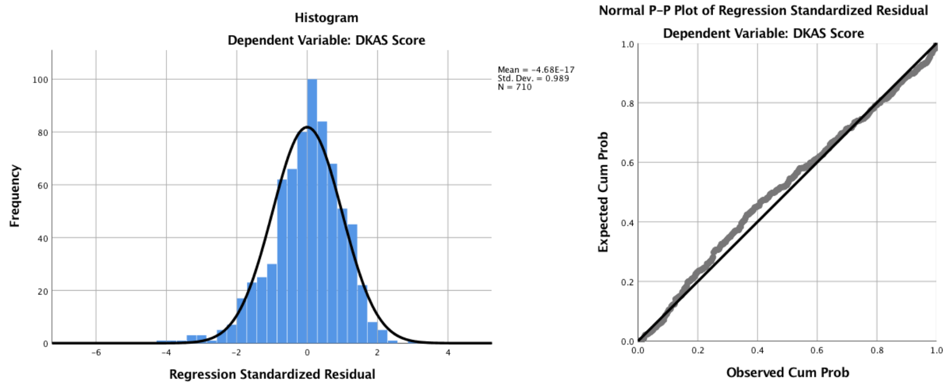


Appendix I

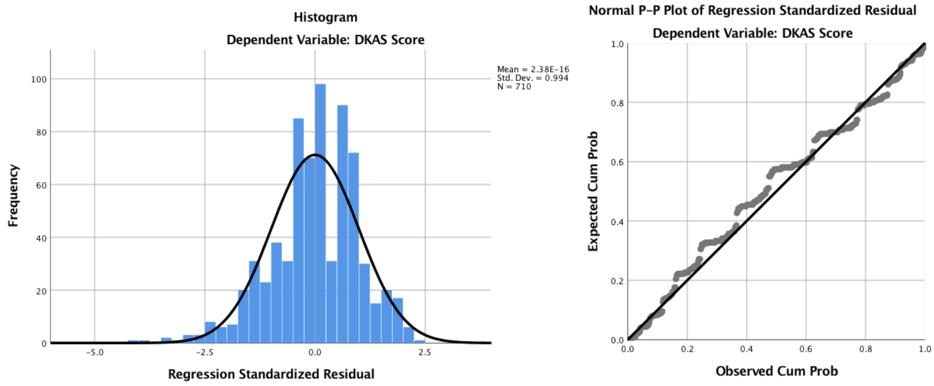
The Educational Characteristics regression standardised residual with dementia attitude scores



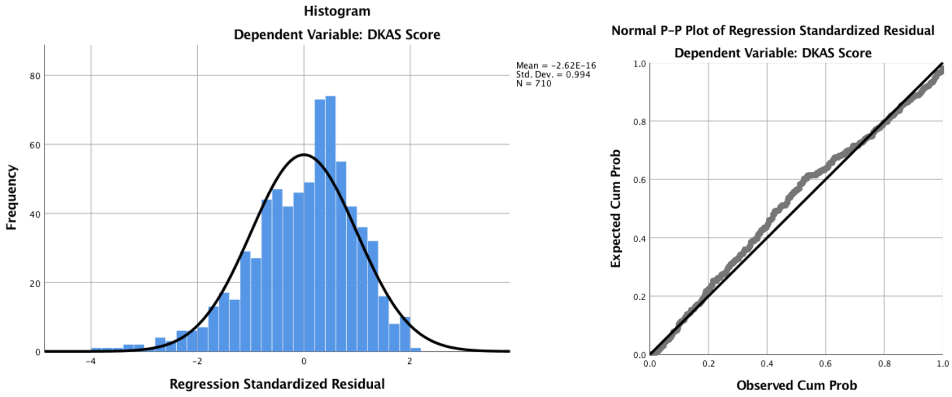
The Environmental Characteristics regression standardised residual with dementia knowledge scores



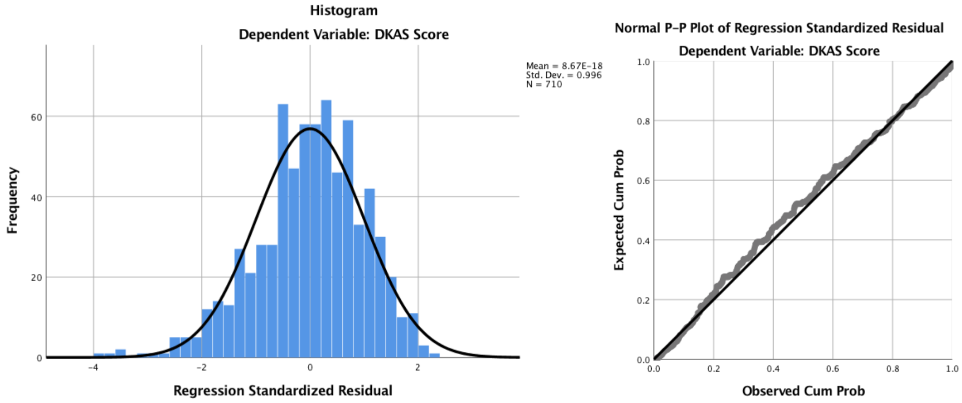
The Personal Demographics regression standardised residual with dementia knowledge scores



The Experience Characteristics regression standardised residual with dementia knowledge scores



The Educational Characteristics regression standardised residual with dementia knowledge scores



## I.2 Linear Regression Analysis

### Linear Regression Analysis of Dementia Attitude Scores Table

| | | | | | | Partially Adjusted | | | | Fully Adjusted | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Unadjusted Coefficient | Partially Adjusted Coefficient | Fully Adjusted Coefficient | Adjusted R Square | P Value | Confidence interval Lower Bound | Confidence interval Upper Bound | Adjusted R Square | P Value | Confidence interval Lower Bound | Confidence interval Upper Bound |
| Environmental Characteristics | Hospital | (Constant) | 94.763 | 107.46 | 71.828 | 0.055 | .000 | 95.448 | 119.48 | .302 | .000 | 54.791 | 88.866 |
| | | KAMC | 3.790 | 2.758 | -.826 | | .140 | -.906 | 6.422 | | .675 | -4.686 | 3.034 |
| | | KFGH | | | -2.130 | | | | | | .148 | -5.016 | .755 |
| | | EJGH | -4.524 | -2.108 | -2.411 | | .326 | -6.323 | 2.107 | | .210 | -6.183 | 1.361 |
| | | KAH | -1.678 | -.334 | | | .839 | -3.557 | 2.889 | | | | |
| | | ALT | -5.748 | -3.857 | .566 | | .085 | -8.254 | .539 | | .777 | -3.354 | 4.485 |
| | | PSY | -2.036 | -2.920 | 4.292 | | .510 | -11.62 | 5.777 | | .298 | -3.800 | 12.384 |
| | Ward | (Constant) | 91.212 | | | | | | | | | | |
| | | Clinics | 1.990 | .206 | 2.023 | | .917 | -3.671 | 4.082 | | .549 | -4.610 | 8.657 |
| | | Convalescence Departments | 5.758 | 5.077 | 3.174 | | .028 | .557 | 9.596 | | .138 | -1.022 | 7.369 |
| | | Emergency Department | .847 | -.515 | -1.834 | | .803 | -4.562 | 3.532 | | .316 | -5.419 | 1.751 |
| | | Intensive care unit | 2.788 | 2.997 | -.315 | | .250 | -2.115 | 8.110 | | .893 | -4.906 | 4.277 |
| | | Mixed wards | 9.237 | 6.514 | 4.953 | | .002 | 2.351 | 10.676 | | .010 | 1.206 | 8.699 |
| | | Medical wards | | | | | | | | | | | |
| | | Surgical wards | -.245 | -.243 | .064 | | .903 | -4.183 | 3.696 | | .971 | -3.397 | 3.524 |
| | | Psychiatry | 3.304 | 4.052 | -1.045 | | .447 | -6.408 | 14.511 | | .827 | -10.454 | 8.363 |
| | Evidence Based at work | (Constant) | 95.148 | | | | | | | | | | |
| | | | -.714 | .306 | 2.590 | | .816 | -2.270 | 2.882 | | .026 | .309 | 4.871 |
| | Reading groups at work | (Constant) | 104.918 | | | | | | | | | | |
| | | | -5.648 | -4.249 | -3.383 | | .095 | -9.233 | .734 | | .137 | -7.840 | 1.074 |
| | Computer at work | (Constant) | 99.670 | | | | | | | | | | |
| | | | -3.533 | -2.369 | -1.474 | | .053 | -4.767 | .029 | | .173 | -3.595 | .646 |
| | Access to Internet at work | (Constant) | 98.633 | | | | | | | | | | |
| | | | -2.884 | -2.045 | -.062 | | .092 | -4.423 | .334 | | .954 | -2.178 | 2.054 |
| Personal Demogra | Age range | (Constant) | 93.215 | 81.548 | | 0.091 | .000 | 75.031 | 88.064 | | | | |
| | | 21-30 | | | | | | | | | | | |
| | | 31-40 | 1.650 | 1.513 | 1.557 | | .206 | -.833 | 3.860 | | .199 | -.820 | 3.934 |
| | | 41+ | .710 | -1.769 | -2.884 | | .356 | -5.531 | 1.994 | | .219 | -7.486 | 1.718 |

| | | | Unadjusted Coefficient | Partially Adjusted Coefficient | Fully Adjusted Coefficient | Adjusted R Square | Partially Adjusted | | | Adjusted R Square | Fully Adjusted | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | P Value | Confidence interval | | | P Value | Confidence interval | |
| | | | | | | | | Lower Bound | Upper Bound | | | Lower Bound | Upper Bound |
| | Gender | (Constant) | 83.157 | | | | | | | | | | |
| | | | 5.727 | 3.704 | 3.276 | | .035 | .261 | 7.148 | | .047 | .047 | 6.505 |
| | Nationality | (Constant) | 89.695 | | | | | | | | | | |
| | | Saudi | | | | | | | | | | | |
| | | Indian | 5.505 | 5.610 | 1.959 | | .000 | 2.809 | 8.412 | | .460 | -3.240 | 7.157 |
| | | Filipino | 10.376 | 10.136 | 4.950 | | .000 | 7.391 | 12.881 | | .066 | -.323 | 10.224 |
| | | Other | 3.305 | 4.202 | 1.207 | | .268 | -3.244 | 11.648 | | .751 | -6.254 | 8.668 |
| | Job title | (Constant) | 93.502 | | | | | | | | | | |
| | | Bedside nurse | | | -4.759 | | | | | | .302 | -13.799 | 4.281 |
| | | Community nurse | -.409 | 1.129 | -5.602 | | .453 | -1.820 | 4.077 | | .305 | -16.306 | 5.103 |
| | | administrative nurse | 5.027 | 6.195 | -1.381 | | .001 | 2.492 | 9.898 | | .774 | -10.829 | 8.067 |
| Experience Characteristics | Years of experience | (Constant) | 94.520 | 89.839 | | 0.023 | .000 | 83.114 | 96.564 | | | | |
| | | 1-3 | -1.147 | | | | | | | | | | |
| | | 4-5 | -2.042 | -.225 | -3.290 | | .899 | -3.692 | 3.243 | | .036 | -6.359 | -.221 |
| | | 6-10 | | 4.509 | -.158 | | .014 | .905 | 8.114 | | .926 | -3.495 | 3.179 |
| | | 11+ | 1.585 | 8.901 | 5.529 | | .000 | 4.076 | 13.725 | | .028 | .611 | 10.446 |
| | Experience within the current area | (Constant) | 94.774 | | | | | | | | | | |
| | | <1 | .866 | 2.646 | -1.373 | | .270 | -2.061 | 7.353 | | .526 | -5.624 | 2.878 |
| | | 1-3 | | 1.502 | -.398 | | .358 | -1.702 | 4.705 | | .785 | -3.267 | 2.471 |
| | | 4-5 | -1.214 | | | | | | | | | | |
| | | 6-10 | -2.902 | -5.365 | -3.505 | | .010 | -9.428 | -1.303 | | .053 | -7.062 | .052 |
| | | 11+ | -2.052 | -7.752 | -7.599 | | .013 | -13.89 | -1.620 | | .006 | -13.009 | -2.190 |
| | Provided professional care for people with dementia | (Constant) | 94.545 | | | | | | | | | | |
| | | | -.398 | -.828 | .171 | | .485 | -3.157 | 1.500 | | .874 | -1.941 | 2.283 |
| | Had a family member with dementia | (Constant) | 90.587 | | | | | | | | | | |
| | | | 1.824 | 1.771 | -1.479 | | .253 | -1.266 | 4.808 | | .291 | -4.227 | 1.269 |
| Education Characteristi | Highest educational degree | (Constant) | 89.024 | 62.557 | | 0.261 | .000 | 55.723 | 69.391 | | | | |
| | | Diploma | | | | | | | | | | | |
| | | Bachelor and Master | 8.392 | 3.638 | 2.766 | | .003 | 1.208 | 6.069 | | .039 | .137 | 5.395 |
| | Complete degree in KSA | (Constant) | 81.752 | | | | | | | | | | |
| | | | 7.873 | -.052 | -1.269 | | .967 | -2.562 | 2.458 | | .628 | -6.414 | 3.875 |

Appendix I

| | | Unadjusted Coefficient | Partially Adjusted Coefficient | Fully Adjusted Coefficient | Partially Adjusted | | | | Fully Adjusted | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | Adjusted R Square | P Value | Confidence interval | | Adjusted R Square | P Value | Confidence interval | |
| | | | | | | | Lower Bound | Upper Bound | | | Lower Bound | Upper Bound |
| Had formal dementia education | (Constant) | 80.502 | | | | | | | | | | |
| | | 7.129 | 3.618 | 3.244 | | .023 | .506 | 6.729 | | .059 | -.124 | 6.612 |
| Rate own knowledge | (Constant) | 77.083 | | | | | | | | | | |
| | | 6.513 | -.017 | -.163 | | .987 | -2.000 | 1.967 | | .872 | -2.159 | 1.832 |
| Rate own confidence | (Constant) | 76.267 | | | | | | | | | | |
| | | 6.571 | 2.996 | 2.744 | | .001 | 1.309 | 4.683 | | .002 | 1.033 | 4.456 |
| Rate willingness to learn about dementia | (Constant) | 73.614 | | | | | | | | | | |
| | | 6.467 | 4.621 | 4.470 | | .000 | 3.545 | 5.697 | | .000 | 3.384 | 5.556 |

## Linear Regression Analysis of Dementia Knowledge Scores Table

| | | | Unadjusted Coefficient | Partially Adjusted Coefficient | Fully Adjusted Coefficient | Partially Adjusted | | | | Fully Adjusted | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | Adjusted R Square | P Value | Confidence interval | | Adjusted R Square | P Value | Confidence interval | |
| | | | | | | | | Lower Bound | Upper Bound | | | Lower Bound | Upper Bound |
| *Environmental Characteristics* | Hospital | (Constant) | 24.376 | 28.298 | 19.788 | 0.075 | .000 | 23.199 | 33.397 | 0.163 | .000 | 11.790 | 27.786 |
| | | KAMC | 1.542 | 1.534 | .503 | | .053 | -.021 | 3.089 | | .586 | -1.309 | 2.315 |
| | | KFGH | | | -.671 | | | | | | .331 | -2.026 | .683 |
| | | EJGH | -2.094 | -2.106 | -2.510 | | .021 | -3.895 | -.317 | | .006 | -4.281 | -.739 |
| | | KAH | -.144 | -.105 | | | .880 | -1.473 | 1.263 | | | | |
| | | ALT | -.868 | -.436 | .808 | | .647 | -2.301 | 1.430 | | .389 | -1.032 | 2.648 |
| | | PSY | -2.648 | -5.481 | -3.965 | | .004 | -9.171 | -1.790 | | .041 | -7.764 | -.167 |
| | Ward | (Constant) | 25.591 | | | | | | | | | | |
| | | Clinics | -2.475 | -2.575 | -3.049 | | .002 | -4.220 | -.930 | | .055 | -6.163 | .065 |
| | | Convalescence Departments | -1.197 | -1.560 | -2.189 | | .111 | -3.478 | .358 | | .029 | -4.158 | -.219 |
| | | Emergency Department | -3.203 | -3.181 | -3.675 | | .000 | -4.898 | -1.463 | | .000 | -5.358 | -1.992 |
| | | Intensive care unit | -1.330 | -1.124 | -1.712 | | .310 | -3.294 | 1.046 | | .119 | -3.867 | .444 |
| | | Mixed wards | .951 | -.324 | -.792 | | .719 | -2.091 | 1.442 | | .377 | -2.551 | .967 |
| | | Medical wards | | | | | | | | | | | |
| | | Surgical wards | -2.932 | -2.853 | -2.744 | | .001 | -4.525 | -1.181 | | .001 | -4.368 | -1.120 |

| | | | | | | | Partially Adjusted | | | | Fully Adjusted | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Unadjusted Coefficient | Partially Adjusted Coefficient | Fully Adjusted Coefficient | Adjusted R Square | P Value | Confidence interval | | Adjusted R Square | P Value | Confidence interval | |
| | | | | | | | | Lower Bound | Upper Bound | | | Lower Bound | Upper Bound |
| *Personal Demographics* | | Psychiatry | -2.172 | 3.234 | 1.724 | | .153 | -1.205 | 7.673 | | .444 | -2.692 | 6.141 |
| | Evidence Based at work | (Constant) | 27.435 | | | | | | | | | | |
| | | | -1.904 | -1.541 | -.855 | | .006 | -2.634 | -.448 | | .117 | -1.926 | .215 |
| | Reading groups at work | (Constant) | 23.951 | | | | | | | | | | |
| | | | .103 | .732 | 1.155 | | .497 | -1.383 | 2.847 | | .279 | -.937 | 3.248 |
| | Computer at work | (Constant) | 24.190 | | | | | | | | | | |
| | | | -.023 | .203 | .365 | | .695 | -.814 | 1.221 | | .472 | -.631 | 1.360 |
| | Access to Internet at work | (Constant) | 25.510 | | | | | | | | | | |
| | | | -.830 | -.900 | -.384 | | .080 | -1.910 | .109 | | .448 | -1.378 | .609 |
| | Age range | (Constant) | 24.094 | 19.373 | | 0.068 | .000 | 16.542 | 22.203 | | | | |
| | | 21-30 | | | | | | | | | | | |
| | | 31-40 | .018 | .114 | .200 | | .826 | -.905 | 1.134 | | .724 | -.915 | 1.316 |
| | | 41+ | .449 | .031 | -.358 | | .971 | -1.604 | 1.665 | | .745 | -2.518 | 1.802 |
| | Gender | (Constant) | 19.651 | | | | | | | | | | |
| | | | 2.396 | 1.716 | 1.379 | | .025 | .221 | 3.212 | | .075 | -.137 | 2.894 |
| | Nationality | (Constant) | 22.517 | | | | | | | | | | |
| | | Saudi | | | | | | | | | | | |
| | | Indian | 2.272 | 1.911 | .793 | | .002 | .694 | 3.128 | | .524 | -1.647 | 3.234 |
| | | Filipino | 3.953 | 3.645 | 2.213 | | .000 | 2.453 | 4.838 | | .080 | -.263 | 4.689 |
| | | Other | .358 | .365 | -1.173 | | .825 | -2.869 | 3.600 | | .511 | -4.675 | 2.330 |
| | Job title | (Constant) | 24.228 | | | | | | | | | | |
| | | Bedside nurse | | | -.124 | | | | | | .954 | -4.368 | 4.119 |
| | | Community nurse | -1.085 | -.625 | .523 | | .338 | -1.906 | .656 | | .838 | -4.502 | 5.548 |
| | | administrative nurse | 1.401 | 1.741 | 1.386 | | .034 | .133 | 3.350 | | .540 | -3.049 | 5.821 |
| *Experience Characteristics* | Years of experience | (Constant) | 23.742 | 24.837 | | 0.012 | .000 | 21.936 | 27.738 | | | | |
| | | 1-3 | .836 | | | | | | | | | | |
| | | 4-5 | .121 | -.502 | -1.372 | | .510 | -1.998 | .993 | | .062 | -2.813 | .069 |
| | | 6-10 | | .321 | -.373 | | .685 | -1.234 | 1.876 | | .640 | -1.940 | 1.193 |
| | | 11+ | 1.117 | 1.411 | 1.270 | | .184 | -.670 | 3.492 | | .281 | -1.039 | 3.578 |
| | Experience within the current area | (Constant) | 24.729 | | | | | | | | | | |
| | | <1 | -.448 | .423 | -.423 | | .683 | -1.608 | 2.453 | | .678 | -2.418 | 1.573 |
| | | 1-3 | | .750 | .022 | | .287 | -.632 | 2.132 | | .975 | -1.325 | 1.368 |

