

UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

**What are the experiences of stroke survivors participating within a Work
Rehabilitation Service; including the impact of the Work Rehabilitation Service on
their stroke journey?**

by

Elizabeth Cullen

Thesis for the degree of Doctor of Clinical Practice

June 2015

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF HEALTH SCIENCES

Thesis for the degree of Doctor of Clinical Practice

WHAT ARE THE EXPERIENCES OF STROKE SURVIVORS PARTICIPATING WITHIN A WORK REHABILITATION SERVICE; INCLUDING THE IMPACT OF THE WORK REHABILITATION SERVICE ON THEIR STROKE JOURNEY?

Elizabeth Anne Cullen

A quarter of all strokes occur in people under the age of sixty-five providing stark economic consequences in potential lost productivity in people being unable to return to work. Consequently and not surprisingly, return to work following stroke is considered an important outcome of stroke recovery. However, there is little research evidence exploring the actual process and quality of intervention during the stroke survivor's journey to return to work, or to suggest the wider impact of vocational rehabilitation.

This study took an Interpretative Phenomenological Analysis (IPA) approach using semi-structured interviews as the method to understand the world of seven individuals experiencing vocational rehabilitation at a Work Rehabilitation Service (WRS) including the impact of the WRS on their stroke journey.

Five main themes were identified from the findings – the stroke journey, rebuilding the whole person, the WRS, psychosocial benefits of the WRS and the future. The findings emphasised the less overt or hidden aspects and perceived benefits for individuals attending the WRS, suggesting that it is far from just a process for returning to work, but instead contributes to a far wider set of values and contributions in the individual's stroke journey, road to recovery and future life.

This study has provided a rich and interpretive description, with new and novel exploratory insights, into the lived experiences of individuals attending the WRS. Three key conclusions can be drawn from the findings of this research study:

1. The WRS is a service embedded in the philosophy and principles of OT; consequently this provides a rich vocational rehabilitation experience demonstrating positive patient outcomes due to a successful fusion of client-centred practice and meaningful activity within a group/peer environment.
2. The 'hidden extras' and unexpected outcomes of the WRS in terms of its perceived psychosocial benefits are considered by the participants to be as important to their recovery as the core treatment and rehabilitation.
3. The WRS provides rehabilitation beyond that of vocational rehabilitation to return to work. The philosophy and principles of the WRS combined with the hidden extras to support the individual to develop self-management strategies to prepare them for life post stroke.

Table of Contents

Table of Contents	i
List of Tables.....	vii
List of Figures	ix
DECLARATION OF AUTHORSHIP	xi
Acknowledgements	xiii
Definitions and Abbreviations.....	xv
Chapter 1: Introduction	1
1.1 Background	1
1.2 Research question.....	1
1.3 Rationale for choice of study	1
1.4 Overview of the thesis	3
Chapter 2: Literature review	5
2.1 Introduction	5
2.2 Literature review process	5
2.3 Stroke	5
2.4 Proportion of younger stroke patients	7
2.5 The social consequences of stroke for younger people	8
2.6 The differing needs of younger stroke patients	9
2.7 Vocational rehabilitation	11
2.8 Return to work after stroke	14
2.9 Psychosocial aspects of work.....	18
2.10 Critique of the research literature	19
2.11 Rationale for choice of study	21
2.12 Summary	21
Chapter 3: Methodology.....	23
3.1 Introduction	23
3.2 Choosing the research method to answer the research question	23
3.3 Choosing the methodological approach.....	24
3.4 Phenomenology	25

3.5	Interpretative Phenomenological Analysis (IPA).....	27
3.6	Reflexivity	29
3.7	Limitations of phenomenology and IPA	29
3.8	Summary.....	30
Chapter 4:	Research Methods	31
4.1	Introduction.....	31
4.2	The WRS.....	31
4.3	Research governance	32
4.4	Ethics approval	32
4.5	Risk assessment.....	32
4.6	Gaining access to the setting.....	32
4.7	Gaining access to the clients	33
4.8	Participants.....	35
4.9	Inclusion criteria for clients	36
4.10	Exclusion criteria for clients.....	36
4.11	Recruitment.....	36
4.12	Data collection method	37
4.13	Data analysis.....	40
4.14	Reflective account of the analytical process.....	41
4.15	Reflection on the interviews	43
4.16	Research quality	44
4.17	Reflection at the DClInP interim assessment and viva.....	45
4.18	Summary.....	45
Chapter 5:	Findings	47
5.1	Introduction.....	47
5.2	The journey.....	51
5.2.1	Time.....	51
5.2.2	Structure in life / meaningful activity.....	54
5.2.3	WRS as a transition on the journey to recovery – “ <i>it was the base back to normalish life</i> ” (Daniel, page 7, line 34).....	57
5.3	Rebuilding the whole person.....	59

5.3.1	Self-identity.....	59
5.3.2	Luck	62
5.3.3	Expectation of others.....	64
5.4	WRS	66
5.4.1	Perceptions of rehabilitation	67
5.4.2	The WRS as a group environment / Shared experience “People have got the same issues”	69
5.5	Psychosocial benefits / the “non-tangibles”	74
5.5.1	Confidence	74
5.5.2	Learning new skills	76
5.5.3	Sense of achievement.....	77
5.5.4	Motivation	78
5.6	The future	80
5.6.1	Now see a future	81
5.6.2	Getting back to normal	82
5.6.3	New avenues / new horizons	83
5.7	Summary	84
Chapter 6:	Discussion	85
6.1	Introduction	85
6.2	Synthesis of the research findings	85
6.3	The philosophy and principles of the WRS	86
6.3.1	The underpinning philosophy of the WRS.....	86
6.3.2	Principles of rehabilitation at the WRS.....	90
6.3.3	The WRS as a group environment / Shared experience “People have got the same issues”	92
6.4	‘Hidden extras’ the unexpected outcomes of the WRS and its impact on the individual’s post stroke journey.....	96
6.4.1	Rebuilding the whole person	96
6.4.2	Psychosocial benefits of the WRS.....	100
6.4.3	The future	103

6.5	Supported self-management – the meaning of the WRS	105
6.6	Implications for practice.....	108
6.6.1	Implications for policy makers	108
6.6.2	Implications for commissioners	109
6.6.3	Implications for clinicians	110
6.6.4	Implications for research.....	111
6.6.5	Future research	112
6.7	Research limitations	112
6.8	Personal reflection on the research process.....	112
6.8.1	Choice of theoretical and research approach	113
6.8.2	Collecting the data	113
6.8.3	My influence as a researcher	115
6.8.4	Analysing and presenting the data.....	115
6.8.5	My journey as a researcher	116
6.9	Summary.....	116
Chapter 7:	Conclusion	117
7.1	Introduction.....	117
7.2	What the findings revealed	117
7.3	What the research contributes to knowledge	118
7.4	Summary.....	119
Appendices.....		121
Appendix A	Letter of approval for research governance	123
Appendix B	Letter of research sponsorship	125
Appendix C	Professional indemnity and clinical trials insurance	127
Appendix D	Ethics approval.....	129
Appendix E	Ethics amendment approval	133
Appendix F	Letter of invitation to participate.....	137
Appendix G	Participant information sheet.....	139
Appendix H	Participant reply slip	143
Appendix I	Participant consent form	145
Appendix J	Interview schedules	147

Appendix K	Example of data analysis process	149
List of References	155

List of Tables

Table 1: Numbers recruited to the study.....	36
Table 2: Background information of research participants	48

List of Figures

Figure 1: Overview of thesis.....	4
Figure 2: The roots of interpretative phenomenological analysis (Howitt and Cramer 2011, p385)	28
Figure 3: Research process for initial and follow-up interviews.....	34
Figure 4: Research process for retrospective interviews.....	35
Figure 5: Breakdown of interviews	47
Figure 6: Mind map of the findings themes and sub-themes.....	50
Figure 7: The journey theme and sub-themes.....	51
Figure 8: Rebuilding the whole person theme and sub-themes.....	59
Figure 9: Work rehabilitation service theme and sub-themes	67
Figure 10: Psychosocial benefits of WRS theme and sub-themes.....	74
Figure 11: The future theme and sub-themes.....	80

DECLARATION OF AUTHORSHIP

I, Elizabeth Cullen

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.

What are the experiences of stroke survivors participating within a Work Rehabilitation Service; including the impact of the Work Rehabilitation Service on their stroke journey?

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. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed:

Date:.....

Acknowledgements

I would like to express my gratitude to a number of people without whom this research would not have been possible.

My special thanks go to my supervisors, Dr Alan Borthwick and Dr Maggie Donovan-Hall for their invaluable knowledge, experience, support, encouragement and belief in me.

My grateful thanks to all the patients and carers who gave up their time to take part in this research sharing their experiences and stroke journey's with me; and without whom there would be no findings. Thanks also to the staff at the WRS who facilitated the practicalities of recruitment as well as the manager and Trust for allowing me to conduct my research within their service.

My sincere thanks also go to Fleur Kitsell and Health Education Wessex for funding my Doctorate in Clinical Practice without which my studies would not have been possible.

Special thanks go to my family and friends for their emotional and practical support; encouragement and patience during the course of this long doctoral journey. Not forgetting Barney, my loyal companion, lying patiently at my feet for hours on end as I worked away, as well as unknowingly ensuring my physical and psychological wellbeing on all his walks whilst I pondered my research.

Finally a special mention for my Dad, who taught me the value of education, but sadly never saw me through to the final touch line of my doctoral journey – I dedicate my DClInP to him.

Definitions and Abbreviations

ADLs – Activities of Daily Living

AHP – Allied Health Professions

BSRM – British Society of Rehabilitation Medicine

COPD – Chronic Obstructive Pulmonary Disease

COT – College of Occupational Therapy

CQC – Care Quality Commission

DClinP – Doctorate in Clinical Practice

DH – Department of Health

DWP – Department of Work and Pensions

ESD – Early Supported Discharge

HWB – Health and Wellbeing Board

ICF – International Classification of Functioning

IPA – Interpretative Phenomenological Analysis

LTC – Long-term conditions

PCTs – Primary Care Trusts

PROMS – Patient Reported Outcome Measures

NAO – National Audit Office

NHS – National Health Service

NIHSS – National Institute of Health Stroke Scale

OT – Occupational Therapy/Therapist

PROMS – Patient Reported Outcome Measures

QoL – Quality of Life

RCP – Royal College of Physicians

REC – Research Ethics Committee

RTW – Return to work

TBI – Traumatic Brain Injury

UK – United Kingdom

VR – Vocational Rehabilitation

WHO – World Health Organisation

WRS – Work Rehabilitation Service

5YFV – Five Year Forward View

Chapter 1: Introduction

In this introductory chapter the research question and interest in this area will be presented. This will continue with an overview of the subsequent structure of the Doctorate in Clinical Practice (DClinP) thesis.

1.1 Background

A quarter of all strokes occur in people under the age of sixty-five providing stark economic consequences in potential lost productivity in people being unable to return to work. Consequently and not surprisingly, return to work following stroke is considered an important outcome of stroke recovery. However, there is little research evidence exploring the actual process and quality of intervention during the stroke survivor's journey to return to work, or to suggest the wider impact of vocational rehabilitation. This led to the development of the following research question.

1.2 Research question

This research study aims to gain a deeper understanding of the social world of the stroke survivor experiencing a Work Rehabilitation Service (WRS) in the South of England. Investigating the impact attending the WRS has on the individual's life; considering whether it contributes to their wellbeing, self-worth and self-identity and changes how they view their world. As a researcher I wanted to gain insight into the meanings individuals attributed to their experiences of the WRS and the potential influence of this on their stroke recovery and journey.

The research question is:

What are the experiences of stroke survivors participating within a Work Rehabilitation Service (WRS); including the impact of the WRS on their stroke journey?

1.3 Rationale for choice of study

As a specialist occupational therapist (OT) working in stroke I was aware of the potential different needs for younger stroke patients particularly those wishing to return to work. Having worked across the full patient pathway in stroke, in many clinical areas, I became aware of the discrepancies and variable provision of vocational rehabilitation and how it was delivered.

Chapter 1

In 2008 I worked for the WRS in Southampton, the WRS is a vocational rehabilitation service for patients who have had a stroke or have a neurological condition. The key aim of the service is to get people back to some level of occupation, ideally back to the individual's previous paid employment. Where it is not possible to return to their previous employment the WRS works with individuals to return to a level of purposeful occupation be it hobbies, education, voluntary or unpaid work.

Whilst working at the WRS I became aware of the potential hidden aspects of the service and the impact this may have on the stroke survivor, not only on their pathway and goal to return to work, but also on their overall stroke journey including self-adjustment, wellbeing and self-identity. The WRS is one of the few specialist stroke/neurological vocational rehabilitation settings that presently still exist regionally. I was therefore keen to capture and understand the wider meaning of the WRS as it is experienced by the individuals who attend it and also how this may impact on their wider life and stroke journey. In order to consider the stroke survivors journey I wanted to ideally capture their thoughts and experiences at the beginning of their treatment and then again at the end of their treatment in order to consider how their thoughts and the meanings attributed to their experience of the WRS may have changed over time. I was also keen to capture the retrospective views of individuals who had been through the service and now been discharged to include their reflections of the WRS and the role it played in their recovery journey.

When I started reviewing the literature it became apparent that although return to work was deemed as a significant outcome post stroke there was very little evidence to suggest the wider implications of vocational rehabilitation on the individual's stroke journey. Likewise there was limited clear evidence of what vocational rehabilitation should entail and how it should be delivered. Lastly and possibly most importantly there was a lack of consideration of the stroke survivor's individual perspective of the return to work recovery journey post stroke. As an OT I was frustrated with the lack of consideration for the individual's perspective within this area of rehabilitation, especially considering that the philosophy of OT is built on client-centred practice putting clients at the core of intervention (College of Occupational Therapy (COT) 2010). Hence this appeared to be an area that still required further investigation and an opportunity to capture the qualitative aspects of the impact the WRS may have on the stroke survivor from their individual perspective – a previously unaddressed area of research.

1.4 Overview of the thesis

An overview of the chapters that follow are briefly described here, figure 1 also illustrates the flow of the thesis in diagrammatical form.

Chapter 2 – Literature Review provides a critical review of the literature surrounding the experiences of young people having had a stroke including the relevant research literature and policy relating to return to work and vocational rehabilitation.

Chapter 3 – Methodology outlines the philosophical and theoretical perspectives which inform this research study and explains the background and use of a phenomenological approach and interpretative phenomenological analysis (IPA) employed as the research method for this study.

Chapter 4 – Research methods presents the chosen research procedures used for this study, including the data collection and data analysis procedure chosen, as well as a discussion of the recruitment issues encountered when data collecting.

Chapter 5 – Findings provides an exploration of the themes and subthemes identified from the analysis of the interviews of the study.

Chapter 6 – Discussion provides a discussion of the findings and key themes presented in chapter 5, relating these findings to the relevant research literature and government policy. The chapter then evaluates the research considering the implications for practice as well as reflecting on the research processes. This is followed by a personal reflection on my journey and development as a researcher through the process of the study.

Chapter 7 – Conclusion gives an overview of the study presenting the main conclusions as well as considering what this study contributes to current stroke knowledge and the implications for further research and clinical practice.

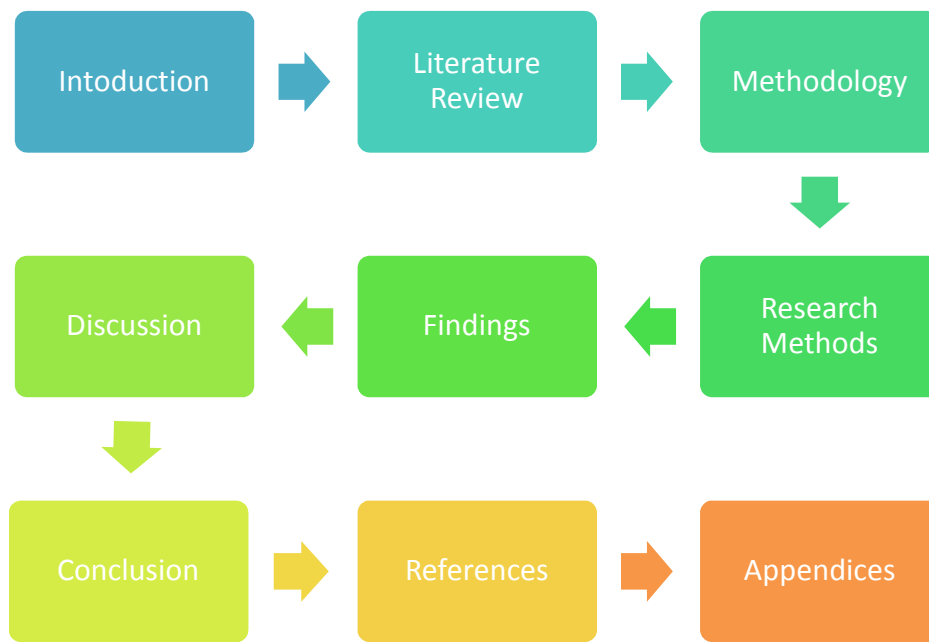


Figure 1: Overview of thesis

Chapter 2: Literature review

2.1 Introduction

This chapter provides a critical review of the literature surrounding the experiences of young people having had a stroke including the relevant research literature and policy relating to return to work and vocational rehabilitation including the literature review process.

2.2 Literature review process

The following process was taken to identify, select and review the literature and the data bases searched. This process was carried out and updated throughout the length of the research.

The electronic research databases that were used for this literature review included AMED, CINAHL, EMBASE, MEDLINE and Cochrane library. The search terms used were “stroke” and its corresponding synonyms “cerebrovascular accident” and “CVA”, these search terms were then combined using Boolean “OR” and then the removal of duplicates. The same process was used for “vocational rehabilitation”, “return to work”, “work” and “employment” with these search terms searched individually and then combined using Boolean “OR” and then the removal of duplicates. The two combined searches for stroke and vocational rehabilitation were then combined using Boolean “AND”.

The search results were then limited by the request for abstract available and further refined through keywords being searched in the title of the article, English language, academic journals and articles from 1980 – current date. Further hand searches were completed from references found in journal articles gained through the main electronic literature search. Articles were appraised and critiqued using the Critical Appraisal Skills Programme (CASP) checklists.

2.3 Stroke

Stroke is defined as a clinical syndrome, of presumed vascular origin, typified by rapidly developing signs of focal or global disturbance of cerebral function lasting more than 24 hours or leading to death (Hatano, World Health Organisation 1976). There are two main types of stroke; ischaemic and haemorrhagic. Ischaemic stroke is the most common form, caused by a blood clot blocking or narrowing the blood vessels preventing blood from reaching the brain, leading to the death of brain cells as a consequence of the lack of oxygen. The other main type of stroke is

Chapter 2

haemorrhagic, caused by bleeding in the brain from a burst blood vessel which causes damage (Department of Health 2007). Stroke incidence per 1,000 population is 1.45 (Rothwell et al 2004). Cerebral infarction is the cause of 69% of strokes, whereas 13% are as a result of primary haemorrhage and a further 6% by subarachnoid haemorrhage; with 12% being of an uncertain type (Wolfe et al 2002).

Research literature indicates that the statistics and impact of stroke are stark. 152,000 people have a stroke in the United Kingdom (UK) each year, equating to over one every five minutes (Stroke Association 2012). Stroke is the third largest cause of death in England resulting in 11% of all deaths, and the single largest cause of adult disability. Stroke has a devastating effect, with 25% of people who have had a stroke dying within the first month following. For those that do survive, stroke has a long lasting impact on their lives and their families, with a third of stroke survivors being left with a long-term disability. This can include communication and cognitive problems, physical disability, depression and other mental health problems (National Audit Office (NAO) 2005).

Until fairly recently stroke was considered to be an inevitable risk of old age, with rather a fatalistic and dismissive approach to stroke medicine with poor outcomes (NAO 2005, Department of Health (DH) 2007). However, better outcomes for stroke patients have increased in the last fifteen years with research illustrating that specialist stroke units lead to improved outcomes for patients in terms of life expectancy and independence one year after stroke (Stroke Unit Trialists' Collaboration 2013). Better outcomes are also due to an increased understanding of stroke medicine through medical, clinical, organisational and technological advances so that stroke is now viewed as a preventable and treatable condition (NAO 2005, DH 2007). These improvements have been encouraged and supported through the publication of many key documents relating to stroke.

Although the Cardiovascular Disease Outcomes Strategy is the most recently published (DH 2013), it is generally viewed that the Stroke Strategy (DH 2007) is without doubt the most influential publication in driving stroke care forward to date. This long awaited document was compiled by all parties involved in the provision of stroke care (medical staff, allied health professions, nurses and user groups) and set out a framework of twenty quality markers for raising the quality of stroke prevention, treatment, care and support over the following decade to 2017. However, a criticism of the Stroke Strategy at the time of its publication was that it only produced guidelines rather than explicit targets, unlike other Department of Health strategies such as the National Service Framework for Coronary Heart Disease (DH 2000). Consequently, in April 2010, the

Accelerating Stroke Improvement (ASI) initiative was developed in order to promote and support improvement work already underway and to identify key issues that needed an additional improvement focus and/or support. As part of this work they identified key targets for services to be measured against in the three domains of (1) joining up prevention, (2) implementing best practice in acute care, and (3) improving post hospital and long-term care. Along with the national drivers there has also been a drive to raise the public awareness of stroke with investment in large publicity campaigns promoting stroke as a medical emergency (Stroke Association 2007, 2010).

2.4 Proportion of younger stroke patients

As has been stated earlier, stroke used to be considered to be an inevitable risk of old age (NAO 2005, DH 2007). However, 25% of all strokes occur in people under the age of sixty-five (NAO 2005) and these statistics are increasing. A recent press release from the Stroke Association (2015) reported that in the last fifteen years there has been a 46% rise in the number of strokes occurring in men aged between 40 and 54 years old. Similarly there has been a 30% increase in the number of women aged between 40 and 54 years old admitted to hospital with a stroke. Overall, in the last fifteen years, there has been a startling 25% increase of the number of strokes in people of working age (20 – 64 years old) (Stroke Association 2015). It is thought that this rise is due to the changing and unhealthy, sedentary lifestyles of the population as well as changes in hospital admission practice (Stroke Association 2015).

Consequently with the increase in the number of strokes in people of working age, the specific needs of younger stroke patients has therefore more recently been acknowledged within the National Stroke Strategy (2007) and Royal College of Physicians (RCP) national clinical guideline for stroke (2008, 2012). For example the RCP national clinical guideline for stroke (2012) stipulates that the needs of younger adults should be accommodated, recognising their particular physical, psychological and social needs including vocational rehabilitation and childcare; as well as ensuring rehabilitation is provided in a suitable environment to meet the individual's social needs.

Although younger stroke patients have more recently been recognised as a distinct group in policy as identified above, historically both policy and the majority of stroke research studies have traditionally focused on the older stroke population. Consequently the different needs of younger stroke patients have often been overlooked. Factors likely to distinguish younger stroke patients

from the older stroke population are their psychosocial needs and the consequential issues of employment, marital stress, and childcare (Teasell et al 2000).

2.5 The social consequences of stroke for younger people

Various studies have considered the unmet needs and social issues of younger stroke patients. Teasell et al (2000) raised some valid points suggesting that young stroke patients present with many unique issues compared to older stroke patients, which include difficulty returning to work, child care issues and relatively high rates of marital separation. They also highlighted depression, anxiety, denial, anger, frustration and reduced self-esteem as psychological impacts of stroke experienced by younger patients. However, the data gained for psychological issues unfortunately had significant limitations. The data analysed were based on retrospective chart review examination. This meant that the charts of all the patients were carefully reviewed to identify which psychological issues were expressed by patients and recorded by staff. The psychological issues had to be expressed by the patient or carer and then the staff member had to deem this information significant or important enough to document it in the patient notes. Therefore this carried a high level of reporting bias.

When considering the sensitive and personal nature of these issues as a consequence of the psychological impact of stroke, the greatest source of anxiety for patients documented by staff within Teasell's study (2000) were return to work, followed by recovery, child care and marriage separation. However, because the data collected were subjective on the part of the staff, it did not explore patients' concerns regarding their return to work (RTW). Therefore the lack of clarification on the part of the patient or carer as to whether what was documented truly represented their concerns can be seen as a limitation to this study.

Kersten et al (2002) also looked at the unmet needs of younger stroke patients in a national UK survey. Similar to Teasell et al (2000) they found an association between younger age and unmet needs relating to family issues. Family support, holidays and intellectual fulfilment were identified as unmet needs that were statistically significant for those aged 18 – 45 years compared to 46 – 65 year olds (Kersten et al 2002). However, surprisingly the proportion of unmet needs reported by young stroke patients was generally modest, with the median number of unmet needs being two and 30% of participants reporting no unmet needs. However the study identified eight most frequently reported areas of unmet need which included: provision of stroke information, financial needs, assistance with non-care activities such as assistance with social/leisure activities, intellectual fulfilment, adaptations, vehicles, social life and physiotherapy (Kersten et al 2002).

In relation to work, young stroke survivors that did not return to work reported statistically significantly more unmet needs than those who had changed their jobs or returned to work on reduced hours. Consequently these patients again reported more unmet need than those who returned to their previous job on the same hours (Kersten et al 2002). However, from the data gained it was not possible to deduce the reasons why people did not return to work. For example whether people would have been able to return to work with appropriate support or whether employers were reluctant for them to do so.

Daniel et al (2009) completed a systematic review of seventy-eight studies of the social consequences of stroke for this younger working-aged adult population. They identified the following categories as the social consequences of stroke: return to work (ranging from 0% to 100%), negative effect on family relationships (5% to 54%), deterioration in sexual relationships (5% to 76%), financial difficulties (24% to 33%) and deterioration in leisure and social activities (15% to 79%) (Daniel et al 2009). As is shown there were often large variation in ranges which makes it difficult to reliably estimate the social consequences of stroke, this was mainly due to differences in study design, population, age range and time following stroke. Another major criticism of this research literature is the emphasis on quantitative data often addressing sensitive issues but not offering any patient or carer perspective through a qualitative element, only 10 of the 78 studies reviewed by Daniel et al (2009) were qualitative in design or contained mixed methods.

2.6 The differing needs of younger stroke patients

When considering the different needs of younger stroke patients, one of the criticisms of stroke rehabilitation for younger stroke patients (under the age of 65), has been the failure to tailor rehabilitation to their specific needs. With the demographic shift in the increase of strokes in people of working age, and improvements in hyper-acute and acute stroke care (DH 2008a) the stroke population is changing with the majority of younger people experiencing a mild to moderate stroke (Wolf et al 2009) where motor deficits are not the primary issue (O'Neill and Wolf 2010). People experiencing a mild stroke as defined by the National Institute of Health Stroke Scale (NIHSS) may typically have no problems with self-care or speech and minimal to no motor impairment. People who have a moderate stroke will typically have some level of motor impairment that will most likely mean that they receive some level of basic rehabilitation. Therefore people having a mild to moderate stroke may be independent in activities of daily living (ADLs), exhibiting only mild impairments on most assessments used, which may not be sensitive

enough to the needs of stroke patients who would benefit from vocational rehabilitation (VR). Consequently the majority are discharged home with limited rehabilitation services including a lack of focus on community reintegration and work rehabilitation (Wolf et al 2009, O'Brien and Wolf 2010). There is an assumption that people exhibiting a mild stroke who perform well on measures of functional independence with basic self-care ADLs as well as neurological assessments are recovered and will subsequently be able to return to all other activities of daily life. However this assumption does not consider that activities such as working and driving are complex tasks that require cognitive functioning of a higher level that is not typically identified in these traditional basic stroke assessments (O'Brien and Wolf 2010, O'Neill and Wolf 2010).