| | | | | | | | Partially Adjusted | | | | Fully Adjusted | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | Confidence interval | | | | Confidence interval | |
| | | | Unadjusted Coefficient | Partially Adjusted Coefficient | Fully Adjusted Coefficient | Adjusted R Square | P Value | Lower Bound | Upper Bound | Adjusted R Square | P Value | Lower Bound | Upper Bound |
| | | 4-5 | -.856 | | | | | | | | | | |
| | | 6-10 | -2.025 | -1.785 | -1.574 | | .046 | -3.537 | -.032 | | .065 | -3.244 | .096 |
| | | 11+ | .123 | -.383 | -.225 | | .776 | -3.028 | 2.262 | | .862 | -2.764 | 2.315 |
| | Provided professional care for people with dementia | (Constant) | 25.653 | | | | | | | | | | |
| | | | -.951 | -1.068 | -.909 | | .037 | -2.072 | -.063 | | .072 | -1.900 | .083 |
| | Had a family member with dementia | (Constant) | 24.101 | | | | | | | | | | |
| | | | .028 | .436 | -1.033 | | .514 | -.874 | 1.746 | | .116 | -2.323 | .257 |
| *Education Characteristics* | Highest educational degree | (Constant) | 22.595 | 14.165 | | 0.097 | .000 | 10.924 | 17.405 | | | | |
| | | Diploma | | | | | | | | | | | |
| | | Bachelor and Master | 2.671 | 1.058 | 1.030 | | .072 | -.094 | 2.211 | | .102 | -.204 | 2.264 |
| | Complete degree in KSA | (Constant) | 19.561 | | | | | | | | | | |
| | | | 2.971 | 1.043 | -.330 | | .086 | -.147 | 2.234 | | .789 | -2.745 | 2.085 |
| | Had formal dementia education | (Constant) | 20.372 | | | | | | | | | | |
| | | | 2.009 | 1.115 | .690 | | .138 | -.360 | 2.591 | | .392 | -.891 | 2.271 |
| | Rate own knowledge | (Constant) | 18.393 | | | | | | | | | | |
| | | | 2.228 | 1.074 | 1.059 | | .025 | .133 | 2.014 | | .027 | .122 | 1.996 |
| | Rate own confidence | (Constant) | 19.562 | | | | | | | | | | |
| | | | 1.709 | .377 | .375 | | .356 | -.423 | 1.176 | | .360 | -.428 | 1.178 |
| | Rate willingness to learn about dementia | (Constant) | 19.617 | | | | | | | | | | |
| | | | 1.445 | .596 | .409 | | .022 | .086 | 1.107 | | .116 | -.101 | .919 |

# Appendix J Diary-interview Data Analysis

## J.1 Participants characteristics

### Education and culture characteristics

| | Saudi | Indian | Filipino | EM | Total |
|---|---|---|---|---|---|
| Bedside | 195 | 167 | 129 | 9 | 500 |
| Community | 90 | 11 | 33 | 6 | 140 |
| Administrative | 36 | 12 | 21 | 1 | 70 |
| Diploma | 232 | 43 | 14 | 7 | 296 |
| Bachelor | 85 | 145 | 168 | 6 | 404 |
| Master | 4 | 2 | 1 | 3 | 10 |
| Degree from KSA | 307 | 6 | 5 | 5 | 323 |
| Had formal dementia education | 57 | 15 | 8 | 4 | 84 |
| Have family members with dementia | 86 | 15 | 20 | 3 | 124 |
| Provided professional dementia care | 156 | 66 | 73 | 4 | 299 |

### Work environment characteristics

| ID | At work have access to | | | |
|---|---|---|---|---|
| | Evidence Based | Internet | Computer | Reading groups |
| P02 | No | Yes | Yes | No |
| P03 | No | Yes | No | No |
| P04 | Yes | No | No | No |
| P05 | No | Yes | No | No |
| P08 | No | No | No | No |
| P12 | No | Yes | No | No |
| P13 | Yes | No | No | No |
| P14 | Yes | No | Yes | No |
| P15 | No | No | Yes | No |
| P16 | No | No | No | No |
| P17 | Yes | Yes | Yes | No |
| P19 | No | No | No | No |
| P20 | No | No | No | No |
| P21 | No | No | No | No |
| P22 | No | Yes | Yes | No |
| P23 | Yes | Yes | Yes | No |
| P24 | Yes | No | Yes | No |
| P25 | No | No | No | No |

# Appendix J

## Experience, education and knowledge information of diary-interview participants

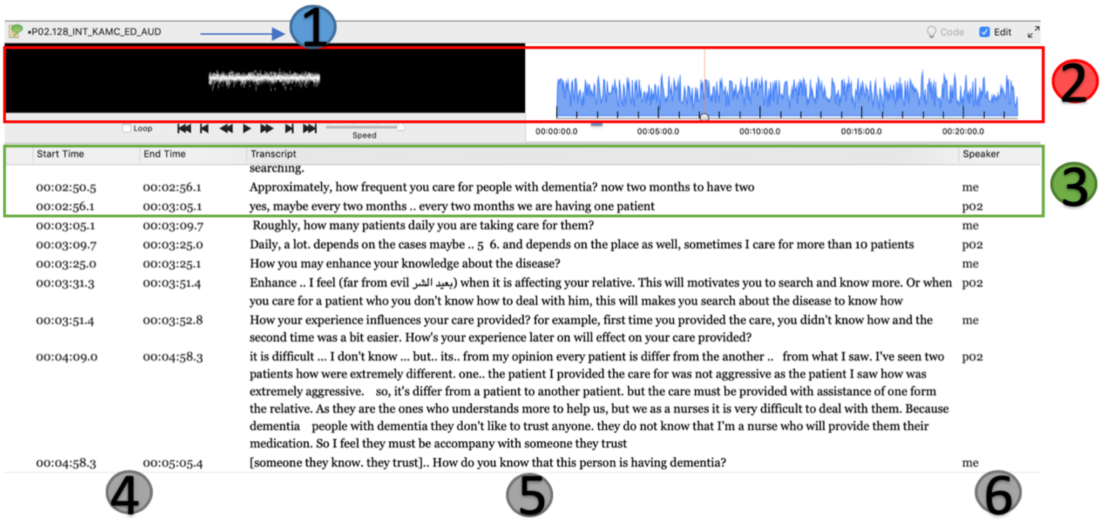
| ID | Years of experience | Experience within the current area | Provided professional dementia care | Had a family member with dementia | Education | Degree from KSA | Had formal dementia education | Rate own |  |  | Scores |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |  | knowledge | Confident | Willing to learn | DAS | DKAT |
| P02 | 1-3 | <1 | No | No | Bachelor | Yes | No | Low | Average | Very | 99 | 26 |
| P03 | 1-3 | 1-3 | yes | No | Bachelor | Yes | No | Average | Average | High | 114 | 22 |
| P04 | 1-3 | 1-3 | No | No | Diploma | Yes | No | No | No | Low | 96 | 22 |
| P05 | 6-10 | 1-3 | No | No | Diploma | Yes | No | Low | No | No | 77 | 12 |
| P08 | 1-3 | <1 | Yes | No | Bachelor | Yes | Yes | Average | Average | Very | 118 | 32 |
| P12 | 1-3 | 1-3 | No | No | Bachelor | No | Yes | High | Ave. | High | 85 | 20 |
| P13 | 6-10 | 1-3 | yes | No | Bachelor | No | No | Average | Average | High | 101 | 30 |
| P14 | 1-3 | 1-3 | No | Yes | Bachelor | No | No | Average | Average | High | 104 | 20 |
| P15 | 6-10 | 1-3 | Yes | Yes | Diploma | Yes | Yes | Low | Low | Low | 75 | 26 |
| P16 | 11-20 | 1-3 | Yes | Yes | Bachelor | Yes | No | Average | Average | Average | 111 | 32 |
| P17 | 11-20 | 11-20 | Yes | No | Bachelor | Yes | No | Average | Average | Very | 122 | 26 |
| P19 | 4-5 | 1-3 | Yes | Yes | Bachelor | Yes | Yes | Low | Average | High | 108 | 12 |
| P20 | 4-5 | 4-5 | Yes | No | Bachelor | Yes | No | Low | Low | Low | 64 | 20 |
| P21 | 11+ | 1-3 | Yes | No | Master | Yes | No | Average | High | Average | 129 | 34 |
| P22 | 1-3 | 1-3 | Yes | No | Diploma | Yes | no | Average | Average | Average | 112 | 34 |
| P23 | 6-10 | 6-10 | No | No | Bachelor | No | No | Average | Average | High | 115 | 32 |
| P24 | 4-5 | 1-3 | Yes | No | Bachelor | No | No | Low | Low | Average | 100 | 34 |
| P25 | 6-10 | 4-5 | Yes | No | Bachelor | No | No | Average | Average | Average | 123 | 32 |

## J.2 Transcription protocol used within this study

### General instructions

The study researcher transcribed all interviews within the NVivo document using the audio tools.

Six elements made-up the transcripts in the NVivo:



| Start Time | End Time | Transcript | Speaker |
|---|---|---|---|
| | | searching. | |
| 00:02:50.5 | 00:02:56.1 | Approximately, how frequent you care for people with dementia? now two months to have two | me |
| 00:02:56.1 | 00:03:05.1 | yes, maybe every two months .. every two months we are having one patient | po2 |
| 00:03:05.1 | 00:03:09.7 | Roughly, how many patients daily you are taking care for them? | me |
| 00:03:09.7 | 00:03:25.0 | Daily, a lot. depends on the cases maybe .. 5 6. and depends on the place as well, sometimes I care for more than 10 patients | po2 |
| 00:03:25.0 | 00:03:25.1 | How you may enhance your knowledge about the disease? | me |
| 00:03:31.3 | 00:03:51.4 | Enhance .. I feel (far from evil بعيد الشر) when it is affecting your relative. This will motivates you to search and know more. Or when you care for a patient who you don't know how to deal with him, this will makes you search about the disease to know how | po2 |
| 00:03:51.4 | 00:03:52.8 | How your experience influences your care provided? for example, first time you provided the care, you didn't know how and the second time was a bit easier. How's your experience later on will effect on your care provided? | me |
| 00:04:09.0 | 00:04:58.3 | it is difficult ... I don't know ... but.. its.. from my opinion every patient is differ from the another .. from what I saw. I've seen two patients how were extremely different. one.. the patient I provided the care for was not aggressive as the patient I saw how was extremely aggressive. so, it's differ from a patient to another patient. but the care must be provided with assistance of one form the relative. As they are the ones who understands more to help us, but we as a nurses it is very difficult to deal with them. Because dementia people with dementia they don't like to trust anyone. they do not know that I'm a nurse who will provide them their medication. So I feel they must be accompany with someone they trust | po2 |
| 00:04:58.3 | 00:05:05.4 | [someone they know. they trust].. How do you know that this person is having dementia? | me |

#### 1 File name (labelling interview transcript)

The file names as exported. It includes (participant number, Survey number, Interview, hospital name, ward and audio.

#### 2 Audio file length

This shows the length of the interview by minutes

#### 3 Transcript entry

That is made up of Timespan and content made up this field. Multiple entries can be made with the same timespan (See Input characteristics bellow)

#### 4 Timespan

Here a transcript entry duration of time. For example, me spoke from *(21:10:4 -21:20:4)*. It can be entered directly into a transcript.

#### 5 Content

This column/field had the transcript text. It can be formatted, coded and annotated.

#### 6 Speaker

These columns/fields capture speakers name. however, it cannot manually coded, annotated or linked the content in custom columns. But it can auto coded transcripts based on content in a custom column. In this study '*me'* referred to the interviewer and '*participant ID'* for the participant

**Input characteristics:**

- Times New Roman,
- 12-point font,
- Auto spacing,
- All text to begin at the left-hand margin (no indents),
- If Arabic words included it starts from the right-hand margin,
- Entire script is left justified,
- Include everything the participant and interviewer says, including the interview's back channel utterances with no exceptions and
- No grammar alteration.

## Transcription protocol

| | |
|---|---|
| End of the interview | - Type END OF INTERVIEW in capital letters to indicate that interview session has finished. |
| Spelling | - UK spelling. |
| Content | - Transcribed verbatim (every ward, including background sounds and all nonverbal).<br>- Include grammatical errors, slang language, mispronunciations, and repetitions.<br>- Filler words: Hm, Hmmm, Mm, Huh? Ooo! Ouch! Oops! Phew, Shh, Uh-huh, Whoa! Wow, Yeah, Yup, Yay and Yes. |
| Non-verbal sounds | - Put sounds in parentheses (circular brackets)<br>- e.g. pen clicking, keys, running water, coughs, sighs, claps, and laughs. |
| Pauses | - Use dots for audible silence.<br>- i.e. 2-3 second insert … and more dots means longer pauses |
| Interruptions | - Insert a hyphen at the end of last letter or audible sound<br>- e.g. someone kno- |
| Overlapping speech | - Insert the speech of the other person in square brackets<br>- e.g. [overlapping speech]. |
| Participant's tone | - Include in circular brackets, i.e. (sound mad) |

## J.3 Codebook

### J.3.1 First cycle codebook

| Code | Description | Source | Files | References |
|---|---|---|---|---|
| Beliefs | Participant's judgment, thoughts and opinions | DIA/INT | 30 | 174 |
| Challenging | Participant's own expression | INT | 2 | 2 |
| Community, society view | Beliefs of participant related to community and society views | INT | 7 | 14 |
| Dementia-the disease- | Participant's opinions and belief about dementia as a disease | DIA/INT | 24 | 46 |
| Norm | The standard beliefs of participants regarding dementia, culture and society | DIA/INT | 14 | 22 |
| Normal ageing | Participant's own expression | INT | 5 | 9 |
| Religion | Any talk related to personal religion or referencing to God | DIA/INT | 13 | 23 |
| Rewarding | Participant's own expression | INT | 5 | 6 |
| Suspect-know dementia | Indication and description of diagnosing dementia and/or suspecting dementia | INT | 14 | 28 |
| Wording - term | Any talk regarding dementia term: mainly related to the Arabic translation | INT | 10 | 24 |
| Feelings | When participants were asked about their feeling in their diary and then any emotions noticed during the interviews. All were participants own expression when described their feelings | DIA/INT | 32 | 181 |
| Aggression | Participant's feeling | DIA/INT | 3 | 3 |
| Ashamed | Participant's feeling | DIA | 1 | 1 |
| Challenge | Participant's feeling | DIA | 4 | 5 |
| Comfortable | Participant's feeling | DIA | 3 | 6 |
| Confident | Participant's feeling | DIA | 1 | 1 |
| Depressed | Participant's feeling | DIA/INT | 4 | 5 |
| Difficult | Participant's feeling | DIA/INT | 4 | 6 |
| Disappointed | Participant's feeling | INT | 2 | 2 |
| Embarrassed | Participant's feeling | INT | 2 | 2 |
| Empathy | Participant's feeling | DIA/INT | 12 | 16 |
| Exhausting | Participant's feeling | DIA/INT | 6 | 7 |
| Fear | Participant's feeling | INT | 2 | 2 |
| Feeling affect the care | Participant's feeling | INT | 2 | 4 |
| Fine | Participant's feeling | DIA/INT | 5 | 12 |

| Code | Description | Source | Files | References |
|---|---|---|---|---|
| Happy | Participant’s feeling | DIA | 5 | 17 |
| Hard | Participant’s feeling | DIA | 1 | 8 |
| lonely, isolated | Participant’s feeling | DIA | 1 | 1 |
| Mercy | Participant’s feeling | DIA | 1 | 3 |
| Need assistance | Participant’s feeling | DIA | 4 | 9 |
| Need time | Participant’s feeling | DIA/INT | 3 | 6 |
| Not easy | Participant’s feeling | DIA/INT | 2 | 2 |
| Positive | Participant’s feeling | DIA/INT | 3 | 4 |
| Relax | Participant’s feeling | DIA | 1 | 1 |
| Sad | Participant’s feeling | DIA/INT | 8 | 8 |
| Satisfaction | Participant’s feeling | DIA/INT | 6 | 7 |
| Stressed | Participant’s feeling | DIA | 4 | 4 |
| Sympathy | Participant’s feeling | DIA/INT | 13 | 16 |
| Thankful | Participant’s feeling | DIA | 2 | 2 |
| Tolerance | Participant’s feeling | DIA/INT | 3 | 4 |
| Uncomfortable | Participant’s feeling | DIA/INT | 3 | 3 |
| Upset | Participant’s feeling | DIA/INT | 4 | 6 |
| Useless | Participant’s feeling | DIA | 1 | 1 |
| want to help | Participant’s feeling | DIA/INT | 5 | 7 |
| Perception | Rendering participants own beliefs about the care: who influence it, what are the barriers and how participants perceived the person with dementia | INT | 20 | 64 |
| Affect/Alter the care | Participants perceptions about the care and what affect/alter it | INT | 5 | 8 |
| Barriers | What perceived as a barrier in providing care, learning caring and/or training | INT | 14 | 28 |
| Person's Life | Perceptions about the life with dementia and how participant imagine the life with dementia | INT | 17 | 28 |
| Thoughts & opinions | All thoughts and opinions about dementia, its diagnosis, wordings and treating the condition from participants. How participants think about the person and the care, what difficulties facing them and how to provide patients with dementia with | DIA/INT | 36 | 465 |
| Background, culture, education level | Descriptions of participant/colleagues’ background and culture | DIA/INT | 13 | 20 |
| Behaviour | Detected from their talk about dementia, the person and the care | DIA/INT | 21 | 40 |

| Code | Description | Source | Files | References |
|---|---|---|---|---|
| Colleague | All opinions about colleagues and instants where they expressed colleagues' influences | DIA/INT | 11 | 18 |
| Communication | How participants described communication with the person with dementia or suspected dementia | DIA/INT | 27 | 70 |
| Difficulty | Level of difficulty and causes | INT | 7 | 11 |
| emotions | Feelings and emotions in general and how this impact the care from participants' perspectives | DIA/INT | 11 | 16 |
| Environment | thoughts and opinions about the care environment including the hospital and current ward | DIA/INT | 11 | 18 |
| Independent | thoughts and opinions about the dependency level of patients | DIA/INT | 4 | 5 |
| Kids | A description of how participant perceived a person with dementia and the way they treat them | DIA/INT | 10 | 13 |
| Learning | Thoughts and opinions about people with dementia learning abilities | DIA/INT | 14 | 23 |
| Lies/ not real | Opinion about patient's complains | DIA/INT | 3 | 5 |
| Love/ caring | Among participants' talk or entries | DIA/INT | 11 | 18 |
| Making decisions | Stimulating participant's reflection on patient's decision making | DIA/INT | 6 | 7 |
| Observation | When participant claimed that patients with dementia need close observation | DIA/INT | 9 | 12 |
| Participant workplace and shift | Related thoughts and opinion regarding participant's own workplace and duty | INT | 4 | 6 |
| Patience | Participant act, express and/or reference to patience as an attitude | DIA/INT | 22 | 37 |
| Prioritise | Participants reflected on prioritising the patient with dementia | INT | 3 | 7 |
| Routine | Related thoughts and opinion regarding ward routine | DIA/INT | 17 | 28 |
| Safety | Related thoughts and opinion regarding patient's safety | DIA/INT | 14 | 27 |
| Sleep | Thoughts about sleep time and sleep pattern of patients | DIA | 1 | 1 |
| Special care | Opinions of participants demanding a special care to be provided to people with dementia | DIA/INT | 12 | 20 |
| Time | Related thoughts and opinion regarding time of nurses | DIA/INT | 16 | 29 |
| Trust | How participant's develop trust | INT | 2 | 2 |
| ways of caring; medication, activities | Thoughts and opinion of participants regarding providing nursing care and implement care intervention to patients with dementia | DIA/INT | 15 | 32 |
| Actions after study | Participants plans and implementation after completing their participation in this study | INT | 9 | 9 |