It has therefore been suggested that the stroke services provided by health care professionals focus on the patient's loss of function and the impairment level, rather than addressing more complex cognitive deficits (Roding et al 2003). Rehabilitation often follows a biomedical approach looking at the impairment of function and limitations in activities of daily living, but does not necessarily consider the wider impact on participation in extended activities such as returning to work (Treger et al 2007). In the early stages of stroke rehabilitation efforts are focused on survival, management and prevention of complications and restoration of basic mobility and functional skills. Therefore, stroke rehabilitation is generally more focused on getting people back on their feet but does not necessarily consider more complex issues and extended activities which prepare and facilitate these patients to return to participation in work, family and community life (Kersten et al 2002, Medin et al 2006, Wolf et al 2009).

The importance of tailoring rehabilitation to the needs of the patient has also been highlighted by patients themselves. Patients perceive that rehabilitation tends to stop when minimal function is regained but is insufficient in time and scope to prepare people for return to work, neglecting the wider work and social context (Medin et al 2006, Lock et al 2005). However, Medin et al (2006) highlighted that for patients, returning to work was perceived as their main goal and a successful recovery from their stroke. This also suggests that rehabilitation should not purely be about reducing problems but also how to develop coping strategies to live with them (Medin et al 2006).

Although the current evidence base for the different needs of younger stroke patients have tended to be quantitative in design there has been some attempt to capture the views of patients through qualitative research studies by Roding et al (2003), Medin et al (2006) and Lock et al (2005). These studies have explored younger stroke patients' experiences of the rehabilitation process. Their findings produce many concurrent themes such as patients perceiving fatigue, cognitive problems and lack of social support as the main barriers to returning to work. More

research is needed to understand what processes and mechanisms help to support a person to return to work following a stroke.

As reported above, most stroke services provide purely short-term input for patients focusing on the acute event and core rehabilitation of everyday function. This is particularly apparent with an ever increasing focus on reducing hospital and service lengths of stay (RCP 2007). Consequently wider, long-term community services, such as tailored specialist vocational rehabilitation services, are rarely provided for stroke patients creating major barriers to successful return to work outcomes for people following a stroke in the UK. Stroke rehabilitation services have not been designed with vocational rehabilitation in mind and vocational rehabilitation is often seen as a bolt on to usual services and care (Chamberlain et al 2009). Vocational rehabilitation will now be considered in more detail.

2.7 Vocational rehabilitation

Vocational rehabilitation is one aspect of rehabilitation post stroke. More generally, as discussed above, it has been raised that a criticism of stroke rehabilitation is that it does not meet the needs of younger stroke patients in terms of employment and return to work.

Vocational rehabilitation (VR) is a broad term referring to the overall process of ‘enabling individuals with either temporary or permanent disability to access, return to, or remain in, employment’ (British Society of Rehabilitation Medicine (BSRM) 2000). For people who have had a stroke in the UK, VR seeks to take account of the factors that may affect an individual’s ability to work including physical, cognitive, emotional, social, environmental and organisational factors. This involves matching the abilities and limitations of the individual following their stroke with the work environment and demands of the given job. This includes assessment of an individual’s functional capacity for work including safety assessment and job evaluation; educating the individual, their family and the employer about the effects of their stroke, their legal requirements and responsibilities; and liaison with the employer regarding any job adaptation, work modification or equipment needs for the individual (Radford et al 2013, Coole et al 2013). Where the individual is unable to return to their existing job, VR can include vocational guidance including retraining, brokering placements and negotiating future work opportunities (Tyerman and Meehan 2004).

Vocational rehabilitation and return to work is a key issue for younger stroke patients as the numbers of younger stroke patients has a direct impact on the workforce population. According

to the UK Department of Work and Pensions (2002) stroke patients make up 0.7% of those receiving incapacity benefits. Stroke costs the UK economy approximately £7 billion per year – £2.8 billion in NHS direct costs, £2.4 billion in informal care costs (e.g. care costs provided by patients' families) and £1.8 billion in income lost to productivity and disability (NAO 2005). These indirect costs include loss of productivity due to mortality or morbidity as well as benefit payments made to people as a result of their stroke disability. It also takes into account the costs of informal care, including the loss of productivity of carers (NAO 2005). Consequently ensuring that those who have the capability to work are offered the opportunity to do so is a UK government priority (Department for Works and Pensions (DWP) 2012, 2004, DWP et al 2005).

Due to the high costs associated with stroke and income lost to productivity and disability, vocational rehabilitation is an area that needs to be widely addressed. Subsequently, there has also been acknowledgement in key national documents that return to work needs should be addressed as part of the stroke patient's rehabilitation. It has been highlighted that "people with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities" (DH 2005a, p39). This was also supported in 2007 by the Stroke Strategy Quality Marker 16 – Return to work "people who have had a stroke, and their carers, are enabled to participate in paid, supported and voluntary employment" (p47). Return to work has further been supported and acknowledged in the Royal College of Physicians (RCP) National Clinical Guideline for Stroke (2008, 2012). In the most recent version of the RCP National Clinical Guideline for Stroke (2012) Work and Leisure are identified and highlighted under section 6.29 as well as Community integration and participation under section 7.3. Ensuring that people with long-term conditions (such as stroke) stay in work is also recognised as a NHS health outcome under Domain 2 (enhancing quality of life for people with long-term conditions) of the NHS Outcomes Framework 2015/16 (DH 2014).

Along with national documents and policy supporting VR and RTW there is also a research evidence base to underpin it. Employment is deemed an important aspect of participation for individuals of working age, who report an increased sense of wellbeing, and quality of life (QoL); and an improved health status compared to individuals who are unemployed (Van Velzen et al 2009). Accordingly, interventions which facilitate re-entry into employment are essential for the individual. VR assists the individual in mitigating work disability, enhances the rate of return to meaningful employment, promotes the productivity of injured workers, decreases work days lost and decreases premature retirement therefore controlling the welfare costs (Disler and Pallant 2001). However in the reality of clinical practice, vocational rehabilitation services in the UK for

people who have had a stroke are uncommon with inequitable provision. It was reported in a review of VR service provision, that the provision met less than 10% of the estimated requirement (Deshpande and Turner-Stokes 2004). In a more recent review of stroke services by the Care Quality Commission (CQC) (2011), still only 37% of NHS primary care trusts (PCTs) offered stroke services that addressed helping stroke patients to RTW.

The main focus of stroke improvement to date has generally been at the front end of the stroke pathway with vast improvements obtained in hyper-acute and acute stroke care in specialist centres providing 24/7 brain imaging and thrombolysis (DH 2008a) resulting in a marked reduction in death and dependency post stroke (NAO 2010). However, services for post stroke rehabilitation other than Early Supported Discharge (ESD) has received little attention and investment, meaning that post stroke vocational rehabilitation services still remain a comparatively neglected Cinderella service (Radford et al 2013).

Radford et al (2013) considered the barriers and enablers to commissioning VR services in their qualitative study interviewing health and social care commissioners. There was a perception amongst commissioners that VR was not a strategic priority and a lack of awareness of the prevalence of stroke in the working age population. Instead VR post stroke was considered to be a relatively small issue for a limited number of people; therefore the cost effectiveness of VR services was questioned with concerns from health commissioners that any cost savings would not be realised within health budgets. As VR has the potential to overlap both health and social care there is a risk that no one takes responsibility for it and that VR services fall through the gap, with evidence that where services were provided they had been unsustainable. In times of austerity, with severe budget restrictions, the focus is on the most vulnerable and their needs and therefore not VR. Without good data, as is collected in the acute setting, it is difficult to define the need for VR and to quantify the benefits and costs (Radford et al 2013).

It is hoped that with the changing commissioning landscape and the introduction of Health and Wellbeing Boards (HWPB), integrated commissioning and the Vanguard Sites that there is an opportunity for real innovation and new ways of working across health and social care. It is also important that research such as that presented in this thesis is available to commissioners to inform the development of stroke services in the interests of those who have had a stroke, to demonstrate and articulate their needs and the consequent need for VR.

2.8 Return to work after stroke

Historically studies of vocational rehabilitation have looked at musculoskeletal and mental health conditions (Gobelet et al 2007). Other research has looked at return to work and vocational rehabilitation following Traumatic Brain Injury (TBI) which shares some similar characteristics of stroke. A large review of the research literature in TBI was completed by Shames et al (2007). They found parallels with the stroke research in that there is insufficient research evidence in this area to draw general conclusions and much research still needs to be completed in order to give a better understanding of vocational rehabilitation outcomes. However, with increased focus on the cost to the economy of disability following stroke and the reduction in age of stroke patients (NAO 2005), studies have begun to look more closely at the predictors and determinants of return to work for stroke patients, if not the specific role of vocational rehabilitation.

With a central research theme within this area being the consideration of the predictors or determinants of return to work post stroke, studies have investigated pre and post stroke variables including functional ability (Hofgren et al 2007), motor performance (Lindstrom et al 2009), cognition (Hofgren et al 2007), executive functioning (Onsworth and Shum 2008), psychiatric morbidity (Glozier et al 2008), positive attitude (Lindstrom et al 2009), location of stroke (Saeki and Hachisuka 2004), neglect and aphasia (Hinckley 2002). The conclusions of these studies suggest that return to work rates are often low but tend to increase with the time lapsed post stroke (Hofgren et al 2007, Onsworth and Shum 2008, Hinckley 2002).

Stroke location appears to be less important in predicting return to work post stroke (Saeki and Hachisuka 2004) compared to the person's physical ability and the assessment of their neurological status such as cognition or body functions (Hofgren et al 2007, Lindstrom et al 2009) as well as positive attitude and support from others (Lindstrom et al 2009). Non-white ethnicity, part-time employment pre-stroke, stroke severity and psychiatric morbidity at 28 days post stroke have all been independently associated with a significantly reduced chance of returning to work (Glozier et al 2008). However, one of the criticisms of the current evidence base on return to work post stroke is the widespread differences in study design, including inclusion criteria, age categories of participants, data collection methods, definitions of work and follow-up times post stroke (Daniel et al 2009). These will now be discussed in more detail.

a) Age of participants

Within the current evidence base considering return to work post stroke there is inconsistency in the different age categories of participants that have been investigated. This varies from 15 – 64

years (Saeki and Toyonaga 2010, Tanaka et al 2011), 18 – 55 years (Lindstrom et al 2009), 20 – 57 years (Hannerz et al 2011), 17 – 65 years Hackett et al 2009) 18 – 64 years (Saeki et al 1993) and 18 – 65 years (Hofgren et al 2007). Alternatively, other studies do not even stipulate the age category for their study population, therefore instead of defining their study sample by age they defined them as working prior to their stroke (Hinckley 2002, Glozier et al 2008, Wozniak et al 1999, Teasdale and Engberg 2005, Lock et al 2005).

b) Definition of work

There is also a discrepancy and use of different terminology defining what work or employment is, within the literature. For example some studies considered return to work or employment broadly to be working full or part-time at follow-up irrespective of the number of working hours per day (Lindstrom et al 2009, Hinckley 2002, Glozier et al 2008). Saeki and Hachisuka (2004) defined it more specifically as active employment of one month or more duration after stroke. Whereas other studies specified the amount of work per week ranging from 8 hours to 10 hours or 25% of full-time work at a workplace or on the open market (Hofgren et al 2007, Onsworth and Shum 2008); as well as some classifying study or part-time and full-time courses at an academic institute as employment (Hofgren et al 2007, Onsworth and Shum 2008).

c) Follow-up times post stroke

Another criticism of the present literature is the vast range and timing of follow-up that return to work has been considered within ranging from 3 months to 10 years post stroke (Leng 2008). It could be considered that some of the studies offer a follow-up period which is too short, especially when considering that the evidence suggests that return to work tends to increase with the time lapsed post stroke (Hofgren et al 2007, Onsworth and Shum 2008, Hinckley 2002).

The identified discrepancies in study design as discussed above, including age criteria, definition of work and time post stroke, have contributed to the wide variation in reported return to work rates post stroke. Consequently this variation prevents the ability to reliably estimate return to work after stroke (Daniel et al 2009).

As discussed above many studies have focused on the predictors and determinants of RTW, however there has been little focus on the process of RTW itself. For example, Gilworth et al (2009) sought to gain insight into individuals' personal experiences of RTW post stroke. They found that there was a distinct lack of support, advice and guidance through the RTW process for stroke survivors which in cases delayed RTW. They highlighted the need for comprehensive support, advice, information and guidance for stroke survivors to consider RTW, alternative

Chapter 2

employment options, as well as emotional support and coping strategies to consider and make decisions about their future working prospects (Gilworth et al 2009). The research suggests that successful reintegration into employment post stroke is based on a combination of interrelated factors including the impact of the stroke itself; help and support from family, carers, health professionals, fellow workers and employers; and personal characteristics including motivation, determination, creativity, adaptability and a positive attitude (Koch et al 2005, Vestling et al 2013, Alaszewski et al 2007) further research is required in this area.

In consideration of the predictors and determinants of RTW there also appears to be an assumption that once employment is established and someone has RTW that they will remain in work. Few studies have sought to explore this further. Of those who have considered this area of focus, O'Brien and Wolf (2010) investigated work outcomes in mild to moderate strokes. Of the 98 participants recruited to their study 37% (n=36) never returned to work despite having mild to moderate strokes. For those who did RTW post stroke it was not necessarily sustained, with 15% no longer employed at six months post stroke. This brought their total unemployment rate of the study to 46%, nearly half of all participants. Of those that did RTW and remain in employment, most returned immediately to their previous role and employment status. However many reported poor performance based satisfaction ratings and continued symptoms relating to their stroke. All participants (those who did and did not RTW) reported factors that could negatively affect both their performance at work as well as their ability to sustain employment (O'Brien and Wolf 2010) which similarly concur with the findings of others (Wolf et al 2009, Corr and Wilmer 2003).

Despite O'Brien and Wolf's findings (2010) there were large limitations to their study, with an assumption that the individual's stroke symptoms were the main reason for not returning to work and that executive functioning deficits were the main contributing factor. However, executive cognitive functioning was not assessed in their participant population to give any weight or confirmation to this argument. Likewise no consideration was given to other possible contributing factors such as co-morbidities and environmental factors which may also affect RTW. Therefore it can be questioned whether the limitations of the study outweigh the findings, nevertheless it does demonstrate people with outwardly mild to moderate stroke are presenting poor work outcomes. It also highlights the important issue of not only RTW but sustainability of work post stroke that requires further investigation.

When considering the sustainability of work post stroke, Trygged (2012) investigated RTW and wellbeing after stroke, highlighting the importance to the individual of not just RTW but also

remaining in the labour force. Unexpectedly participants reported ongoing difficulties in the work place rather than stabilisation of the situation over time. There was a sense of enduring vulnerability even after a prolonged period of time of many years post stroke, with a fear of losing their job, consequential loss of independence and the support of services to enable them to keep their jobs (Trygged 2012).

Mitchell et al (2006) considered the wider sustainability of work post disability encompassing stroke as one of the five disabilities reported. They investigated the effect of aging on employment of people with and without disabilities. They found that not surprisingly employment rates declined for individuals in both groups with age, however the decline was at an earlier age, usually around the 40s decade, and more widespread for those that had disabilities. Although having a college education improved the overall chances of someone with disabilities being in employment, it did not prevent the onset of earlier and greater job loss in comparison to those without disabilities. Although stroke was included in the 5 disability groups considered in this study, conclusions should be considered in light of disability in general rather than stroke specifically and further research is needed in this area to draw more conclusions specifically for stroke. However it does highlight the need to consider vocational needs throughout the individual's life span and not just within the first few years post stroke (Mitchell et al 2006).

The role of the employer has also been considered in terms of the RTW process post stroke. For example the size of enterprise, defined as "the number of persons working at the local unit of the firm of the stroke patient" (Hannerz et al 2012, p456) has been considered in relation to RTW. Hannerz et al (2012) found a statistically significant pattern association between RTW post stroke and enterprise size, the bigger the enterprise so the estimated odds increased for successful RTW. However Alaszewski et al (2007) in their qualitative study considering 'Survivors experiences and perceptions of barriers and facilitators of the return to paid employment' provided a conflicting view where stroke survivors reported the work environment where they were working at the time of their stroke as being unsupportive in the process to RTW. This was particularly identified by those who had worked in large organisations or the public sector and especially where occupational health checks were involved (Alaszewski et al 2007). Clearly further research is required in this area to fully understand the intricacies of this phenomenon.

The role and experience of the employer as a key stakeholder in the RTW process has also been considered (Coole et al 2013). Despite employers, and especially line managers being pivotal to the RTW and retention of work process post stroke, most employers reported that they felt unprepared for this role. There appeared to be a distinct lack of communication and support

between health care providers and employers, despite limited experience on the part of the employer in managing and understanding the complex issues and problems encountered by employees following a stroke. However where employers did receive support from health care professionals they reported finding this generally beneficial. The choice and quality of support networks accessible to the employer is inequitable (Coole et al 2013). This research highlights the need for appropriate provision of support to both employee and employer in the RTW process, if RTW is to be successful and sustainable; and requires further studies to address what support is currently provided and what would be of most mutual benefit to employers and employees in providing the best outcomes for both.

The current evidence base for return to work have tended to be mainly quantitative and large scale in design rather than qualitative as this study has been designed. It is felt that by using a qualitative research design more rich data will be gained as to the specific experiences of a small cohort of people about a given vocational rehabilitation service. It is also apparent that many of the studies have considered return to work as the outcome of post stroke recovery; rather than investigating the specific qualities of the intervention and vocational rehabilitation provided to the individual aiming to return to work on their post stroke journey, as the current study is investigating. This is an important area to consider as research has suggested that where people with illness or injuries are offered adapted work programme they are twice as likely to RTW compared to those who are not offered this (Vestling et al 2013). What is also often absent in the research literature is the specifics of the time taken for an individual to return to work, in addition to the proportion of people undertaking unpaid and voluntary work, as well as the quality of the work undertaken (Glozier et al 2008).

2.9 Psychosocial aspects of work

It is evident from the body of research considering the predictors or determinants of return to work post stroke that return to work is generally considered to be a successful outcome of recovery after stroke. Generally a rapid RTW would indicate a good recovery; however this is not always the case (Alaszewski et al 2007). Consequently what is often overlooked is the actual process and quality of intervention on the patient's journey to return to work. For example, Treger et al (2007) identified that surprisingly the research does not tell us anything about the effectiveness of interventions; consequently there is a need for the effectiveness of vocational rehabilitation programmes to be evaluated. It is acknowledged that return to work is one of the most important outcome measures for stroke patients, their family and wider society. However, it must also be recognised that not all patients may be able to return to paid employment and

therefore it is also important to investigate the role of vocational rehabilitation in the stroke patient's journey and recovery process. This research area requires further investigation.

It has been suggested that RTW does not necessarily equate to full mental and physical recovery post stroke but does equate to a level of mental and physical wellbeing (Trygged 2012). In contrast, some studies have highlighted the social and psychological consequences of non-return to work which has been correlated with social withdrawal, depression and marital and child care problems (Treger et al 2007, Vestling et al 2003, Teasell et al 2000). Corr and Wilmer (2003) identified the change in roles for individuals following stroke particularly in the area of work and hobbies. Included in this role was the value given by individuals to work (77% of participants hoped to return to work in the future) and the dissatisfaction with not being able to carry out this previous role. They also considered the experience and influencing factors on the decision making of individuals to return to work and the support sought and/or obtained. Three key themes emerged that of motivation, the experience itself and the support in returning to work.

Accordingly Vestling et al (2005) considered the differences in subjective aspects of work and quality of life post stroke. Financial aspects (source of income) and intrinsic aspects (personal development, use of knowledge and freedom to decide) were considered by stroke patients to be the most important, followed by social aspects (something to do and contact with fellow workers), these are similar to findings of others (Alaszewski et al 2007). Those who rated intrinsic aspects of work as most important were consequently more satisfied with the subjective dimensions of quality of life incorporating physical, mental and social wellbeing. It is therefore suggested that it should be acknowledged that the subjective aspects of work and quality of life are different for different individuals and that by understanding this and incorporating this into an individual's vocational rehabilitation might influence outcomes and would at least identify motivating factors for returning to work making rehabilitation more goal directed.

2.10 Critique of the research literature

The research literature and government policy in stroke illustrates that there have been strong advances in stroke care during the last fifteen years, however sadly the number of people of working age having a stroke has increased dramatically. RTW post stroke is considered to be a good outcome by policy makers, researchers, health professionals, patients and carers alike and therefore retaining people in work is a key agenda item of current government health and social care policy.

Chapter 2

The specific needs of younger stroke patients as a distinct group has been highlighted by both research literature and consequently policy, however the research literature suggests that there is a disconnect between the sensitivity of assessments, as well as the provision of stroke rehabilitation, to suitably address the complex requirements and needs of stroke survivors to RTW. From the research literature it appears evident that current service provision does not adequately prepare stroke survivors for the more complex issues and extended activities of community integration and RTW; whilst also highlighting the negative social consequences of non-RTW and lack of VR service provision nationally.

A central research theme is the predictors and determinants of RTW post stroke and the current research corpus suggests that RTW rates are overall poor for stroke survivors, as well as consequential difficulties of work retention long-term. However, the research literature in the area of RTW and VR post stroke is weak. The current evidence base on RTW post stroke suffers from an inherent weakness of widespread differences in study design, data collection methods, sample sizes, inclusion criteria, age categories, definitions of work and follow-up times post stroke. This variation and discrepancy in study design prevent the ability to draw any strong conclusions from the research literature. This research field is dominated by quantitative studies of which many of the studies also unfortunately exhibit fundamental limitations in study design including inherent assumptions made on behalf of the stroke survivor, addressing sensitive issues, without the acknowledgement or inclusion of the perspective from stroke survivors themselves. There is a need for further good quality qualitative research in this subject area.

There is insufficient research evidence to draw general conclusions from the research literature, which also prevents the ability to reliably estimate both the social consequences of stroke as well as RTW rates post stroke. Fundamental gaps in the research literature and evidence base also remain regarding the time taken to RTW, the proportion of stroke survivors undertaking unpaid and voluntary work and the quality of the work undertaken by this cohort group post stroke. Consequently, more research is required to provide a better understanding of various aspects of VR and RTW post stroke including what mechanisms prevent people from RTW post stroke and conversely what mechanisms would help to support a person to RTW post stroke. A better knowledge and understanding is required of what support is currently provided to employers and what would optimise positive RTW outcomes and sustainability in RTW for employers and employees. There is also a paucity of research investigating the actual process of RTW rather than RTW as an outcome post stroke and therefore further research is required to give a better understanding of the process, quality and effectiveness of VR and RTW interventions.

Although it is widely accepted and acknowledged that the provision of VR services remains poor nationally, there is still a paucity of research looking specifically at the role of VR, the impact VR has on the stroke survivors post stroke recovery, quality of life and longer-term VR outcomes. Until there is a better evidence base to support and promote the outcomes of VR post stroke, it is unlikely that the commissioning of service provision will be improved. The current research literature in this area unfortunately leaves more questions than answers and further good quality research is required to provide a better understanding of the need and benefits of RTW and VR post stroke.

2.11 Rationale for choice of study

The research study focus stems from my personal area of interest as a stroke specialist clinician working with younger stroke patients in rehabilitation. Whilst working in the area of vocational rehabilitation within a structured workshop environment it became apparent that not only were the patients attending in a privileged position to be receiving vocational rehabilitation, but there were also many potential hidden elements to this design of rehabilitation. Not only did clients have a structured approach to follow in a “mock-up” work environment which is viewed as quite a traditional approach to rehabilitation but there was also an underlying support system provided through peer support from the client group. This appeared to have an impact on the individual’s stroke experience, self-identity and adjustment following stroke which inspired the researcher to investigate this area further and led to the development of the research question:

What are the experiences of stroke survivors participating within a Work Rehabilitation Service (WRS); including the impact of the WRS on their stroke journey?

2.12 Summary

This chapter has presented a critical review of the literature relating to this research study. The existing research has explored the social consequences of stroke as well as the differing needs of young stroke patients highlighting the lack of tailored rehabilitation to meet the specific needs of the individual. Research specifically focused on vocational rehabilitation post stroke is sparse and the main area of focus instead has been on return to work as an outcome of stroke recovery. This body of research has considered the predictors and determinants of RTW post stroke, as well as some limited consideration of the sustainability of work post stroke and the role and experience of the employer. However, the existing research has not specifically considered the individual role

Chapter 2

of a vocational rehabilitation service in the process of RTW and the individual's stroke journey and recovery process as is the focus of this study.

Chapter 3: Methodology

3.1 Introduction

This chapter outlines the philosophical and theoretical perspectives which inform this research study and explains the background and use of a phenomenological approach and interpretative phenomenological analysis (IPA) which has been employed as the research method for this study.

3.2 Choosing the research method to answer the research question

The aim of this study is to explore stroke survivor perceptions of the role of a work rehabilitation service; in order to gain an understanding of their experience of the role of the WRS on their stroke experience, self-identity, adjustment following stroke and the impact on their current occupation and work/job role. In order to explore these perceptions, it appeared essential to ask stroke survivors themselves. Therefore a quantitative approach was deemed to be inappropriate as it would yield numerical data which would not provide deep, detailed explanations or insights in to experiences and perceptions.

Instead a qualitative approach was chosen to explore and capture the meaning and understanding of the individual's work rehabilitation experience. At this point it would be beneficial to discuss the main differences between the quantitative and qualitative approach in order to then further justify the choice of a qualitative research approach.

Quantitative research is underpinned by the philosophical standpoint called positivism, which proposes that there are facts and truths that can be observed and measured. The underpinning principle of quantitative research is that external influences in research can be controlled in order to reduce any bias that could otherwise affect the findings. Consequently through the methods used, bias can be removed from the process of investigation therefore gaining more generalisable data to indicate trends. Quantitative research collects evidence that can be generated into valid and reliable numerical data and that can provide statistical evidence to prove or disprove the research hypothesis or question (Topping 2010).

In contrast, qualitative research is more attuned to the interpretivist tradition which is based on the premise that interactions between people allow us to make sense of the world. Qualitative research is more concerned with gaining an understanding of human behaviour. As part of this,

the role of the researcher within this process is acknowledged and often becomes an intertwined part of the data analysis. Reflexivity, involving critical self-reflection on the research process and data collected, is used to ensure that the role of the researcher is made explicit (Topping 2010).

Therefore it was considered that qualitative methods are most suited to this research project as they allow the researcher to inquire into the subjective meanings and the socio-cultural context which are not phenomena that can be meaningfully quantitatively measured, but instead interpretations to make sense of the individual's actions and feelings (Yardley and Marks 2004). A qualitative approach also enables a holistic picture to be considered, recognising the connections between other aspects of the individual's life that would be more difficult to capture using a less exploratory design (Holloway 2008). Qualitative data will help to provide rich personal data concerning what it is like to be a patient experiencing work rehabilitation within a given clinical setting following a stroke. This qualitative approach allows me, as the researcher, to enter the world of the participants gaining insight into their thoughts and feelings (Murray and Harrison 2004).

3.3 Choosing the methodological approach

When looking at the full spectrum of research positions, from realism and positivism at one end, to constructivism and idealism at the other, an interpretive/humanist model was felt to be most fitting for this study. Interpretative research sits within the field of qualitative research design and focuses on the human being and how they interpret and attach meaning to their experiences in order to make sense of their reality (Pope and Mays 2000). Alternatively, positivists at the other end of the spectrum emphasise the importance of gaining accurate facts and causes about objective reality with less regard for the subjective view of individuals. (Yardley and Marks 2004, Bogdan and Taylor 1975). Therefore interpretivism closely mirrors the aim of this research in gaining understanding rather than seeking a truth.

Within an interpretive qualitative research design there are several qualitative approaches that could have been adopted which would have been appropriate to the research study. Of these, the main approaches to be considered were Grounded Theory, a biographical/narrative approach, and Phenomenology.

Although Grounded Theory could have been used, this approach did not neatly meet the core aims of the research project as the intention of the project is not to develop theory. Instead it is focused on gaining an understanding of the world of the Work Rehabilitation Service (WRS)

through the eyes of the individuals who attend the service. Therefore, aiming to present interpretations of the lived experience, but without developing theory. The project also did not fit one of the key elements of Grounded Theory in terms of the literature review. In Grounded Theory there is usually a delay in the literature review as the data and its analysis informs the literature review, however in the case of this research study the literature review had helped to shape its design, aims and objectives from the beginning.

A biographical or narrative approach could also have been used. A narrative approach bases itself on the premise that we tell stories about our lives and that the accounts we exchange are organised into narratives. From these stories we develop a narrative sense of who we are and our history (Yardley and Murray 2004). However the aim of the research is not to explore the individual's narrative of their experience and life, but instead to understand their lived experience of a specific phenomenon (the WRS), how they make sense of their experience and interpretations of what it may mean.

Consequently it was felt that a phenomenological approach was the most appropriate method fitting the aims of the study due to my interest as a clinician and an Occupational Therapist in the lived experience of the individuals who attend the WRS. A phenomenology approach linked nicely to the core philosophy of occupational therapy which focuses on the experience of the individual. A phenomenological approach using interpretative phenomenological analysis (IPA) fitted the aims of my study and as there is a considerable amount of text books and information detailing IPA this also provided a clear explication of the process of IPA data analysis which was helpful as a relatively inexperienced researcher.

3.4 Phenomenology

Phenomenology is a philosophical approach in the study of phenomena and human experience with links in both psychology and philosophy. There is a distinction to be made between phenomenology as a philosophy and way of thinking regarding human existence and phenomenology as a research method to explore people's lived experience (Holloway 2008). Phenomenological philosophy is related to the epistemological question regarding the theory of knowledge "how we know", as well as being connected to the ontological question of "what is being", concerned with the knowledge and nature of reality (McLeod 2001, Holloway and Wheeler 2010). Phenomenology, therefore aims to capture the context of the individual's life, in which the experience takes place, as closely as possible and attempts through analysis to determine the psychological essence of the phenomenon (Giorgi and Giorgi 2008).

The history of phenomenology is divided into three phases: the preparatory phase, the German phase and the French phase. The preparatory phase was influenced and shaped by Franz Brentano, who also influenced the work of Edmund Husserl, the most influential scholar of phenomenology from the German phase. Husserl developed the concept of the lifeworld (Lebenswelt) referring to everyday experiences that the individual lives and reflects upon, suggesting that the environment is not independent of the individual, this has become central to phenomenology (Bloor and Wood 2006) (Holloway 2008). Husserl also developed the concepts and key phenomenological terms of intuition, essence, phenomenological reduction – bracketing, and intersubjectivity. Phenomenological intuition is closely linked with that of imagination, suggesting that experience can not only be linked to something real such as an event but that of one's imagination and memory as well. Phenomenological reduction is the process to study what is present, whilst bracketing refers to the process of suspending preconceived assumptions and beliefs. Intersubjectivity refers to the subjectivities shared by individual persons within a community who share a common ground (Holloway and Wheeler 2010). Husserl's work is often termed as descriptive phenomenology within the tradition of transcendental phenomenology (Willig 2008).

Heidegger, an assistant of Husserl, further influenced the German phase of phenomenology. Heidegger was interested in the notion of personhood. He also developed the concept of temporality where time is perceived to include the now the no longer and the not yet (Leonard 1994). From these ideas phenomenology was developed into interpretive philosophy and hermeneutic phenomenology, moving from description to the theory of the interpretation of meaning (Holloway and Wheeler 2010).

Heidegger also influenced the French phase with Jean-Paul Sartre being the most influential figure but who termed himself an existentialist rather than a phenomenologist. Existentialist phenomenology focuses on the concept of existence and essence, that a person's consciousness and behaviour (existence) shape their character (essence). Merleau-Ponty's work looked at the science of human beings focusing on perception (Holloway and Wheeler 2010).

Therefore there are essentially three main streams of phenomenology, descriptive phenomenology from the work of Edmund Husserl, hermeneutic phenomenology from the work of Martin Heidegger and existentialist phenomenology from the work of Merleau-Ponty and Jean-Paul Sartre.

3.5 Interpretative Phenomenological Analysis (IPA)

In contrast to other strands of phenomenology, IPA does not separate description and interpretation. IPA is a phenomenological approach in that it involves detailed examination of the lived experience of the participant, exploring their personal experience and perception of a given event. IPA also acknowledges the active role of the researcher in this dynamic process. The researcher is trying to gain an “insider” view of the participant’s personal world. This therefore takes a two-stage approach in which the participant is trying to make sense of their world and then the researcher is trying to make sense of the participant making sense of their world. IPA is therefore additionally connected to theories of interpretation and hermeneutics (Packer and Addison 1989, Smith 2007). The interpretative tradition focuses on knowledge from the ‘inside’ with the aim of capturing the world of people through their own voices via descriptions of their thoughts, feelings, situations and actions. The researcher seeks to understand how the individual constructs their experience (Charmaz 2001).

Furthermore, IPA has a concern for how individuals construct meanings within both a social and personal world therefore acknowledging symbolic interactionism (Denzin 1995). The social influence in symbolic interactionism adds a dimension to the personal experience of phenomenology, thus a potential strength of IPA. IPA assumes a link between people’s cognitive, affective and linguistic state although acknowledging that this connection is complicated, for example, people struggle to explain what they are thinking and feeling and that the researcher has to interpret people’s emotional state from what they say (Smith and Osborn 2008). See figure 2 for the roots of IPA.

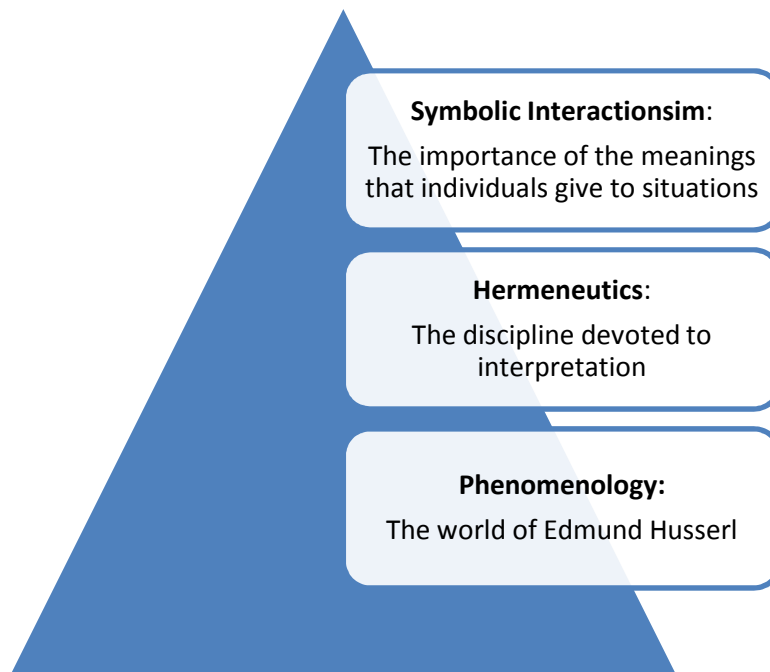


Figure 2: The roots of interpretative phenomenological analysis (Howitt and Cramer 2011, p385)

The study and use of IPA aims to gain rich detail as to the perceptions, experiences and understanding of the given group, in this case stroke survivors, rather than make more general claims. This is described as an idiographic method of enquiry which is in contrast to a nomothetic approach or study where analysis is at a group and population level, where probabilistic claims can be made about individuals but generalised to the wider group or population (Smith et al 1995, Smith and Osborn 2008).

IPA follows purposive sampling establishing a more closely defined group, where the sample is fairly homogenous, for which the research will be significant, therefore providing a detailed interpretative account of the small sample cases included in the study (Smith and Osborn 2008). This is therefore fitting to the research project looking at an individual work rehabilitation service where the boundaries of the relevant sample are already clearly defined as people that have participated in rehabilitation at the given service with a diagnosis of stroke. Consequently the research will be able to draw conclusions and give detailed reports of the given community of the WRS but will not claim to be able to generalise this to say something about the experiences of individuals at other work rehabilitation services. Consequently the sample size attained for the study is small, seven participants, however this reflects the philosophical position of phenomenology and IPA outlined above, and thus is smaller than might be anticipated for other qualitative studies.

As the researcher completing the interviews, my main concern is to portray the individual's account of their psychosocial world, however at the same time the researcher must acknowledge that they bring their own conceptual framework and background to the research. Therefore it is important that as the researcher I use reflexivity in order to self-reflect on this and consider any factors that may have influenced the project at any stage through either my interactions within the interviews and/or my own conceptions and pre-conceptions (Smith et al 2009). Reflexivity will now be discussed further.

3.6 Reflexivity

Reflexivity is divided into two types, personal reflexivity and epistemological reflexivity. Personal reflexivity involves reflecting upon my own values, experiences, beliefs and social identities and how they have influenced and shaped the research project. As well as considering how the research may have affected me as the researcher. Epistemological reflexivity encourages the researcher to reflect on the assumptions about the world and about knowledge and how these assumptions may affect the course of the research. For example how a different epistemological stance could potentially alter the method design and data analysis (Willig 2008). Reflexivity is also important in ensuring the validity of the research process.

At this point it would be pertinent to mention epistemological position. As this research study is part of a clinical doctorate I chose a study based on my area of clinical specialism knowledge and expertise. Thus I have expert knowledge in the area that I am studying and so could claim to be in an epistemologically privileged position, for example I appreciate what is going on and the phenomenon because that is my area of specialism and expertise. However, conversely it could be argued that because I have insider knowledge I am more likely to make assumptions and less likely to see the whole situation clearly because either I'm looking too closely at small details, or because I'm too closely involved. It is important to acknowledge epistemological position but it is important to state that I am wary of assuming it.

3.7 Limitations of phenomenology and IPA

A criticism of IPA is that the analysis of data is reliant on texts and language. IPA suggests that language provides the appropriate medium for participants to attempt to communicate their experiences. Therefore phenomenological data analysis is reliant 'upon the representational validity of language' (Willig 2008 p 66). However others would argue that language is a construct

rather than a descriptive. Language therefore provides meanings and may shape the expression of the experience rather than giving the true experience (Willig 2008).

IPA also relies on the ability of the participant to adequately articulate their experience to the researcher, this may therefore limit the application of the phenomenological approach to certain participants (Willig 2008). For example in the given study the exclusion criteria applies to individuals with severe aphasia, which would prevent them from being able to participate in the interview, due to lack of access to speech and language therapy to assist with these communication issues. Therefore this could limit the diversity of the data gained; however, the researcher felt that as long as these limitations are clearly identified and discussed within reflexivity, phenomenology and IPA still provide the best structure and framework in which to conduct the study.

A further criticism of phenomenology and IPA is that it is concerned with the individual's perceptions of their experience and that although this can provide detailed and rich data of the participant's experience, it can be argued that the research does not further our understanding or provide reasons why there are differences between participants 'phenomenological representations' (Willig 2008 p68). However the aim of the given research project is to describe and document the experience of individuals at the WRS and not to explain the phenomena.

3.8 Summary

This chapter has outlined the philosophical and theoretical perspectives informing this research study. An explanation of the background and use of a phenomenological approach and interpretative phenomenological analysis (IPA) has also been given and justification of its use as the chosen research method and analysis approach for this study.

Chapter 4: Research Methods

4.1 Introduction

Previously the rationale of why a qualitative and phenomenological framework approach was chosen has been discussed in chapter 3. As stated, the study followed an IPA approach where individuals who had had a stroke attending the Work Rehabilitation Service (WRS) were interviewed using semi-structured interviews. In this chapter the WRS will be introduced and the research procedures used for this study are presented, including the data collection and data analysis procedure chosen. There will also be a discussion of the recruitment issues encountered when data collecting.

The research procedure for the study will be discussed below.

4.2 The WRS

The WRS is a therapy led work rehabilitation service offering bespoke vocational rehabilitation for individuals with a neurological diagnosis including stroke. The referral criteria varies for individuals depending on the funding Clinical Commissioning Group (CCG) ranging from the restricted age criteria for attending the WRS being any individual aged 16 – 65 years and the full criteria being any individual over the age of sixteen. The main referral criteria is any client with a neurological diagnosis, including stroke, who has an identified goal to return to vocational occupation be it paid or unpaid, work or education.

The frequency of attendance at the WRS is bespoke and tailored to the individual needs of the client. Clients attend for an initial assessment of their needs and treatment goals and then a treatment plan and attendance schedule is agreed with the client. Clients tend to build up their frequency of attendance as fatigue and tolerance allows, building up their stamina. Generally most clients attend the WRS two days a week. This often increases to three days a week prior to the client starting either a voluntary / test out period at work, or starting a formal graded return to work, in order to build or assess stamina levels. Based on the needs of the individual client however, there are no real boundaries for example, where appropriate there have been clients who have attended the WRS every day for one week for assessment prior to a report and recommendations being given for return to work. In terms of duration of attendance at the WRS, the average attendance is twelve weeks however; likewise, this is also flexible depending on the given needs of the individual client and their goals.

4.3 Research governance

Approval for the research was sought and granted from Hampshire and Isle of Wight Shared Research Management and Governance Service, which covered the Trust where the researcher already had an honorary contract (Appendix A). The University of Southampton acted as a sponsor for the research (Appendix B) and the university also provided professional indemnity and clinical trials insurance for the researcher and research project (Appendix C).

4.4 Ethics approval

Ethical approval was sought from the NHS via Southampton and South West Hampshire Research Ethics Committee (REC) A in October 2009 and on 11th November 2009 the researcher attended the regional ethics committee meeting where the research project was discussed. Following this the ethics committee provided provisional approval dependent on suggested alterations which were completed by the researcher and then resubmitted, with full ethical approval being granted in March 2010 (Appendix D).

In January 2011 the researcher submitted a notification of substantial amendment to the research study and REC application. The substantial amendment was with regards to the recruitment process of the study. It requested additionally recruiting clients who had recently been discharged (within the previous year) from the Work Rehabilitation Service (WRS). This amendment was sought in order to assist in gaining the appropriate numbers required for data collection for the study as recruitment had proven to be an issue. Substantial ethical amendment approval was given in February 2011 by the REC (Appendix E).

4.5 Risk assessment

A risk assessment was completed in line with the University of Southampton Policy. The key aspect that needed to be addressed was lone interviewing. It was agreed that for each interview completed within a participant's own home environment the lone interviewing contact procedure would be followed and the location form completed, alternatively interviews would be completed at the Work Rehabilitation Service where there were other staff on the premises.

4.6 Gaining access to the setting

The Therapy Services Manager from the Trust was contacted by e-mail and a meeting arranged to explain and give further details of the research project explaining the purpose of the research and

the level of involvement required by participants. Following this a letter of collaboration was obtained from the Therapy Services Manager for the research to take place within the Work Rehabilitation Service.

4.7 Gaining access to the clients

With agreement from the Therapy Service Manager, the researcher attended a therapy team meeting at the Work Rehabilitation Service. A short presentation was given to therapy staff in order to provide an overview of the study and explain the purpose of the research. They were also provided with the opportunity to ask any questions and seek any further information.

The Senior Occupational Therapist at WRS was provided with research packs to give out to clients, which were to be distributed near the beginning of their treatment sessions at WRS. Following ethical approval for the substantial amendment, in addition clients who have been discharged from the WRS within the previous year were also sent a research pack by the WRS staff. The research packs included:

- A covering collaboration letter of invitation from the researcher and the Therapy Services Manager supporting the research project (Appendix F).
- A participant information sheet regarding the research project and process (Appendix G).
- A reply slip with stamped addressed envelope (Appendix H).
- A consent form (Appendix I).

Those clients who were willing to participate completed the reply slip and returned it in the stamped addressed envelope to the researcher. Once a reply slip was received the researcher contacted clients by telephone to arrange an interview at a time and place that was convenient to the client. It was suggested that interviews either took place in the client's home environment or the WRS environment, but the exact location was the client's own choice. Below is a diagram of the research process (see figure 3).

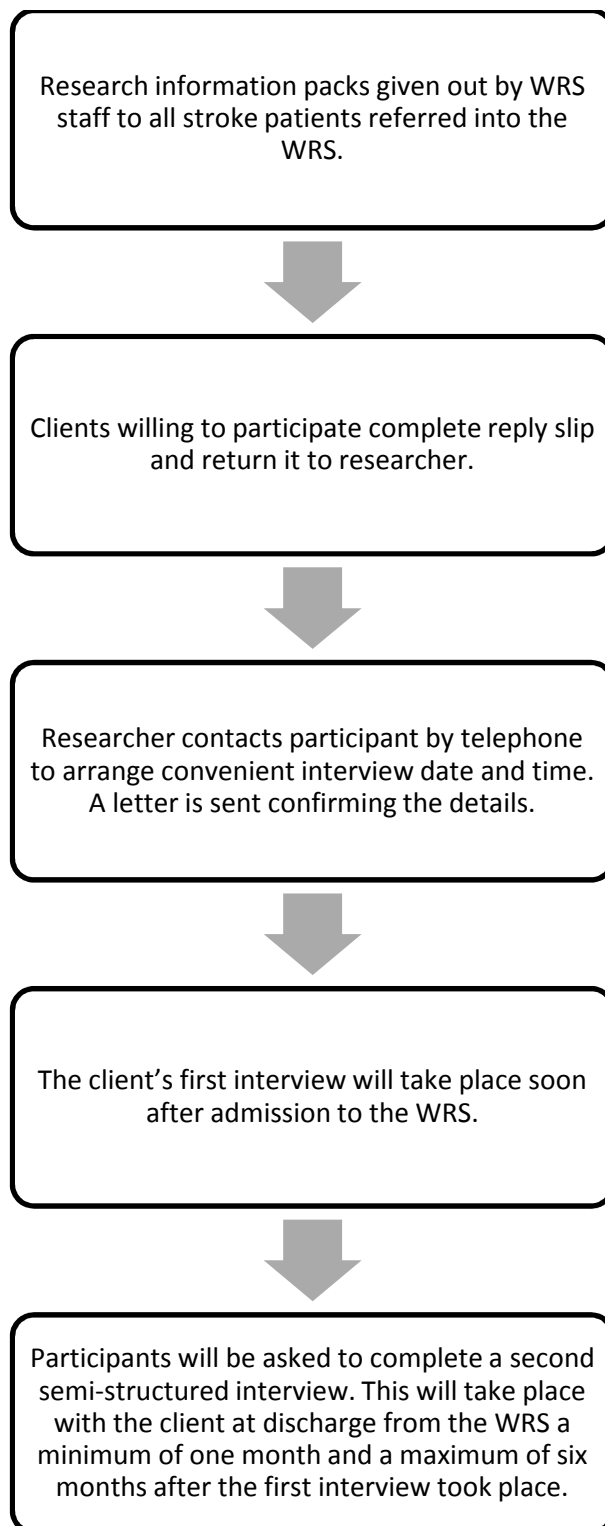


Figure 3: Research process for initial and follow-up interviews

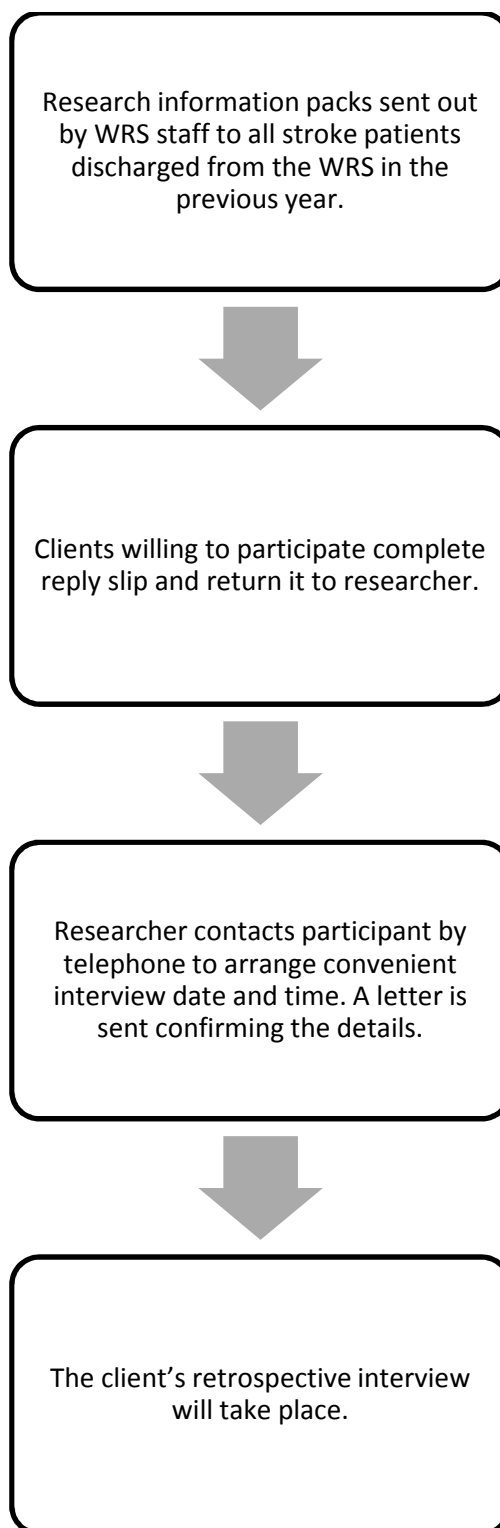


Figure 4: Research process for retrospective interviews

4.8 Participants

Initially the researcher was looking to recruit a maximum of 15 clients to be interviewed. Convenience sampling was used to identify potential research participants however this still

provided a broad understanding and variety of views from different clients who were of different age, stroke severity and length of time post stroke.

4.9 Inclusion criteria for clients

Any client:

- With a diagnosis of stroke.
- Who is currently attending or has attended and been discharged within the previous year from the work rehabilitation service (WRS).

4.10 Exclusion criteria for clients

Clients with severe aphasia which would prevent them from being able to participate in the interview were excluded from the study due to the lack of access to speech and language therapy to assist with these communication issues.

4.11 Recruitment

Initially recruitment was very slow and this proceeded to the need to gain ethical approval to also recruit retrospectively those clients that had been discharged from the WRS in the previous year. Although this enabled recruitment of a couple of extra clients, recruitment remained slow. Table 1 shows the breakdown of the total number recruited to the study.

Table 1: Numbers recruited to the study

	Initial interviews completed	Follow-up interviews completed	Retrospective interviews completed
Client numbers	5	1	2

Although this remained a small number compared to the recruitment numbers initially sought it has become evident as the research study has developed and the researcher has completed further reading on IPA, that for a study of this type the numbers are sufficient for IPA analysis where the researcher is seeking to gain the idiographic, in-depth insights of the individual's experiences of the WRS (Smith et al 2009). Studies using IPA have tended to more recently reduce in sample size with numbers comprising of 4 to 10 people being acceptable for studies using

interviews this is in comparison to larger sample sizes used by other qualitative methods and studies (Smith and Osborn 2008).

4.12 Data collection method

Semi-structured interviews were used as the method to understand the world of the individual experiencing the WRS. Semi-structured interviews rather than structured interviews were chosen, as the researcher felt that structured interviews would not give the flexibility required to explore the avenues that the client felt was important to them. This is also in keeping with semi-structured interviews being the preferred data collection method for IPA which was important to ensure sensitivity to context within the relevant theoretical and methodological standpoint (Yardley 2015). This provided a flexible data collection method where I, as the researcher/interviewer, in conjunction with the participant, were able to engage in a discourse where initial questions could be modified as a consequence of the participant's responses and further interesting and important areas could be explored (Smith and Osborn 2015).

As an occupational therapist I am used to interviewing patients/clients within a clinical context however it was important to take on the role of researcher rather than therapist and develop my skills as a researcher interviewer. Consequently, prior to commencing data collection I attended a university interviewing skills full day workshop which gave me the opportunity to practice my interview skills within a research context and was useful in developing my skills and confidence in this area. I also discussed and practised my interviewing techniques and skills further with my research supervisors, including piloting the interview questions.

Once the client had replied agreeing to take part in the research project I contacted the participant by telephone to arrange a convenient interview date and time. Following this a letter was sent confirming the details of the interview. The option was given to the clients as to where they wanted the interview to take place, either at the WRS, or their home environment, or an alternative location of their choice; therefore interviews were always held at the location of the client's own choice. Generally clients chose to have their interview(s) at the WRS and so interviews were arranged for a convenient time on a day when the client was attending the WRS. The WRS staff were also informed of the date and time of the interview and a quiet room was booked for the interview to take place in where there would be no interruptions. One of the retrospective interviews was completed in the client's home environment as that was his chosen location and fitted into his lifestyle having now left the WRS. Although it could be perceived that the environment chosen for the interview may have affected or impacted on the data generated

at the interview, this was not the experience of the researcher and did not appear to be the case. Likewise who was present at the interviews could have affected the data generated, however all interviews were conducted with the client on their own. Most interviews were conducted at the WRS where the client was attending on their own and even in the home environment, the clients, by their choice, were interviewed on their own. Consequently, the details of the clients' accounts in the interviews were not influenced or affected by a third party and the participant was free to talk openly.

In terms of the timings of the interviews, the initial interviews were completed as soon as was feasibly possible to the client's admission and start of treatment at the WRS. Initially it had been planned that this would take place in the first two weeks of the client's admission to the WRS, however with clients just starting at the WRS they were often unsure of signing up straight away to a research project. Therefore, although the research packs were given out on admission, this was generally followed up and revisited by the WRS staff during the first couple of weeks after admission when the client had settled into the WRS and was more ready to consider participation in the research project. Retrospective interviews were completed for anyone who had been discharged from the WRS in the previous year. It is important to note, that although the researcher was happy to and offered to complete interviews in the evenings or weekends if clients had already returned to work, the uptake from these retrospective clients was limited as they appeared to have moved on from the WRS and were getting back to life. Similarly, although clients who completed an initial interview also agreed to take part in a follow-up interview at discharge from the WRS this proved difficult to complete and conduct. Clients were lost to the research project as they were starting back at work, or had moved onto other vocational activities and were not able to easily spare the time to take part in the follow-up interview. This was disappointing for the researcher however, the richness of the data generated from the interviews already completed, as well as the combination of the data generated from the retrospective interviews completed, it was felt that this did not negatively impact on the research study. Where a follow-up interview was completed this took place a couple of weeks before discharge from the WRS, when the client was in the process of planning for the next step of their stroke journey post WRS.

The aim of the semi-structured interviews, as the data collection method, was to investigate what are the experiences of stroke survivors participating within a WRS; including the impact of the WRS on their stroke journey. The duration of the interviews varied between 30 minutes and one hour. With experience of working with stroke patients this seemed a reasonable duration for an interview considering many of the participants suffered from fatigue.

Each interview was recorded using a digital dictaphone with prior written consent obtained from the participant. The interview schedules used had been developed and checked with both my research supervisors, the WRS therapy staff and a selection of WRS clients for relevance, clarity and understanding prior to ethics and subsequently following the ethics amendment and approval process. The interview schedule was used to facilitate the interview process highlighting question topics to cover during the interview (Appendix J) and prompt questions were used to encourage the participant to elaborate on their responses giving further clarification and explanation. The interview schedule provided some structure giving an area of focus and questions to pursue as a guide, however the researcher was keen to enter, where possible, the psychosocial world of the participant and therefore the semi-structured nature of the interviews enabled the flexibility to do this. The participant was therefore perceived by the researcher as the expert and encouraged to share their story. Consequently the semi-structured interview offered the opportunity to develop rapport between the researcher and participant as well as enabling greater flexibility of the direction of travel of the interview, allowing the researcher to explore new and novel aspects, thus generating rich insights and data (Smith and Osborn 2015).