Appendix J

| Code | Description | Source | Files | References |
|---|---|---|---|---|
| Dementia | Participants' codes regarding what they know about dementia, its progress and care. From three categories: the brain, the disease and the person. | INT | 16 | 56 |
| the brain -diagnosis-: Neurology, pathology, changes occurs | the brain: neurology, pathology and changes in the brain | INT | 7 | 17 |
| the disease: Progression, stages, challenges, treatments, medications | the disease: progression and changes, Challenges and Intervention and treatment | INT | 4 | 5 |
| the person: Living with dementia, person, cares, relationships, communication | the person: living with dementia, person's life, norms, community, society, culture, carers, family, communication and role of nursing | INT | 14 | 34 |
| Difficult to care | Participants used this expression (exact wording) | DIA/INT | 18 | 36 |
| influenced the care | Who participants assume that they impact on the care provided. Including family and relatives, personal experience with a family member with dementia and colleagues | DIA/INT | 36 | 219 |
| Co-workers | Colleagues and other healthcare professionals | DIA/INT | 18 | 44 |
| Culture | Both patient and carers culture | DIA/INT | 10 | 17 |
| Environment | The workplace environment and surroundings | DIA/INT | 9 | 18 |
| Experience | Participant's own experience | INT | 6 | 8 |
| Family, relative | A carer with a direct contact to the patient | DIA/INT | 24 | 68 |
| Language | Language of participants and patients | DIA/INT | 3 | 9 |
| Love | Among participants' talk or entries | DIA/INT | 4 | 4 |
| Nurse family, experience | nurse's personal experience of relative with dementia | DIA/INT | 9 | 13 |
| Other patients than dementia | In work implications | DIA/INT | 2 | 2 |
| Patient's history | Medical and psychological history | DIA | 3 | 6 |
| Religion | Any talk related to personal religion or referencing to God | INT | 2 | 2 |
| Social worker | Other healthcare professional at work | DIA/INT | 5 | 5 |
| The care | The type of care provided or need to be provided | DIA | 2 | 4 |
| The patient | The patient with dementia him/her-self | DIA/INT | 12 | 19 |
| Mental vs Physical illness | The comparison made by participants on treating psychological and physical illnesses | DIA/INT | 11 | 29 |
| Negative | Overall negative statement | DIA/INT | 5 | 9 |
| Participant's learning | participant's learning this includes gaining knowledge during nurses' study days, work/personal experience, own reading and searching and this study. When participants were asked about their source of information | INT | 19 | 85 |

| Code | Description | Source | Files | References |
|---|---|---|---|---|
| Degree (school-college days) | What participants taught about dementia as requirement to accomplish their nursing degree | INT | 15 | 29 |
| Experience | A claim by participant that they learn by experience | INT | 8 | 15 |
| Searching | Using internet, reading and/or asking experts | INT | 14 | 19 |
| This study | This study implication on participant's knowledge | INT | 11 | 17 |
| Want to know | Spotting what areas participants need to know more about | INT | 5 | 5 |
| Quantitative | Number of patients with dementia when enter the diary and Likert scale about rating own confident and working shift that participant cared for a person with dementia in | DIA/INT | 31 | 436 |
| # dementia with diagnosis | Number of patients with written dementia diagnosis according to their hospital files. | DIA | 15 | 102 |
| # suspected dementia | Number of patients with suspected dementia according to nurses' own interpretations and/or mentioned by family members verbally as diagnosed in another healthcare facility | DIA | 14 | 90 |
| Frequent care for dementia | Participants claim during interviews about frequency of caring for a person with dementia | INT | 14 | 20 |
| How confident during the shift (1-5) | Participants own rating within the diary entry about their level of confidence during their shift | DIA | 17 | 112 |
| 1 | Not confident | DIA | 1 | 1 |
| 2 | Low confident | DIA | 5 | 9 |
| 3 | Average | DIA | 9 | 39 |
| 4 | Confident | DIA | 12 | 41 |
| 5 | Very confident | DIA | 9 | 22 |
| How good was the shift (1-5) | Participants own rating within the diary entry about the goodness of their shift | DIA | 17 | 112 |
| 1 | Very bad | DIA | 4 | 6 |
| 2 | Bad | DIA | 7 | 10 |
| 3 | Average | DIA | 11 | 38 |
| 4 | Good | DIA | 13 | 40 |
| 5 | Very good | DIA | 6 | 18 |
| Recommendation & suggestions | All recommendations, suggestions and ideas of nurses to enhance the care provided to people with dementia and dementia care | DIA/INT | 34 | 321 |
| Accompaniment | Having a watcher for every patient with dementia (carer to sleep at hospital with her/him) | DIA/INT | 9 | 14 |
| Activities | Creating activities within the ward | DIA/INT | 8 | 9 |

| Code | Description | Source | Files | References |
|---|---|---|---|---|
| Aromatherapy | Type of complementary medicine and therapy suggested by participants | DIA | 1 | 1 |
| Awareness | Call for action to rise nurses' and society's awareness | DIA/INT | 20 | 35 |
| Book | Having Arabic book to enhance knowledge | DIA/INT | 6 | 9 |
| Cards | Recommending using cards as sort of identification of people with dementia | INT | 2 | 6 |
| Cultural background | Suggestions to overcome cultural differences | DIA/INT | 2 | 2 |
| Environment | Recommendations for developing appropriate care environment | DIA/INT | 14 | 30 |
| Meals | Suggestions about meals and feedings preferences | DIA | 2 | 3 |
| Medication | Idea about providing medication | INT | 1 | 1 |
| More care | Participant's own wording when asked about their recommendations | DIA/INT | 8 | 8 |
| Nursing care | Ideas for evolving nursing dementia care in term of care, environment, experience and awareness | INT | 17 | 77 |
| +ve experience | When asked participants about how to create a positive hospitalisation experience for the patient with dementia | INT | 13 | 19 |
| Nursing care | Ideas for developing nursing dementia care | INT | 8 | 11 |
| want to know | Spotting what areas participants need to know more about | INT | 11 | 20 |
| Workplace | Ideas for enhancing the nursing dementia care workplace | INT | 14 | 27 |
| Occupational therapy | Type of therapy suggested by participants to assist patient's development, recovery and maintaining meaningful activities | DIA | 2 | 2 |
| Organisation | Call for action for organisational changes | DIA/INT | 7 | 12 |
| Patience | Nurses to develop such behaviour | DIA/INT | 2 | 2 |
| Policies | Suggested policies for dementia nursing practice | INT | 14 | 20 |
| Primary nursing care | Nurse to provide patients with dementia their basic need and assist them with their activities of daily living is a system consist of registered nurse and nursing assistant | DIA/INT | 3 | 8 |
| Psychiatrist | A specialised physician in psychiatry | DIA | 1 | 2 |
| Psychological support | Suggested to have an integrated psychological support for patients with dementia | DIA/INT | 10 | 19 |
| Ratio | Nurses to patient's ratio recommendation by bedside nurses | DIA/INT | 10 | 17 |
| Recreational therapy | Type of therapy suggested by participants to utilise patient's recreation and maintaining meaningful activities | DIA/INT | 5 | 8 |

| Code | Description | Source | Files | References |
|---|---|---|---|---|
| Research | Call for action and conducting researches | DIA | 3 | 11 |
| Social worker | Academic personnel suggested to be a vital member of care team for people with dementia | DIA/INT | 6 | 9 |
| Socialisation | Suggested by participants to overcome the norms and important for people with dementia to be engaged with the society | DIA/INT | 3 | 4 |
| Specialised care | Idea to support people with dementia | DIA/INT | 21 | 31 |
| Stigma | Importance of overcome the stigma around dementia | DIA | 1 | 1 |
| Teamwork | Recommendation of having a teamwork engaged in the care provided to patients with dementia | DIA/INT | 7 | 12 |
| Time | Ideas on time issue and its management | DIA/INT | 7 | 7 |
| Tools and equipment | Recommendation for providing tools and equipment to improve the care provided | DIA/INT | 3 | 3 |
| Training | Call for action to equip nurses with the needed training to enhance the dementia nursing care practice | DIA/INT | 19 | 34 |
| Translator | A translator to overcome language issues | DIA | 1 | 1 |
| Reflection | Participants own reflections on this study | INT | 18 | 113 |
| about Diary | Participants own reflections on entering the diary | INT | 18 | 83 |
| about Survey | Participants own reflections on the survey | INT | 15 | 18 |
| about the Study | Participants own reflections on this study in general | INT | 7 | 12 |
| Type of care | Type of care provided to people with dementia that offered by nurses during this study | DIA/INT | 34 | 307 |
| ADL | Activities of daily living: walking, feeding, toileting, bathing, dressing… etc | DIA/INT | 13 | 19 |
| Blood investigation | Blood tests | DIA | 3 | 3 |
| Cannula and catheter | Incursion of blood and infusion canula and urinary catheter | DIA | 3 | 4 |
| Clothes | Changing cloths and dressing | DIA/INT | 8 | 13 |
| Communication | Developing conversations with people with dementia | DIA/INT | 15 | 34 |
| Convincing | Participants trying many times to satisfy or assure patients with dementia | INT | 7 | 13 |
| Discharge | Completing patient’s file to leave the hospital and end their hospitalisation as a result of doctor’s decision and end of their treatment | INT | 1 | 1 |
| Dressing | Wound dressing and sterilisation intervention | DIA/INT | 6 | 8 |
| Exercise | Practicing with patient | DIA | 1 | 1 |
| Fall prevention | Actions and cautions by nurses to reduce the risk of fall of patients with dementia | INT | 1 | 1 |

| Code | Description | Source | Files | References |
|---|---|---|---|---|
| Feeding | Provide patients with food | DIA/INT | 18 | 38 |
| General nursing care | Participant's own expression: relates to vital signs, bed-making, feeding, medication, hygiene and mobility | DIA/INT | 10 | 21 |
| Medication | Provide patients with medication and treatment | DIA/INT | 27 | 58 |
| Morning care | bed changing and personal hygiene for patients | DIA | 7 | 15 |
| Patient cantered care | Provide care with respect to patient's needs | DIA | 1 | 3 |
| Psychological care | Reassuring patients and support them psychologically | DIA/INT | 10 | 16 |
| restrain | Restrain patients to prevent harming and/or causing injuries to themselves | DIA/INT | 4 | 4 |
| Safety | Provide patients with dementia with protection from injuries and danger | DIA | 2 | 4 |
| Shower and hygiene | Provide patients with shower and maintain their personal hygiene such as tooth brushing, changing diapers and toileting | DIA/INT | 13 | 33 |
| Toileting | Assist patients with changing diapers and toileting | DIA | 1 | 2 |
| Vital signs | Measure patients' body temperatures, pulse rate, respiratory rate and blood pressure | DIA | 2 | 5 |
| Walking | Assist patient with their mobility and walk them | DIA | 7 | 10 |
| Wisdom & Quotes | It was a question to answer and the end of every diary entry for participants | DIA/INT | 17 | 66 |