Prior to each interview I familiarised myself with the interview schedule. I introduced myself to the participant at the beginning of the interview offering the opportunity for them to ask any questions that may not have been answered by the participant information sheet (Appendix G). Following this the participant was asked to sign the research consent form (Appendix I). When the participant was comfortable and ready to start the interview I switched on the digital dictaphone which remained on for the duration of the interview, once the interview came to its natural conclusion I thanked the participant for their contribution and asked them if they were happy for the digital dictaphone to be switched off. If the participant was due to have a follow-up interview I explained the process of this.

During the interview itself, as the researcher, I focused on putting my participants at ease through the use of my verbal language and body language, listening intently and being mindful of the development of the discussion to my study aims. At points during the interview I would summarise what the participant had said and seek clarification of understanding. Through the process of interviewing I developed my skills and learnt to give more time for participants to consider their responses and to be comfortable with any silences. Immediately after the interview I jotted down any field notes and reflections of the interview in my research journal. I would then further reflect on the process of the interview and discuss this, as well as the content of the interview, with my research supervisors at my supervision sessions.

4.13 Data analysis

Each participant was interviewed and the digital recordings from each interview were transcribed verbatim. These and any field notes I, the researcher, had made during or after the interview were used in the analysis process. All digital recordings of the interviews were downloaded to a secure folder on my computer and number coded for confidentiality reasons. The initial interviews were then transcribed by myself, the researcher, in order to immerse myself in the data. The whole interview was transcribed including the interviewer's questions, with the transcription detailed at the semantic level including all spoken words, false starts, significant pauses, laughter and anything else felt to be important and worth recording (Smith and Osborn 2015). My initial transcripts, which I had transcribed myself, were then shared with my supervisors for their comments and to aid analysis discussions when deriving themes.

Due to time constraints, which were discussed at my DClinP interim assessment and viva, it was agreed that I would pay for the latter interviews to be transcribed by a professional transcriber who was recommended and did regular work for the University of Southampton. However, once these interviews had been transcribed, I read the transcripts whilst listening to the recordings of the interviews to ensure I was fully familiarised with the data and reminding myself of the verbal content and meaning of the interviews.

IPA was used as the process of analysis in this study and therefore the following analysis stages, as suggested by Smith and Osborn (2008), were followed as a guide:

1. Listen to the interview.
2. Read and re-read to become familiar with the transcript.
3. Identify meaningful elements, including paraphrasing of text, own thoughts, use of language etc.
4. Identify emerging patterns or themes.
5. Form a preliminary list of themes.
6. Cluster similar themes but keep close to transcript with identifiable quotations.
7. Develop super-ordinate/major themes from clusters.

4.14 Reflective account of the analytical process

Although Smith and Osborn's (2008) stages of IPA analysis were useful as a guide to follow, in reality this was not a straight forward linear process and instead it was a continuously circular evolving process in which the transcripts and the raw data were revisited time and time again. I spent a vast amount of time immersing myself in the raw data in order to become as familiar with each of the interview recordings and transcripts as possible and this I felt helped me with the overall data analysis process.

Initially each of the transcripts were read and re-read, in the left hand margin of the transcript key words were written identifying potential meaning. There was no standardised pattern of doing this and instead it developed in the sense that where there were richer sections of the interview so there were more words and comments in the left hand margin. What was written in the left hand margin also varied from summarising and paraphrasing to some initial interpretations as an attempt to understand the individual's account. The purpose of this initial process was an attempt to make sense of the individual's experience and to document this sense-making (Smith and Osborn 2015).

Following this the right hand margin was used to identify any emergent themes at a higher level. The difficulty here was to get the balance between identifying themes or terms to summarise that were high level enough to allow theoretical threads across different individual accounts whilst remaining true and grounded in the original meaning of the account (Smith and Osborn 2015). From this process an initial chronological list of themes was written for each transcript and shared regularly with my research supervisors at supervision sessions. I shared my list of themes with my supervisors as a process of inter-rater comparison to ensure that the analysis was not confined to just my own perspective, as the researcher, but also made sense to them, as my supervisors. By sharing and discussing the themes with my supervisors, this enabled me to identify further potential themes and highlight any modification of codes to increase the coherence of the analysis process (Yardley 2015).

The next stage was to use flipcharts to cluster and start to map out themes. I covered my dining room table and floor with flip chart, paper mapping what appeared to be key themes, clustering similar themes together and then going through a process of identifying what appeared to be the overarching theme and then subordinate themes which were elements that related to and helped to make sense of the overarching theme. I presented these visually, initially as lists and then spider diagrams and mind maps of the developing themes. This was more of an analytical process

trying to make sense of the connections between the emerging themes (Smith and Osborn 2015). This analytical process was something I toiled with, going back and forth to the raw data, checking back that the themes suggested remained true to the original account. My supervisors were very supportive and we booked time aside to discuss the process of my analysis and go through interpretations of the data to ensure that they felt my interpretations were justified and similar to their own, again ensuring inter-rater comparison.

The clustering of themes in the mind maps were then turned into a table of themes. It was a challenge to reduce and distil the number of themes and this was done with the support of my research supervisors. With there being too many themes I worked through a process of distilling and clustering them further to ensure important insights weren't lost but were gathered in a manageable level of grouping. The final distilled themes, agreed with my research supervisors, were chosen as they were felt to provide the richest explanation and insight into the lived experience of the participants attending the WRS.

It was also important to include a balanced view of the data and therefore also highlight where there may be different opinions from participants within themes in order to provide a true representation of all the data. This is a process referred to as disconfirming case analysis (Yardley 2015). This again was an analysis process which I discussed regularly with my supervisors in supervision, reporting where there appeared to be any conflicting or negative responses from participants that were not in keeping with the core data. Within the data set there were very few conflicting accounts, however where they existed they have also been reported in the findings chapter in order to give a true representation of the data.

As the researcher I felt that it was important to keep the interpretation of the data as close as possible to the essence of the lived experience and accounts of the participants, in order to keep my findings true to a phenomenological approach. Therefore, I did not want the theme and sub-theme titles to lose this essence and sound as if they were out of a research textbook instead I wanted to make the interpretations "real". For that reason, the theme titles used were grounded in the data, taken directly from the participants' accounts, giving them authenticity in order to provide a meaningful and novel representation of the lived experience of the WRS and the return to work journey after stroke for the reader. Continuing this strive for authenticity, supporting quotes were gathered from the transcripts to map out each of the themes. This submersion in the data and detailed verbatim quotes enabled me to use low-inference descriptors demonstrating the raw data in order to stay as close as possible to the original meanings and context rather than my own interpretation and reconstruction of what was said by the participants (Silverman 2005,

Seale 1999, Jones et al 2008). The use of low-inference descriptors is also a way of further demonstrating internal validity and plausibility, dependability and authenticity through the research analysis process. In order to protect anonymity and confidentiality, pseudonyms were assigned to each of the research participants. The researcher chose to use pseudonyms rather than numerical identifiers for quotations as it was felt this conveyed more of a sense of the real person and their life experience in keeping with the chosen phenomenology methodology.

The process of analysis was an extremely time-consuming, continuous, cyclical process, of revisiting the data, checking the meaning and refining it, which continued to develop, evolve and expand throughout the process of writing up. As a novice researcher I found this process overwhelming at times and had to ensure that I remained focused, grounding myself by referring back to the overall research question and the aims and objectives of the study. An example of a transcript with initial notes and the development of emergent themes can be found in Appendix K.

4.15 Reflection on the interviews

One of the challenges of the interviews was maintaining the role of researcher and bracketing my professional role as an Occupational Therapist (OT). From a professional perspective although I have previously worked at the WRS, I no longer do and therefore none of the research participants were patients of mine. However having previously worked at the WRS gave me an insider knowledge of the service and having specialised as an OT in stroke for the last eleven years also gave me insider knowledge as to my own experiences and perceptions of what individuals may be experiencing. This insider knowledge can be classed as an epistemological privilege, as discussed earlier, (Mason 2002) as the researcher knows the clinical area and service and therefore can be better equipped and better informed of the situation and life experience being studied. Equally it can also be perceived as a disadvantage, as the researcher brings preconceptions of their lived experience of the situation to the research and interviews which may bias their approach.

As an experienced OT I am use to interviewing patients in order to assess the individual's needs and formulate treatment plans however, in the research context I was there to facilitate the participants to tell me about their lived experience, in order for me to gain an understanding of their lifeworld. When I replayed the recording of the initial interviews I became aware that at times I was asking leading questions in order to find reasons or answers to the participant's situation rather than allowing the participant to speak openly and not lead them in any way. I had

to make a conscious effort to subdue the therapist in me and learn to feel at ease in the role of the researcher allowing the direction of the flow of the interview to be guided by the interviewee rather than myself.

It is clear that being an 'insider' has both positive and negative aspects to it. One advantage was having a prior knowledge of the pathways and processes in place as to what should happen for a stroke patient. It was also apparent that when participants talked about the different stroke services and professionals they assumed that I knew who and what they were talking about. Having worked extensively across the Wessex region equipped me with this knowledge, but conversely that meant that initially I did not ask participants to clarify who or what service they were talking about and therefore possibly lost some of the participant's interpretation and perception of things. As the interviews went on I began to try and bracket some of my professional knowledge in order to ensure that I gained the true perception and interpretation of the participant, of the situation. Taking on the role of researcher over therapist is something that became easier over time but was a beneficial learning and developmental process within my research journey.

4.16 Research quality

It is important to describe the research quality, therefore throughout the thesis thus far I have attempted to demonstrate the quality assurance processes employed to this research study. I have firstly endeavoured to demonstrate sensitivity to the context of existing research literature as well as theory in developing this research study (Yardley 2015). The literature review process and discussion provided in chapter 2 stated what is already known from existing research, in order to formulate a research question that is relevant to stroke, RTW and vocational rehabilitation, and has not yet been addressed in the current research literature. In chapter 3, in order to provide theoretical transparency, I clearly stated my position as a clinician, therapist and researcher employing a phenomenological perspective through an IPA approach.

In this chapter I have sought to demonstrate the internal validity and confirmability of the research data collection and analysis process through providing the reader with a transparent account of both the method and rationale employed, in keeping within an IPA approach, in order for the adequacy of the process to be judged. I have further aimed to achieve this through discussions of reflexivity and the provision of reflective accounts of decisions made throughout the research process. I have also sought to provide a transparent account of the data analysis process including a detailed description of how data themes were developed and modified,

showing how the findings flow from the data, including the use of inter-rater comparison to further demonstrate the coherence of the analysis process. These descriptions all aim to authenticate the plausibility, credibility and trustworthiness of this research study.

4.17 Reflection at the DClinP interim assessment and viva

Initially the study had proposed to also capture the insights and experiences of the stroke survivors' carers through interviewing them as well. However recruitment of carers was also poor, with only two carers having been interviewed by the stage of the DClinP interim assessment and viva, one having completed an initial interview and one a retrospective interview. The reason for poor recruitment may be partly because the carer is not actively involved in the client's treatment at the WRS and therefore did not feel that they had anything to contribute. Alternatively it may be that as the study is not specifically looking at the needs of the carer, but is instead looking at what impact the stroke and attending the WRS has impacted on the client and consequently the carer, they may not feel this addresses their own needs. Of the two carers who were interviewed, within the interview they certainly talked about their own needs and the impact of the stroke on themselves as well as the client as the researcher expected.

At the point of the interim viva the researcher discussed with the examiner whether the two completed carer interviews should be included in the overall data analysis and final thesis or whether to exclusively concentrate on and analyse the interviews of the seven clients for the purpose of the final thesis. It was agreed that the two carer interviews might distract from the main insights gained from the stroke survivors and therefore the focus of the data analysis for the thesis should be purely on developing the depth within the client cohort. For this reason the research process which followed a similar procedure to that of the client recruitment and data collection has not been included in this thesis nor has the data been analysed, however it is not to say that this data could not be revisited in the future.

4.18 Summary

This chapter has presented a systematic and transparent account of the research procedures used for this study including the data collection and data analysis procedures chosen in order to demonstrate the credibility of this research study and its internal validity. A discussion of the recruitment issues encountered when data collecting have been considered as well as a reflection of the data collection process.

Chapter 5: Findings

5.1 Introduction

This chapter explores the findings from the interviews with the participants at the WRS. The findings presented encompass the eight interviews completed, comprising of five initial, including one follow-up and two retrospective participant interviews as part of the study, figure 5 provides a diagrammatical breakdown of the interviews. The aim of the study is to explore the experiences of stroke survivors participating within a WRS; including the impact of the WRS on their stroke journey. Therefore my aim was to understand the world of the individual experiencing the WRS. For example how does the WRS impact on the individual's life, does the WRS contribute to the individual's wellbeing, does it change how they view their world, and is there an impact on their sense of self-identity and self-worth.

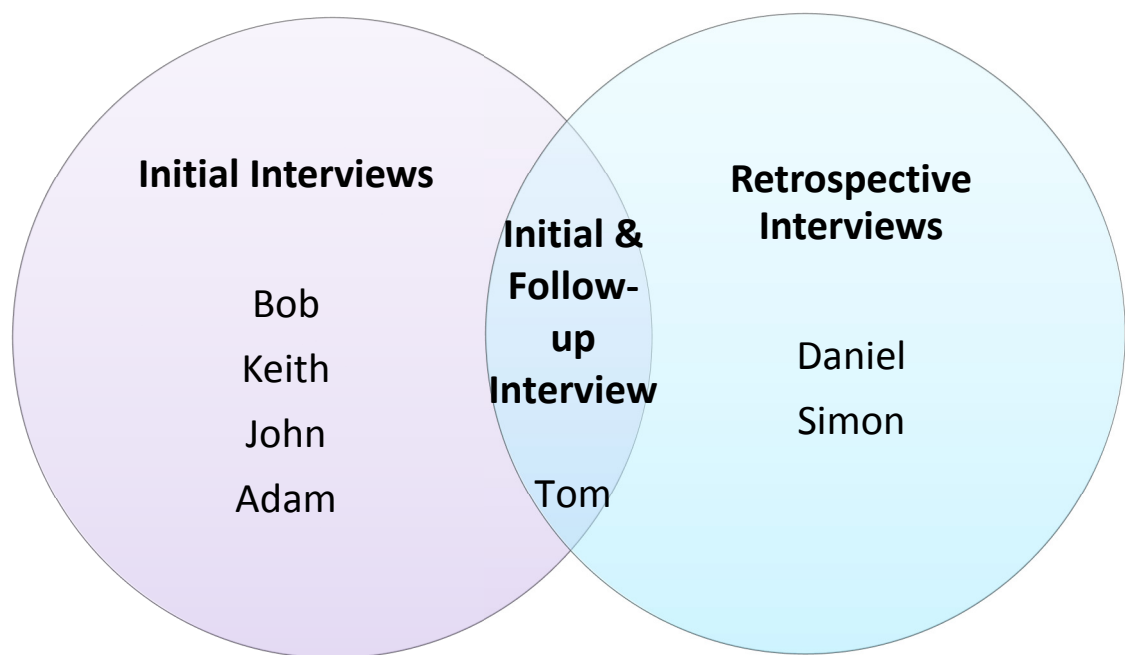


Figure 5: Breakdown of interviews

Table 2 below provides a brief overview of the background information of each of the research participants, therefore giving a brief insight into their lives before the stroke. This is followed by figure 6 which presents a mind map of the themes and sub-themes from the interviews that are explored in this chapter.

Table 2: Background information of research participants

Participant	Bob	Keith	Tom	John	Adam	Daniel	Simon
Age	60 years	60 years	64 years	55 years	58 years	47 years	61 years
Previous Employment	Trade buying and selling bearings, large warehouse, been with the company 15 years and doing that work for 46 years	Professional relations manager for a larger pharmaceutical company with head office in Helsinki	Engineer at BBC area office working as a contractor, employed by Balfour Beatty	Made redundant, previously worked in London for the audit commission, managed a team of 10 people, opted to receive pension on redundancy	Self-employed electrician, own business “My work is one of the main things in my life”	Trained mechanical engineer, just made redundant prior to stroke	Fabrication engineer been with the company 17 years
Hobbies	Gardening, DIY	Keen gardener, 2 dogs, rebuilding his MX5, rotary club	Cycling, walking fast, running, cycling, swimming, holidays	Walking the dog, gardening, cycling	DIY, sports	Cross country running 25km, cycling	National Trust, English Heritage, gardening, cycling, fascination for history, “keeping house up as nice as I can”
Family situation	Family – wife, son who works at the same company, daughter	Wife	Wife, 2 daughters, grandchildren	Lives with partner, has one dog, had 2 dogs but one had just died	Wife, daughter	Lives alone	Wife, 2 sons, 2 grandchildren

Past relevant medical history			Previous stroke 15 – 17 years ago	2 strokes – 1 January 2011, current stroke March 2012 Chronic fatigue since Easter 2010			
Time since stroke	5 months	12 months	5 months	6 months	4 months	17 months	10 months
Interviews completed	Initial	Initial	Initial and follow-up	Initial	Initial	Retrospective	Retrospective



Figure 6: Mind map of the findings themes and sub-themes

5.2 The journey

The participants' accounts of their experiences provided an overarching essence that they view the experience as a journey of their survival following their stroke. Throughout this journey different elements and themes intertwined and threaded into this overarching experience and were directly impacted on by their experience of attending the WRS. Although participants were at different stages of their own journey it appeared that there were collective experiences along the way.

The journey was not necessarily a linear process and for most participants it was a meandering journey where there were setbacks along the way, for example secondary complications, operations and so forth. Three key sub-themes were identified under the umbrella of the journey (see figure 7), these will now be considered in turn.

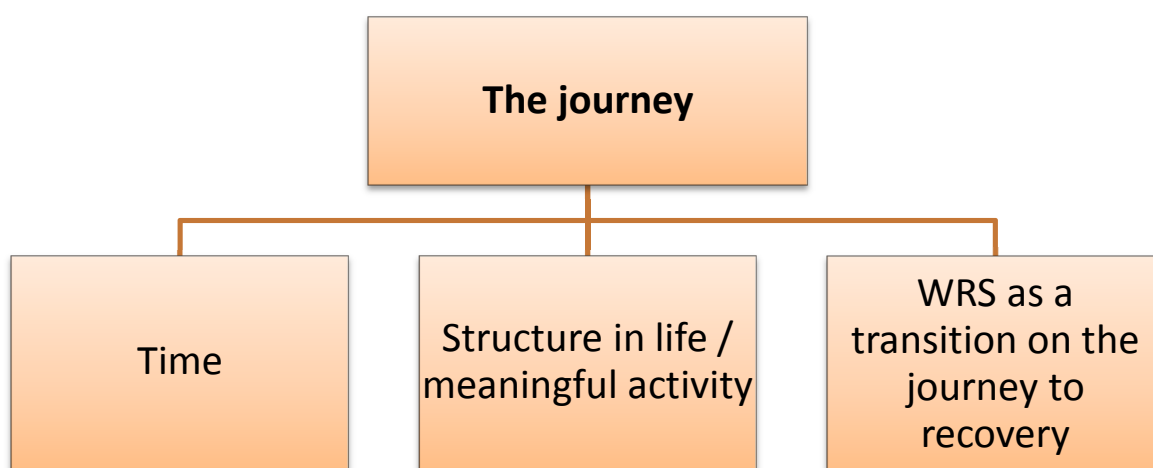


Figure 7: The journey theme and sub-themes

5.2.1 Time

A strong sub-theme interlinked with the whole of the individual's stroke journey was that of time. Time was a complex concept that developed throughout the individual's journey as they moved further from the point of experiencing their stroke. Time was not necessarily defined in its core sense as a unit of measurement, such as months and days, but instead became an indefinite period of time as a process and period of recovery, conceptualised as an event experienced in a particular individualised way.

In the initial stages following the stroke the issue of time was reportedly about filling it as described by Adam:

"I realise that when I was in hospital that a lot of it is about managing your time, you have to keep occupied all the time, so, I mean when I was in hospital, and you know they don't want you sleeping all day long because you have got to do your exercises and they like to get you back into the routine of life, you know, so I would either watch the telly, listen to music, do Sudoku books or read a book as well. I had something to keep me going all the time because otherwise you just lay there and sleep and that's not good, so I realised that when you have got a lot of time on your hands, you have to manage it, and it doesn't matter how you do that, it is just you find your own." (Adam, page 4, lines 11 – 19)

At this early stage of the stroke journey time seemed endless to the participants and appeared to be perceived as having a detrimental effect on the participant's psychological wellbeing, as in the case of Bob:

"Bob: ...since the stroke, obviously when you are sort of alone at night, if you like, sort of feel as though you are on your own in the world, the lights out like, you are in hospital and that's the time you start thinking, and when you are thinking and when you are sort of down and you are worrying about different things in your life; I mean no matter if you have nothing to worry about, we do tend to still worry about something (laughs).

Q: Sounds like almost having too much time to think about things?

Bob: Yes, absolutely, instead of having a sort of application or something, like to occupy the mind, to occupy the brain. That's why, I mean before the stroke, I mean, I never noticed anything like that, because if I was sitting down and there was no joy with what I was doing, I would get up and I was doing something else if I didn't like that." (Bob, page 7, lines 35 – 47)

The importance of having something to occupy the mind will be further explored again later in this theme under section 5.2.2.

In the early stages of attending the WRS the participants tended to reflect on their stroke, this in turn provided them with a realisation of the impact of the stroke on the individual's life as well as the time needed for recovery.

"It certainly changes your life...it does that..." (Bob, page 16, line 35 – 39)

*"Then you start thinking, you know, this is going to be with me for the rest of my life."
(Adam, page 7, lines 44 – 45)*

This time element of recovery was perceived as an important aspect that individual's needed to come to terms with. However, there appeared to sometimes be a conflict between the perceived recovery time anticipated by others, as opposed to that experienced by the individual themselves.

"It's no ten minute thing...People, like you know, are pull yourself together, like you know, I'm not a pair of curtains just yet you know! Come on, you are alright it happened six months ago, I nearly died six month ago, so I'm not rushing now, hang on." (Bob, page 16, lines 43–47)

As time progressed the participants were able to look back at their recovery journey so far and identify the progress they had made.

"Well I have seen progress, me [sic] arm is moving a lot better now, but it is sometimes difficult to pin it down on what it is that you are doing, is it the exercises I am doing, is it the physio, is it coming here, I suppose in a way every bit of it helps, if you are moving your arm and your leg and exercising at the same time, it is all part of the same thing. But there has definitely been progress, because when I came here my arm was near enough frozen, but I mean like that, the exercises I have been doing, well I can stretch it out above my head now, and you know, doing things like that." (Adam, page 5, lines 9 – 15)

Adam reflected on what had made the difference in his progress, such as elements of exercise, therapy or treatment and appeared to conclude that it was a combination of everything. As a therapist I know that the evidence base suggests that the more a patient does, including the intensity of treatment, the better the outcomes are likely to be for the patient, as recognised by Adam.

Reflections from the participants included their physical progress and recovery as Adam stated, as well as the wider elements of progress back to everyday functional and social tasks. For example, Tom reflected at the end of his time at the WRS on the progress he had made during his period of attendance both at the WRS itself but also the wider aspects resulting from attending the WRS. He talked about the progress he has made in terms of the projects he had completed at the WRS, as well as his progress getting to and from the WRS. Initially Tom had used hospital transport to

get to the WRS, but now he was independently travelling into town using different mediums of transport and successfully facing different challenges in order to get to and from the WRS for each session.

“...when I first came here I was using a walking stick and consequently I was, I was being ferried from pillar to post basically, by hospital car, now I am sort of walking, sort of like 15 minutes into the village to get the bus, I am getting on the bus and then going into town and then walking across the common to get the next bus and so, and coming up to here and then fighting the traffic over the X road to come across, which in itself is probably the most hardest thing I have to do, yeah so, and the dexterity and the confidence has built up, in that sense of the word as well, and of course the fitness. I do feel as far as (WRS) goes I am really enjoying here, I have had lots and lots of projects to think about and do and they have been very, very helpful here in what I have decided to do, some have been pretty bizarre but I think, I think it's well worth it.” (Tom 2, page 2, line 47 – page 3, line 7)

These wider elements of progress back to everyday functional and social tasks provided the participants with both structure in their lives as well as meaningful activity, both fundamentally important things for our psychological wellbeing, as identified by the participants themselves which will now be explored.

5.2.2 Structure in life / meaningful activity

An important element identified by the participants was that of having structure in life and conversely the negative impact of not having any structure in life. John described how after his first stroke he had returned to work very quickly, however prior to his second stroke he had been made redundant and therefore did not have a job to return to. He perceived that not having the routine of work and structure in his life had had the negative impact of taking him longer to recover.

“...going back to work sort of helped me get back into normal routine, but after the second stroke, not working seems to have taken me longer.” (John, page 1, lines 41 – 42)

For John at the early stages of his stroke journey and time at the WRS he described this as having a negative impact on his psychological wellbeing:

“I am not as bright and cheerful as I was, but I think that's just the nature of the days and how I live.” (John, page 2, lines 35 – 36)

For John there appeared to be an internal conflict between being pleased he was recovering from the stroke and that he had his partner to help him, to that of feeling that without any structure to his days there was no purpose to life.

“Well things are pretty good, except for if I take a normal day, I tend to get up late, I shower, dress, and then there is nothing, I tend to just watch day time TV, which is fairly soul destroying and that continues into the evening. I stay up late because I don’t have to get up the next day; it feels as if there is no purpose to life. But, I mean, it is generally good, my partner is very good, he cooks for me, looks after me, hmmm.” (John, page 2, lines 40 – 44)

John compared his current post stroke life to his pre-stroke life, openly acknowledging that life was now more leisurely and less stressful, but conversely it seemed to have little purpose and he missed the social interaction that work provides the individual with.

“Well not working has made a huge difference, because I worked in London so I used to get up at 5.30am, get the train and I had, I worked for the audit commission and I managed a team of ten people, so I was under quite a lot of pressure. I am quite pleased I haven’t got that, but I do miss the interaction with people, so life is more leisurely now, but it doesn’t seem to have a purpose.” (John, page 2, line 49 – page 3, line 3)

This negative impact was expressed by other participants at the WRS including Daniel who described how he had felt worthless initially, but how this had changed as he had started to get structure and activity back into his life.

“Feel a bit worthless sometimes, you know, not anymore, because I am doing stuff now and I achieve stuff still, which I thought is all gone basically and obviously didn’t help living on your own, so, but I have got good friends and I went straight, as soon as I could, I went to obviously volunteer work to get out and do stuff, rather than sitting in my place and then just getting madder and madder, it is all better.” (Daniel, page 3, lines 2 – 6)

As an OT, where the professions core philosophy and treatment is based around meaningful activity, this resonated with me. Activity, and more importantly meaningful activity, is an important aspect of life and was identified and acknowledged as such by the participants themselves. For example Adam identified that work had been an important aspect of his pre-stroke life, providing structure and something to aim for.

"Well, like anybody really, I mean you can have your moans about your job, and all this and everything, and I was no different, but it does give you structure in life and things to aim for, you know, it gives you, it gets you up in the morning and gets you out all day and, you know, I am just a work conscious person to be honest, you know." (Adam, page 3, lines 18 – 21)

This view was shared by many of the participants and particularly the conflict for those who were nearing retirement age but not yet ready to give up work as described by Tom. Tom discussed the importance of work and that although his contemporaries were ready to retire, despite his stroke, he was not yet ready to give up work in his life.

"...I think everyone needs work and I know a lot of my, I say contemporaries of my age, are quite happy to retire and, you know, take their wife down the X beach or wherever it is, I am not quite happy to do that..." (Tom 2, page 4 lines 25 – 27)

For many the WRS took on the role previously fulfilled by their work in providing this structure, meaningful activity and social interaction in their lives.