## J.3.2 Second cycle codebook

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| **Attitudes** | **Thoughts, Feelings and Beliefs** | DIA/INT | **37** | **479** |
| Beliefs | Participant's judgment, thoughts and opinions. The care and who influence the care (Challenging, religion, rewarding) - Influence the care | DIA/INT | 37 | 236 |
| Influence the Care | What participants assume that is impact on the care provided | DIA/INT | 36 | 213 |
| Co-workers | Colleagues and other healthcare professionals | DIA/INT | 21 | 49 |
| Culture & Language | Both patient and carers culture and language | DIA/INT | 11 | 21 |
| Environment | thoughts and opinions about the care environment including the hospital and current ward | DIA/INT | 9 | 19 |
| Experience | includes nurse's work & family experiences | INT | 19 | 30 |
| Family, relative | A carer with a direct contact to the patient | DIA/INT | 24 | 69 |
| The patient | The participant perception about patient with dementia | | 13 | 25 |
| Religion | Any talk related to personal religion or referencing to God | | 13 | 23 |
| Feelings | When participants were asked about their feeling in their diary and then any emotions noticed during the interviews. All were participants own expression when described their feelings. Categorised according to Ropert Plutchik (fear, anger, sadness, happy, surprise, & love) (Shaver et al. 2001) | DIA/INT | 32 | 180 |
| Anger | Main category | DIA/INT | 11 | 23 |
| Aggression | Participants feeling | DIA/INT | 4 | 6 |
| Exhausting | Participants feeling | DIA/INT | 6 | 7 |
| Uncomfortable | Participants feeling | DIA/INT | 3 | 3 |
| Upset | Participants feeling | DIA/INT | 4 | 7 |
| Fear | Main category | DIA/INT | 6 | 6 |
| Fear | Participants feeling | INT | 2 | 2 |
| Stressed | Participants feeling | DIA | 4 | 4 |
| Happy/ Joy | Main category | DIA/INT | 15 | 48 |
| Confident | Participants feeling | DIA | 1 | 1 |
| Fine | Participants feeling | DIA/INT | 5 | 12 |
| Happy | Participants feeling | DIA | 5 | 17 |
| Positive | Participants feeling | DIA/INT | 3 | 4 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Relax | Participants feeling | DIA | 1 | 1 |
| Satisfaction | Participants feeling | DIA/INT | 6 | 7 |
| Thankful | Participants feeling | DIA | 2 | 2 |
| Tolerance | Participants feeling | DIA/INT | 3 | 4 |
| Love | Main category | DIA/INT | 16 | 32 |
| Comfortable | Participants feeling | DIA | 3 | 6 |
| Empathy | Participants feeling | DIA/INT | 12 | 16 |
| Mercy | Participants feeling | DIA | 1 | 3 |
| want to help | Participants feeling | DIA/INT | 5 | 7 |
| Sadness | Main category | DIA/INT | 26 | 50 |
| Ashamed | Participants feeling | DIA | 1 | 1 |
| Depressed | Participants feeling | DIA/INT | 4 | 5 |
| Disappointed | Participants feeling | INT | 2 | 2 |
| Embarrassed | Participants feeling | INT | 2 | 2 |
| lonely, isolated | Participants feeling | DIA | 1 | 1 |
| Need assistance | Participants feeling | DIA | 3 | 8 |
| Need time | Participants feeling | DIA/INT | 3 | 6 |
| Sad | Participants feeling | DIA/INT | 8 | 8 |
| Sympathy | Participants feeling | DIA/INT | 13 | 16 |
| Useless | Participants feeling | DIA | 1 | 1 |
| Surprise | Main category | DIA/INT | 8 | 21 |
| Challenge | Participants feeling | DIA | 4 | 5 |
| Difficult | Participants feeling | DIA/INT | 4 | 6 |
| Hard | Participants feeling | DIA | 1 | 8 |
| Not easy | Participants feeling | DIA/INT | 2 | 2 |
| Thoughts | All thoughts and opinions about dementia, its diagnosis, wordings and treating the condition from participants. | DIA/INT | 17 | 63 |
| Challenging | Participant’s own expression | INT | 3 | 4 |
| Mental vs Physical illness | The comparison made by participants on treating psychological and physical illnesses | DIA/INT | 11 | 29 |
| Rewarding | Participant’s own expression. Perceived caring for people with dementia | INT | 5 | 6 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Wording | Any talk regarding dementia term: mainly related to the Arabic translation | INT | 10 | 24 |
| **Knowledge** | **Participants' codes regarding what they know about dementia, its progress and care. From three categories: the brain, the disease and the person. 1- the brain: neurology, pathology and changes in the brain 2- the disease: progression and changes, Challenges and Intervention and treatment 3- the person: living with dementia, person's life, norms, also, community, society and culture, carers, family, communication and role of nursing** | INT | **32** | **316** |
| Participant's learning | participant's learning this includes gaining knowledge during nurses' study days, work/personal experience, own reading and searching and this study. When participants were asked about their source of information | INT | 20 | 106 |
| Degree (school-college days) | What participants taught about dementia as requirement to accomplish their nursing degree | INT | 15 | 29 |
| Experience | A claim by participant that they learn by experience | INT | 8 | 16 |
| Searching | Using internet, reading and/or asking experts | INT | 14 | 19 |
| This study | This study implication on participant's knowledge | INT | 11 | 17 |
| Want to know | Spotting what areas participants need to know more about | INT | 15 | 25 |
| The Brain | The brain: neurology, pathology and changes in the brain. Brian changes and normal ageing | INT | 16 | 49 |
| Changes in the brain | The brain: neurology, pathology and changes in the brain. Brian changes and normal ageing | INT | 10 | 16 |
| Suspect-know dementia | Indication and description of diagnosing dementia and/or suspecting dementia | INT | 15 | 33 |
| The Disease | the disease: progression and changes, Challenges and Intervention and treatment | INT | 7 | 9 |
| Challenges | the disease: progression and changes, Challenges and Intervention and treatment | INT | 4 | 5 |
| Intervention, treatment | the disease: progression and changes, Challenges and Intervention and treatment | INT | 1 | 1 |
| Progression and Changes | the disease: progression and changes, Challenges and Intervention and treatment | INT | 3 | 3 |
| The Person | the person: living with dementia, person's life, norms, community, society, culture, carers, family, communication and role of nursing | DIA/INT | 28 | 105 |
| Carers, Family | A carer with a direct contact to the patient | DIA/INT | 8 | 12 |
| Community, Culture, Society | Beliefs of participant related to community and society views | DIA/INT | 22 | 54 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Living with dementia | + explanation of person's life by participants | INT | 19 | 39 |
| What is Dementia | Participant's own understanding and definition about dementia | INT | 24 | 47 |
| **Perceptions** | **Interpretation of nursing behaviours based on thoughts, public opinion and knowledge. The care: difficult, communication, patience. The person: behaviour, emotions, learning, decision-making, lies, kids, independent. The environment: colleague, routine, shift and environment** | **DIA/INT** | **37** | **545** |
| The care | Perceiving the care for people with dementia | DIA/INT | 36 | 254 |
| Barriers | What perceived as a barrier in providing care, learning caring and/or training | INT | 15 | 30 |
| Communication | How participants described communication with the person with dementia or suspected dementia | DIA/INT | 27 | 71 |
| Difficulty | Level of difficulty and causes | INT | 20 | 43 |
| Observation | When participant claimed that patients with dementia need close observation | DIA/INT | 9 | 12 |
| Patience | Participant act, express and/or reference to patience as an attitude | DIA/INT | 22 | 37 |
| Special care | Opinions of participants demanding a special care to be provided to people with dementia | DIA/INT | 14 | 27 |
| ways of caring; medication, activities | Thoughts and opinion of participants regarding providing nursing care and implement care intervention to patients with dementia | DIA/INT | 16 | 34 |
| The environment | thoughts and opinions about the care environment including the hospital and current ward | DIA/INT | 32 | 158 |
| Colleague | All opinions about colleagues and instants where they expressed colleagues' influences | DIA/INT | 11 | 18 |
| Routine | Related thoughts and opinion regarding ward routine | DIA/INT | 17 | 28 |
| Safety | Related thoughts and opinion regarding patient's safety | DIA/INT | 14 | 27 |
| Time | Ideas on time issue and its management | DIA/INT | 17 | 30 |
| Workplace, shift & time | thoughts and opinions about the care environment including the hospital, current ward, routine and time | DIA/INT | 23 | 55 |
| The person | the person: living with dementia, person's life, norms, community, society, culture, carers, family, communication and role of nursing | DIA/INT | 34 | 133 |
| Behaviours | The person with dementia behaviour | DIA/INT | 22 | 46 |
| Emotions, love, caring | Among participants' talk or entries | DIA/INT | 17 | 33 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Kids | A description of how participant perceived a person with dementia and the way they treat them | DIA/INT | 10 | 13 |
| Learning | Thoughts and opinions about people with dementia learning abilities | DIA/INT | 14 | 24 |
| Lies/ not real | Opinion about patient's complains | DIA/INT | 3 | 5 |
| Making decisions | Stimulating participant's reflection on patient's decision making | DIA/INT | 10 | 12 |
| **Quantitative** | | **DIA/INT** | **33** | **519** |
| # dementia with diagnosis | Number of patients with written dementia diagnosis according to their hospital files. | DIA | 15 | 102 |
| # suspected dementia | Number of patients with suspected dementia according to nurses' own interpretations and/or mentioned by family members verbally as diagnosed in another healthcare facility | DIA | 14 | 90 |
| Frequent care for dementia | Participants claim during interviews about frequency of caring for a person with dementia | INT | 14 | 20 |
| How confident during the shift (1-5) | Participants own rating within the diary entry about their level of confidence during their shift | DIA | 17 | 112 |
| 1 | Not confident | DIA | 1 | 1 |
| 2 | Low confident | DIA | 5 | 9 |
| 3 | Average | DIA | 9 | 39 |
| 4 | Confident | DIA | 12 | 41 |
| 5 | Very confident | DIA | 9 | 22 |
| How good was the shift (1-5) | Participants own rating within the diary entry about the goodness of their shift | DIA | 17 | 112 |
| 1 | Very bad | DIA | 4 | 6 |
| 2 | Bad | DIA | 7 | 10 |
| 3 | Average | DIA | 11 | 38 |
| 4 | Good | DIA | 13 | 40 |
| 5 | Very good | DIA | 6 | 18 |
| kharaf | Word query | DIA/INT | 17 | 83 |
| **Recommendation & suggestions** | All recommendations, suggestions and ideas of nurses to enhance the care provided to people with dementia and dementia care | **DIA/INT** | **33** | **368** |
| Awareness and Training | including trainings, research, and education | DIA/INT | 25 | 70 |
| Multidimensional Team | Teamwork, Primary nurse, OT, PT, Recreational therapy, Psychiatrist, Translators, Social workers | DIA/INT | 18 | 41 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Nurses | Ideas and recommendations for enhancing dementia nursing practice | DIA/INT | 29 | 82 |
| Nursing care | Ideas for developing nursing dementia care | INT | 11 | 16 |
| Policies | Suggested policies for dementia nursing practice | INT | 18 | 24 |
| Psychological support | Suggested to have an integrated psychological support for patients with dementia | DIA/INT | 10 | 19 |
| Ratio | Nurses to patient's ratio recommendation by bedside nurses | DIA/INT | 13 | 23 |
| Organisational changes | Ideas for evolving nursing dementia care in term of care, environment, experience and awareness. Includes: environment, wards, tools, equipment, & IDs | DIA/INT | 30 | 153 |
| +ve experience | When asked participants about how to create a positive hospitalisation experience for the patient with dementia | INT | 13 | 19 |
| Accompaniment | Having a watcher for every patient with dementia (carer to sleep at hospital with her/him) | DIA/INT | 9 | 15 |
| Environment | Recommendations for developing appropriate care environment | DIA/INT | 16 | 33 |
| Identifications | Recommending using cards as sort of identification of people with dementia | INT | 7 | 16 |
| Specialised care |  | DIA/INT | 24 | 38 |
| Workplace | Ideas for enhancing the nursing dementia care workplace | DIA/INT | 16 | 32 |
| Therapeutic interventions | Non-pharmacological, includes activities, Aromatherapy, Socialisations, Recreational therapy, Occupational therapy | DIA/INT | 12 | 22 |
| **Reflection** | **Participants own reflections on this study** | INT | **19** | **122** |
| about Diary | Participants own reflections on entering the diary | INT | 18 | 83 |
| about Survey | Participants own reflections on the survey | INT | 15 | 18 |
| about the Study | Participants own reflections on this study in general | INT | 7 | 12 |
| Actions after study | Participants plans and implementation after completing their participation in this study | INT | 9 | 9 |
| **Reflexivity** | **Researcher's own diaries, field notes and reflexion during data collection process** | **RD** | **18** | **385** |
| 01_KAMC | Reflexivity about this setting | RD | 1 | 8 |
| 02_KFGH | Reflexivity about this setting | RD | 1 | 15 |
| 03_EJGH | Reflexivity about this setting | RD | 1 | 9 |
| 04_KAH | Reflexivity about this setting | RD | 1 | 10 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| 05_ALT | Reflexivity about this setting | RD | 1 | 5 |
| 06_PSY | Reflexivity about this setting | RD | 1 | 12 |
| 07_PHC | Reflexivity about this setting | RD | 1 | 17 |
| Behaviours and feelings | Researcher’s own behaviours and feelings | RD | 1 | 48 |
| Dementia cases | According to gatekeepers when collecting the data | RD | 1 | 33 |
| Education & Learning | Thoughts and opinions about people with dementia learning abilities | RD | 1 | 6 |
| Staffing, organisation | General reflection | RD | 1 | 29 |
| DIA | Reflection about the diary | RD | 18 | 139 |
| DIA condition | The booklet condition | RD | 17 | 17 |
| Follow-up | How follow-up with participant goes | RD | 1 | 41 |
| Recruiting | First time approaching the participant | RD | 1 | 42 |
| Summary | Summary of the participant from recruiting and follow-up to interview or withdrawn | RD | 1 | 26 |
| Withdrawn | Causes and details | RD | 1 | 12 |
| INT | Reflection about the interview | RD | 1 | 49 |
| My reflection... | In general researcher’s feelings and thoughts before, during and after the interview | RD | 1 | 7 |
| Participant | Thoughts and opinions about participants | RD | 1 | 25 |
| Place | Reflection on the place of the interview | RD | 1 | 17 |
| SUR | Reflection about the survey | RD | 1 | 5 |
| Hospitals & wards | Reflection about the hospitals and wards | RD | 0 | 0 |
| 01_KAMC | Reflexivity about this setting | RD | 1 | 1 |
| 02_KFGH | Reflexivity about this setting | RD | 1 | 2 |
| 03_EJGH | Reflexivity about this setting | RD | 1 | 2 |
| 04_KAH | Reflexivity about this setting | RD | 1 | 2 |
| 05_ALT | Reflexivity about this setting | RD | 1 | 1 |
| 06_PSY | Reflexivity about this setting | RD | 1 | 2 |
| Recruitment & collection | Reflection about the recruitment and collection | RD | 1 | 2 |
| 01_KAMC | Reflexivity about this setting | RD | 1 | 4 |
| 02_KFGH | Reflexivity about this setting | RD | 1 | 9 |
| 03_EJGH | Reflexivity about this setting | RD | 1 | 5 |
| 04_KAH | Reflexivity about this setting | RD | 1 | 8 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| 05_ALT | Reflexivity about this setting | RD | 1 | 3 |
| 06_PSY | Reflexivity about this setting | RD | 1 | 13 |
| 07_PHC | Reflexivity about this setting | RD | 1 | 6 |
| **Type of care** | **Type of care provided to people with dementia that offered by nurses during this study** | DIA/INT | **34** | **307** |
| Activities of Daily Livings | includes: Feeding, Clothing, Walking, Positioning, Toileting, Showering and Hygiene | DIA/INT | 28 | 134 |
| ADL | Activities of daily living: walking, feeding, toileting, bathing,<br>… etc | DIA/INT | 13 | 19 |
| Clothes | Changing cloths and dressing | DIA/INT | 8 | 13 |
| Feeding | Provide patients with food | DIA/INT | 18 | 38 |
| Morning care | bed changing and personal hygiene for patients | DIA | 7 | 15 |
| restrain | Restrain patients to prevent harming and/or causing injuries to themselves | DIA/INT | 4 | 4 |
| Shower and hygiene | Provide patients with shower and maintain their personal hygiene such as tooth brushing, changing diapers and toileting | DIA/INT | 13 | 33 |
| Toileting | Assist patients with changing diapers and toileting | DIA | 1 | 2 |
| Walking | Assist patient with their mobility and walk them | DIA | 7 | 10 |
| Nursing Roles | - Physical and Pathological - Psychological | DIA/INT | 34 | 172 |
| Physical & Pathological | including: blood investigation, vital signs, discharge patient, cannula and catheter, wound dressing, medication | DIA/INT | 30 | 106 |
| Blood investigation | Blood tests | DIA | 3 | 3 |
| Cannula and catheter | Incursion of blood and infusion canula and urinary catheter | DIA | 3 | 4 |
| Discharge | Completing patient's file to leave the hospital and end their hospitalisation as a result of doctor's decision and end of their treatment | INT | 1 | 1 |
| Dressing | Wound dressing and sterilisation intervention | DIA/INT | 6 | 8 |
| Exercise | Practicing with patient | DIA | 1 | 1 |
| General nursing care | Provide patients with medication and treatment | DIA/INT | 10 | 21 |
| Medication | bed changing and personal hygiene for patients | DIA/INT | 27 | 58 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Safety & fall prevention | Actions and cautions by nurses to reduce the risk of fall of patients with dementia and opinion regarding patient's safety | DIA/INT | 3 | 5 |
| Vital signs | Measure patients' body temperatures, pulse rate, respiratory rate and blood pressure | DIA | 2 | 5 |
| Psychological & Sociological | Psychological and Sociological care provided by participants | DIA/INT | 23 | 66 |
| Communication | Developing conversations with people with dementia | DIA/INT | 15 | 34 |
| Convincing | Participants trying many times to satisfy or assure patients with dementia | INT | 7 | 13 |
| Patient cantered care | Provide care with respect to patient's needs | DIA | 1 | 3 |
| Psychological care | Reassuring patients and support them psychologically | DIA/INT | 10 | 16 |
| **Wisdom & Quotes** | **It was a question to answer and the end of every diary entry for participants** | **DIA/INT** | **17** | **67** |

## J.3.3 Third cycle codebook

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| **Environmental factors** | | DIA/INT | **37** | **517** |
| Cultural factors | - Experience: nurses with relatives with dementia (+ve impact on the care provided; similar survey finding). - Saudi culture. - Language. - Religion. - People (healthcare professionals, family, patient) usually care for the physical wellbeing rather than mental health. - People view dementia as mental illness that does not require immediate health attention from healthcare facilities. - Appropriateness of the Arabic translation of dementia; despite that nurses used that in diary and interviews. | DIA/INT | 32 | 187 |
| Community, Culture, Society | Beliefs of participant related to community and society views | DIA/INT | 22 | 54 |
| Culture & Language | Beliefs of participant related to community and society views and language | DIA/INT | 11 | 21 |
| Experience | includes nurse's work & family experiences | INT | 19 | 30 |
| Mental vs Physical illness | The comparison made by participants on treating psychological and physical illnesses | DIA/INT | 11 | 29 |
| Religion | Any talk related to personal religion or referencing to God | DIA/INT | 13 | 23 |
| Rewarding | Participant's own expression. Perceived caring for people with dementia | INT | 5 | 6 |
| Wording | Any talk regarding dementia term: mainly related to the Arabic translation | INT | 10 | 24 |
| Organisational, Political factors | Routine, time, shift, shortage | DIA/INT | 23 | 58 |
| Routine | Related thoughts and opinion regarding ward routine | DIA/INT | 17 | 28 |
| Time | Ideas on time issue and its management | DIA/INT | 17 | 30 |
| Physical factors | Equipment, noise | DIA/INT | 27 | 74 |
| Environment | thoughts and opinions about the care environment including the hospital and current ward | DIA/INT | 9 | 19 |
| Workplace, shift & time | Related thoughts and opinion regarding time of nurses | DIA/INT | 23 | 55 |
| Social factors | Who participants assume that they impact on the care provided | DIA/INT | 36 | 198 |
| Carers, Family | A carer with a direct contact to the patient | DIA/INT | 8 | 12 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Co-workers | Colleagues and other healthcare professionals | DIA/INT | 23 | 65 |
| Family, relative | A carer with a direct contact to the patient who could be the nurse | DIA/INT | 31 | 94 |
| The patient | The patient with dementia him/her-self | DIA/INT | 14 | 27 |
| **Feelings** | **When participants were asked about their feeling in their diary and then any emotions noticed during the interviews. All were participants own expression when described their feelings. Categorised according to Ropert Plutchik (fear, anger, sadness, happy, surprise, & love) (Shaver et al. 2001)** | DIA/INT | **33** | **181** |
| Anger | Main category | DIA/INT | 11 | 23 |
| Aggression | Participant's feeling | DIA/INT | 4 | 6 |
| Exhausting | Participant's feeling | DIA/INT | 6 | 7 |
| Uncomfortable | Participant's feeling | DIA/INT | 3 | 3 |
| Upset | Participant's feeling | DIA/INT | 4 | 7 |
| Fear | Main category | DIA/INT | 6 | 6 |
| Fear | Participant's feeling | INT | 2 | 2 |
| Stressed | Participant's feeling | DIA | 4 | 4 |
| Happy/ Joy | Main category | DIA/INT | 16 | 49 |
| Confident | Participant's feeling | DIA | 1 | 1 |
| Fine | Participant's feeling | DIA/INT | 5 | 12 |
| Happy | Participant's feeling | DIA | 6 | 18 |
| Positive | Participant's feeling | DIA/INT | 3 | 4 |
| Relax | Participant's feeling | DIA | 1 | 1 |
| Satisfaction | Participant's feeling | DIA/INT | 6 | 7 |
| Thankful | Participant's feeling | DIA | 2 | 2 |
| Tolerance | Participant's feeling | DIA/INT | 3 | 4 |
| Love | Main category | DIA/INT | 16 | 32 |
| Comfortable | Participant's feeling | DIA | 3 | 6 |
| Empathy | Participant's feeling | DIA/INT | 12 | 16 |
| Mercy | Participant's feeling | DIA | 1 | 3 |
| want to help | Participant's feeling | DIA/INT | 5 | 7 |
| Sadness | Main category | DIA/INT | 26 | 50 |
| Ashamed | Participant's feeling | DIA | 1 | 1 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Depressed | Participant's feeling | DIA/INT | 4 | 5 |
| Disappointed | Participant's feeling | INT | 2 | 2 |
| Embarrassed | Participant's feeling | INT | 2 | 2 |
| lonely, isolated | Participant's feeling | DIA | 1 | 1 |
| Need assistance | Participant's feeling | DIA | 3 | 8 |
| Need time | Participant's feeling | DIA/INT | 3 | 6 |
| Sad | Participant's feeling | DIA/INT | 8 | 8 |
| Sympathy | Participant's feeling | DIA/INT | 13 | 16 |
| Useless | Participant's feeling | DIA | 1 | 1 |
| Surprise | Main category | DIA/INT | 8 | 21 |
| Challenge | Participant's feeling | DIA | 4 | 5 |
| Difficult | Participant's feeling | DIA/INT | 4 | 6 |
| Hard | Participant's feeling | DIA | 1 | 8 |
| Not easy | Participant's feeling | DIA/INT | 2 | 2 |
| **Knowledge** | **Participants' codes regarding what they know about dementia, its progress and care. From three categories: the brain, the disease and the person. 1- the brain: neurology, pathology and changes in the brain 2- the disease: progression and changes, Challenges and Intervention and treatment 3- the person: living with dementia, person's life, norms, also, community, society and culture, carers, family, communication and role of nursing** | **INT** | **25** | **170** |
| Gaining knowledge | participant's learning this includes gaining knowledge during nurses' study days, work/personal experience, own reading and searching and this study. When participants were asked about their source of information | INT | 19 | 77 |
| Degree (school-college days) | What participants taught about dementia as requirement to accomplish their nursing degree | INT | 15 | 28 |
| Experience | A claim by participant that they learn by experience | INT | 7 | 15 |
| Searching | Using internet, reading and/or asking experts | INT | 13 | 18 |
| This study | This study implication on participant's knowledge | INT | 10 | 16 |
| Known about dementia | Known/ believe what dementia is (the brain) | INT | 23 | 93 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Changes in the brain | The brain: neurology, pathology and changes in the brain. Brian changes and normal ageing | INT | 10 | 16 |
| Suspect-know dementia | Indication and description of diagnosing dementia and/or suspecting dementia | INT | 15 | 31 |
| What is Dementia | Participant's own understanding and definition about dementia | INT | 23 | 46 |
| **Recommendations** | **All recommendations, suggestions and ideas of nurses to enhance the care provided to people with dementia and dementia care** | **DIA/INT** | **33** | **393** |
| Awareness, training and research | Recommendations and ideas regarding improving dementia nursing practice | DIA/INT | 28 | 95 |
| Awareness and Training | including trainings, research, and education | DIA/INT | 25 | 70 |
| Want to know | Spotting what areas participants need to know more about | INT | 15 | 25 |
| Multidimensional Team | Teamwork, Primary nurse, OT, PT, Recreational therapy, Psychiatrist, Translators, Social workers | DIA/INT | 18 | 41 |
| Nursing policies | Ideas and recommendations for enhancing dementia nursing practice | DIA/INT | 29 | 82 |
| Nursing care | Ideas for evolving nursing dementia care in term of care, environment, experience and awareness | INT | 11 | 16 |
| Policies | Suggested policies for dementia nursing practice | INT | 18 | 24 |
| Psychological support | Suggested to have an integrated psychological support for patients with dementia | DIA/INT | 10 | 19 |
| Ratio | Nurses to patient's ratio recommendation by bedside nurses | DIA/INT | 13 | 23 |
| Organisational changes | Ideas for evolving nursing dementia care in term of care, environment, experience and awareness. Includes: environment, wards, tools, equipment, & IDs | DIA/INT | 30 | 153 |
| +ve experience | When asked participants about how to create a positive hospitalisation experience for the patient with dementia | INT | 13 | 19 |
| Accompaniment | Having a watcher for every patient with dementia (carer to sleep at hospital with her/him) | DIA/INT | 9 | 15 |
| Environment | Recommendations for developing appropriate care environment | DIA/INT | 16 | 33 |
| Identifications | Recommending using cards as sort of identification of people with dementia | INT | 7 | 16 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Specialised care | Idea to support people with dementia | DIA/INT | 24 | 38 |
| Workplace | Ideas for enhancing the nursing dementia care workplace | DIA/INT | 16 | 32 |
| Therapeutic interventions | Non-pharmacological, includes activities, Aromatherapy, Socialisations, Recreational therapy, Occupational therapy | DIA/INT | 12 | 22 |
| **Reflection** | **Participants own reflections on this study** | **INT** | **19** | **122** |
| about Diary | Participants own reflections on entering the diary | INT | 18 | 83 |
| about Survey | Participants own reflections on the survey | INT | 15 | 18 |
| about the Study | Participants own reflections on this study in general | INT | 7 | 12 |
| Actions after study | Participants plans and implementation after completing their participation in this study | INT | 9 | 9 |
| **Reflexivity** | **Researcher's own diaries, field notes and reflexion during data collection process** | **RD** | **18** | **386** |
| 01_KAMC | Reflexivity about this setting | **RD** | 1 | 8 |
| 02_KFGH | Reflexivity about this setting | **RD** | 1 | 15 |
| 03_EJGH | Reflexivity about this setting | **RD** | 1 | 9 |
| 04_KAH | Reflexivity about this setting | **RD** | 1 | 10 |
| 05_ALT | Reflexivity about this setting | **RD** | 1 | 5 |
| 06_PSY | Reflexivity about this setting | **RD** | 1 | 12 |
| 07_PHC | Reflexivity about this setting | **RD** | 1 | 17 |
| Behaviours and feelings | Researcher's own behaviours and feelings | **RD** | 1 | 48 |
| Dementia cases | According to gatekeepers when collecting the data | **RD** | 1 | 33 |
| Education & Learning | Thoughts and opinions about people with dementia learning abilities | **RD** | 1 | 6 |
| Staffing, organisation | General reflection | **RD** | 1 | 29 |
| DIA | Reflection about the diary | **RD** | 18 | 140 |
| DIA condition | The booklet condition | **RD** | 18 | 18 |
| Follow-up | How follow-up with participant goes | **RD** | 1 | 41 |
| Recruiting | First time approaching the participant | **RD** | 1 | 42 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Summary | Summary of the participant from recruiting and follow-up to interview or withdrawn | **RD** | 1 | 26 |
| Withdrawn | Causes and details | **RD** | 1 | 12 |
| INT | Reflection about the interview | **RD** | 1 | 49 |
| My reflection... | In general researcher's feelings and thoughts before, during and after the interview | **RD** | 1 | 7 |
| Participant | Thoughts and opinions about participants | **RD** | 1 | 25 |
| Place | Reflection on the place of the interview | **RD** | 1 | 17 |
| SUR | Reflection about the survey | **RD** | 1 | 5 |
| Hospitals & wards | Reflection about the hospitals and wards | **RD** | 0 | 0 |
| 01_KAMC | Reflexivity about this setting | **RD** | 1 | 1 |
| 02_KFGH | Reflexivity about this setting | **RD** | 1 | 2 |
| 03_EJGH | Reflexivity about this setting | **RD** | 1 | 2 |
| 04_KAH | Reflexivity about this setting | **RD** | 1 | 2 |
| 05_ALT | Reflexivity about this setting | **RD** | 1 | 1 |
| 06_PSY | Reflexivity about this setting | **RD** | 1 | 2 |
| Recruitment & collection | Reflection about the recruitment and collection | **RD** | 1 | 2 |
| 01_KAMC | Reflexivity about this setting | **RD** | 1 | 4 |
| 02_KFGH | Reflexivity about this setting | **RD** | 1 | 9 |
| 03_EJGH | Reflexivity about this setting | **RD** | 1 | 5 |
| 04_KAH | Reflexivity about this setting | **RD** | 1 | 8 |
| 05_ALT | Reflexivity about this setting | **RD** | 1 | 3 |
| 06_PSY | Reflexivity about this setting | **RD** | 1 | 13 |
| 07_PHC | Reflexivity about this setting | **RD** | 1 | 6 |
| **The care** | **Perceiving the care for people with dementia** | DIA/INT | **36** | **589** |
| Barriers and difficulties | including communication | DIA/INT | 34 | 145 |
| Barriers | What perceived as a barrier in providing care, learning caring and/or training | INT | 15 | 30 |
| Communication | How participants described communication with the person with dementia or suspected dementia | DIA/INT | 27 | 71 |
| Difficulty | Level of difficulty and causes | INT | 20 | 44 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Specialised care | Idea to support people with dementia | DIA/INT | 33 | 137 |
| Observation | When participant claimed that patients with dementia need close observation | DIA/INT | 9 | 12 |
| Patience | Participant act, express and/or reference to patience as an attitude | DIA/INT | 22 | 37 |
| Safety | Related thoughts and opinion regarding patient's safety | DIA/INT | 14 | 27 |
| Special care | Opinions of participants demanding a special care to be provided to people with dementia | DIA/INT | 14 | 27 |
| ways of caring; medication, activities | Thoughts and opinion of participants regarding providing nursing care and implement care intervention to patients with dementia | DIA/INT | 16 | 34 |
| Type of care | Type of care provided to people with dementia that offered by nurses during this study | DIA/INT | 34 | 307 |
| Activities of Daily Livings | includes: Feeding, Clothing, Walking, Positioning, Toileting, Showering and Hygiene | DIA/INT | 28 | 134 |
| ADL | Activities of daily living: walking, feeding, toileting, bathing, dressing… etc | DIA/INT | 13 | 19 |
| Clothes | Changing cloths and dressing | DIA/INT | 8 | 13 |
| Feeding | Provide patients with food | DIA/INT | 18 | 38 |
| Morning care | bed changing and personal hygiene for patients | DIA | 7 | 15 |
| restrain | Restrain patients to prevent harming and/or causing injuries to themselves | DIA/INT | 4 | 4 |
| Shower and hygiene | Provide patients with shower and maintain their personal hygiene such as tooth brushing, changing diapers and toileting | DIA/INT | 13 | 33 |
| Toileting | Assist patients with changing diapers and toileting | DIA | 1 | 2 |
| Walking | Assist patient with their mobility and walk them | DIA | 7 | 10 |
| Nursing Roles | - Physical and Pathological - Psychological | DIA/INT | 34 | 172 |
| Physical & Pathological | including: blood investigation, vital signs, discharge patient, cannula and catheter, wound dressing, medication | DIA/INT | 30 | 106 |
| Blood investigation | Blood tests | DIA | 3 | 3 |
| Cannula and catheter | Incursion of blood and infusion canula and urinary catheter | DIA | 3 | 4 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Discharge | Completing patient's file to leave the hospital and end their hospitalisation as a result of doctor's decision and end of their treatment | INT | 1 | 1 |
| Dressing | Wound dressing and sterilisation intervention | DIA/INT | 6 | 8 |
| Exercise | Practicing with patient | DIA | 1 | 1 |
| General nursing care | Provide patients with medication and treatment | DIA/INT | 10 | 21 |
| Medication | bed changing and personal hygiene for patients | DIA/INT | 27 | 58 |
| Safety & fall prevention | Actions and cautions by nurses to reduce the risk of fall of patients with dementia and opinion regarding patient's safety | DIA/INT | 3 | 5 |
| Vital signs | Measure patients' body temperatures, pulse rate, respiratory rate and blood pressure | DIA | 2 | 5 |
| Psychological & Sociological | Psychological and Sociological care provided by participants | DIA/INT | 23 | 66 |
| Communication | Developing conversations with people with dementia | DIA/INT | 15 | 34 |
| Convincing | Participants trying many times to satisfy or assure patients with dementia | INT | 7 | 13 |
| Patient cantered care | Provide care with respect to patient's needs | DIA | 1 | 3 |
| Psychological care | Reassuring patients and support them psychologically | DIA/INT | 10 | 16 |
| **The Person** | **the person: living with dementia, person's life, norms, community, society, culture, carers, family, communication and role of nursing** | DIA/INT | **35** | **177** |
| Behaviours | The person with dementia behaviour | DIA/INT | 22 | 46 |
| Emotions, love, caring | Among participants' talk or entries | DIA/INT | 17 | 33 |
| Kids | A description of how participant perceived a person with dementia and the way they treat them | DIA/INT | 10 | 13 |
| Learning | Thoughts and opinions about people with dementia learning abilities | DIA/INT | 14 | 24 |
| Lies/ not real | Opinion about patient's complains | DIA/INT | 3 | 5 |
| Living with dementia | + explanation of person's life by participants | INT | 20 | 44 |
| Making decisions | Stimulating participant's reflection on patient's decision making | DIA/INT | 10 | 12 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| **Wisdom & Quotes** | **It was a question to answer and the end of every diary entry for participants** | **DIA/INT** | **17** | **67** |

## J.3.4 Identified themes codebook

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| **Attitudes** | **Attitudes interpret nurses' behaviours. Including emotions (affective attitude), act and avoidance (behavioural attitudes) and beliefs (cognitive attitude)** | **DIA/INT** | **36** | **342** |
| Behaviour | behavioural aspect of attitude that was detected from their talk about dementia, the person and the care act. avoidance and want to help | DIA/INT | 25 | 44 |
| Patience | Participant act, express and/or reference to patience as an attitude | DIA/INT | 22 | 37 |
| want to help | Participant's behavioural attituded and feeling towards patients with dementia | DIA/INT | 5 | 7 |
| Beliefs | Participant's judgment, thoughts and opinions. Cognitive aspect of attitudes: beliefs about psychological and physical care and patience as required attitude when providing dementia nursing care | DIA/INT | 27 | 124 |
| Believe | clear beliefs query on DIA and INT data | DIA/INT | 26 | 95 |
| Mental vs Physical illness | The comparison made by participants on treating psychological and physical illnesses | DIA/INT | 11 | 29 |
| Emotions | the emotions interpreting of nursing care. sadness, happiness and any uncomforted feelings. Affective attitude. When participants were asked about their feeling in their diary and then any emotions noticed during the interviews. All were participants own expression when described their feelings. Categorised according to Robert Plutchik (fear, anger, sadness, happy, surprise, & love) (Shaver et al. 2001) | DIA/INT | 33 | 174 |
| Anger | Main category | DIA/INT | 11 | 23 |
| Aggression | Participant's feeling | DIA/INT | 4 | 6 |
| Exhausting | Participant's feeling | DIA/INT | 6 | 7 |
| Uncomfortable | Participant's feeling | DIA/INT | 3 | 3 |
| Upset | Participant's feeling | DIA/INT | 4 | 7 |
| Fear | Main category | DIA/INT | 6 | 6 |
| Fear | Participant's feeling | INT | 2 | 2 |
| Stressed | Participant's feeling | DIA | 4 | 4 |
| Happy/ Joy | Main category | DIA/INT | 16 | 49 |
| Confident | Participant's feeling | DIA | 1 | 1 |
| Fine | Participant's feeling | DIA/INT | 5 | 12 |
| Happy | Participant's feeling | DIA | 6 | 18 |
| Positive | Participant's feeling | DIA/INT | 3 | 4 |
| Relax | Participant's feeling | DIA | 1 | 1 |
| Satisfaction | Participant's feeling | DIA/INT | 6 | 7 |
| Thankful | Participant's feeling | DIA | 2 | 2 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Tolerance | Participant's feeling | DIA/INT | 3 | 4 |
| Love | Main category | DIA/INT | 13 | 25 |
| Comfortable | Participant's feeling | DIA | 3 | 6 |
| Empathy | Participant's feeling | DIA/INT | 12 | 16 |
| Mercy | Participant's feeling | DIA | 1 | 3 |
| Sadness | Main category | DIA/INT | 26 | 50 |
| Ashamed | Participant's feeling | DIA | 1 | 1 |
| Depressed | Participant's feeling | DIA/INT | 4 | 5 |
| Disappointed | Participant's feeling | INT | 2 | 2 |
| Embarrassed | Participant's feeling | INT | 2 | 2 |
| lonely, isolated | Participant's feeling | DIA | 1 | 1 |
| Need assistance | Participant's feeling | DIA | 3 | 8 |
| Need time | Participant's feeling | DIA/INT | 3 | 6 |
| Sad | Participant's feeling | DIA/INT | 8 | 8 |
| Sympathy | Participant's feeling | DIA/INT | 13 | 16 |
| Useless | Participant's feeling | DIA | 1 | 1 |
| Surprise | Main category | DIA/INT | 8 | 21 |
| Challenge | Participant's feeling | DIA | 4 | 5 |
| Difficult | Participant's feeling | DIA/INT | 4 | 6 |
| Hard | Participant's feeling | DIA | 1 | 8 |
| Not easy | Participant's feeling | DIA/INT | 2 | 2 |
| **Knowledge** | **Participants' codes regarding what they know about dementia, its progress and care. From three categories: the brain, the disease and the person. 1- the brain: neurology, pathology and changes in the brain 2- the disease: progression and changes, Challenges and Intervention and treatment 3- the person: living with dementia, person's life, norms, also, community, society and culture, carers, family, communication and role of nursing. Nurses' knowledge acquisition and belief system** | **INT** | **25** | **170** |
| believe system | Known/ believe what dementia is (the brain) this includes their understanding about dementia, its symptoms, personal characteristics and causes. in addition to the dementia diagnosis and how participant suspect dementia | INT | 23 | 93 |
| Changes in the brain | The brain: neurology, pathology and changes in the brain. Brian changes and normal ageing | INT | 10 | 16 |
| Suspect-know dementia | Indication and description of diagnosing dementia and/or suspecting dementia | INT | 15 | 31 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| What is Dementia | Participant’s own understanding and definition about dementia | INT | 23 | 46 |
| Knowledge acquisition | participant’s learning this includes gaining knowledge during nurses’ study days, work/personal experience, own reading and searching and this study. When participants were asked about their source of information | INT | 19 | 77 |
| Degree (school-college days) | What participants taught about dementia as requirement to accomplish their nursing degree | INT | 15 | 28 |
| Experience | A claim by participant that they learn by experience | INT | 7 | 15 |
| Searching | Using internet, reading and/or asking experts | INT | 13 | 18 |
| This study | This study implication on participant’s knowledge | INT | 10 | 16 |
| **Perceptions** | **Nurses’ perceptions toward people with dementia and dementia care this includes perceiving a life with dementia, challenges and barriers. Rendering participants own beliefs about the care: who influence it, what are the barriers and how participants perceived the person with dementia** | **DIA/INT** | **37** | **746** |
| Barriers and difficulties | including communication | DIA/INT | 34 | 145 |
| Barriers | What perceived as a barrier in providing care, learning caring and/or training | INT | 15 | 30 |
| Communication | How participants described communication with the person with dementia or suspected dementia | DIA/INT | 27 | 71 |
| Difficulty | Level of difficulty and causes | INT | 20 | 44 |
| Life with dementia | living with dementia, the person with dementia learning/understanding abilities and decision-making abilities as perceived by the study participants | DIA/INT | 36 | 198 |
| Kids | A description of how participant perceived a person with dementia and the way they treat them | DIA/INT | 10 | 13 |
| Learning | Thoughts and opinions about people with dementia learning abilities | DIA/INT | 14 | 24 |
| Lies- not real | Opinion about patient’s complains | DIA/INT | 3 | 5 |
| Living with dementia | Explanation of person’s life by participants | INT | 20 | 44 |
| Making decisions | Stimulating participant’s reflection on patient’s decision making | DIA/INT | 10 | 12 |
| Specialised care | Idea to support people with dementia | DIA/INT | 31 | 100 |
| Observation | When participant claimed that patients with dementia need close observation | DIA/INT | 9 | 12 |
| Safety | Related thoughts and opinion regarding patient’s safety | DIA/INT | 14 | 27 |
| Special care | Opinions of participants demanding a special care to be provided to people with dementia | DIA/INT | 14 | 27 |
| Ways of caring; medication, activities | Thoughts and opinion of participants regarding providing nursing care and implement care intervention to patients with dementia | DIA/INT | 16 | 34 |
| Type of care | Type of care provided to people with dementia that offered by nurses during this study | DIA/INT | 34 | 307 |
| Activities of Daily Livings | includes: Feeding, Clothing, Walking, Positioning, Toileting, Showering and Hygiene | DIA/INT | 28 | 134 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| ADL | Activities of daily living: walking, feeding, toileting, bathing, dressing… etc | DIA/INT | 13 | 19 |
| Clothes | Changing cloths and dressing | DIA/INT | 8 | 13 |
| Feeding | Provide patients with food | DIA/INT | 18 | 38 |
| Morning care (bed changing) | bed changing and personal hygiene for patients | DIA | 7 | 15 |
| restrain | Restrain patients to prevent harming and/or causing injuries to themselves | DIA/INT | 4 | 4 |
| Shower and hygiene | Provide patients with shower and maintain their personal hygiene such as tooth brushing, changing diapers and toileting | DIA/INT | 13 | 33 |
| Toileting | Assist patients with changing diapers and toileting | DIA | 1 | 2 |
| Walking | Assist patient with their mobility and walk them | DIA | 7 | 10 |
| Nursing Roles | - Physical and Pathological - Psychological | DIA/INT | 34 | 172 |
| Physical & Pathological | including: blood investigation, vital signs, discharge patient, cannula and catheter, wound dressing, medication | DIA/INT | 30 | 106 |
| Blood investigation | Blood tests | DIA | 3 | 3 |
| Cannula and catheter | Incursion of blood and infusion canula and urinary catheter | DIA | 3 | 4 |
| Discharge | Completing patient's file to leave the hospital and end their hospitalisation as a result of doctor's decision and end of their treatment | INT | 1 | 1 |
| Dressing | Wound dressing and sterilisation intervention | DIA/INT | 6 | 8 |
| Exercise | Practicing with patient | DIA | 1 | 1 |
| General nursing care | Provide patients with medication and treatment | DIA/INT | 10 | 21 |
| Medication | bed changing and personal hygiene for patients | DIA/INT | 27 | 58 |
| Safety & fall prevention | Actions and cautions by nurses to reduce the risk of fall of patients with dementia and opinion regarding patient's safety | DIA/INT | 3 | 5 |
| Vital signs | Measure patients' body temperatures, pulse rate, respiratory rate and blood pressure | DIA | 2 | 5 |
| Psychological & Sociological | Psychological and Sociological care provided by participants | DIA/INT | 23 | 66 |
| Communication | Developing conversations with people with dementia | DIA/INT | 15 | 34 |
| Convincing | Participants trying many times to satisfy or assure patients with dementia | INT | 7 | 13 |
| Patient centred care | Provide care with respect to patient's needs | DIA | 1 | 3 |
| Psychological care | Reassuring patients and support them psychologically | DIA/INT | 10 | 16 |
| Workplace environment | thoughts and opinions about the care environment including the hospital, current ward, routine and time | DIA/INT | 30 | 96 |
| Environment | thoughts and opinions about the care environment including the hospital and current ward | DIA/INT | 16 | 27 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Routine | Related thoughts and opinion regarding ward routine | DIA/INT | 19 | 37 |
| Time | Ideas on time issue and its management | DIA/INT | 18 | 32 |
| **Professional factors** | **Professional factors effecting nurses' attitudes and perceptions of dementia this includes society and cultural factors and emotions the interpreting the nursing care.** | **DIA/INT** | **35** | **317** |
| Culture | this includes social norms, wording, and religions influences on attitudes and perceptions. and perceiving rewarding experience. | DIA/INT | 32 | 158 |
| Community, Culture, Society | Beliefs of participant related to community and society views | DIA/INT | 22 | 54 |
| Culture & Language | Beliefs of participant related to community and society views and language | DIA/INT | 11 | 21 |
| Experience | includes nurse's work & family experiences | INT | 19 | 30 |
| Religion | The comparison made by participants on treating psychological and physical illnesses | DIA/INT | 13 | 23 |
| Rewarding | Any talk related to personal religion or referencing to God | INT | 5 | 6 |
| Wording | Any talk regarding dementia term: mainly related to the Arabic translation | INT | 10 | 24 |
| Society | society influences on the care provided to people with dementia. Including family and relatives, personal experience with a family member with dementia and colleagues | DIA/INT | 33 | 159 |
| Co-workers | Colleagues and other healthcare professionals | DIA/INT | 23 | 65 |
| Family, relative | A carer with a direct contact to the patient who could be the nurse | DIA/INT | 31 | 94 |
| **Recommendations** | **All recommendations, suggestions and ideas of nurses to enhance the care provided to people with dementia and dementia care** | **DIA/INT** | **33** | **393** |
| Awareness, training and research | Recommendations and ideas regarding improving dementia nursing practice | DIA/INT | 28 | 95 |
| Awareness and Training | including trainings, research, and education | DIA/INT | 25 | 70 |
| Want to know | Spotting what areas participants need to know more about | INT | 15 | 25 |
| Nursing policies | Teamwork, Primary nurse, OT, PT, Recreational therapy, Psychiatrist, Translators, Social workers | DIA/INT | 29 | 82 |
| Nursing care | Ideas and recommendations for enhancing dementia nursing practice | INT | 11 | 16 |
| Policies | Ideas for evolving nursing dementia care in term of care, environment, experience and awareness | INT | 18 | 24 |
| Psychological support | Suggested to have an integrated psychological support for patients with dementia | DIA/INT | 10 | 19 |
| Ratio | Nurses to patient's ratio recommendation by bedside nurses | DIA/INT | 13 | 23 |
| Organisational changes | Ideas for evolving nursing dementia care in term of care, environment, experience and awareness. Includes: environment, wards, tools, equipment, & IDs | DIA/INT | 31 | 216 |
| +ve experience | When asked participants about how to create a positive hospitalisation experience for the patient with dementia | INT | 13 | 19 |
| Accompaniment | Having a watcher for every patient with dementia (carer to sleep at hospital with her/him) | DIA/INT | 9 | 15 |