"...it gets you out of the house which is a very good thing, it also gets you mixing with people, and you are doing things with your hands which obviously you wouldn't be doing at home, you would be just sitting around, or moping, or something or other. It is very good for people who haven't started back to work yet, or who do physical work and things like that." (Bob, page 12, lines 10 – 14)

Tom also found that not only did it impact on his life on the days that he attended the WRS but it also appeared to have a continued effect providing more structure to the rest of his week away from the WRS.

"The first thing is getting up in the morning, well you know, I do know I have never been one for lying in bed in the mornings, you know, and so consequently that hasn't been a problem, but I can understand if you have got nothing to do, week after week, how it is quite easy to fall into the lapse of it and getting up later, and later, and later; and I notice with going to the rehab on the Tuesday and Thursday, I am now getting up the same time every morning, much to my wife's annoyance of course, but she does get a cup of tea, so that's not too bad is it! So I am more or less getting back into that routine of things and that is good as far as that goes." (Tom 2, page 4, lines 8 – 16)

The sense of achievement the participants gained from purposeful activity at the WRS will be further explored in section 5.5.3.

The WRS was identified by the participants as having a very positive impact on their stroke journey; it was a transition on the journey to recovery, this will now be explored.

5.2.3 WRS as a transition on the journey to recovery – “it was the base back to normalish life” (Daniel, page 7, line 34)

“I think it is all progress of rehab, it is like a (in-patient rehabilitation setting) outside, but slightly different, more normal like, work wise you live at home rather than staying there, but it is as important I would say.” (Daniel, page 6, lines 17 – 19)

The WRS revealed itself to be a pivotal point in the individual’s stroke journey back to “normalish” life. Participants talked about their experience of acute hospital care and in-patient rehabilitation. However, the WRS was perceived quite differently from that of the other rehabilitation that they had experienced on their journey thus far. Daniel referred to the WRS as rehabilitation back to life, in other words true functional rehabilitation, whereas the other rehabilitation received had focused on the impairment level of disability.

“Basically, (in-patient rehabilitation) did the first bit, more the movement part of it and this here does, is more like back to life basically, and then from here on next step back to some kind of work whatever it is, voluntary at the moment, there might be a job later, so yes, it is another step on the ladder to go back to being a human being.” (Daniel, page 7, 38 – 41)

The WRS is quite a unique service in the level of rehabilitation it offers, providing rehabilitation holistically focusing on function rather than disability and impairment. With the current service and financial pressures on the NHS there are often competing priorities and the service priorities are often different to that of the patient/client. From a service and health professional point of view, in order for someone to be discharged from hospital they need to be safe and this often limits the extent of rehabilitation given in the acute setting. There is often a discrepancy between the goals of a health professional to discharge someone safely and the hopes and goals of the individual to rebuild and maintain previous roles and activities that identify them as a person. For the individual, getting back to life and their previous activities is key, not only for themselves but also for the benefit of wider society. However many of these specialist services, like the WRS, no

longer exist as they are often perceived as a nice to have, an adjunct to core treatment, rather than an essential rehabilitation service.

“I would say it is very important to go back to normal life, yeah it is a base, a must have base, because you cannot go just out of hospital, where will you go, you know. You need to know people, say like the job agency, I would never have found out myself because I would never know there is one, they work with disadvantaged people or whatever....but I would say it is a very important part of the rehab, yeah.” (Daniel, page 8, lines 18 – 27)

The WRS not only provided participants with holistic rehabilitation but also, as identified by Daniel, signposted them to important services such as the job agency all helping in their journey to return to work. This was also highlighted by Tom:

“I do believe it (WRS) gives people the motivation and the openings to find out these places.” (Tom 2, page 9, lines 7 – 8)

The WRS appeared to provide the participants with the information they needed to equip them to prepare for work through a staged process depending on the individual's needs. Many of the participants went from the WRS to volunteering opportunities before returning to paid employment, be it their previous job or new employment as discussed by John:

“Well I think as I say, coming here for a certain time and being here for a period of six hours is a start with that structure, and knowing that I can cope with that is important. I think it is kind of a process and it is the starting point of the process, so, in a supportive environment learning those things and then being able to take them further in voluntary work and hopefully paid work.” (John, page 6, lines 5 – 9)

Tom referred to the WRS as being “a nice transition” in his stroke journey, where the WRS appeared to help him to see the positives again. This perhaps impacted on his psychological adjustment and ability to come to terms with what had happened and start to feel good about himself again.

“It has been a nice transition, it is a nice transition really, from, you know, what could have been a bummer for many people, you know, and going up to a stage where you feel, if you achieve something in life, if it is making a bird box or whatever, it may be you feel good about yourself and that's what it is all about I think.” (Tom 2, page 10, lines 28 – 31)

The WRS provided Tom and the other participants with hope and aspirations for the future which will be discussed in section 5.6 as well as contributing to rebuilding the whole person which will be discussed now.

“It is like another chapter open.” (Tom 2, page 10, line 16)

5.3 Rebuilding the whole person

Rebuilding the whole person was identified as a key theme for the participants with three sub-themes relating to self-identity, luck and expectations of others (see figure 8) these will now be explored in turn.

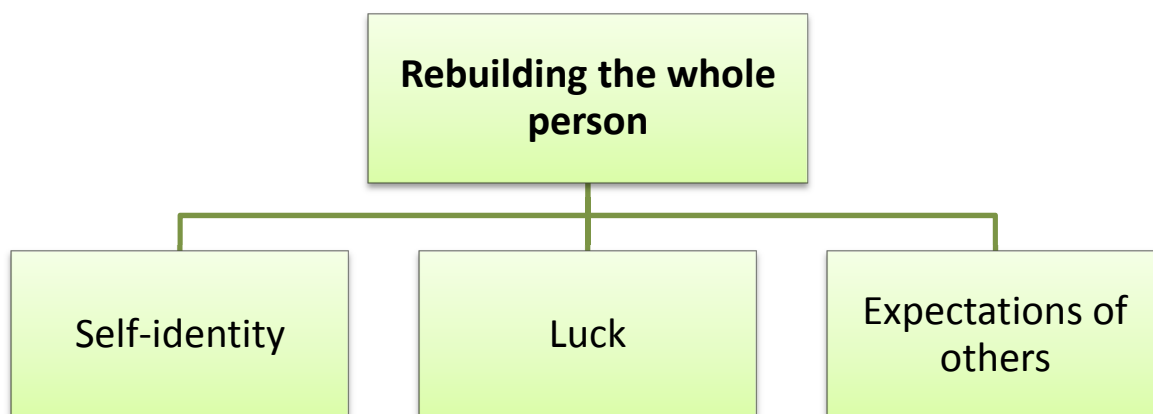


Figure 8: Rebuilding the whole person theme and sub-themes

5.3.1 Self-identity

Regaining a sense of self-identity was very important to the participants. It was very apparent that when some participants talked about their life and portrayed their sense of self-identity prior to the stroke, there was a noticeable change in their tone of voice and their body language became more animated. Conversely it appeared that there was, at least initially, a sense of loss of self-identity following the stroke and this was highlighted in the way that participants appeared to define themselves by who they were prior to their stroke.

Self-identity through occupation appeared to be very important to several participants. When participants were asked to say a little bit about themselves they generally defined who they were initially by stating what they did for a job. Participants were generally passionate about their jobs

and keen to return to work. It appeared that their work provided them with a sense of status and level of expertise.

"I was with (the company) 15 years, but in that particular type of work, I've been doing it 46 years." (Bob, page 5, lines 36 – 37)

For some, such as Adam, it was difficult to differentiate work from the rest of their life.

"My work is one of the main things in my life..." (Adam, page 2, line 4)

Similarly participants also defined who they were by their family circumstances, whether they were married, had children and/or grandchildren, pets and so forth; as well as their hobbies.

"I have got two grandchildren, they take up a lot of my time, but they are adorable, we both belong to the National Trust and English Heritage and we like gardening and general running everything..." (Simon, page 4, lines 46 – 48)

Part of rebuilding the whole person and their sense of self-identity was perhaps part of the process of coming to terms with having had a stroke. It appeared that the participants' sense of self-identity had changed following their stroke in several aspects of their lives, such as home, work and hobbies. Participants talked about their life pre-stroke as being *"Pretty simple"* (Bob, page 6, line 17) being able to do what they wanted without having to think about it.

"Well I was busy at work... a bit of travelling involved, but yeah, so life was pretty good...well to be honest it was keeping me quite busy. I usually cycle during the summer but I haven't really got round to doing that as yet; I swim, I like swimming as well, holidays of course, like everyone else does, you know what's the point of working if you can't have a holiday." (Tom 1, page 4, lines 12 – 32)

This was in contrast with their post-stroke life, where they tended to perceive themselves as being limited in their abilities. With these limitations often came frustration as described by Bob:

"...I get very frustrated that you can't do what you used to do, I mean you used to be able to get up and just do anything you wanted to do within reason obviously, but now you have to think about everything and you have to rely on other people to do things for you, like you can't sort of do things like gardening, well you can do bits and bobs and things

like that, but you can't sort of get both hands and really stuck into it type of thing,..."
(Bob, page 4, lines 41 – 46)

Accompanied by the frustration of the limitations in their abilities was that of having to rely on others to help.

"...I like to be able to do everything and not relying on other people, to do this for me, get that for me." (Bob, page 5, lines 20 – 21)

The loss of previous ability was difficult for the individual to come to terms with and was part of the adjustment to life post stroke. However, over time as individuals were further along their stroke journey, they appeared to start to come to terms and be more at ease with their new situation, sense of self and potential uncertainty with regards to their recovery.

"Oh it (recovery) just stretches on and on, so yeah it's getting to have a bit of patience and take things as it comes, that's all you can do." (Bob, page 17, lines 16 – 17)

This demonstrated both a level of acceptance of their post stroke situation and identity as well as coming to terms with a changed concept of the future for individuals; as described by Tom, who was discussing how he felt about whether he would return to his previous job or not, referring to a belief of 'what will be, will be':

"...how do I feel about this (going back to work), and I feel quite comfortable about it you know, and I suppose I am comfortable either way I guess, to a certain extent yeah, so I think, what happens...I think the longer time goes on the more, what's the word I am looking for...you know not bothered either way, you know, 'Inshallah' like the Arabs say, yeah that sort of thing 'Inshallah', so I am not, what happens is I am realistic now, I am probably not as, I am not as, I am not as, I will not be as upset now if they said no we don't want you back, you know I wouldn't be upset now as I would have been when I first applied." (Tom 2, page 7, lines 38 – 46)

The experience of the stroke seemed to shape and become part of the individual's new sense of self-identity. The stroke had become part of who they were now which was perceived as having both positive and negative consequences. For example Bob described his stroke as widening his horizons and he described life before the stroke as living a *"life blinkered"*. Since the stroke he had become more aware of disability and other people's disabilities.

“When you went shopping and things like that before the stroke, you didn’t see things as you do now you know, now I see people that are in wheelchairs, walking sticks, I have never seen so many people with walking sticks....Blimey I have never noticed that before in my life....Before as well you just don’t notice because everything is, I think you are living a life blinkered you know, you are sort of going in one dimension sort of thing, but now you turn around and you see, hang on there are more people living like, there really is a lot of people out there that have got their ups and downs, their stresses and strains and everything else, so it is a real mind opener that one, yeah absolutely.” (Bob, page 16, lines 1 – 17)

Similarly other participants described their strokes as indirectly positive providing new avenues and new horizons which will be explored in section 5.6.3.

5.3.2 Luck

During the interviews the participants referred to the concept of luck; be it their own perception or the perception of others. This concept of luck was very much an individual thing where the individual considered themselves to be lucky.

Most participants compared themselves to the other people at WRS in order to benchmark how badly affected they were and what their chance of recovery was.

“I am lucky, because in the work rehab there was [sic] people in there, oh so badly traumatised with it, their legs and their arms, they couldn’t speak very well and I just felt so fortunate that I didn’t have any of that.” (Simon, page 3, lines 34 – 36)

This comparison in line with social comparison theory generally enabled them to consider themselves in a more fortunate situation to those around them. For example, both Simon and Tom, reported feeling better about their own situation when comparing themselves to the other people in the group. Tom referred to himself as feeling like a fraud as he felt he had made a better recovery from this, his second stroke, then from his first stroke when he had received no input following.

“Tom – To be honest, looking at these guys here I am probably the luckiest of all of them, although I am the last in, I hopefully may be the first out, you know, so if I get my

Q. And how does that make you feel?

Tom – Well sometimes a bit of a fraud I guess, only in as much I never had that opportunity last time around, so it is really to get on with whatever you know” (Tom 1, page 5, line 46 – page 6, line 3)

Participants seemed to compare themselves not only in terms of disability, but also in terms of age. For example Simon was shocked at the age of the other members of the group and their level of disability compared to his own.

“I must admit I do feel extremely lucky, that erm, the stroke I had was relatively small in the respect, that er, I could walk ok and I could speak ok, and I saw there was one girl in the class, she was only 18 and I thought lovely looking girl and she had had two, one when she was 11 and one when she was about 15 and I thought god the world is not right is it, I can expect it at my age if you like and I was the oldest one in the class, there was her at 18, a couple of guys there about 30, one woman of 42 and another guy there 50, so it doesn’t blind itself to age.” (Simon, page 10, line 49 – page 11, line 5)

Others such as Daniel considered themselves to be lucky in terms of their skills and being able to match them to that of the WRS.

“I was lucky, as well, I was kind of gifted in terms of doing stuff with your hands, basically working and stuff, you know other people probably see it differently, they are more into computers or different life than they had before, but for me it was good because it was practical work and you could create something.” (Daniel, page 12, lines 31 – 35)

The underlying theme underpinning the social comparison that the participants referred to during the interviews was this concept of luck, be it mainly their own perception or the perception of others. The perception of ‘luck’ appeared to play an important part in participants adjusting to their own disability and feeling better about themselves through comparison with others.

Conversely, individuals responded negatively when others perceived them to be lucky. This negative perception by the participant that someone else could make a judgement that they were lucky was possibly linked to both the (lack of) understanding of others and the hidden aspects of the stroke which will be discussed in section 5.4.2. For example Bob talked about others perceiving him as being lucky as he was not visibly badly affected by the stroke. However, he demonstrated an internal conflict between feeling unlucky having had the stroke in the first place

and angry that other people felt he was lucky, whilst on the other hand he admitted to feeling lucky in terms of already being in the ambulance at the critical moment when he actually had the stroke. He therefore felt that he had received the right treatment in a timely manner and this had consequently led to him making a better recovery.

“If anybody says, you are really lucky I have seen some people a lot worse than you, look after them then and leave me alone, because I don’t feel lucky. But obviously I know in my own heart I am lucky that I was caught in time, that I got the right drugs in time, got into the ambulance when I had the main stroke.” (Bob, page 9, lines 3 – 6)

The psychological effects of the perception and expectations of others was an important aspect of the individual rebuilding themselves as a person and will be explored next.

5.3.3 Expectation of others

Unfortunately the expectation of others was often perceived as a negative experience for the participants trying to rebuild themselves as a whole person, particularly in the area of return to work. Two of the participants had attempted to return to work unsuccessfully.

Bob had returned to work prior to coming to the WRS. He reported being given mixed professional advice as to whether he should return to work or not from his GP and consultant.

“My doctor (GP) said I shouldn’t go back, my consultant said yes go back, but only do x amount of hours, or do whatever your body tells you what to do. I am not happy with that at times, you can’t just pop in and out” (Bob, page 13, lines 24 – 26)

This mixed advice was unhelpful for both the individual and their employers. Bob chose to go back to work on reduced hours but described his employer’s expectations that he would be back to normal quite quickly:

“Bob: He (employer) was alright like, you know, coming in half a day and things like that, but he sort of thought like, he said to me, I thought you would come in five hours a day for the first week and then six hours a day for the second week and then now you should be back full time and everything.

Q: So it sounds like they were expecting you to be back to normal quite quickly.

Bob: Full time absolutely now, which obviously again is an awful lot of pressure on you as well, when you are just not up to it and you know in your own heart and soul you are not

up to it, but people are expecting of you and that, just, I think the pressure suddenly sets in and you think

Q: It sounds like that must have been a difficult time

Bob: yeah, yeah it was stressy like, you know.” (Bob, page13, lines 30 – 44)

This lack of understanding on the part of the employer put a lot of extra pressure and stress on Bob, which in turn led to the breakdown of the return to work situation and him being signed off sick. At this point he started attending the WRS.

It appeared the return to work process had mainly been unsuccessful due to the unrealistic expectations of the employer and lack of understanding of the stroke. Unfortunately this was not an isolated experience, as described by Simon:

“Simon: When I went back to work they wanted me to come back on full hours and work like 100 hours a week, not literally, but as many hours as I could get out of the day.

Q: And how soon was this afterwards?

Simon: This was about 6 months after it (the stroke), I wasn’t really, didn’t really feel like it really, they said we have been paying you all the time, and they did, they paid me my full wages and everything, and I said I would like to come back gradually if I could, and they said no, and I said well I am sorry, but I am either going to go back on the sick or I will come in three days a week, and they said well if you do that you can consider yourself fired, and I said I beg your pardon, and it all got rather nasty and out of hand and I asked (WRS member of staff) if she could come to work with me.” (Simon, page 6, lines 26 – 37)

Similarly when Simon went back to work he was not able to cope.

“I went back to work and I said I just can’t cope with this, because I just, I couldn’t cope with the intensity of it all...” (Simon, page 6, lines 42 – 43)

In Simon’s situation the WRS became involved whilst Simon was trying to return to work and despite the advice and input from the WRS the employer appeared not to take on board this information.

“...she (WRS staff) came in to see my employers with me and they didn’t really agree with her findings, so they then sent me along to a working solutions consultant in X and he found out the same findings, I think that’s right, as (WRS)... they (work) referred to my

contract at work, that I had had enough time of sick now to be reduced pay, I said I am not worried about that, go ahead. So they did and then they started saying that erm it wasn't in line with their customers' requirements that I was hardly ever there and I said look, I am trying, and I am getting better, but as it was it didn't get better and they just said no we can't keep up with this anymore, there is only four of us in the company and to have a quarter of their work force out, they said we just can't take this no more. So they asked me to resign and they would give me an ex-gratia payment, just to cover, not making me redundant or anything, it was the same as, but it was legally another way around and when I left I just let out a big sigh of relief" (Simon page 6, line 46 – page 7, line 16)

Simon had worked for his firm for seventeen years and really struggled to come to terms with the lack of understanding shown by his employer who had been so unsympathetic to his recovery and needs post stroke. Simon's employers were keen for him to return to work full time which he was not able to do because of his fatigue levels post stroke. Simon consequently felt that he was accused of being difficult by his employer, as if the fatigue was his own fault; this was despite the tried effort of the WRS to educate his employer about the stroke.

"Why they would respond to me like this, with something that was an accident, I didn't cause it myself, I didn't stab myself in the chest, it wasn't something that was planned or anything like that..." (Simon, page 10, lines 26 – 28)

Both participants had a negative experience of their return to work at a vulnerable stage of their stroke recovery and journey which consequently had an effect on their self-esteem and confidence. This demonstrates the need for coordinated advice and support to both the individual and their employer as provided by the WRS, however also an awareness that not all employers are willing to accept advice and open to accommodate the individual's needs and disabilities. The WRS as a theme will now be explored.

5.4 WRS

There were a number of themes that emerged surrounding the WRS itself and the impact it had on the participants' journey as presented in figure 9. These themes will be explored in turn.

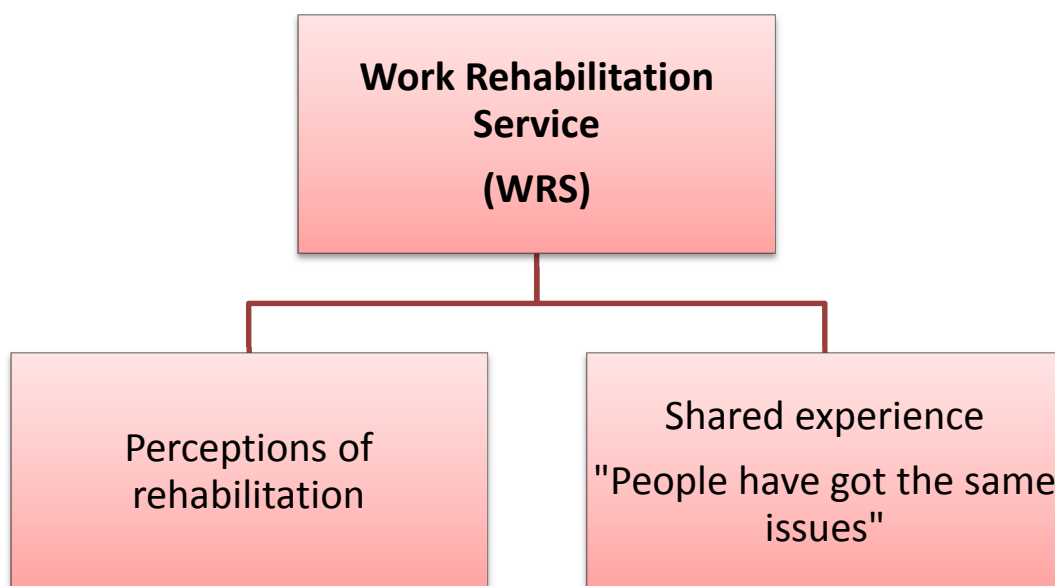


Figure 9: Work rehabilitation service theme and sub-themes

The amount of sessions an individual had attended at the WRS had a direct impact on their perceptions of the WRS thus far – the journey starting at basic rehab level, building up to understanding of the shared experience and an awareness of the psychosocial benefits and the non-tangibles, before considering the future.

5.4.1 Perceptions of rehabilitation

Initial perceptions of the WRS were discussed with each of the participants and it was apparent that prior knowledge of the WRS was very limited. Bob suggested that this limited knowledge was also shared by other health professionals.

“None of the physiotherapists in...(location) or (location) had ever heard of you (WRS)!”
(Bob, page 34, line 1–2)

Bob referred to the WRS as a “secret society”. This concept of the WRS being a “secret society” is interesting and could suggest that if other health care professionals and members of the public are unaware of the service then people may be missing out on the opportunity to receive vocational rehabilitation from the WRS. It may also suggest that the individuals that do attend consider themselves to be in a privileged position that they are part of this “secret society” who now know about the WRS and can benefit from what it has to offer.

Chapter 5

This lack of prior knowledge of the WRS impacted on Bob's perception of what the WRS would be. This was interesting and it appeared that he went with pre-conceived ideas that rehabilitation must be physiotherapy as opposed to the wider aspect of therapy.

"Well, what I expected wasn't what I've got when I came here, if you know what I mean?...I thought, well obviously this is physiotherapy, I'm gonna go through all physiotherapy and do leg, walking and shoulder, up, down, do this...and obviously I came in and it's a workshop (laughter)." (Bob, page 34, lines 12 – 20)

Bob also felt that there wasn't enough physiotherapy input.

"It would be good to see, actually a unit like this, having more physiotherapy on the side...Well this is all occupational basically... But really, it should both be intermingled I think...Well that's my opinion, because I think one without the other is no good." (Bob, page 35, lines 19 – 20, page 36, lines 4 – 8)

This is interesting as physiotherapy is probably the most well-known form of rehabilitation and therefore is this what patients expect when they are told they are going for rehabilitation. However, Bob also makes a valid point in line with the evidence that the best form of rehabilitation is *"intermingled"* or integrated as previously discussed in section 5.2.1.

However it appeared that the wider aspects of the WRS were also acknowledged and appreciated in terms of peer support, social interaction and occupation, all perceived hidden benefits of the WRS.

"It gets you out of the house, which is a very good thing... Urh, it also gets you mixing with people and you're doing things with your hands and which, obviously you wouldn't be doing at home, you'd just sort of be sitting around, or moping, or something or other. Umh, whereas it would be very good for people who haven't started back to work yet...or who do physical work and things like that." (Bob, page 35, line 1 – 10)

This again emphasises the importance of activity and occupation to human beings perceived as being positive to our wellbeing.

The participants generally perceived the WRS as very positive.

"I can only describe it as 100% positive...I always look forward to it, I always look forward to nearly every day coming in here you know..." (Tom 2, page 6 lines 12 – 14)

It was felt that the WRS not only benefitted the individual themselves but also had wider benefits and advantages to the individual's family and employer as stated by Keith:

"...it is an advantage for them (employer), and it is an advantage for me, advantage to my family..." (Keith, page 8, lines 26 – 27)

When starting at the WRS John perceived that there was a greater level of understanding as it was a group environment where people had shared experiences.

"...I haven't really spoken to anyone about why they are here, but I would imagine it is positive, in that there is a greater level of understanding of things I can do and things I have difficulty with, and everyone seems very pleasant, so it is a conducive atmosphere." (John, page 6, lines 36 – 39)

The WRS as a group environment and shared experience will now be explored in more detail.

5.4.2 The WRS as a group environment / Shared experience *"People have got the same issues"*

Often following stroke, survivors feel an acute sense of isolation as their experiences cannot be shared or fully appreciated by those around them.

"Since the stroke, obviously when you are sort of alone at night, if you like, sort of feel as though you are on your own in the world." (Bob, page 7, lines 35 – 36)

Stroke was described as a hidden illness or disability because the effects of the stroke were not always visible *"people forget stroke is a very disabling thing"* (Keith, page 12, lines 23 – 24).

Therefore it was perceived that others may react differently if the person had a visible injury.

"No I mean, most people nowadays, they don't see illness unless they see a big gash and stitches all over your body, or your face mashed in, or something like that; and then they say, oh poor sod like, you know, but they only see you, and they see the shell, and they think nothing wrong there, it's a book and a cover isn't it." (Bob, page 17, lines 1 – 17)

This quote not only resonated with the perception that others did not understand the full extent of the stroke and the hidden aspects of it such as the psychological aspects, but also more importantly that people did not look and consider the full person, they saw the *"shell"*, the *"book and a cover"*. This was also iterated by Adam:

“The hand has come back and it looks normal to be honest, and people say to me, oh you’re ok, you know, but it is still not quite there.” (Adam, page 2, lines 46 – 47)

Not only is it difficult that individuals are coping with a new disability which may not be overt such as the cognitive and psychological consequences of stroke, but the individual is also coming to terms with a disability that has no set recovery time and therefore their new sense of self is surrounded by uncertainty.

“Exactly, I mean, if you broke your leg, they’d (people would) understand that; I wish I’d broke both my legs because then I’d know they’d be repaired, and then you’d get up and walk in a few months’ time like, you know...You’d be out and away again, but strokes don’t go like that...Oh it stretches on and on...It’s getting to have a bit of patience and take things as it comes... urh, yeah, that’s all you can do.” (Bob, page 17, lines 1 – 17)

The participants are living in a world where most people do not have disabilities whilst also trying to adjust to the uncertainty of their newly acquired disability themselves. Conversely the WRS provides individuals with an environment where stroke and disability are the norm and therefore they are in an environment and group setting where they are not perceived as being different. The participants described the WRS as an environment where they felt more at ease and less self-conscious about their stroke and disabilities.

“With this group here, it is a comfortable group to be with and to talk too. I mean some people are, you know, sort of, you know, they have been here a lot longer than I had, and even talking to them and listening to them, what their hopes and ideals are and what they have achieved out of it, it gives me great encouragement.” (Tom 1, page 9, lines 3 – 7)

Speaking to others who had similar experiences was perceived as being both comforting and encouraging. The group offered individuals peer support as they were all at different stages of their stroke journey and therefore could share insight and experience with each other as well as being able to see how people had progressed in their recovery which gave people hope. The participants talked about how they found it particularly helpful speaking to others who were further along their stroke journey, when they themselves were new to the WRS setting. For example discussing the journey ahead, how long recovery might take as well as considering whether the individual themselves was making progress as Daniel reports.