| Name | Description | Source | Files | References |
|---|---|---|---|---|
| Environment | Recommendations for developing appropriate care environment | DIA/INT | 16 | 33 |
| Identifications | Recommending using cards as sort of identification of people with dementia | INT | 7 | 16 |
| Multidimensional Team | Teamwork, Primary nurse, OT, PT, Recreational therapy, Psychiatrist, Translators, Social workers | DIA/INT | 18 | 41 |
| Specalised care | Idea to support people with dementia | DIA/INT | 24 | 38 |
| Therapeutic interventions | Ideas for enhancing the nursing dementia care workplace | DIA/INT | 12 | 22 |
| Workplace | Non-pharmacological, includes activities, Aromatherapy, Socialisations, Recreational therapy, Occupational therapy | DIA/INT | 16 | 32 |
| **Wisdom & Quotes** | **It was a question to answer and the end of every diary entry for participants** | **DIA/INT** | **17** | **67** |

## J.4 An example of data extract

**Categories and quotes** **21/Sep/2019** 1

| | | | |
|---|---|---|---|
| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
| **1.1/ Acquisition of knowledge and belief system** | | | |
| Gaining knowledge | Brief from nursing school | - ***‘In the college, we learnt about it briefly […] A name of illness with brief talk about it only. I have not learnt that much’*** **P22.**<br>- *‘In college, yeah. Only a subject. Only A subject’* P24.<br>- *‘Maybe, I remember that it was mentioned. But unnoticed’* P19.<br>- *‘YES mentioned in a lecture. I remembered I did a brief presentation about Alzheimer around eight slides only, in the gerontology course. It was one of the topics for presentation, we discussed that but we did not go deeply into it, and not the nursing care’* P19.<br>- *‘We studied psychiatry and it was just a subject … Alzheimer's and dementia’* P02. INT<br>- ***‘We studied about it, however, it was just an idea. Dementia and that’s it. And when we start working, we suppose forgot about it and start all over again to gain knowledge with experience’*** **P03.**<br>- *‘Still only a brief information presented about dementia. Not a book for studying. No, it is a lecture only not even a chapter’* P16.<br>- *‘Honestly, I am from an old school.* ***To be honest they were not teaching us these things, unfortunately nothing was given […] No one motivating us to learn, or called to train us, unless you have the courage yourself’*** **P04.**<br>- *‘In my study period really I did not come across, but we had a visit to this Psychiatric hospital, we had a posting for one month […] for dementia I think one or two patients only I just met that time […] They had lectures for the psychiatric. They had taken class on all the topics […] one topic each day we were discuss […] what are or how the people are reacting, what are the sign and the symptoms, things like that. All the topics were discussed […] Delirium, Dementia that time only, like we were in touching all the topics’* P14. | |
| | Training | - *‘Actually, I do not have it […] when we are in college that we studied about neuro medical issues about the brain […] I do not have this training […] It is just in the anatomy and in the medical surgical nursing, so that is it’* P25.<br>- *‘Actually, I have no training just from the school what I learn and I am just applying what I remember’* P13.<br>- ***‘Even during the intern no one provide information, we had spent the most in the medical, surgical, OR and such wards. But dementia was not anyone’s concern’*** **P16.** | - |
| | Theory and practice | - ***‘When you care and work with them is differ than when you study.*** *Honestly, when you deal with them you will develop kindness, forbearance, and tolerance toward them […] Toleration and patience, things that we did not have it while learning theoretically but we learn it from the experience when you face the patient’* P15.<br>- *‘Overall it was hard because what we have studied differ from when we had real things. Even though I learnt about Alzheimer during study days but I never dealt with Alzheimer's patients, so, this is the core obstacle’* P02. INT<br>- *‘It was in the theory only, but never cared for them during the placement, study days or intern. Only theory’* P08. | - |
| | Experience | - *‘From my opinion every patient is differ from another ... from what I saw. I've seen two patients how were extremely different. One ... the patient I provided the care for, was not aggressive as the patient I saw how was extremely aggressive… so, it's differed from a patient to another’* P02. INT<br>- *‘It is differed for sure. Even by number of patients experienced. The greater number of patients you care for the more you become understand'* P15. | - |

| | | | |
|---|---|---|---|
| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
| **1.1/ Acquisition of knowledge and belief system** | | | |
| | | - *‘From my experience, when I know that this patient with dementia in certain situations I know that he will behave like this. And accordingly, I can deal with him’* P21.<br>- ***‘Every day I become more aware and learn new things regarding them, know their suffering, and know that is not their will to talk or behave like that’*** **P05.**<br>- *‘The information I have, is from my experience with my dad. He is affected with Alkharaf’* P15.<br>- ***‘[…] there are some instances I remember my grandmother […] this should not be done, this is not the proper way, she should have done this […] I thought that something might be wrong to her’*** **P13.**<br>- *‘I started discovering patients. Before I did not know why she is doing this! I do not know and I did not have any idea. I had no idea that it is dementia; was far from my thinking. Then later I discovered that it is her memory as she is calling people and things that was suspicious to me and abnormal. So, I surfed the net it Kharaf what came to me especially when I saw the staged and what is going to happen next. Then with seeing more patients I kind know that this had dementia and so. But regarding courses and trainings I never attended and I did not see any’* P16.<br>- *I like to learn more about Alzheimer’s, and that because my grandfather I mentioned also in this that he had Alzheimer’s also.* | |
| | Self-learning | - *‘In my work I had the chance to care for patient with dementia, from his behaviour I discover the diagnosis and possibility of having dementia from the symptoms. Then I read from the internet and so’* P21.<br>- *‘Honesty, I did not know about the term dementia. I was working and one of the colleagues said dementia; then I searched on the net about it, I did some reading. I have some knowledge from one of the family members who have dementia. But the problem I was not familiar with the term only’* P04.<br>- *‘[…] gather information in the Wikipedia […] I read in the internet I checked what is dementia, what causes dementia, what are the stages of dementia? All the things I just read. So […] maybe I can help the patients and their family members’* P13.<br>- *‘I searched the main topics. Such as Alzheimer and what is happening in the brain […] I saw different photos of before and after. Also, I saw pictures of carers and how they treat their loved ones; for example, a couple wearing a T-shirt written this is my husband and the other written I am […] What I admit that it is widely spread, also there are some solutions. Some are having devices for elderly to use when they are going out. There are several things been developed and available out there’* P19.<br>- *‘We do not have here educational courses for Alkharaf and dementia. Nothing. Only briefing information available in the internet to read. But not widely speared, No’* P16.<br>- *‘I love reading articles. Reading articles in English. That’s why I had somehow an idea regarding dementia’* P03. | - |
| | This study | - *‘Before the survey, I had basic knowledge. But after I started reading more. especially when I was looking for the cases; how to treat patients, what obstacles nurses may face and general awareness to be knowledgeable about the topic’* P04.<br>- *‘Before I had simple knowledge such in providing the care we need to be kind to them. But after involving in the study, I asked doctors and I felt it is another world. A world that no one notices its existence’* P20.<br>- *‘I had been encouraged to look for the differences between Alzheimer and dementia’* P19.<br>- ***‘I felt that I become more curious about this subject. I was looking for these patients to investigate the differences and how the behave. I mentioned that I was not focusing on this matter before […] definitely I benefited from writing diaries’*** **P19.**<br>- *‘Really I was not knowing anything. But when I read I had the feeling to dive deeply into it’* P22. | - |

| **1/ Nurses' perceptions toward people with dementia and dementia care** | | | |
|---|---|---|---|
| **1.1/ Acquisition of knowledge and belief system** | | | |
| | | - *'I am now eager to know more about it because of this study. But before that, I was like, "Okay, I am in surgery, so I do not need to learn" But after you conducted the study ... I Become curious'* P24.<br>- *'Honestly, the diary added a lot […] really from the diary, I get to know dementia and its patient better'* P21.<br>- *'On the first two days it was very difficult, and I was thinking about drop off or leaving the case. But then on the fourth day […] he smiled (the patient). this motivated me and on the next day I came excited to see him and read the documentation of the nurses to see how was his day and night after my shift yesterday'* P05.<br>- *'I feel, far from evil, when it is affecting your relative. This will motivate you to search and know more. Or when you care for a patient who you don't know how to deal with him, this will make you search about the disease to know how'* P02. INT<br>- *'I didn't undertake any search about it because I feel the time fly so quickly. I mean 12 hours we stay here to work without rest'.* P02 INT | |
| Known about dementia | Definition/ Characteristics | - *'[…] he can forget names or places and cannot recall except the long-time memory. I never knew that even small things the disease is affecting'* P03. DIA<br>- *'He is forgetting a lot, the recent event mostly forgetful and remembering things happened in a very long time ago or the opposite mostly this is'* P08.<br>- *'Well for me generally in school what I learn is dementia is a there is problem in thinking cognitively and everything is deteriorate as if you will lose memory like that'* P13.<br>- *'Forgetfulness, forgetting information and confusion about the past, overlapping times, and not remembering the does things happened. My dad used to tell me about things happened 20 years ago, he talked about a land that been sold since then and insisting that he still own it and he never sold it. We convoy him 'yes you have this land, it is correct, what do you want now! Why you are looking for is what the benefit of knowing that is or finding it!' Just convoying, cannot say that 'what you are saying is lies, from your imaginations, something past or ends''* P15.<br>- *'Not only forgetfulness. He will lose everything; the joy of life, joy. Everything. Will back like a new baby. You have to deal with him like a baby that need to be raised again. And he will forget what you taught him as well'* P22.<br>- *'Dementia and Alzheimer are one thing. Which is Kharaf and forgetfulness'* P19.<br>- *'Is kind of Kharaf, somehow Kharaf... mmm It is actually Alkharaf. Something happened in the brain, inside the brain that makes the person's memory differ than before. He will be having and storing the old memories but not the recent events. He will... the person will be with you for a while then later he will not be; changing and swings. It is a brain disorder, disorder inside the brain'* P16.<br>- *'As far as I know dementia is not really a disease. It is caused by brain cells that has been damaged so that made the person confused or lost his memory. So, we have different types of dementia. The common is the Alzheimer's disease that made the people lost their memory. They cannot even do their daily activities and then they tend to forget what are the things really need to do such as brushing the teeth and then also there is vascular dementia. So, it is caused by post patients with experiencing having stroke and then we have this Lewy body dementia and then alcohol type dementia. Those who are alcoholic patients'* P23. | Progressive brain disease<br>Brain cell damage<br>Group of symptoms<br>Short-term memory loss, recall long-term memory<br>Forgetfulness<br>Confused day/time , delusions<br>Cognitive problem<br>Affect reasoning and thinking |

**Categories and quotes** **21/Sep/2019** 4

| 1/ Nurses' perceptions toward people with dementia and dementia care | | | |
|---|---|---|---|
| **1.1/ Acquisition of knowledge and belief system** | | | |
| | | - *'Dementia is disease that effect the brain. The person will lose part of the memory, gradually of course. Firstly, he will forget about his stuff and things around him, maybe where he places a key! Then gradually he will starts forgetting anything around him even his valuables'* P22.<br>- *'Dementia is progressive changes in the person's ability to think and perceive things, so that is how I define it by myself. There are lots of courses, some are more on the disease process when they have some diseases. Others like degenerative when the person are getting old so we have brain degenerative issues so that makes some changes in our brain. So it is dementia it is more changes on the brain, so how it works'* P25.<br>- *'Dementia is a group of symptoms. It is chronic, I mean progressive. Researchers say 70 to 80% of Alzheimer's disease will progress to dementia. Alzheimer's disease is the first main contributor to dementia. That is what I know. They lose this cognitive skills. They have the skills then they will lose it'* P24.<br>- *'As far as I know it is a lack of neurons or something that has to do with the brain. One of his symptoms is forgetfulness and so on'* P21.<br>- *'Mainly it is about memory loss and forgetfulness, then it's due to, there is, in the brain cells there is supply of oxygen and due to that you can have Dementia. It includes another the worst disease also like Alzheimer's disease and Parkinsonism, all this is included in this dementia, so its wide area to say'* P14.<br>- *'I already wrote in my experiences that I always know. Because irrelevant talking and delusion, they can feel something. One day one patient, we are caring her, then she was telling somebody standing there "I can't see." It's a delusion it is a kind of delusion'* P12<br>- *'A patient who have a problem in his short memory. The things that happen, events, people and faces that he forgets. His old stuff since he rises-up, his family and events some can recall them back but others how are in advanced stage they won't'* P03<br>- *'Patient with dementia are confused about day and night'* P23.<br>- *'I believe it is a disease just like any other disease is. like cardiac patient, it is not impossible to get and it is happening'* P02<br>- *'Dementia in younger age!! no never faced'* P08<br>- *'Alzheimer's patients are very sensitive as everything around them is different, the disease hinders social relationships that cause their sensitivity. I observed, they are so nervous because the easy tasks they used to do before now they struggle to do'* P22.<br>- *'I just know that always people with dementia is not remembering the recent. Mostly they remember old things that remains in their memories. I know hmmm that they are at risk of being lost; forgetting their house location, even their medication'* P02<br>- *'(Laughing) Frankly, I do not have much information about dementia. What I know is it is a cognitive impairment, rather it is Kharaf, and I cannot get it exactly it is kharaf. Mentally will be incomplete, mmm I do not know how to say they will be confused about the place sometimes this is an outline but I do not know its definition exactly'* P04.<br>- *'(laughs) Dementia is an organic mental disorder. Usually it's happening from the old age, there will be memory loss, and there will be oppression in consciousness and orientation'* P12.<br>- *'He is Alkharaf patient that affect people above 60 years old or maybe 70. They will be affected by Alkharaf which is forgetting information and forget where he is. Remember old events and unreal things! things from his head he making it'* P15 | Risk being lost<br>Like cardiac illness<br>Negative-mentally incomplete<br>Few participants said dementia is part of normal ageing and other claimed it is a cultural norm<br>Kharaf<br>Dementia is Alzheimer's... few admit that Alzheimer is one of dementia types |