“There is another good here, because you have got people, got the same issues which is good to, well I found it quite good to, to ask other people, because it is a question of how long did it took you [sic] to get this movement roughly, so, you know, just to know am I getting better, can I get better or is this going to be the rest of my life now, so, and then other people say patience, it takes a long time but hey do this and this and then getting there, that’s important.” (Daniel, page 9, lines 14 – 19)

The findings suggested that the WRS offered a sense of collective experience with shared issues compared to that of the outside world where people tended to feel as if they were the only one in such a situation, as described by Daniel:

“People have got the same issues, and which is a good thing because they have got experience, maybe some other experience than you have, so you can always interchange, so it was good. Some people know, do this like this and this which helps, or it helped me and stuff, and then you have got more data because of the more people they have got the same, where about, where I am now I am the only one who has got these problems.” (Daniel, page 8, lines 45 – 50)

This was further backed by Tom who suggested that by being in a collective environment he felt like he belonged, whereas in other settings he was aware of his disabilities and felt different from others, considering himself to be the “under-dog”.

“When you are away from this environment you don’t actually see people who have disabilities, you know, all you are surrounded by people who usually are non, do not have disabilities, so consequently you feel slightly, you find a little bit, maybe, the under-dog, is that the word I am looking for? You know what I mean, so consequently, you know, when you come down and you meet and you work with other people who have got disabilities, you find, you know, you don’t feel so bad about it.” (Tom 1, page 9, lines 13 – 18)

A basic tenet of OT theory, it is important that we feel we belong and the relationships that we build are often based on communal and shared experiences. For these individuals the WRS provided a supportive environment where they had a shared experience and collective identity that was rich in peer support, offering help and advice. This shared experience was generally considered very positively in terms of peer support and helping each other out.

“Some people have the right hand, and some speech difficulties, but the thing is the same, everybody had a stroke here, so, and in one way or another it is good; help communicating with each other and saying hey, how are you doing, helping each other out as well, you know, one can move the right hand the other can move the left hand, which helps always.” (Daniel, page 9, lines 6 – 10)

Not only was the shared experience perceived by participants as being positive in terms of giving them a sense of sharing and belonging, but Daniel also took this a stage further. He described an interesting concept with regards to his perceptions of value and importance given to that of the lived experience as opposed to the expert professional knowledge and experience held by the clinicians. He attributed greater value to that of the lived experience of the individual having perceived higher value than that of the expert professional knowledge and experience held by the clinicians. He perceived and considered this in terms of the theory of the professional versus the lived experience or real life practice of the stroke survivor. He suggested that only the individuals who have lived the experience can truly understand, therefore accrediting higher value to their suggestions and advice.

“It is always good to see in practice obviously if somebody has had it (stroke) for real. The professionals, ok, they help is more than one because they know more about the theory and about, yeah, we know that this is going to happen, but they are not living it. So they can say, ok your movement here, there and there, and this muscle is doing this, and we need to activate it, or whatever; but they are not actually in the skin, and say hey, but the other people here, they had it, or they got the same thing, they know, hey, how to get around certain things because they live it, they are not just talking about it, or analysing it....Yes it is a difference, it is like between theory and practice.” (Daniel, page 9, lines 24 – 35)

This suggests the perceived value and influence attributed to peer support and the cohesiveness of a group.

Although many considered the peer support and group shared experience to be only positive, this was not the case for everyone. Adam perceived the peer support to be generally positive but also identified the more negative aspects of this. He found talking to others initially rather frightening as it made him aware of the fact that many of the clients had had more than one stroke which he had not considered until that point. Consequently he was made aware of the greater impact that

the stroke could have on the rest of his life in addition to the risk of having a further stroke which was a daunting prospect.

“Well, what I have realised since all of this has happened and I talk to other people it has happened too and everything else; and one thing you come across is they are talking about, oh yeah the first time I had a stroke, and you think hang on, what do you mean the first time, you have had more than one, oh yeah. Then you start thinking, you know, this is going to be with me for the rest of my life, it is not just a one off thing you know, and it could happen again at any time.” (Adam, page 7, lines 41 – 46)

Adam’s quote suggests that when confronted with the reality that many of the clients had had more than one stroke, he was not aware, or necessarily ready to hear this information at his current stage of his stroke journey, consequently that could have had a negative effect on his psychological adjustments and coming to terms with the stroke. Adam’s perception highlights the fact that every person is an individual and each individual is ready to take on board information at different stages of their stroke journey as well as adjusting psychologically to their stroke at different stages. As therapists it is our role to ensure that individuals are given information at a time that is appropriate to them and then we should ensure that we are to provide appropriate support and discussion. However, Adam soon identified that comparing and sharing with others was helpful and that even though it could be perceived as negative, many people had good news stories to tell about people recovering and getting back to work.

“It is always good to talk to people in a similar situation, so you can compare, you know the feeling you can talk about, because a lot of us we talk about got pins and needles or something like that, you know, or what I always think it is a numbness myself, but in my leg and my arm, but they might, it might be different for them and they say it is like pins and needles, but you know, so you can talk to them about what they’re experiencing and relate it to yourself, and also it is a bit negative, about, when they say they have had two or three strokes, but then you can talk to other people and they say, oh yeah my dad had one, or my brother had one last year and he is back at work now and you wouldn’t even know any different, you know so it is all a varying.” (Adam, page 8, lines 24 – 32)

The collective, shared experience of the WRS was deemed as being generally positive by all the participants interviewed, during their interviews further psychosocial benefits of the WRS were identified which will now be considered.

5.5 Psychosocial benefits / the “non-tangibles”

Through the interviews a strong theme that developed was that of the psychosocial aspects of the WRS or the “non-tangibles” (see figure 10). It appeared that on face value the individuals were there to receive treatment within a WRS environment, however what became more apparent was the influence the other informal aspects of the service such as *“the behind the scenes”* (Tom 2, page 5, line 15) talking to others, tea breaks, and getting to and from the WRS had on the individual’s stroke journey and recovery.

“At the time of course, I didn’t realise that the group works in many strange ways doesn’t it, you know, and so consequently with those things being brought in like the conversation at tea time and lunch time, and things like, it was all part of the therapy you know.” (Tom 2, page 5, lines 4 – 7)

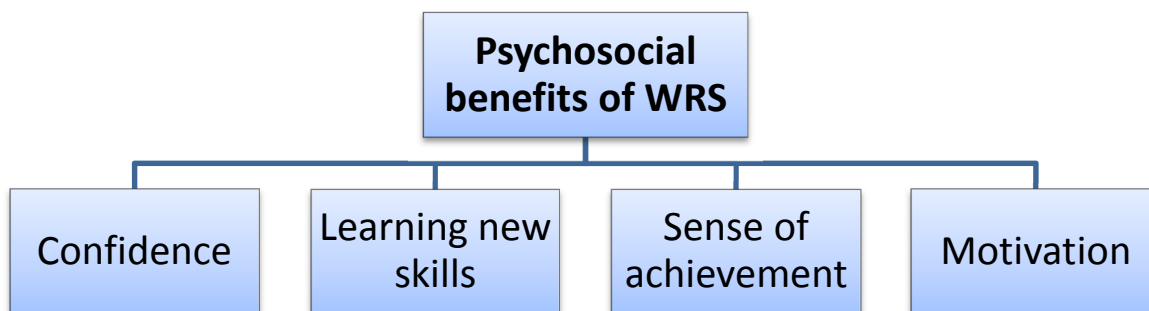


Figure 10: Psychosocial benefits of WRS theme and sub-themes

Four sub-themes were identified under the main theme of the psychosocial benefits of the WRS and these will now be presented in turn.

5.5.1 Confidence

Confidence was identified by the participants as one of the non-tangible aspects that they gained from their time spent at the WRS. Participants perceived that the time spent at the WRS assisted them in getting back into the routine of life; it prepared them for what would be expected of them if they were in work. For example John identified that by going to the WRS he needed to be there for a certain time and manage a period of working for a set number of hours just as he

would at work. By going through this process he felt that the WRS was building his confidence and preparing him to get back into work.

“But I think it is more about the non-tangible things, like confidence of travelling on the bus, getting here for a certain time and working for a period of hours, I think I will feel more confident that I can cope with that and more able to identify employment that will, erm, give me the opportunity to get the structure back again.” (John, page 6, lines 19 – 22)

However, John identified the actual time spent at the WRS as just one aspect of his treatment and in fact the actual getting to the WRS was also part of his wider treatment, gaining confidence and getting back into society and work.

Psychological adjustment following stroke is key and many people struggle with issues of reduced self-confidence and readjustment as identified above. Participants, such as Daniel, perceived the WRS as a positive base where they could develop their confidence within a supported environment.

“It is a base I think, without the base you couldn’t do this, because a) the mental thing, you thinking you can’t do it, you can’t do it; and then when you think you can’t do it and you can do it, you can do it. You say to yourself I am not capable of doing this and here they push you a bit, not hard but, you know, like making sure you progress and then the confidence builds up and you can obviously do other things, or carry on from there, I think without it (WRS) I wouldn’t have probably done it, I don’t think so.” (Daniel, page 6, lines 7 – 13)

Not only did this help in building confidence in skills that the participants had held prior to their stroke but also in terms of developing new skills. This appeared to have a big impact on self-confidence and feeling valued in terms of their contributions.

“It does good for the confidence, it is good to know you can do other things than you have done before, or you can still do something, anyway and not, you know, a waste of space basically, no it is all positive, much more positive than it was last year this time probably, yeah it is all good.” (Daniel, page 10, lines 29 – 33)

5.5.2 Learning new skills

As discussed by Daniel above, one of the psychosocial aspects identified was that of learning and developing new skills. The participants referred to the WRS as an opportunity to learn new skills that would equip them for life back in society and work.

The core medium for treatment at the WRS is that of woodwork, many of the participants commented that until coming to the WRS they had not done any woodwork since school.

"I mean the last time I did any wood work was doing wood work at school, and I wasn't very good then, so it's, it's been very good in terms of showing me what I am capable of doing and building my confidence." (John, page 5, lines 12 – 14)

For others, such as Daniel, wood work was identified as a brand new skill. These and other new skills were perceived as positive outcomes of the stroke that he would not have otherwise had the chance to learn.

"I am doing wood carving now, so that is good, yeah, I learnt because of the stroke, I learn new things which is quite a thing, but I am not saying the stroke helped me, (laughs) definitely not, but in a way it has helped." (Daniel, page 6, lines 39 – 41)

Woodwork projects varied from bird boxes to more advanced items such as Tom's project. Tom discussed how he had chosen to make a ukulele as part of his wood work project which required an advanced level of planning and execution. He had chosen to make the ukulele in order to then join a club and start playing, demonstrating the wider aspect of using the newly developed and learnt skills to equip the individual to return to a broader role in society.

"I am also taking up other outside interests like the ukulele club." (Tom 2, page 3, lines 32 – 33)

Tom discussed how the WRS had assisted with his confidence to do this.

"It has been something which probably I had the opportunity to do, but not the confidence to go and do it as well, you know, hence making this ukulele of course." (Tom 2, page 3, lines 43 – 45)

This suggests a real richness of the overall experience of the WRS, of individuals developing and acquiring new skills, putting them into practice and using the skills to benefit them in other aspects of their lives. It is clear that these skills have a wider impact on the individual not just in

terms of their journey with regards to return to work, but more importantly with regards to their journey to get back to hobbies and a social role in wider society. Tom referred to this as *“all the jigsaws fall into place”* (Tom 2, page 3, line 47).

5.5.3 Sense of achievement

Learning new skills was one of the aspects that really helped to boost the participants' confidence and sense of achievement. Participants talked particularly about how their woodwork projects, that each of them undertook as part of their treatment, had added to this. This aspect of the treatment was considered to be very important and valued by the participants. This was partly perceived as being about having an end product a *“tangible thing”*.

“That’s the thing, that’s what it is all about, you have an end product and hey I did this, I think it is very important...yes you can show it, you know people say, oh yeah this looks really good who did this, I did it yeah. ...That’s important as well, mentally wise, because when you are so down and you think, hey I can’t do no, nothing anymore and you do something, and it is ok, builds your confidence up.” (Daniel, page 12, line 40 – page13, line 3)

As well as the process it took and what they learnt during the process it also added to their psychological wellbeing. Meaningful activity, creating something as part of their project at the WRS provided them with a sense of achievement, feeling proud of what they had made, which directly impacted on their confidence levels and self-esteem.

“When you actually make something and take it home, ok, you might not get the same response as you felt yourself, but I think, I have always felt good about it at the time, I really have.” (Tom 2, page 10, lines 36 – 38)

This sense of achievement and ability to succeed was really important, giving participants the insight that they were capable of doing more than they realised, as John describes:

“I think that, err, the atmosphere here is very good, and the bird box I am making, it is coming on slowly and it will be nice to have something to take away, and it has told me that I am capable of doing more than I realised.” (John, page 4, lines 29 – 32)

John perceived this as a really positive process and an opportunity to build his confidence to equip him with the skills he needed back in society.

“I am hoping that by coming here I build up the confidence and the know-how, of how to secure some work.” (John, page 5, lines 23 – 24)

5.5.4 Motivation

Linked to confidence and sense of achievement was that of motivation. Participants felt that the WRS helped them to keep motivated and gain in confidence as suggested by Bob:

“Motivating myself to do things, basically just to get out there and to be able to do things with people and converse with people and that sort of thing.” (Bob, page 12, lines 19 – 20)

The theme of motivation was often identified from the start of the individual’s stroke journey. For example Adam discussed this in terms of the WRS identifying that the effort he put in would have a direct impact on how he would benefit and what he would get out of the treatment and experience.

“Well I realise now that a lot of this is down to me; you know, it is not, it is what you put into it, what is going to happen at the end, you know, so it’s certainly, you are not going to come here and they are going to give you a bit of paper at the end of ten weeks and you are going to go out running up and down the road sort of thing, you know you have got to put all the effort in, otherwise you get nothing out of it.” (Adam, page 7, lines 6 – 10)

This appeared to be linked to the concept of having a locus of control, where individuals perceive that either they have an internal locus of control as in the case of Adam, who believed he could influence the outcome of events. Whereas, someone with an external locus of control blames outside forces for everything.

“I used to say to the other people at the hospital, when the new people would come in, you know, and I realised that when I watched them they would just sit there and I would try and cheer them up a bit, but I would say to them, that when you are in here there are two queues to get in, you know, I said there is one queue where you can help yourself and listen to what the physio tells you to do and get on, and then when you get out of here you will be, you know, half way to being normal. Or, I said, there is the other queue, where you don’t do nothing, you just sit there, sit around and lay about I says, and all they do is they end up chipping you out down some care home, or something like that, you know. So I said, you decide which queue you want to get in, you know, and it worked with a couple of them (laughs).” (Adam, page 7, lines 14 – 23)

This suggested insight into his own potential for recovery following the stroke as well as his observation of others. It appeared that Adam felt that he as an individual was the only one who could make a difference and it was up to him to show motivation and determination in order to make a good recovery.

This concept of having a locus of control where it is reliant on the individual requiring self-motivation and determination was also perceived by others as articulated by Simon:

"...I said, look anything to help me recover, I will go..." (Simon, page 5, line 16)

Being at the WRS itself was also perceived as helping participants to be motivated.

"Yes, I have got to be motivated, and this (WRS) is helping me....Because if I didn't have this (WRS) to give me the emphasis to keep going....I don't know what I would be doing, but I wouldn't be having the enthusiasm I have got from here." (Keith, page 10, lines 28 – 34)

Keith's quote suggested that it was also very important for the participants to have a sense of hope and belief that things would get better, a view that was shared by others.

"You have to have something to believe in, otherwise it is a waste of time." (Daniel, page 10, line 23)

Determination was a key personality trait of the individuals attending the WRS demonstrated in the way they talked about their stroke journey and recovery.

"But I'll get through this, I'll come through, and now I've got a goal to go back to work, and there's reassuring here, that's helping me go back to work." (Keith, page 5, lines 16 – 17)

"Oh yeah, I don't let anything beat me (laughs)." (Adam, page 6, line 38)

This made me wonder whether by default the WRS attracted a particular type of individual and personality type. For example if someone was not motivated would that mean that they would choose not to attend the WRS in the first place? Tom discussed this stating that his daughter had been surprised that he had agreed to attend the WRS, but stating his reasons why.

"It was really a bit of open mindedness, you know, to say at my initial, and my daughter was with me at the time and she said to me, I thought you were actually going to say no and just walk away from it, so she was quite surprised I said yes, and that I would like to do it. So that was, and I did it for two reasons I think. I think the first one, because again I am determined to get back to work one way or the other....and secondly it really gives you the incentive to get up in the morning and do things, you know, you have got a project to do, get on and do it, you know. So I think it is a wonderful thing, especially at the age I am now, I guess it is very easy nowadays, you know, hundreds of satellite T.V. things, you know what it is like... It is keeping me motivated." (Tom 1, page 6, lines 32 – 46)

This personal motivation, determination and potential link with personality type was further highlighted to me by the fact that most of the clients talked about how prior to their strokes they had not been the type of people to sit down and take it easy.

5.6 The future

During the interviews each of the participants discussed their perceptions of the future. This concept developed and changed depending on where the individual was on their stroke journey. Three sub-themes were identified, corresponding to stages of the stroke journey (see figure 11). These will now be explored in turn.

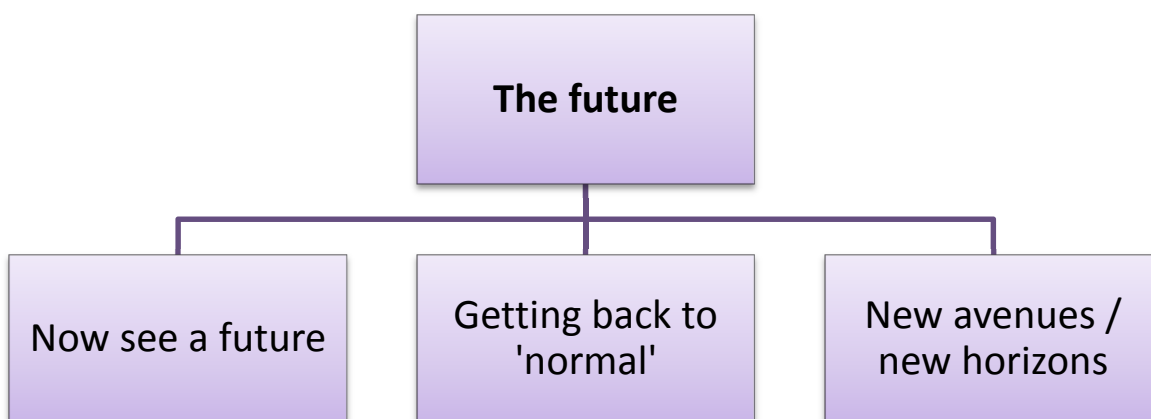


Figure 11: The future theme and sub-themes

5.6.1 Now see a future

The concept of the future evolved through the individual's stroke journey. Initially participants found it difficult to even consider a future.

"When I see what I was like in hospital, like after you couldn't walk and you see people walking around, and you sort of, it was just horrendous like, you couldn't see any life in front of you." (Bob, page 15, lines 44 – 46)

John talked about how no-one had discussed the future with him when he was in hospital and this had left him with a low level of confidence and self-esteem.

"Following both strokes, the time I was in hospital was a surprise to me that no-one spoke to me about my stroke, about the effect of it and how I might get back to how I was... So it is very positive to come here, and the conversations I have had with X have been very helpful, and recognise that I can get back to having a normal life. I think that's the main thing, I was just shocked that the consultants I saw in hospital, they all expressed some surprise at my age that I had had a stroke, but didn't talk about how I would get back to how I was, and I think that left me with a low level of confidence and perception of what life would be like." (John, page 7, lines 30 – 41)

This demonstrates the devastating effect the stroke can have on an individual's self-esteem as well as the interlinked psychological implications. This highlights an important point that as health professionals we maybe consider talking about the future in the very acute stages to be too early for the individual; however the implications of not addressing this at an early stage could have long-lasting psychological implications that could be damaging for the individual. Instead we should be discussing the individual's goals and hopes for the future at an early stage, being realistic, but ensuring that the individual has the opportunity to discuss and ask questions.

"I think my time in the hospital led me to think this was it, particularly being in a stroke ward with lots of elderly people, some suffering paralysis, and no-one spoke about the future; so it's (WRS) helped me to think more about the future and recognise there will be a future." (John, page 8, lines 33 – 36)

John discussed that talking at the WRS was the first time in his stroke journey that someone had talked to him about how there was a future ahead of him which was very positive and helped instil hope and increase his self-esteem and psychological wellbeing.

Keith similarly discussed how he had been told about the WRS and the reasons for attending and how by attending the WRS this could provide him the opportunity to extend his career and the hope that he had a working future and that his career was not over yet.

“Keith: We want you to go here, and the reasons we want you to go here is because we think you are suitable to come through there because you will get something from it at the end, and they told me what it was, and they told me what I could get from it, and that

Q: And what were those things that they told you?

Keith: Well, those things to me was I could extend my career, my career was not finished, and I think for somebody like me doesn’t want it to come to an end, no matter how old you are or how young you are, you want to continue, and you want to be able to continue in a way which you can manage and if the opportunity is there...” (Keith, page 7, lines 40 – 50)

Again this reinforces the psychological importance for the individual of having the belief that there is a future ahead of them.

5.6.2 Getting back to normal

The stroke was a life changing event impacting on the individual’s sense of self and had both physical and psychological implications. Once the participant was at a point in their stroke journey that they recognised that there was a future the participants’ perception of the future was about getting back to “normal” and to return to their pre-stroke self-identity as discussed by Adam:

“My work is one of the main things in my life, working, so I have not got that anymore, but I mean it can return and that’s what I am aiming for. But it is very frustrating... you have got to be realistic and something like this has happened, you have just got to get through it all and aim to get back to normal hopefully.” (Adam, page 2, lines 4 – 8)

In these initial stages there was the hope of returning to their pre-stroke life but also some perceived doubt as to whether that was possible or not.

“Well I would like to see my leg and my arm back to how they was before, and me being back at work; that’s what I am aiming for, whether that can be achieved or not we will have to wait and see, you know.” (Adam, page 6, lines 31 – 33)

As they started to progress through their stroke journey often the perception changed slightly and although they were aiming to get back to their pre-stroke life there was some compromise attributed to this.

“For everything to get back to as near normal as possible, looking at it and reading about it, I will safely say that if I can get back to about 85% that would be pretty good.” (Bob, page 15, lines 37 – 38)

As Bob describes he considered that if he got back to as near normal as possible that would be pretty good and he was no longer aiming to return to 100%. This demonstrates the psychological adjustment and coming to terms with what had happened. This may also be perceived as the individual gradually coming to terms with the loss of their pre-stroke self and beginning to define a new sense of self, coming to terms with their disability. Participants referred to this as rebuilding a new life.

“Well, I am a self-employed electrician, but I had my own business, just a one man band type of thing, you know, so I was doing quite well and everything was going along quite nicely, you know, until June 5th. And yeah, so I mean, that’s all gone now so, I have got to start all over again as far as the business is concerned, so we will see how all that goes; but I mean hopefully, I have set a sort of a target January, February of next year, but I realise that you can’t really say when you are going to be ready because you just don’t know, you know it is just not, the whole thing you know is like a piece of string isn’t it, you just don’t know how long it is.” (Adam, page 1, lines 43 – 50)

5.6.3 New avenues / new horizons

As time progressed and the individual was further along their stroke journey, the future changed to a new sense of self with the broadening of horizons and the anticipation of new opportunities. This change in thinking and perception developed as the individual progressed through their stroke journey, as they recovered and as they began to come to terms with what had happened. This was the case for Daniel, who no longer wanted to go back to his old life and his old job, instead he felt that the stroke had enabled him to embrace other skills and new opportunities.

“I am not going to dream about going back to my old job; a) I don’t want to anymore, because I sniffed too much other stuff which is more creative, the artistic side of it.” (Daniel, page 9, lines 48 – 50)

The stroke had allowed Daniel to consider other options which he found an exciting and adventurous prospect.

“So that is a good thing out of the stroke, basically I have got different things to aim at, where about before I had more of like a tunnel vision, because this is what I have done for twenty years, this is what I was really good at, and you know it was safe, or I was safe, you know, and now it is more like adventurous, because I have to start anyway with something in the future. But what I want is to be in paid work again, or even see how it goes, but there is a future.” (Daniel, page 10, lines 12 – 17)

5.7 Summary

This chapter has presented and explored the findings from the eight interviews completed with the seven participants at the WRS, considering the five main themes of:

1. The stroke journey
2. Rebuilding the whole person
3. The WRS
4. Psychosocial benefits of the WRS
5. The future

The findings have explored the experiences of individuals participating within the WRS; including the impact of the WRS on their stroke journey. This has provided an understanding of the world of the individual experiencing the WRS; including how the WRS impacts on the individual's life, how the WRS contributes to the individual's wellbeing, how it changes how they view their world and the impact on their sense of self-identity and self-worth.

These findings have emphasised the less overt or hidden aspects and perceived benefits for individuals attending the WRS, suggesting that it is far from just a process for returning to work, but instead contributes to a far wider set of values and contributions in the individual's stroke journey, road to recovery and future life.

The above themes and findings will now be considered in further detail in relation to theory and the research literature in the discussion chapter which follows.

Chapter 6: Discussion

6.1 Introduction

The findings in chapter 5 explored the life-worlds of the participants in relation to their experiences of participating within the WRS, including the impact of the WRS on the individual's stroke journey. This revealed individual accounts, but also highlighted key similarities at the thematic level. This has provided a rich interpretive description, with exploratory insights, into the experiences of individuals attending the WRS.

This study used IPA to explore the research question and therefore the purpose of this discussion is to present the interpretations and understandings of the experiences of participating within the WRS, including the impact of the WRS on the individual's stroke journey. Interpretation of participants' accounts are considered an essential part of IPA research (Larkin et al 2006), however these should be considered in the wider context of the existing literature (Smith et al 2009). Therefore this chapter provides a discussion of the findings and key themes presented in chapter 5 and relates these findings to the relevant research literature and government policy. The chapter then evaluates the research considering the implications for practice as well as reflecting on the research processes. This is followed by a personal reflection on my journey and development as a researcher through the process of the study.

A final chapter will follow this discussion, which will present a conclusion to the thesis. This will consider what the study has revealed and consider the unique contributions this research study adds to the existing research literature.

6.2 Synthesis of the research findings

Five key themes were identified from the findings in chapter 5, however it is felt that for the purposes of this discussion these themes can be further synthesised into three key main findings and lines of argument in order to most effectively articulate the lived experience of the research participants at the WRS. Firstly, 'the philosophy and principles of the WRS' – what does the WRS set out to do; secondly, 'hidden extras' – the unexpected outcomes of the WRS and its impact on the individual's post stroke journey; and thirdly, 'self-management' – the meaning of the WRS. These three key findings and lines of argument will be presented in turn.

6.3 The philosophy and principles of the WRS

The WRS's main objective is to rehabilitate individuals post stroke to return to work, be it their existing job, new employment opportunities – either paid or voluntary, or other alternative meaningful activity as well as community integration. It was apparent from the findings that the participants' accounts conveyed the sense of a fundamental philosophy and associated principles that underpinned the rehabilitation at the WRS. This section will therefore discuss the participants' perceptions of the philosophy and principles the service is underpinned by and how this relates to what it sets out to do.

6.3.1 The underpinning philosophy of the WRS

Firstly, it felt clear from the participants' accounts and will therefore be argued here that the WRS is founded in the underpinning philosophy of occupational therapy (OT) with occupation and meaningful activity at its core. This is maybe not particularly surprising as the WRS is an OT led service, however this underpinning philosophy consequently provides a unique experience to individuals that is not commonly found in rehabilitation services today.

Occupational therapy is built on the fundamental concept that humans are occupational by nature; 'To do is to be' (Cracknell 1993, p391). People "are most true to their humanity when they are engaged in occupation" (Yerxa et al 1989, p7) and all of our knowledge is said to come from engagement in activity (Piaget 1969 cited in Cynkin and Robinson 1990). Occupational therapy has five basic assumptions relating to occupation as listed below:

Five basic assumptions in occupational therapy

- A fundamental link exists between health and occupation
- Healthy occupation maintains a balance between existing, thinking and acting
- A unity exists between mind and body
- When participation in occupation is interrupted mind and body deteriorate
- As occupation maintains mind and body it is suited to the restoration of functional ability

(Turner 1997 p10, based on Meyer 1922)

These five basic assumptions were represented in the participants' accounts and were seen to be key components of the philosophy of the WRS. Although the terminology of occupation was not directly referred to by the participants, time and occupying it, structure in life and meaningful activity, as components of occupation were identified by the participants. Consequently these were identified as key sub-themes within the findings chapter. When relating the findings to the five basic assumptions, the participants identified both the positives and negatives of having structure in their lives and occupying their time with purposeful and meaningful activity. They recognised the negative impact that not having structure in one's life could have on their psychological wellbeing and feelings of self-worth, as described by Adam, Bob and John, relating this to their feelings when they were in the acute hospital before attending the WRS. Conversely, whilst participating at the WRS, participants such as Tom, Bob, Daniel and Adam identified the importance of the benefits the WRS provided in terms of structure in life, routine and meaningful activity and the impact this had on their recovery and wellbeing. Accordingly, they appreciated the importance of work and were motivated to participate in the rehabilitation provided at the WRS reporting that not only did they benefit from attending the WRS whilst they were there, but that it also had a positive consequence in providing structure and meaning to their wider lives. Therefore it is felt that the five basic assumptions in OT were evident in the participants' accounts of their experience at the WRS.

In relation to the findings, one of the core skills of OT is to provide treatment through purposeful activity to achieve occupational goals and a balance in health. Theories of motivation underpin the overarching philosophy of occupation and meaningful activity. There is a theoretical assumption that our need for activity comes from our intrinsic desire to master and explore our environment (Turner 1997). As individuals we measure our self-worth and enhance our wellbeing by gaining information about ourselves and our environment, endeavouring to develop skills and confidence and achieve mastery in a given area. We are personally motivated to do certain activities because they bring rewards. These rewards are known as intrinsic motivators (Ryan and Deci 2000) providing the link between mind and body – our thinking and our doing are the principal motivators of our actions. Therefore activities that one deems as being purposeful are the ones that we put most effort into, they are the activities that give us most satisfaction and enhance our wellbeing. In contrast, extrinsic motivators – those external to the individual, being imposed on the individual – may in the short term engage a person in activity but are unlikely to ultimately lead to wellbeing (Ryan and Deci 2000, Turner 1997). Therefore assumptions can be made that if rehabilitation is to be successful and have the best outcomes it must engage the individual's intrinsic motivators. This can be applied to the VR provided at the WRS and would support the findings, where participants spoke of their motivation and sense of achievement in

attending the WRS in order to RTW and were able to identify the perceived benefits of the service in achieving this.

In order for rehabilitation to be meaningful to the individual it is agreed that it must be based on their individual needs and wishes, considering their intrinsic motivators. This concept is both central to the philosophy of OT, and the underlying principle of client-centred practice. OT philosophy asserts that people are individuals and therefore a key component of therapeutic intervention is getting to know the individual, building up a therapeutic relationship with the individual based on mutual respect and cooperation. Working in partnership with the individual, understanding their motivations, is essential in order to identify their needs and consequently develop appropriate intervention and treatment strategies (Turner 1997). Participants discussed their individual goals, treatment plans and interventions and discussed the contrast in the approach taken at the WRS as opposed to the approach taken in other clinical settings on their stroke journey. For example both Keith and Adam referred to the WRS being the first place that conversations had taken place about goals, getting back to 'normal' and looking to the future.

Although client-centredness has a long-standing tradition within the philosophy of OT, it has not traditionally been recognised as common practice for all healthcare professions and has not been commonplace in the research literature. Though more recently client-centred practice has come to the fore of health care and rehabilitation practice, being an important theme in UK health policy such as the Five Year Forward View (NHS England et al 2014), the Cardiovascular Outcomes Strategy (DH 2013), the Stroke Strategy (DH 2007) and the National Service Frameworks (DH 2005a, DH 2001). However, the terminology and thus meaning used in professional literature is often inconsistent and there has ironically been a lack of the client's perspective portrayed within the professional literature (Cott 2004).

Traditionally however, there has been more of a focus on the patient perspective and experiences through the literature investigating the sociology of rehabilitation and experiences of living with disability (Cott 2004). Cott (2004) in her qualitative study of client-centred rehabilitation identified that clients considered client-centred practice to mean tailoring their rehabilitation programmes to meet their individual needs. Clients felt they should be actively involved in identifying their needs, goals and outcomes in collaboration with their health professionals. The findings of this study would support those of Cott (2004) but go one stage further. In this study the participants identified active client involvement and collaboration as common practice at the WRS; rather than a desire it was a reality. Cott (2004) identified seven components of client-centred rehabilitation as listed below:

Seven components of client-centred rehabilitation:

1. Individualisation of programmes to the needs of each client to prepare them for life in the real world.
2. Mutual participation in decision making and goal setting.
3. Outcomes that are meaningful to the client.
4. Sharing of information and education that is appropriate, timely and according to the clients wishes.
5. Emotional support.
6. Family and peer involvement throughout rehabilitation.
7. Coordination and continuity across the multiple service sectors.

(Cott 2004, pp1418 – 1419)

Not surprisingly although the terminology of client-centred practice was not directly articulated by the participants, the principles appeared to be. Therefore these seven components of client-centred rehabilitation identified by Cott (2004) can be directly applied to specific examples within the findings of this study underpinning the philosophy and key principles of the WRS. For example Daniel referred to the WRS as providing rehabilitation back to life which can be related to component one of the seven components. Daniel, Tom and John also referred to the WRS providing them with appropriate information to be able to plan for the future relating to component four as well as providing the continuity across their stroke journey linking them to other agencies relating to component seven. Many of the participants including Keith and Tom discussed their involvement in decision making and goal setting relating to component two as well as outcomes that are meaningful to the individual – component three.

The theoretical underpinnings from Cott (2004) applied to my findings demonstrate how client-centredness is being applied in clinical practice providing the essence of the WRS and becomes a motivational factor for the participants giving drive to their recovery and reintegration post stroke. Therefore, although the seven components of client centred rehabilitation identified by Cott (2004), are articulated by the participants as already being commonplace and incorporated into the rehabilitation provided by the WRS, this is not generally the experience of patients in other clinical settings. Within the growing body of research considering the patient perspective, there is often much criticism that current healthcare and rehabilitation services do not fully take into account the holistic needs of the individual (Ellis-Hill et al 2008, Cott 2004, Ellis-Hill and Horn 2000, Burton 2000). However, this is not in keeping with the findings from this study, which

provided individual accounts of high levels of satisfaction with the WRS intervention in being tailored to the individual needs and identified goals of the individual.

This research offers a different perspective to that of the research evidence base for client-centred practice, it suggests that client-centred practice is being provided in its true essence to the participants attending the WRS. It may be reasonable to suggest that this is because the service is steeped in the philosophy of OT and the subsequent delivery of its principles. This directly impacts on the experience of the participant providing a positive and conducive setting for rehabilitation and recovery tailored to the needs of the individual based on the principle of meaningful activity. Having considered the underpinning philosophy of the WRS its application to the principles of the rehabilitation provided at the WRS will now be considered further.

6.3.2 Principles of rehabilitation at the WRS

The philosophy of OT influences and underpins the principles of rehabilitation provided by the WRS and experienced by the participants. A general criticism of rehabilitation has been that the context of therapeutic activity and the clinical environment differs substantially from the reality of the individual's own social environments and that the translation of skills from therapy into the individual's home and social life is often difficult (Burton 2000). However, this did not appear to be the experience of the participants at the WRS who conversely, reported the WRS to be a therapeutic environment providing meaningful activity, replicating that of a work environment, providing not only rehabilitation but also the social elements and peer support of a workshop environment. The participants reported that the WRS provides and achieves this balance preparing them for future life with positive transference into their daily and social life. Clearly the environment plays a significant role in the process of rehabilitation (Widen Holmqvist et al 2001) and this will be considered in relation to other research evidence in this area. The WRS was perceived quite differently from that of the other healthcare services and rehabilitation services that the participants had experienced in their stroke journey thus far. Daniel referred to the WRS as 'rehabilitation back to life'. There are different models of care underpinning the delivery of healthcare, the historical and traditional medical model of healthcare is that of the biomedical model. The biomedical model focuses purely on the biological factors and excludes the psychological, social and environmental influences. In contrast the biopsychosocial model, traditionally adopted as a model by OT and also the model adopted by the WRS, considers that biological, psychological and social factors together influence human functioning in the role of health, disease and illness and therefore should be considered collectively rather than in isolation from each other (Wade and Halligan 2004).

In recent years there has generally been a shift in healthcare towards the biopsychosocial model as recognised in the World Health Organisation (WHO) (2001) International Classification of Functioning (ICF), which defines the consequences of disablement at three levels: body functions and structures (impairment); the person or performance of activities (activity limitations); and the person in their environment and in society (participation restrictions). The WRS focuses its client-centred rehabilitation with the individual at the participation level, linking to that of community integration and RTW. However the participants themselves identified the rehabilitation they received at the WRS as being distinctly different to that experienced on their stroke journey thus far, prior to attending the WRS. The rehabilitation that the participants reported having received prior to attending the WRS had initially been at an impairment level within the acute phase of stroke care treatment and then moving to activity limitations. Daniel clearly articulated this highlighting the different areas of focus, which can be related to the WHO ICF (2001) classification. For example, Daniel stated that the in-patient rehabilitation he received had focused on his movement, which would be classed as treatment at the impairment level moving to the activity limitations level according to the WHO ICF (2001). Rehabilitation in the acute stages had therefore sought to address impairment of function and limitations in activities of daily living (ADLs), rather than focusing on participation restrictions. However, the WRS focus on rehabilitation reportedly took into consideration the wider impact of the stroke on the individual's participation in extended activities such as their role within their home life, hobbies, work life and social integration. Daniel referred to this as rehabilitation "back to life", with the WRS offering a unique rehabilitation experience.

Unlike the experiences of the participants at the WRS, one of the general criticisms of rehabilitation from a patient perspective is that it does a good job of addressing the physical issues of the individual's condition and their basic care needs but does not prepare the individual for life in the real world (Cott 2004). In contrast to the rehabilitation provided at the WRS, participation restrictions are not something that generally gets addressed within rehabilitation. Instead, recovery is often perceived by health care professionals in terms of performance in ADLs (Burton 2000), and physical ability and recovery are often perceived as the main focus of recovery and outcome post stroke (Ellis-Hill et al 2000). Consequently rehabilitation outcomes are often measures of isolated impairments and disabilities, rather than being meaningful and relevant, therefore these clinical measures have little translation into society and everyday life for the individual (Doolittle 1991, Cott 2004). However, for the participants in this study, the rehabilitation, advice and support provided by the WRS was considered to be an essential

signposting element of getting back to normal life, highlighting the benefits of such an holistic approach.

With increased financial and service pressures on the NHS, many rehabilitation services focus mainly on the physical recovery and are not able to offer the extended rehabilitation addressing participation restrictions, preparing and enabling the stroke survivor for life in the real world. If services are based on physical recovery alone the evidence base suggests that recovery is mainly complete at six months post stroke (Lindmark and Hamrin 1995, Wade and Langton-Hewer 1987). Therefore, the role of the WRS may be seen as a luxury adjunct rather than an essential component of physical rehabilitation. However, it is argued that this extended rehabilitation provided by the WRS has vast benefits to both the participant and society in the long-term. The implications if the individual does not make a psychological, as well as a physical recovery, in order to integrate back into society are vast. Not only for the wellbeing of the individual; but also the wider costs for society as a whole in terms of lost productivity and the burden of care needs (NAO 2005).

6.3.3 The WRS as a group environment / Shared experience “People have got the same issues”

As well as being described as a unique rehabilitation setting in terms of providing rehabilitation back to life, the participants also gave insights into the distinct benefits and added value of the WRS being a group environment, providing peer support and shared experience. Daniel described this shared experience as “people have got the same issues”.

Prior to attending the WRS participants, such as Bob and Keith, described their sense of isolation following the stroke due to the lack of understanding of others, referring to their stroke as a hidden illness or disability as the effects of the stroke were often not visible to others. It was perceived by the participants that an overt physical disability would be easier for others to understand. These findings are in keeping with other studies, such as Murray and Harrison (2004) who report, “participants felt that physical, observable disability elicited more understanding and empathy from others” (p 811). Likewise this was identified as an issue for stroke survivors in the Ellis-Hill et al (2000) study where participants also referred to the invisible difficulties as a consequence of the stroke and that there was often a dismissive lack of understanding of others.

Interestingly the language used by participants to describe the hidden aspects of the stroke was also similar. For example both Bob in this study and a participant in Murray and Harrison’s (2004)

study referred to how it would be easier for people to understand if they had broken their leg. Whereas, in the Ellis Hill et al (2000) study, a participant compared the issue of understanding the stroke as opposed to if she had broken her arm. The lack of understanding appeared to impact on the participants' ability to come to terms with what had happened and feel accepted by others. It was important to them that their issues following the stroke although not necessarily physically overt were given equal weighting and considered just as important.

The comments made in relation to having a stroke as opposed to breaking a leg or an arm by both this study's participants and those in other studies (Murray and Harrison 2004, Ellis-Hill et al 2000) also highlighted the issue of the unpredictable and ongoing nature of the stroke journey and recovery which was difficult for participants to cope with. This was in contrast to the belief that if the individual had broken a bone there was a set predictable and contained recovery time period after which the individual would be back to 'normal'.

It has been considered that part of the issue is the fact that there is no common language and understanding for those who have not experienced a stroke and therefore no ability to appreciate the individual's changed situation and challenges (Ellis-Hill et al 2000, 2008), which resonate with the experiences of this study's participants prior to attending the WRS. However, unlike the findings of the other studies, the WRS group environment provided participants with a supportive, comfortable environment. Tom expressed this when he described feeling more at ease and less self-conscious about his stroke and disabilities. The shared environment was perceived as both comforting and encouraging.

The group environment of the WRS offered the distinct opportunity for the participants to compare themselves to the other clients at the WRS as a means of benchmarking how badly affected they were and what their chance of recovery might be. For example Daniel and Tom described talking to clients who were further down their post stroke recovery journey in order to get advice and tips. Likewise Simon and Tom described comparing themselves in age and ability post stroke to other clients at the WRS and how this made them feel better about their situation as they felt more fortunate in terms of their level of ability and recovery to date. Here, the participants were engaging in social comparison with regards to their level of recovery. Social comparison theory, originating from the work of Festinger (1954), refers to the process of comparing ourselves to others. The original theory suggested that people compare themselves with others in a lateral or upward direction as a means of self-evaluation. The theory was elaborated by Schachter (1959) who demonstrated through his research that anxiety or a threat was a factor in affiliation with similar others as a source of self-evaluation in a lateral or upward

direction. Wills (1981) then further developed the theory proposing that we socially compare more after a threat, such as a stroke, yet conversely in a downwards rather than an upward direction. By comparing in a downwards direction it increases the individual's self-esteem resulting in a positive effect. The theory was taken yet another stage further by Taylor and Lobel (1989) who proposed that both upward and downward comparisons are used, though for different reasons. They proposed that downward comparisons (interacting with or gaining information from people that are worse off) are used for self-enhancement, raising self-esteem through making people feel fortunate or "lucky" compared to others. This serves as an evaluation function, resulting in a positive effect. Whereas upward comparison (interacting with or gaining information from people who are slightly or much better off) is used for information and problem solving purposes. The use of upward contacts helps to provide inspiration and hope through role modelling of others.

The findings of this study are in keeping with Taylor and Lobel's (1989) Social Comparison Theory where it appeared that participants were engaging in both downward and upward comparisons. The stroke itself was perceived as a threat to the participants. It appeared that the participants engaged in downward comparison within the WRS environment for self-enhancement, for example both Simon and Tom talked about the other clients being worse off than them in terms of disability resulting from the stroke, which enabled them to consider themselves in a more fortunate situation to those around them. It appeared the participants compared aspects where they felt they were more "lucky" as a means of coping with their situation. Their comments regarding comparison with others were positive and therefore it appeared to have a positive effect on their outlook increasing their self-esteem. This is similar to findings in other stroke studies (Alaszewski et al 2004, Boger et al 2015) as well as studies exploring positive adjustment in people with spinal cord injury (Dibb et al 2013).

Participants also appeared to use upward comparison as part of the consideration of WRS as a group environment and shared experience. For example Tom described how talking to people who had been at the WRS a lot longer than him gave him great encouragement. Being able to talk to others who were further into their stroke journey and being able to see how people had progressed in their recovery gave participants hope. Daniel also talked about seeking advice from others who were further into their stroke journey and recovery which he appeared to use as a problem solving mechanism to apply to his own recovery. It therefore appears that downward and upward social comparison were used by the participants of this study, to their benefit, in order to meet differing needs of self-evaluation as well as information and problem solving.

Without a group environment these social comparisons would not have been possible and are a perceived benefit of the group rehabilitation environment.

Due to the perceived lack of understanding of others to the participants' changed situation as a result of their stroke, the participants appeared to take solace in the shared identity and experience offered by the WRS. The peers had a shared understanding of the difficulties faced following the stroke and provided participants with an important source of encouragement, insight, guidance and practical advice as has been identified by other studies (Murray and Harrison 2004, Cott 2004). It has been suggested that communication with other people who have similar conditions can not only promote recovery but also enable the individual to come to terms with their condition, therefore generating a restored sense of normality (Dickson et al 2008). This would resonate with the findings of this study and the participants' use of social comparison.

With the changes in self-identity and roles, participants talked about no longer participating in the hobbies or social activities they had previously been a part of before the stroke, this is similar to the findings of Murray and Harrison (2004). However, despite diminished social contact and participation in previous activities, the participants identified that the WRS also provided them with a social environment, especially with the group workshop environment. For example Tom referred to how the conversations at tea time and lunchtime were all part of the therapy and enabled support networks and friendships to be developed; as well as the learning of new skills. This unique shared experience of peer support as well as comparison with peers, provides inspiration and fosters confidence, leading to the promotion and use of self-management strategies (Boger et al 2015).

The accounts from the participants provide insights into the rehabilitation provided at the WRS as a unique rehabilitation service which appears to successfully achieve the balance of tailoring interventions and rehabilitation to meet the needs of the individual. This is achieved through the WRS being steeped in the philosophy of OT and a client-centred approach, whilst encompassing the benefits of a group environment. Consequently, the rehabilitation provided is based on the principles of gaining an understanding and appreciation of the individual's experiences and social context, with a focus on adapting to life. This has been proposed by others as an essential element of stroke service provision (Burton 2000) yet rarely successfully achieved from the patient's perspective.

6.4 'Hidden extras' the unexpected outcomes of the WRS and its impact on the individual's post stroke journey

Rebuilding the whole person, the psychosocial benefits of the WRS and the future were all key and important insights gained from the participants' accounts. These were identified as the hidden extras and the unexpected outcomes of the WRS which positively impacted on the individual's post stroke journey. Surprisingly, in their accounts the participants appeared to give equal weight to the impact of these hidden aspects of the WRS as they did to the key principles and rehabilitation treatment provided to them. These hidden aspects provide unique and rich insights into the WRS and its added value in providing more than just VR. The impact of these 'hidden extras' could therefore be seen important for consideration in terms of implications for clinical practice, commissioners and policy.

The WRS was identified by the participants as having a positive and significant impact on their post stroke journey and adjustment. The journey of the participants appeared to be an overarching concept throughout all of the transcripts and across themes and metaphorically appeared like the individual's river of life. The key themes varied from being static and fluid; static like rocks – such as the WRS itself, these static themes or rocks were at stationary points along the river. There were also fluid themes that were both flowing themes – such as the future, like reeds along a section of the river, and then moving themes – such as the concept of time and rebuilding the whole person, which flowed at different speeds depending on the metaphorical flow of the current of the river and the individual's recovery and journey itself. The impact of the WRS on rebuilding the whole person will now be considered.

6.4.1 Rebuilding the whole person

The participants attending the WRS generally already had well established work, family and social roles prior to their stroke. Self-identity was perceived as being very important to the participants and therefore the issues for these individuals revolved around adjusting to changes and/or losses in these roles as a result of the stroke. This is similar to reported experiences of other patients when adjusting to living with a chronic condition such as arthritis or chronic obstructive pulmonary disease (COPD) (Cott 2004). Many theories and models have sought to explain self-adjustment post illness in relation to self-identity. Consequently the adjustment to life post stroke has also been considered in relation to various models that will now be reflected upon in relation to the findings of this study.

Bereavement models have previously been explored in terms of their use by professionals to manage the rehabilitation of stroke survivors (Alaszewski et al 2004). It has been proposed that as stroke can create a severe loss for the individual, which necessitates psychological adjustments for the individual to a changed sense of self, status and identity, this is a concept that is in keeping with the theory of bereavement models (Alaszewski et al 2004). It has been suggested by clinicians (Alaszewski et al 2004) that individuals can become 'stuck' at one stage of the acceptance process, which hampers their ability to then proceed and progress with their rehabilitation and recovery. However this does not necessarily appear to be the perception of stroke survivors themselves, and in keeping with the findings of Alaszewski et al (2004), there was no evidence from the participants at the WRS of them being 'stuck' or passive in their stroke journey. Instead, the WRS appeared to have a positive impact on their post stroke recovery and readjustment. Participants took a dynamic and active approach to their recovery and rehabilitation at the WRS, in which individuals sought to recover, learn and develop themselves and their new self-identity. It can be argued that the concepts of bereavement or grieving have been found to be more of an explanatory framework which is of use to clinicians and a concept that is not necessarily identified or considered pertinent by the stroke survivor themselves (Alaszewski et al 2004), as in the case of this study's findings. However, listening to the accounts from the participants and being a clinician, the researcher can relate to how the different stages of the bereavement model could be applied to the individual's journey of recovery. Nonetheless, although the participants attending the WRS described a sense of loss following their stroke especially in the initial acute stages, as well as a process of coming to terms with the stroke, they did not seem to relate their experiences to that of bereavement or grieving. Likewise, the perceptions and descriptions of their experiences did not appear to resonate with bereavement models. Therefore it is argued that the bereavement models do not offer any explanation or value to this research study as they do not reflect the individual experience and process of adjustment as articulated by the participants.

Alternatively, medical sociologists have considered the impact of chronic illness on people's lives and self-identities. Bury (1982) classically coined the concept of biographical disruption which suggests that the experience of illness and chronic illness interrupts the structures of everyday life and disrupts the knowledge which underpins them. This leads to the structures in daily life becoming disjointed and a fundamental rethinking of the individual's biography and identity in terms of their expectations and plans for the future. Bury (1982) considered that there were three key aspects of disruption. Firstly the disruption of taken for granted assumptions and behaviours, secondly, the fundamental rethinking of the individual's biography and self-concept and thirdly

the response to the disruption in confronting the altered situation and restructuring future priorities and goals.

The disruption to the normal pattern of personal development creates a biographical discontinuity in which individuals need to make sense of what has happened, come to terms with and normalise their new situation (Bury 1982). The process of the individual making sense of what has happened in order to create a sense of stability and coherence has been described by Williams (1984) as narrative reconstruction. By assigning meaning to what has happened and to the biographical disruption, the individual can “realign present, and past and self with society” (Williams 1984, p197).

The individual has to identify what aspects of their self-identity have been altered or lost through their injury or illness, what aspects of their self-identity still remain and what is their new self-identity, based on their changed situation (Corbin and Strauss 1987). Alternatively Frank (1993) suggested three self-change narratives, firstly the discovering again of the previous self, secondly the developing and radical new self and thirdly, no new self.

In relation to the above concepts, all of which have been considered in relation to chronic illness literature as well as acute onset of disability such as spinal cord injury and stroke (Bury 1982, Williams 1984, Cott 2004, Dickson et al 2008, Alaszewski et al 2004, Ellis-Hill et al 2008, Radcliffe et al 2013), the theories can similarly be related and applied to the findings of this study. It was evident from the accounts of the participants that initially in the acute stages there was a sense of loss of self-identity especially in relation to the individual’s previous roles and responsibilities in terms of work, family and social, including hobbies. This is in keeping with Burton’s (2000) findings where respondents similarly reported a threat to work, family, finance and social network roles and responsibilities following stroke.

There was a process as part of the participant’s stroke journey recovery in adjusting and coming to terms with what had happened. The participants talked about their pre-stroke life in terms of how the stroke had altered their life and how previously taken for granted activities were affected and now presented new challenges and significant effort as described by Adam and Bob (Dickson et al 2008, Burton 2000). Reliance on others and the frustration that accompanied this, as also identified by Jones et al (2008), was perceived as a negative aspect of the biographical disruption by participants such as Bob. However, over time participants appeared to start to come to terms with what had happened. At this stage it might be argued that some participants, such as Keith, had adjusted to their pre-stroke life rather than accepted their new situation. This concurs with

Burton's (2000) findings which reported that reappraisal of the individual's situation suggested an adjustment of role rather than an acceptance of the individual's new situation. However, some participants such as Daniel and Tom appeared to have moved beyond the adjustment of role and were instead positively embracing new avenues and horizons and a new sense of self that had developed as a consequence of their stroke.

This journey described by the participants at the WRS, also showed similarities to that of the concept of the Life Thread Model, developed in the area of stroke, by Ellis-Hill et al (2008). According to the life-threads approach, as life proceeds the concept of self-identity and the sense of self are fluid within a person. The life threads are developed through narrative and discursive interaction contributing to a sense of shared understanding and belonging. Narratives provide links to the individual's past which is known and their unknown future, this process provides confidence that the life thread will continue into the future. However, in the case of a stroke this predictability to life is suddenly lost where the life threads are broken or frayed. As the individual adjusts to their stroke they either start to join up the life threads that make up the wider rope or they have to tie off loose ends (Ellis-Hill et al 2008).

The Life Thread Model (Ellis-Hill et al 2008) suggests that social and psychological processes are part of the rehabilitation process rather than simply just physical recovery and can be applied to the findings of this study and the journey and experiences described by the participants. This was evident in the accounts given by the participants providing equal consideration and parity of esteem to their psychosocial and psychological recovery as well as their physical recovery following the stroke. The Life Thread Model (Ellis-Hill et al 2008) also considers that narratives or stories are generated between people during periods of one's life and from the accounts of the participants it appeared that this developed through the shared experiences fostered amongst the clients, within the WRS group environment. These interactions and relationships were at a static point in the river shaped by the WRS, but influenced more widely on their future and journey of recovery. Like the Life Thread Model (Ellis-Hill et al 2008) the participants were describing a journey of rebuilding their life again following their stroke, with some elements of continuity from the past, but also facing the prospect of a new future with a perceived changed sense of self-identity.

All of the models and theories of self-adjustment following stroke that have been discussed go some way to explain the process of readjustment and can be related to the findings of this study. However, it is believed that they do not go far enough in explaining the process of readjustment as experienced by some of the participants. For example, it is shown that Daniel and Tom went

beyond their life threads being broken and their biography being disrupted to a stage of recovery and reconstitution that was built on a new sense of self, perceived as a positive outcome of the stroke offering new opportunities and the broadening of horizons. This provided a unique and novel insight into the positive perceptions of having had a stroke and the perceived consequential new opportunities it offered the individual's future life.