**Categories and quotes** **21/Sep/2019** 5

| | | | |
|---|---|---|---|
| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
| **1.1/ Acquisition of knowledge and belief system** | | | |
| | | - *‘She is an old lady, gradually she starts being forgetfulness. Some of the signs been shown; telling something and after five minutes forgetting’* P04.<br>- *‘It is as a result of them getting older and this is normal at this age […] not everyone will have dementia. I do not expect too. There are so many people became aged but did not affected by dementia. Maybe the health. if the person is taking care of his own health, exercise and lifestyle, I believe if he was a healthy person he might not be affected by this, somehow’* P19.<br>- ***‘Most people say this old lady is aged and she is Kharaf. It is normal to get Kharaf, part of the normal aging*** *[…] they thinks this is a part of normal aging, and they are old aged. And they don't care if the situation deteriorated, though we can maintained their brain. By braining; brain exercise’* P03. | |
| | Nursing care | - *‘Nursing care … nursing care. Nothing special for patient with dementia as they are like other patients. Maybe the only different is the patient behaviour and some are isolated’* P04.<br>- *‘Ah from my school. The most thing I remember is people with dementia you should orient them to the reality if they are having difficulty remembering things like that. You can help them remember things like for example knowing what is their daily routine usually, what are their favourite things, what makes them stimulated like that’* P13. | orient them, have a routine, treat them different isolate them |
| | Difficulties | - *‘Dementia is a little bit difficult to handle, good communication and patience is needed’* P25.<br>- *‘Every patient with dementia has different needs should be met all these needs’* P21.<br>- *‘He has not got any basic information that lead him to communicate.* ***Also, he cannot express his needs! I have to discover what his needs are? Especially if he has gait and movement problems; If I was not there to help he will be laying only stiffed in one place’*** **P05.**<br>- *‘In childhood, the person is expressing by screaming. In adulthood he can express by all means. But they in a phase of despair, psychologically ill with disability, they are in a very critical and difficult phase. So, the person when he knows the problem he must try to help them as much as they can. They are in trouble and need anyone. Besides they are not asking for help, they are not asking. only the sympathetic people to them will knows (* *في مرحلة الطفولة ممكن يعبر الواحد فيها بالصراخ، ومرحلة البلوغ ممكن ان يعبر بكل الوسائل، لكن هم في مرحلة يأس ونفسية مع عجز هم في مرحلة جدا صعبة في داخل مشكلة بحاجة أي أحد)’* P20 | Communication<br>Cannot express needs<br>Gait, posture, movement<br>Every patient has different needs<br>Require patience |
| | Causes | - *Likely to happen after CVA (Cerebrovascular accident). Some cases of CVA and some psychology cases... and sometimes Genetic but it is rare. Only this is most of the information I have’* P20.<br>- *‘I asked A female doctor about it and she told me that "most of cases, after CVA they starts developing somehow Alzheimer that worsen by time gradually until they are done"’* P20.<br>- ‘[…] it is normal due to some brain some area damage contusion that is the things this one. But to the diagnosing as the patient is delayed maybe due to some atrophy happening in the brain’ P17<br>- *‘So Alkharaf can resulted from hereditary, Alcohol or drugs that may result in disease deterioration. as a risk factor’* P08<br>- ***‘I believe that if the person was well educated, read a lot, looking for information and gaining knowledge […] may minimise or delay the occurrence […] using google, I found most risk factors that may cause Alkharaf are; hard life events, genetics, and sometime they do physical jobs rather than cognitive as journalists or teachers’*** **P05** | CVA and strokes<br>Brain atrophy<br>Genetic and heredity<br>Life events<br>Life style<br>Busy brains and exercise |

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| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
| **1.1/ Acquisition of knowledge and belief system** | | | |
| | Suspect/know a person got dementia | - *‘If it wasn't diagnosed ... from his talk, he don't know where he is, he doesn't remem- don't know who is with him his/her wife/husband. This thing may lead me to know that he got it. That is to say, if there is decrease in the level of consciousness it is impossible to forgot the person, accompanying person’* P02<br>- *‘Some patients they came with the diagnosis, from the patient's history taken in the ED; the family were saying that the patient been diagnosed by patient's neurological or medical doctor who told them that they got symptoms of Alzheimer. Some patient I say they got dementia by experience I knew and I claim that’* P03<br>- *‘Basically, from his diagnosis in the file. Otherwise, we may suspect and observe that the patient is mostly forgetfulness, telling something and soon after a minute or five minutes later he is forgot what just said. From patient's behaviour it will clarify that’* P04.<br>- *‘He is having unrelated thoughts, never related, not talkative, also he is not bothered about his movement and cleanliness. Sometimes may get hurt by something and he could not realise that or will be unaware of the consequences’* P05.<br>- *‘If their language and their movements are not coordinating. If they are doing things that are not pleasant to the environment to the society. So, I think that is dementia patient’* P23<br>- *‘They will be uncomfortable to the place at all. Distracted in thinking. Disturbed by voices and lights, and cannot set stably always want to move. This is my observation’* P22.<br>- *‘Well, actually, when I’m giving care to the patients I suspected they have this disorder dementia. Because their function is not normal like that once other older... I encounter what is normal like that’* P13.<br>- *‘How do I know this patient had dementia? His symptoms, dementia symptoms; more forgetfulness, he is making you nervous. Mostly, patients who are admitting here are having dementia with bipolar, mostly. This patient I cared for him had dementia with bipolar. The majority of his actions are volatile. He has mood sewing up and down only the behaviour change’* P08.<br>- *‘One patient with already diagnosis, the others, only suspected’* P12.<br>- *‘This dementia peoples, they will have the memory losses. I think it's the first sign we can identify in dementia patients. Their disoriented and we rely on talking, sometimes they are not talking related to the person things’* P12.<br>- *‘I already wrote in my experiences that I always know. Because irrelevant talking and delusion, they can feel something. One day one patient, we are caring her, then she was telling somebody standing there “I can't see.” It's a delusion it is a kind of delusion’* P12.<br>- *‘Because there are things they are doing that from what I learnt from school that categorized us dementia, Alzheimer's and so like forgetfulness, not thinking correctly, like that’* P13.<br>- *‘Yes prospect never diagnosed’* P15<br>- *‘I do not know. Maybe lack of awareness, or maybe the social norm and society do not like that’* P15.<br>- *‘For example I treated the patient and I told her that I am the nurse I will care for you today then routine checks for example after two hours you will check and then she will ask you who are you! She forget me like that dementia’* P13.<br>- *‘Because their ... What is this? Their behaviour do not coincide with what they show. You get me? The just show is different from what they say. Yeah.* ***They behave differently from what they are saying and they have mood swings. Sometimes they are friendly and sometimes you are their worst enemy they have, like this’*** **P24** | The person being forgetful<br>Delusions<br>Unrelated thoughts and talks<br>Acting different than what appear.<br>Mood-swings<br>Long-term stay<br>Quite<br>Irritated<br>From the experience<br>Makes you nervous<br>(add the quant from diary-suspected)<br>Comorbidities (not diagnosed, family informed) |

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| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
| **1.1/ Acquisition of knowledge and belief system** | | | |
| | | - *‘Actually when you know that the people, like there are some, what do you call this, with abnormalities in how they perceive things like when you ask question they deviate from what is normal answer, the normal answer. So, you will think that they, like for example you go to the patient you ask him and then he will have different answer and then when you did something to them then they said you have not done this things to me so maybe. You can observe like the patient himself is forgetting a lot of things. So, you, for me, I am thinking maybe this patient, we can see say that, like for example, age, the patient's age. So, maybe a patient is already having dementia having forgetfulness, because that is how I perceive this’* P25.<br>- *‘From the history, I read the file of the patient from the history collection. The doctors also did initially but I may personally I just gathered information from the patient. Possible information from the patient and other relevant information was from the family members and also the social worker they cooperated with me during-‘P14.*<br>- *‘Diagnosis in the file, secondary diagnosis it is written, like Alzheimer’s, Parkinsonism and like that it is mentioned, but the initial diagnosis it’s something else due to which they came here, but the secondary diagnosis it's written like Alzheimer’s and Parkinsonism like that’* P14<br>- *‘Always with other diagnosis’* P08.<br>- *‘Honestly in the emergency we had cases but not the main complain. It is not the main case that we concentrate on. But when the patient is long-stay I observe. But with minimum simple care by communicating and so’* P20.<br>- <u>*‘NO, no no, Although at the time of admission his family told us that he got dementia, they have a family history of dementia, some are providing numbers of how many in the family having dementia but still not written. They are treating him physically like any other patient and ignoring the dementia’* P21</u><br>- *‘If patient old age like I think five or less than three who admitted here in the ward with dementia. But not really diagnosed. Suspected’* P23<br>- *‘[…] But I do not see especially in Saudi Arabia and I hope I wish these things will be because more our patients especially those who he has age there is some age they can be categorised regarding the dementia. But here the problem is in the hospital late to specify the people. And that is why the care is not what I mean’* P23/17 | Slow system in diagnosing dementia |
| | Explain dementia to the person with dementia | - *‘For the patient himself!! No this is difficult. He cannot understand his case! He cannot understand, cognitively unaware’* P05.<br>- *‘I do not think that I can explain it. What can I say to him? I will tell him his current condition, I will not say that you are a dementia patient. Maybe for example tell him you are a little bit forgetting. I do not know’ P22.*<br>- *‘I will tell him that now you can't memorise the recent events that is happening but you do remember the old memories from the past.... you may don't know ... some moments you don't remember your family, but in some moments, you can recall them back and you know who they are’* P02.<br>- *‘Explain dementia to him!!! I believe it is difficult to say it frankly or explain. Though it is important to let him understand it, but even I told him he will forget after a while what he have been told. Try to convoy him (تأخذيه بالسياسة). "You are here to check up on you and making investigation to be assure you of your health". I may treat him like that 'Convoying' (بالسياسة) and will not say it frankly that you had Kharaf. If he have his family with him I will leave it to them to explain that information as they it may deliver better than from me as a nurse’* P19. | Difficult to be frank and say they got Kharaf; rode and they will not understand<br>Leave it to the family and must tell the family in |

| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
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| **1.1/ Acquisition of knowledge and belief system** | | | |
| | | - *‘Not all patients are wondering or asking why I am forgetful. Only one patient interested me who asked how my leg been fractured, why I can't remember. me and her daughter told her the story as one day you waked-up and fell out from bed then we brought you her. That is ok that you do not remember, do not worry, we are caring from you. She may not understand my talk in details but she will feel safe and I reassure her that I am with you. This is what she understands and feels’* P03.<br>- *‘Mmm I will not be frank and rode in my expression. I will say that "you are going to forget these days more but do not worry we will remind you" and being kind. "You are going to help me...." be kind and nice. But being honest in telling the diagnosis it is very hard. He will spend time thinking about it more than in treatment that will collapse him psychologically.’* P20.<br>- *‘It is very difficult. But anyway, if I talk to the patient having dementia I will tell to him the truth. If he understands or he will not understand, you should give him the exact thing that is happening to him. So, I will explain to him that you are undergoing a process of dementia. It is not a disease but you are experiencing memory loss. Eventually, with the help of your family with the help of your nurses your doctors, you will be okay. I need your cooperation. I need you to be with me whatever our activities, I hope that you will cooperate because this is for your own good. What we are doing is for your own good’* P23.<br>- *‘In simple language we can tell them that what is dementia basically that initially will try, even you may not be able to remember the things, the recent events so do not get worried, do not be panic. If like that we are there to support you, we are there to take care of you. We can assure them that we are always with them and this is not a condition or a disease that it is very serious or, it can be cured if you are taking proper care of them. We can assure them with positive thoughts’* P14.<br>- *‘Fine I can explain to them and tell them about the disease.*<br>- *"He is having a disease called Kharaf. In his case he may not remembering every things, even not remembering people and places. Also his behaviour's changes, he may act aggressively..."’* P21.<br>- *‘The family, it is their right also to know and we will just say she has some […] her mind is challenged and you (the family) just need to support her’* P24.<br>- *‘The family, I will rise their awareness regarding his ability to understand and cognitive ability. His movement maybe random. This what will happen’* P05.<br>- *‘Now family members are the most important that we should explain to them about this topic because they are the ones also caring for the patient with the dementia. So we can explain to them how it is, how do they feel and how the family member should cooperate with them and also take care in their activities of the daily living and participate with them. Communicate with them most importantly. Each words whatever you are talking it should be specific and not, it should be simple. Keep it simple whatever you are talking to them so that they can understand and concentrate so that just when you are talking to them look into their eyes and talk so that they will also have cooperation with you’* P14. | nice way ‘not kharaf’<br>Convoying<br>The person will not recognise. No need to upset them |

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| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
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| **1.2/ Perceiving a life with dementia** | | | |
| Preceding a life with dementia | Living with dementia<br>Behaviours | - *‘It is not a nice thing, because you can see some patients and family were really struggling and they see the disease is critical for them. The families overthink to know about how they care in detail. Some patients are not honest with their families. So, the care is depending on how the patient-family relationship is and how they care with them. When the family knows how they care for their patient it makes things easy for me and I can care smoothly. On the other hand, if the family were hiding some from the truth, or they abuse the patient here I don't know what I must do, shall I be with the patient against her family or what. They are the carers and the patient will live with them at the end, so we don't want things to get worse. And here in the hospital, the social workers role are not activated and they will not take a part unless a major problem or conflict happened. Even when major things happened, their actions are useless. Mainly, it depends on us, if you are educated, reading a lot, and knows advises you will offer them. But if you don't know and you don't care that is it, no bother’* P03.<br>- *‘They been through a lot of ups and down’* P03.<br>- *‘One day, while I'm with my patient she was very sad and crying. She touched my feelings deeply. When the day started she was normal; eating and drinking as routine, suddenly from nothing she starts crying, they have a mood swings while it looks nothing happened that cause her to cry. But she was in a moment of clarity, her memory came back then she realised that she is abandoned and no one wants her. So, she felt sad and cried because she can't do anything for herself. She was sad, sad for herself, she said I'm sad for what happened to me. You can say it touched me and my feeling that she was lonely’* P03.<br>- *‘He has not got any basic information that lead him to communicate. Also, he cannot express his needs! I have to discover what his needs are? Especially if he has gait and movement problems; If I was not there to help he will be laying only stiffed in one place’* P05.<br>- *‘There is no expressions! But from what I have observed on my case; when he was hungry he looked like searching for something but this was for expressing his hunger. But was not looking for entertaining or reading. When he is looking for something it will be about food, and when I give him the food any kind he will directly put into his mouth without seeing what it is! Not caring if he likes it or no! He cannot distinguish’* P05.<br>- *‘Of course, it is increasing. every day I become more aware and learn new things regarding them, know their suffering, and know that is not their will (ليس بارادتهم) to talk or behave like that’* P08<br>- *‘Yes, they are hearing so many voices that can confound the patient (يرتبك)’* P08.<br>- ‘That patient, they have memory losses. Sometimes they will be in confused state. They need assistance in their daily activities’ P12.<br>- *‘Mmm suspended between heaven and earth’* P19.<br>- *‘He is not living the disease totally nor communicating with people on earth and living people on it. He is lost and do not know what to do, go up or stay down!’* P20.<br>- *"Today I am a stranger to my grief, a strange to my heart ... I stand in front of grief I cannot understand it, and I did not want before."* P03.<br>- *‘Exactly. The patient is always sleeping and in a depressed mode. When I talk with him he is interacting and I believe he is happy that result happiness come to me’* P21. | Undesired condition, do not want beloved ones to be affected with<br>Patient is a stranger to the self and living in unorganised world.<br>This due to person with dementia being confused and confound<br>Went through a lot<br>Unstable, mood swings<br>Cannot express their feelings or needs<br>And demanding on others<br>Need their families to be around<br>Despite that, people with |

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| **1/ Nurses' perceptions toward people with dementia and dementia care** | | | |
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| **1.2/ Perceiving a life with dementia** | | | |
| | | - *'Indeed. Most of the times he is not remembering. Not remembering me he is asking "who are you? do you know me?" even though that I am daily with him'* P21.<br>- *'Dementia patient always unstable having mood swings (متقلب). You will see him smiley, quiet, and peaceful at a time. Then he will be aggressive in another and that is normal. He may refuse eating at a time, the other times his appetite is increased. Sometimes he become completely blanked and does not remember anything, then other times he is memory is back to him'* P21.<br>- *'His life. First of all, he will be exhausted and exhausting his family with him. I never can care for a patient with dementia alone, all the family must contribute in the care. We need to help each other's on him because it is very difficult. Once, a patient with dementia having fear of sunset he is afraid of dark. I need to arrange his day and control his sleep. I will not let him fall asleep during the day. So once the night came he will sleep peacefully. Also, the patient will be almost all the time forgetfulness. Forgetting his family and you, a moment is knowing you then not and so. I expect like that'* P22.<br>- *'I feel that somehow the life will be not organised. Maybe he will be with you in the living room then leave to another place without knowing where. Maybe asking for something he does not need, but he remembered it and asked for. Even his personal care is little. The fear for them will increase, fear of getting lost, and they need the care more often. He might not be concentrating, does not know his needs, he does not know his needs and what exactly he wants and he does not know his needs priorities. This is how I imagine the patient with dementia'* P19.<br>- *'I am thinking because of visual hallucination only or if suddenly she remembers something from her past I do not know. Maybe some traumatic thing happened to her because that patient was neglected by the children and when she was in the ER her history, she stayed long time in ER because no one wants to take her even if they contacted the family members. At first they are able to contact the family members suddenly no longer able to contact the family'* P13.<br>- 'Right, some family members, after the patient will get sick, they will throw them in the hospital, or in here we handle the things of that nature. In my opinion they should assist the patient, and they should give more psychologic as sample. Patient need always the present of family, more than the nurses (laughs)' P12<br>- *'Well, I can say that for us how do not have dementia are really lucky that sometimes our day to day life we complain because of this because of that but for them they are stuck in the reality they believe in. for example, they can only remember one person one event like that! And its I pity them also if the thing that can remember is the thing that makes them feel not good like that'* P13.<br>- *'(Laughing) their life! How I am going to do? It is different not like our normal, how we are normal human being, it is different for them. Their way of expression, their way of thinking, their thoughts, and their feelings towards everything is different. So our perspective how to look after them it should be different also. For that we should first study about this how it is and how to care for such patients. And their routine things are also different. How they verbalise their feelings that is different, how they communicate, maybe if we are doing, we are communicating well with it is not necessary they will respond to us in the same manner. So we should be patient enough to listen to whatever they are telling and accordingly we must care for them'* P14. | dementia are abandoned as a result of causing a burden to their families and carers<br>Their behaviours and acts are not of their will and something they do not have control on<br>Difficult life and awful<br>Lies/ delusions |

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| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
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| **1.2/ Perceiving a life with dementia** | | | |
| | | - *‘KFSH but he is not 100% forgetful, he is forgetfulness somehow and sometimes he is remembering things happened 20 years ago and telling that it is happening now’* P15.<br>- *‘He will be insisting that his talk is correct and right. Insisting and nervous (عصبية) that he is right. He is unexpected that what he says is from the past or did not happen! So we have to convoy (مسايسة) the patient 'yes you are correct, even I do not believe what you said but I will not make you feel that you are liar'. He have feelings and emotions and will start being aggressive and maybe change-over you so we have to convoy him 'yes you are right, when it happened, give me details, and tell me more' and so on. Take as much details as you can to investigate his talk and to compare’* P15.<br>- *‘A person's life with dementia, it is awful. It is awful because it is not normal. Because they want something they do not understand. They are psychologically and cognitively challenged. They do not understand what they feel. So, it is sad to know. Unlike people with physiological diseases, it is different. You have hypertension, you have diabetic, but at least you have your sane mind. You are still you, but people with dementia they do not know what they are doing. They somehow lose themselves and so it is sad’* P24.<br>- *‘Actually maybe his life is like, it is difficult, for a person, especially if the people surrounding him does not know or does not have any idea what he is having. Like for example, he might feel like he is a burden. To the others, especially to his family, and to other people. But there are some maybe that they don't have the idea, maybe they just feel that it's just normal for them having this’* P25.<br>- *‘We have to feel that dementia patient is a client who got feelings even though some of his talk is lie or unreal but we must deal with mortality, fear of Allah and kindness’* P15.<br>- *‘We must feel/understand that Alkharaf patient is a human who got emotions and feelings and that some of his talk is not real and lies, but must care with empathy and mercy’* P15.<br>- *‘The patient sometime insists on not-existing events that stuck on his/her mind, which makes him sad or happy The person lives the situation until proven otherwise, so insisting on opinion and sometimes changes and become forgetting’* P16.<br>- *‘He is Alkharaf patient that affect people above 60 years old or maybe 70. They will be affected by Alkharaf which is forgetting information and forget where he is. Remember old events and unreal things! Things from his head him making it ( يجيب أشياء من راسه يؤلفها)’* P15.<br>- *‘The patients I receive in OPD and then in patients as well. At the beginning I was wondering why the patient is denying and wonder about his behaviours maybe the patient is lying but then I discovered that the patient is not a liar his family admits that he is affected by Alkharaf and I have to provide a special treatment (dealing) for him. But still we did not reach the sufficient information and acquired knowledge that makes us provide care for them. We really need courses and awareness in each hospital. It will be better to have an intensive training for it’* P15. | |
| | Kids | - *‘Mmmmm the life of the person! A kid at the end, consider a kid. With much pureness and spontaneously. Sometimes like kids. finally they will be like kids’* P04<br>- *‘If the person is ambulatory he may open the door and go without return, he may be gone. So, he need someone observing and watching him. The ambulatory person is differ than the bedridden one. The bedridden one he may watch TV, stay next to* | Most participants perceived the person with dementia as a kid, demand and … |

| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
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| **1.2/ Perceiving a life with dementia** | | | |
| | | *him talking, tell story for him, show him stories, old photos or old memories. So, he will be smiling remembering these things. Events or stuff and so’* P16.<br>- *‘Care for this patient sometimes is easy and days are easy going, and there some days are heavy and difficult. I treat this patient as little kid who need care love and attention from family and relatives. I never blame her if she said something inappropriate or abuse or even was aggressive. At the end she has no one but us, nurses, we are her family/daughters who will be always there after her real family. No one deserve this disease that caused by Fate (Gadar)’ P03. DIA*<br>- *‘Yes, it is Gadar and a test from Allah. He is testing our patience. It need patience especially when the person is becoming forgetful, it is harder than when have a patient with his cognitive functioning well. He need care. It is a test and Gadar ( ابتلاء/من الله وقضاء وقدر). Mostly, from medical point it is caused by depression or been exposed to grief of a family member, it is highly relying on his psychological status’* P16.<br>- *‘Nursing care focused of self-care deficit my patient refuses to take her medicine. I mixed it to her food (jelly) and acted as a mother giving food to her toddler’* P13.<br>- *‘In my opinion on dementia patient is to treat him as we treat children; from the care, simplifying what is difficult to understand and flexibility in communication to not make him feel that he is unable to communicate’* P20.<br>- *‘In general, because I am a quite person, have patience and I do not lose my temper. I treat them like children, who needs patience, watching the words never say wrong word or treat with disrespect. Some are saying that is fine to be harsh on them as sooner or later they will forget. No, I refuse that, I treat them like kids, I need to simplify the sentences in small easy words’* P03.<br>- *‘Well, for me I think it depends also on the contact they are having to the persons. if you talk to that person frequently, then they can adapt, they will and can adapt that 'oh someone here for me, so the is it, this is that..' like children learning how to stick again’* P13<br>- *‘Frankly this is what I observe. You cannot imagine how much they are struggling in performing their tasks; in eating by time they returns like kids, some of them they have tremors and unintentionally throwing the foods. They have difficulties and clear significant differences. They need to have somebody with them accompanying them and watching them exactly like kids. As we fear that kids can exposed to anything. They may be getting lost and harm themselves without they realise that’* P20.<br>- *‘(Laughing) Oh God. I feel the patient with dementia is like a kid. I mean... He always like familiar faces for him and when you are familiar face to him he will treat you differently. Even though that he is forgetting but 'Glory of Allah سبحان الله' he can know that this person is frequently coming to see him. Maybe trick him by words, I have to do introduction (مقدمات له) not directly coming and asking them to do the task. Must be in a good manner (باسلوب حلو) "Take this medication uncle to recover and you can go home to your kids...” and so’* P21.<br>- *‘The patient treated by the nurses you are abnormal because he is the one who remove these, you know back as baby that is the dementia. He will go back like and in this time no one he understood as the patient and he has this problem on dementia and this doctor maybe dr *** our neurosurgery doctor consultant. He shout to nurses and to people here you cannot do this to tell this about baba now is crazy. You should need to understand what he has exactly’* P23. | They perceived the person with dementia as a kid who need… Requires close observation and more time to spend with |

| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
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| **1.2/ Perceiving a life with dementia** | | | |
| | | - *‘Yeah, starting from feeding them, you need to give time, because those people, sometimes they became like babies that they need to be taken care of. It's the same, like [...] yeah, feeding, assisting with the ambulating’* P25.<br>- *‘The doctor just they take care about the nurses and do not hear that I need you to explain for you something and then you never and remember this is what I need to tell you. When the patient discharged. They think the problem with the family. You know some family will accept it. Some family not accept it. What is this disease is different from them? But he has more acknowledgeable and more of his patient he will take care or he will send them back what she said to rehabilitation and then that is the program. Because the patient everywhere will come again and then best what I get to tell the patient. Because you know sometimes the memory back. Sometimes memory not back. The same baby I told you will attitude everything this one. But the best things a treatment used. Sit with him, let him to try to like something and everything the best and the best if really, he knows how to read just give him every day at least to read one book one journal this one. He will back. But if you neglected for him and never and ever’* P23.<br>- *‘Well, for me I think it depends also on the contact they are having to the persons. If you talk to that person frequently, then they can adapt, they will and can adapt that 'oh someone here for me, so the is it, this is that.’ like children learning how to stick again’* P13. | |
| | Learning abilities<br>Understanding the condition | - *‘He will not understand, even if I told him, even millions of times he will forget. His family for sure knows that he got dementia’* P02.<br>- *‘No, it is difficult to explain. It is something inappropriate to do. Firstly, he will not understand what you are saying. He may understand sometimes but it is useless’* P04.<br>- *‘No, I will not tell her of course. She is not caring and unaware about her condition’* 04.<br>- *‘It is a difficult question ... from my experience and what I have been through, that arguing the patients is useless; that is why I said it may be inappropriate to talk to them. Because he is already a patient and will not understand. He will not get benefit of telling him neither you. He will not understand. Maybe for the family, it is usual to educate them about the disease and so’* P04.<br>- *‘For the patient himself!! NO this is difficult. He cannot understand his case! he cannot understand, cognitively unaware’* P05<br>- *‘I may not describe well, but what I know is he is unaware and insensible. His mobility requires close observation to protect him from accidents. The main problem in dementia as he is not expressing his hunger, need toileting he is not complaining’* P05.<br>- *‘Well, actually I am not telling that they have dementia, because they cannot understand. I am just orienting them what is here, what is now and what is reality that is for them’* P13.<br>- *‘He will not believe you, he will say "No, I do not have this disease". I will say "Mama you are forgetting things and do not remembering. You have a disease and that is from God. But thanks God I am around and your family will assist you. It is a test in our life from God". But the patient himself will deny, and will say "No, I have nothing. I am clear of any diseases. I am healthy thanks God, what is wrong with me!"’* P16.<br>- *‘Explain dementia to him!!! I believe it is difficult to say it frankly or explain. Though it is important to let him understand it, but even I told him he will forget after a while what he have been told. Try to convoy him (تأخذيه بالسياسة). "You are here to check* | People with dementia are having problem in understanding and they are not aware of their own condition.<br>*insensible*<br>Notwithstanding, participants prefer not to talk about the dementia with the person with dementia as they perceive that as inappropriate act also this cause drain the person and cause |

| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
|---|---|---|---|
| **1.2/ Perceiving a life with dementia** | | | |
| | | *up on you and making investigation to be assure you of your health". I may treat him like that 'Convoying' (بالسياسة) and will not say it frankly that you had Kharaf. If he have his family with him I will leave it to them to explain that information as they it may deliver better than from me as a nurse’* P19.<br>- *‘I do not know. (Laughing). Hopefully I will not be experience such situation. Even if I did explain it to him he will not understand and will forget. I cannot tell him that "You got dementia and you are having Kharaf, and you cannot remember" Just cannot say that!’* P21.<br>- *To not hurt his feelings’* P21.<br>- *‘It is very difficult. But anyway, if I talk to the patient having dementia I will tell to him the truth. If he understands or he will not understand, you should give him the exact thing that is happening to him. So, I will explain to him that you are undergoing a process of dementia. It is not a disease but you are experiencing memory loss. Eventually, with the help of your family with the help of your nurses your doctors, you will be okay. I need your cooperation. I need you to be with me whatever our activities, I hope that you will cooperate because this is for your own good. What we are doing is for your own good’* P23. | aggression and hurts their feelings.<br>So, participants agreed that It is useless to argue with them |
| | Learn new things | - *‘I do not think so. To develop cognitively and intellectually no I do not think so. Maybe if I spend more time with them I may discover that! But I do not know. In term of communication it can be developed and being understood by us or his family from his behaviours. But the patient himself to develop cognitively and intellectually no I do not think so’* P05<br>- *‘Even though, no he will never be trained’* P05.<br>- *‘I do not know, maybe if I cared for him for long period I may discover that he can be trained. But he may not accept the training. This is what I have gained from reading and experience. Because the patient is not aware or mindfulness and will not understand that he has to do this or act like that. the problem will occur when the carers changing or the environment is changed’* P05<br>- *‘For sure in the activity of daily living, giving medication, sometimes he was refusing and I had to approach him many times to convince him to take his medication. Regarding activity of daily living it is difficult to teach him new things or simple activities such walking him to the toilets’* P08.<br>- *‘To assist me! At first, explain what we are going to do in case of taking him for shower I explain the showering for him and show him how to clean and assist in showering before taking him to the bath. Teach him the full procedure before doing it’* P08.<br>- ‘Mmm cannot be too much because whatever things they are learning or whatever we are telling maybe they do not remember for a long period of time. Just the recent things maybe they cannot remember their memory is affected, so daily needs to be, we need to keep on repeating whatever we are teaching them simple things. Once a day you can repeat to them that today, this is the thing that I taught you or how this is how you will have to learn. So daily on one topic of simple things we can teach them, reinforcement can be done so it is easy for them so that they remember’ P14.<br>- *‘For sure it depends on what stage he is in with dementia, some stages it is impossible to teach him anything but other fine he can learn anything. even though in early stages it will be difficult to teach them’* P08<br>- *Yes, they can adapt and they can learn, but if you neglect them like not talking to them they will not talk also’* P13. | Participants refer as *difficult* for the person with dementia to learn new things is early stages of dementia and *impossible* in later stages<br>On the other hand, numerous participants admit that the person with dementia is smart and can learn new things – to some extent- with more cooperation, encouragement and patience |

| **1/ Nurses’ perceptions toward people with dementia and dementia care** | | | |
|---|---|---|---|
| **1.2/ Perceiving a life with dementia** | | | |
| | | - *‘Their ideas. I mean their level of knowledge also, or how much we know about this topic. If you do not know anything or we are not even interested in learning, then we cannot care for such patients. We will think it is just like normal, like any other person, so we should have that enough gathering, we should learn to gather the knowledge or information and so that we can help them also’* P14<br>- ‘They are smart. I feel if patients being taught and trained doing things will be 100% better. I believe 9 out of 10. They do not have people caring for them, he is Kharaf patient, so just stay on place, stuck there until God take your soul. I feel that way because they never developing them. People must have a license how to deal with it; write early at once that will solve many issues, document to have official note that written by him and can refer to it to help remembering things, they are smart not stupid’ P15<br>- ‘Some of dementia patients can learn new things such how to use computer. But sometimes they need your cooperation as she is forgetting things. Deal with stuff as new things to them. Then you need to tell her "look from here we did this and that." However, they are rarely remembering, occasionally, they remember and even if you give him instructions he will remember little. It is possible by repetition’ P16.<br>- ‘Give him attention, if he got a hospital appointment tell him from the night before "You have tomorrow a hospital appointment, you have blood investigation that requires you to be fast, you cannot eat after 12 for example" then he will say "ok" and in the next day he will ask for food "We said that you have an appointment, come on let us get ready to go" assist him with cloths..’ P16.<br>- ‘Their understanding is slow (استيعاب بطيء). When I ask they are repeating and his moves are slow. He only deals with familiar people to them sometimes. And so on’ P20.<br>- ‘If in early stage I believe it can be. I remember one patient in the mental health hospital I could not forget about her. She was having some 'rituals' (طقوس) when she is going to bed, reading, and practice her hobby. I observed that all people around her were supporting her and encouraging her, and she was happy when she hears nice talk. Like kids, fantastically she was HAPPY to hear encouraging from other. Every time she is doing something she was asking "what do you think? Do you like it? How is that...?” By only encouraging (كلام مشجع وتحفيز) she was doing crochet nicely’ P20.<br>- ‘He can learn but a little (بنسبة ضئيلة. By repeating, for instance every time I approach the patient try to teach him certain think, simple things such how to assist with his own care. I ask him to contribute with his own care, not only on me. If every time I teach him a task with patience I believe he can learn’ P21.<br>- ‘I do not think so. No, I believe they cannot learn. I can control them but learning things all over again no. Especially if he is an elderly’ P22.<br>- ‘As what madam said it is really difficult to tell them that you should learn. You should do what I am doing, you should do this one. This one. It is very difficult so you should go along with the patient and slowly slowly he can understand what you are trying to convey to him. So sometimes he will participate. Sometimes they will not participate because dementia people are like that right!’ P23.<br>- ‘The best of their understanding, because they... for my observation, if they are dealing with them always talking to them, always. They have this also that they are learning, they are following. So it is more ... it is communication important, they | |

| **1/ Nurses' perceptions toward people with dementia and dementia care** | | | |
|---|---|---|---|
| **1.2/ Perceiving a life with dementia** | | | |
| | | need care and communication with this patient, so that they can adjust on their… to be in their activities of day ... normal activities of daily lives' P25. | |
| | Making decisions | - *'Allow the patient the freedom of choice; about everything about his food and drink as that raises his morale'* P04. DIA<br>- *'Never disregard the psychological status of the patient to boost the patient's contribution to the care and communicating properly with him'* P04. DIA<br>- *'Helping the patient reinforce their retained skill makes them feel independent'* P13.<br>- *'Some patients may feel burdensome to others, which is why they want to feel independent as much as possible'* P13.<br>- *'A specialised nurse or accompany with Alkharaf patient must be with him at all time with a special book to record private information'* P15.<br>- *'Let patient chose what he wants to eat'* P21.<br>- *'Patients to have a notebook or file for their appointment and medical reviews from time to time'* P22.<br>- *'I do not know, maybe if I cared for him for long period I may discover that he can be trained. But he may not accept the training. This is what I have gained from reading and experience. Because the patient is not aware or mindfulness and will not understand that he have to do this or act like that. The problem will occur when the carers changing or the environment is changed'* P15.<br>- *'I feel like (Laughing)... I care about his best interest as he may not knowing his own benefit. You know better than him as you are caring for him'* P16.<br>- *'Let them chose what they want to eat for example. Assist them with eating as I believe that they lose the skill of holding the spoon. Only'* P22.<br>- *'Like as what you have said from the very beginning, the patient is admitted until the patient will be discharged. You need to be aware and educate the family on what is ongoing with the patient, his medication, his treatment' P23.*<br>- *'Let the patient do her own choice and if you see some deficiencies, only at that moment you have to fill in. But as long as she can, let her because we cannot deny her her right to do the things for her. Once you see any deficiency, you have to fill in, but you do not do all the things by your own and just let the patient stand like a dummy. Let her use her hands at least. You just have to reinforce only' P24.* | Whilst people with dementia has problems in making decision, participants declared that leaving the choices for them is important as value of their self-esteem. Observe their decisions and interfere when defaults occur.<br>Refer to nurses' recommendation to care for a person with dementia. |

# Appendix K RAND Appropriateness Method

**The RAND Appropriateness method**

| Chapter | Section | Sub-section | Status |
|---|---|---|---|
| INTRODUCTION | Background | Dementia as an illness | Completed |
| | | Dementia prevalence | Completed |
| | | Dementia in the KSA | Completed |
| | | Different between guidelines, competencies and framework | Completed |
| | Purpose of this Manual | Aim | Completed |
| | | objectives | Completed |
| | An Overview of the Method | | Completed |
| REVIEW AND SYNTHESIS OF THE LITERATURE | Purpose Search Methodology | | Completed |
| | Healthcare organisations | WHO, WHO regional | Completed |
| | | Alzheimer's associations | Completed |
| | | Geriatric associations | Completed |
| | | Nursing organisations | Completed |
| | Selection and Classification of Articles | | Completed |
| | Synthesising the Evidence | | Completed |
| | Resources Required | | Completed |
| DEVELOPING THE LIST OF INDICATIONS AND DEFINITIONS | Characteristics of the List of Indications | | InProgress |
| | Structure of the List of Indications | | InProgress |
| | Modifying the List of Indications (Before the Panel Meeting) | | InProgress |
| | Definitions of Terms | | InProgress |
| THE EXPERT PANEL | Panel overview | Composition | InProgress |
| | | Nominations | InProgress |
| | Panel members | Motivation to Participate | InProgress |
| | | Contacts with Panellists | InProgress |
| THE RATING PROCESS: APPROPRIATENESS AND NECESSITY | Rating Appropriateness | First Round | Not yet started |
| | | Second Round | Not yet started |
| | Tools and materials | Documents Required | Not yet started |
| | | Automating the Rating Process | Not yet started |
| | | Other Materials and Resources for the Panel Meeting | Not yet started |
| | Panel Observers | | Not yet started |
| | Rating Necessity | Third Round | Not yet started |
| CHAIRING AN EXPERT PANEL | The Moderator | | Not yet started |
| | Preparing for the Meeting | | InProgress |
| | At the Meeting | | Not yet started |
| | Modifying the List of Indications (During the Panel Meeting) | | Not yet started |
| | Guiding the Discussion | | Not yet started |
| CLASSIFYING APPROPRIATENESS | Introduction | | Not yet started |
| | Findings | Appropriateness levels | Not yet started |
| | | Disagreement levels | Not yet started |
| | Discussion | | Not yet started |
| | The guidelines | | Not yet started |
| REFERENCES | | | |

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