What was clearly evident from the findings was that the stroke is a life changing event that has a major impact on the flow of the individual's life. Consequently the individual needs to adapt, come to terms with and rebuild their life. The WRS itself contributed to the participant's self-adjustment and provided unexpected outcomes in terms of the participants perceived psychosocial benefits of attending the WRS, these will now be considered.

6.4.2 Psychosocial benefits of the WRS

The psychosocial aspects or "non-tangibles" of the WRS was a dominant theme articulated by the participants in the interviews. The participants identified the psychosocial benefits as the informal aspects and hidden extras of rehabilitation referred to by Tom as "the behind the scenes". Four core components were identified as part of the overarching psychosocial benefits – confidence, learning new skills, sense of achievement and motivation. Motivation was also closely linked to that of personal or self-determination and the individual having an internal locus of control. These psychosocial aspects will now be discussed.

As already discussed in this chapter the psychosocial aspects of stroke are complex. Participation in meaningful activities, social relationships and return to work as well as mood and self-identity are often significantly affected following a stroke (Knapp et al 2000). It has been argued that the meaning of the illness or injury to the individual is more important than the severity of the illness or injury in terms of psychological impact (Howes et al 2005, Dickson et al 2008). During phases of transition, for example being discharged from a service and when attempting to resume roles and activities such as return to work, patients are considered to be especially vulnerable to psychological stress (Kirkevold et al 2012). It has therefore been suggested that psychosocial support, if targeted, could facilitate post stroke adjustment and adaptation (Kirkevold et al 2012). This would strongly support the findings of this study where participants appeared to make a good psychosocial recovery reporting the positive outcomes and transference of these to their wider life. These findings are also supported by other studies where it has been suggested that support with emotions and motivation, as well as the provision of practical advice and

information are all important in addressing psychosocial needs post stroke (Ellis et al 2010, Redfern et al 2006, Smith et al 2008).

Kirkevold et al (2012) in their literature review suggested that by enhancing the individual's psychosocial resources this could enable better coping mechanisms and wellbeing. They defined psychosocial wellbeing encompassing four dimensions as stated in the box below.

The four dimensions of psychosocial wellbeing:

1. A basic mood of joy, pleasure and wellbeing and the absence of sadness or a feeling of emptiness
2. Participation and engagement in meaningful activities beyond oneself
3. Good social relations and a feeling of loving and being loved in mutual relationship(s)
4. Self-concept characterised by self-acceptance, usefulness and a belief in one's own abilities

(Kirkevold et al 2012, p392)

It is suggested that post stroke these four dimensions may be threatened and therefore should be targeted as part of intervention as suggested goals or outcomes (Kirkevold et al 2012). These four dimensions link to the philosophy and principles of the WRS through meaningful activity, client-centred practice and rehabilitation within a group environment. Therefore, this would account for such positive perceived psychosocial benefits of attending the WRS from the participants' accounts.

Within this study all four dimensions were aspects that participants discussed in their interviews. Participants discussed the importance of meaningful activity and the translation of this from activities for themselves to widening this to wanting to give back to others as well as to society as discussed by Keith and Tom. The importance and value given to peer support and feeling that they belonged was clearly articulated in the perceived benefits of the WRS being a group environment. As well as the identification of the importance of their social and family relationships and the support that provided them with during their stroke journey and recovery. Part of the psychosocial benefits identified by the participants themselves was that of rediscovering a belief in their own abilities through gaining confidence, which came with the sense of achievement of what they had made at the WRS and the new skills they had learnt as described by Daniel, John and Tom. It would therefore appear from the accounts given in the

findings that the WRS, whether overtly or covertly within its interventions, is addressing the four dimensions of psychosocial wellbeing for its participants.

Regaining and developing confidence post stroke was an important psychosocial aspect identified by the participants. Confidence was considered in the context of making progress with physical recovery as well as building confidence in wider skills to prepare the individual for reintegration back into society and working life. According to the participants, confidence was further boosted through the learning of new skills and the sense of achievement that came with that. Confidence gained from progress to date in their stroke recovery was perceived as an indicator of further progress and improvement (Jones et al 2008).

Mixed in with confidence and motivation was a sense of optimism, hope and belief. This was in relation to their recovery thus far and their future recovery and goals. This sense of optimism, hope and belief appeared to be linked to the concept of self-efficacy, where an individual's belief in their own ability and capability to adapt in behaviour is perceived to be critical to success (Bandura 1997). This positive attitude conveyed by the participants may enable them to cope more effectively with the challenges the stroke provides them with (Jones et al 2008). It is also suggested that self-efficacy, depression and quality of life post stroke are relational (Robinson-Smith et al 2000) and this would relate to the findings of this study where participants appeared to establish a strong sense of self-efficacy re-establishing themselves through attending the WRS. Consequently participants adapted to and developed a positive perception of post stroke life through self-adjustment and re-establishing their self-identity and further developing it, as discussed earlier in this chapter.

Linked to self-efficacy the participants discussed their motivation and determination. This included their motivation to attend the WRS which was directly linked to their desire for recovery. The WRS environment encompassing both therapy staff and the participants' peers together, offered encouragement and support pushing them to achieve their goals, which provided the individual with further positivism, confidence, optimism and motivation (Cott et al 2004, Jones et al 2008). Participants considered the WRS as a positive environment and means of achieving their desired outcomes which would support the evidence which suggests that there is a relationship between optimism and rehabilitation outcomes (Herbert and Powell 1989). Also, that motivation is a positive determinant of outcomes post stroke (Maclean et al 2000, Maclean et al 2002) again supported by the findings of this study.

Determination and motivation appeared intertwined and Boger et al (2015) have suggested that determination appears to be a way for individuals to create order and control post stroke. Incorporated into the participant's accounts appeared to be the concept of locus of control. The concept of locus of control was developed by Julian Rotter (1966) which considers the beliefs people hold regarding how much control they can exert over events affecting them in their lives. For example a person who believes in an external locus of control would consider that control is located external to the individual, by factors that they cannot influence and therefore outcomes are dependent on chance or fate. Conversely a person who believes in an internal locus of control would consider that control lies within their own realm of responsibility and ability to influence. Hence someone with an internal locus of control is more likely to be motivated to overcome difficulties, such as a stroke, believing that they have the ability to change things and influence their progress and recovery. Locus of control is also linked to self-efficacy as discussed above.

The participants considered that the outcome of their stroke recovery was reliant on their own motivation and determination to influence the outcome of events, thus linked to a strong belief in an internal locus of control. Participants felt and articulated a personal responsibility for the effort they put into their recovery and the consequential outcomes as has been described by others (Jones et al 2008). The value prescribed to an activity in terms of its perceived meaning and purposefulness has been described as an important facilitator of personal control (Bosworth et al 2000). This again emphasises the importance of client-centred practice, meaningful activity and self-management as demonstrated at the WRS, acknowledging that individuals should be deemed as active partners within their own rehabilitation and recovery process (Kirkevold et al 2012, Boger et al 2015). Locus of control has also been identified as playing an important role within adjustment following other sudden illness including spinal cord injury, as well as being an indicator of performance of activities of daily living, productivity status, community integration, satisfaction and quality of life (Boschen et al 2003).

6.4.3 The future

The psychosocial benefits experienced by the participants from attending the WRS, as discussed, impact on their positive adjustment to post stroke life and the individual's ability to look to the future. The participants' sense of future changed as their psychosocial wellbeing increased.

The future was perceived by the participants as a key aspect of their stroke journey and recovery process. Their perceptions of the future developed and changed as they travelled through their stroke journey. Initially participants were so devastated by the stroke that they did not believe

that there was a future. Although the research literature has considered the psychological implications of stroke there does not appear to be insight into this initial stage of how the psychological impact affects the ability to even consider a future post stroke in the early stages and this is something that requires further investigation.

Once the participants had psychologically adjusted to the fact that there was a future, albeit a changed future, ahead of them the initial concerns were focused on physical recovery (Kirkevold et al 2012). From physical recovery the focus of recovery and the goals set developed and were related to the participants' pre-stroke identity and activities, where the individual sought to re-establish their pre-stroke life including their roles, relationships and hobbies (Alaszewski et al 2004, Kirkevold et al 2012). Qualitative research to date has widely supported this notion that the individual's expectations and goals seek to regain their pre-stroke life and are set within this context (Jones et al 2008, Dowswell et al 2000, Burton 2000, Alaszewski et al 2004, Kirkevold et al 2012).

However, the experience of the WRS took participants a stage further in providing individuals with a new sense of self and the confidence to look at new avenues and new horizons. Attending the WRS was not just about RTW it is about changed perceptions, the added value. This was described by some of the participants, such as Daniel, where he was at a stage of his stroke journey where he reported having a changed sense of self which was discussed in the context of his changed outlook in life (Dickson et al 2008) through which aspects of his post-stroke identity were based on his new situation (Corbin and Strauss 1987). This also relates to a new concept of self (Frank 1993) where the individual seeks new activities to engage with in order to establish a new sense of self in the context of the consequential changes from the stroke (Kirkevold et al 2012). For example as in the case of Tom who not only made his own ukulele but then took up playing the ukulele and joined a band as a new hobby. For these participants their post stroke identity and changed sense of self which had been impacted on through attending the WRS was perceived as a positive aspect and outcome of the stroke providing new horizons.

Rebuilding the whole person, the psychosocial benefits of the WRS and the future were all hidden extras that were unexpected outcomes of the WRS which positively impacted on the individual's post stroke journey in terms of their self-adjustment, new sense of self, motivation, determination, confidence, sense of achievement, internal locus of control and psychosocial wellbeing. These attributes contributed to the individuals' ability to self-manage equipping the individual to embrace the future and new horizons positively. In support of these findings it has been suggested that an important attribute of self-management is that as individuals obtain the

coping skills to adapt to and manage their new post-stroke life, their quality of life and sense of control will improve (Catalano et al 2003). The concept of self-management in relation to the psychosocial aspects and 'hidden extras' identified from the findings will now be discussed.

6.5 Supported self-management – the meaning of the WRS

The psychosocial aspects discussed above encompassing confidence; optimism, hope and belief; self-efficacy; motivation, determination and an internal locus of control; are all important attributes that contribute to the ability to self-manage. Therefore it can be argued that the amalgamation and culmination of the philosophy and principles OT and client-centred practice combined with the psychosocial benefits of the WRS inadvertently leads to self-management being promoted and incorporated into the rehabilitation and treatment that is provided to clients. However, it does not appear to be explicitly identified and labelled as such. The concept of supported self-management in relation to the findings will now be explored.

The WRS as a self-management service emerged from the researcher's interpretation of the participants' accounts. Although the participants did not use the words and terminology of self-management their descriptions of the component parts led to the conclusion that the WRS is equipping clients for long-term self-management as part of its rehabilitation and treatment service provision. This is possibly because the philosophy of OT and client-centred practice implicitly promote that of functional independence and self-management.

The use of self-management techniques post stroke has been encouraged in terms of supporting individuals' progress and ability to cope (Jones and Riazi 2011, Jones 2006). Supported self-management is most commonly associated with the effective management of long-term conditions. Although a stroke is an acute event, as the longer term effects of stroke are often considered in terms of living with a long-term condition, more recently stroke has been included in this area of focus. Supported self-management signifies an ideological shift from the traditional biomedical model of health towards an increased partnership between health professionals and patients, including their families, in order to equip the individual with the skills and confidence required to manage their own health needs (Wilkinson and Whitehead 2009). This ideological shift from the biomedical model to biopsychosocial model and partnership health relationships is in keeping with the already well established philosophy and principles of the WRS. This shift has also been promoted by health policy (DH 2005b, DH 2008b) including the National Clinical Guideline for Stroke which advocate that all patients should be offered training in self-management skills, to include active problem-solving and individual goal setting (RCP 2012).

Self-management has generally been considered within the research literature as a specific intervention programme and there is little evidence that has considered the influences of self-management in the absence of any formal self-management intervention (Boger et al 2015). Conversely it has therefore been suggested that in order to incorporate these interventions into everyday practice, for the benefit of individuals, it would be more appropriate to embed self-management within the usual treatment and care provided (Lennon et al 2013). From the participants' accounts this was the case and inadvertent approach taken at the WRS where there was no evidence of any formal self-management intervention, however the rich descriptions provided by the participants gave details of the component parts.

Four behaviour change processes have been suggested as practical principles to enable individuals to effectively self-manage as shown in the box below.

Practical principles to enable individuals to self-manage:

1. Joint agenda setting
2. Problem solving
3. Collaborative goal setting
4. Goal follow-up

Wagner et al 2001

The principles of self-management are in alignment with the principles and components of client-centred practice and were exhibited within the individual accounts of the participants. Each of these principles appeared to be encompassed into the rehabilitation experienced and described by the participants, whilst attending the WRS. It could be argued that self-management was a key aspect provided as part of the rehabilitation at the WRS but not explicitly identified as such by the participants. This is in keeping with other studies where the terminology of self-management was unfamiliar to patients and this has been deemed to be unsurprising, as the concept has developed in the circles of policy and clinical practice (Boger et al 2015).

Although not explicitly identified as such, self-management and its meaning as explored by other people who have had a stroke in the study by Boger et al (2015) resonated with the findings of this study. The findings of Boger et al (2015) suggested that although the terminology of self-management was not familiar to people post stroke, they were able to identify a range of activities relating to managing their health post stroke encompassing psychological, physical and

social aspects. Self-management was considered to be a means of maintaining autonomy and independence, which was reliant on the individual's capacity in terms of their readiness and ability to respond to the given demands of self-management. This included both the absence of barriers as well as the presence of skills. Six key components that could affect an individual's ability to self-manage were identified including physical impairment, self-confidence, decision making, determination, communication and finding resources (Boger et al 2015). These are all aspects that correspond with the discussions of the participants in this study and the psychosocial benefits identified in the findings and discussed earlier in this chapter.

In order for self-management to be successful it has been suggested that appropriate support including the role of professionals, access to resources, the role of carers, a supportive environment, the positive response from others, political influences and peer support are all necessary requirements (Boger et al 2015). Again this would support the themes and issues identified by the participants in the study as being important aspects of rehabilitation attributing to the wider success of self-adjustment and recovery following a stroke. The WRS appears to provide the appropriate fusion of client-centred professional practice incorporating partnership working, with a supportive environment fostered by peer support and access and signposting to appropriate resources and other services. Boger et al (2015) suggested that stroke self-management comprises of three conceptual layers – individual capacity, self-management support and a self-management environment all of which are able to facilitate successful self-management. It is believed that the participants of this study had the right mix of these three components to benefit accordingly, in order to equip themselves for their ongoing / continued stroke journey.

It is clear that the stroke journey and recovery process is not a linear journey and is instead fraught with challenges, setbacks and uncertainty (Kirkevold et al 2012). However the participants' accounts described how the WRS provided them with a supportive environment which assisted them through the transition on their stroke journey from rehabilitation back to life, community integration and work. The WRS reportedly had a positive impact on the participants' psychosocial wellbeing and adjustment post stroke and was perceived as a very positive experience and rehabilitation service with acknowledged benefits and implications for the participants' wider lives. It would therefore appear that the WRS provides rehabilitation beyond that of vocational rehabilitation. The philosophy and principles of the WRS combined with the benefits of the hidden extras to support the individual to develop self-management strategies to prepare them for life post stroke.

6.6 Implications for practice

This study provides a unique insight into the life-worlds and experiences of seven stroke survivors participating within a WRS. An interpretative research approach, such as that employed in this study, aims to report on the subjective experiences of the study participants and not to generalise to larger populations, however this study is able to raise and offer “interesting, important or useful considerations” (Smith et al 2009, p183) for stroke rehabilitation particularly in the area of vocational rehabilitation and return to work. Consequently, these in turn can contribute to improved patient experience, clinical practice, service provision and wider health policy.

6.6.1 Implications for policy makers

It is acknowledged that the number of strokes in people of working age is rapidly increasing (Stroke Association 2015) and the related costs in income lost to productivity and disability are vast (NAO 2005) if stroke survivors do not RTW. However, despite the recognition in national documents and policy that RTW is important for the individual as well as society, research evidence suggests that the focus of stroke improvement to date has remained at the front end of the pathway with little focus on services for post stroke rehabilitation other than early supported discharge (Radford et al 2013). Consequently, there is still a large gap in the provision of services that address helping stroke patients to RTW (CQC 2011, Radford et al 2013). This research study has demonstrated the benefits of vocational rehabilitation within a group workshop environment as a key component of the post stroke recovery process and pathway.

The findings suggest the broader benefits of a tailored vocational rehabilitation service focused on treatment at the ICF participation level (WHO 2001) enabling both the learning and transference of new skills from the WRS workshop environment to benefit the individual in other aspects of their lives. Participants gave equal weighting to the impact of the WRS on their psychosocial recovery as well as their physical/cognitive recovery. According to the participants self-esteem, confidence, motivation and sense of achievement were all key benefits of the attending the WRS. These self-management skills have a wider impact on the individual not just in terms of their journey with regards to return to work, but also with regards to their journey to get back to hobbies and a social role in wider society. Therefore vocational rehabilitation incorporating the principles of self-management should not be exclusively available just to those individuals who were in existing employment prior to their stroke. Vocational rehabilitation should be available to any individual wishing to return to paid or voluntary work, as well as those who may be unable to return to a formal paid or voluntary work situation but could return to meaningful occupation in their daily lives.

The findings of this study argue that post stroke rehabilitation and in particular vocational rehabilitation should not be an adjunct, but instead an integrated core and essential component of the stroke pathway. Holistic rehabilitation intervention should focus on function rather than impairment or disability with equal consideration being given to the physical, psychological and psychosocial needs of the individual. Supported self-management should also be incorporated as an integral element of vocational rehabilitation in order to equip individuals with the skills and personal resources required for their continuing stroke journey and participation in the community and wider society.

This study suggests true client-centred practice underpinned by the philosophy of OT and the biopsychosocial model deliver positive results for individuals. Therefore, in order for patients to maximise their potential for recovery, wellbeing and quality of life it is essential that rehabilitation is truly holistic and client-centred. Healthcare provision needs to shift from a paternalistic, traditional medical model of healthcare provision to work in partnership with their clients to set meaningful goals that are relevant to the individual's life. It is acknowledged that rehabilitation will need to take different forms with a different focus at various stages along the stroke pathway and the individual's journey, however it is essential that rehabilitation does not cease at the point of basic physical recovery if therapists are to ensure that individuals are able to fulfil their potential and return to meaningful activities that contribute to and also benefit wider society. Rehabilitation should equip individuals with the functional and psychosocial skills and support to enable them to return to life and OT are equipped with the philosophy and skills to provide this.

6.6.2 Implications for commissioners

The findings of this study can be used alongside other research and evaluations to inform commissioners, when planning stroke services, of the unique contributions a WRS can provide and the wider psychosocial benefits of vocational rehabilitation. The focus over recent years has been to shift care and rehabilitation post-acute medical treatment as quickly as possible into the community. In the experience of the researcher, there have often not been the appropriate services or resources in the community to accommodate this in order to provide patients with the rehabilitation they require and deserve. Vocational rehabilitation services, such as the WRS, have an important role to play in the community provision of rehabilitation and should not be seen as an adjunct to treatment or a 'nice to have' service.

Commissioning for outcomes as well as the use of patient reported outcome measures (PROMS) should be a key focus of commissioning contracts these days however, the majority of community rehabilitation services still remain under block activity contracts providing no clear evidence of the quality of the service provided. In order to improve the level of post stroke rehabilitation provision it is essential that the quality of the service is assessed and the findings of this study provide insight into the reported positive patient outcomes achieved by the WRS. The findings of this study consequently suggest the need for flexible access to VR services depending on the individual's stage of recovery. Service provision should not purely be based on predicted timescales for physical recovery (Lindmark and Hamrin 1995, Wade and Langton-Hewer 1987) but should be needs led based on holistic psychosocial recovery as well.

Self-management is currently a key priority for commissioners and this study has given insight into how an OT service with the underpinning principles of client-centred practice and meaningful activity consequently also successfully promotes self-management. Promotion and integration of self-management within vocational rehabilitation successfully prepares and equips the individual with the life skills for reintegration into society.

Provision of vocational rehabilitation is often limited (CQC 2011, Radford et al 2013) and it can be hard to replicate a true working environment for treatment of patients. However the structured workshop environment, as provided by the WRS, is able to offer a unique rehabilitation experience replicating that of a work environment in terms of structure of the day, peer support, and the learning of new skills, providing the individual with rehabilitation back to work and back to life as stated by Daniel. The wider psychosocial aspects of rehabilitation as referred to by the participants in this study should be acknowledged and not underestimated in terms of their contribution to the individual's overall recovery, outcomes and transition back to life in society.

6.6.3 Implications for clinicians

RTW support in the form of VR should be provided for individuals following their stroke as part of their core rehabilitation in order to ensure a successful transition back into the workplace and mitigate the risks of the RTW situation breaking down. Appropriate transitioning between services and from vocational rehabilitation onto voluntary work or return to employment is essential. Many provider rehabilitation services have stepped away from the perceived traditional or old fashioned approach of a rehabilitation workshop environment; however, as has been articulated by the participants of this study, there appear to be clear benefits of treatment within such an

environment for the individual's recovery process through peer support, psychological support, physical and psychological recovery.

The findings of this study suggest that OT led services have a key contribution to make to the provision of quality VR. Their unique skill set, based on the philosophy of OT and client centred-practice, demonstrate the outcomes and benefits of true holistic client-centred practice in facilitating the individual to achieve their maximal potential for recovery, wellbeing and quality of life. The importance of psychological adjustment and recovery as well as physical recovery should be given equal consideration providing parity of esteem. Clinicians need to acknowledge that recovery post stroke is not a straight forward linear process, but is instead a meandering fluid process with set-backs which require an adaptable approach to individuals and their given physical and psychological needs. This study has highlighted the varied adjustment period post stroke and that this is not a quick process but is one that is very personal to the individual. It is also important to acknowledge that psychological adjustment may not necessarily be correlated to that of the individual's physical recovery.

6.6.4 Implications for research

Many studies have considered individual aspects of rehabilitation or the recovery process post stroke, yet few have sought to provide a holistic consideration of a particular rehabilitation service as has been presented in this research. The workshop environment of the WRS appears to have clear benefits to the individual and their recovery process including peer support, psychological support, physical and psychological recovery and self-management. The benefits of this type of group rehabilitation environment should not be underestimated but needs to be considered and researched further.

From the findings it is reasonable to contend that effective rehabilitation comprises a combination and integration encompassing holistic client-centred practice, psychosocial needs and effective supported self-management, which are all intrinsically linked. To date, studies have generally considered self-management in terms of stand-alone programmes (Boger et al 2015). However, this study would suggest that self-management can and should be incorporated into everyday rehabilitation treatment as a philosophy of care. Through enabling people to make a good recovery both physically and psychologically and incorporating self-management into interventions people can be equipped to return to a good quality of life and fulfilment.

6.6.5 Future research

This study has provided a unique insight into the life-worlds and experiences of seven stroke survivors participating within a WRS; including the impact of the WRS on their stroke journey; however more research studies are required in the area of vocational rehabilitation to further understand this phenomenon. Research knowledge would benefit from future studies considering the longer term impact and experience of the WRS on the individual's stroke journey as part of a longitudinal study. The perception of carers and employers in the WRS vocational rehabilitation process would also offer valuable insights and reflections, providing and adding further unique perspectives to the understanding of this phenomenon.

6.7 Research limitations

It is important to consider the potential limitations of this study. Firstly, with regards to recruitment, convenience sampling was chosen due to the limited availability of participants rather than purposive sampling as would normally be used for IPA. However, by default because of the environment and client group being investigated, the boundaries of the sample group were already clearly defined and fairly homogenous as you would aim to achieve through purposive sampling. It is also possible that the participants that volunteered to take part in the study may have been better adjusted to their life post stroke which led to their willingness to discuss their experiences. Those who chose not to partake may have had very different experiences that were not included within this study. Secondly, it is important to acknowledge that the findings of this study represent the experiences of a particular group of individuals from only one WRS. Therefore although the findings provide a rich interpretive description with exploratory insights into the experiences of the individuals attending the WRS, these lived experiences may be very different to the wider stroke population and perhaps those attending another WRS. Thirdly, the issues with carer recruitment have previously been discussed however, further studies into the experiences of carers within this area would provide a useful contribution to the knowledge and research. The carer would provide an invaluable and unique perspective of the effects of the stroke survivor attending the WRS and its impact on their stroke journey. Lastly, further longitudinal qualitative studies in this area, including following up participants at a later stage in their stroke journey would provide a further valuable insight and reflections on the wider temporal experiences and longer impact of the WRS experience on the individual's continued stroke journey.

6.8 Personal reflection on the research process

The final section of this chapter will present my personal reflections on the research process.

6.8.1 Choice of theoretical and research approach

When embarking on this doctoral journey and considering the research literature already in existence as discussed in chapter 2, it was apparent that there was very limited research literature considering the qualitative aspects of return to work and the process of returning to work including the consideration and exploration of vocational rehabilitation services. This highlighted the need for further research in this niche area and the importance of choosing an appropriate theoretical standpoint. My clinical practice experience as an occupational therapist reinforced my desire to explore the subjective, lived experience through the perspective of the stroke clients who attend the WRS and as discussed in chapter 3, phenomenology appeared to most closely compliment this focus area. Consequently it was therefore also important to consider and take an analytical approach that was sensitive to my philosophical standpoint, grounded in phenomenology, hence my decision to use IPA as the medium to analyse the data from this study. Accordingly, my knowledge and understanding of both phenomenology and IPA have developed throughout the course of the research process and my doctoral journey.

6.8.2 Collecting the data

As discussed in chapter 4, recruitment to the study was an issue necessitating the need to widen the recruitment pool to participants who had already come to the end of their treatment at the WRS. At the start of the study I had sought to recruit a maximum of fifteen patients and up to fifteen of their identified key carers to be interviewed. However, as I became more familiar with the IPA approach and research literature in this area, I was confident that for a study of this type where I was seeking to gain the idiographic, in-depth insights of the participant's experiences of the WRS that a smaller sampler size was sufficient (Smith et al 2009). In total I recruited nine participants to the study – seven clients and two carers. This sample size is in keeping with that of other IPA studies where sample sizes comprising of four to ten are acceptable (Smith and Osborn 2008).

At the point of the interim viva it was discussed and agreed with my examiner that I would exclusively use and analyse the seven client interviews for my final data analysis and thesis. It was agreed that as only two carers had been recruited to the study, that their data may detract from the main insights and experiences of the clients and therefore the carer interviews were excluded from the final data analysis. This has enabled me to purely focus on developing the necessary depth of analysis within the client cohort.

Despite the appropriate small sample size used for this study, it is important to consider the various factors which may have contributed to the low response rates for recruitment. Within the methods chapter I touched on the reasons why carers may not have volunteered, considering that as the carer is not an active participant within the WRS environment they may have felt that they did not have anything to contribute. Recruitment of carers may also have been effected as the study was not specifically looking at the needs of carers. With regards to clients, it is difficult to surmise why recruitment numbers were low; however, it is important to consider the timing of recruitment. Clients were approached and given a recruitment pack during the first couple of weeks of attending the WRS. As has been discussed earlier, during phases of transition, patients are considered to be especially vulnerable to psychological stress (Kirkevold et al 2012) and therefore the timing of recruitment may not have been a time when many of the clients felt psychologically ready to talk about their experiences. With regards to retrospective recruitment, many past WRS clients were already back at work and therefore this made it difficult for them to find and spare the time to be interviewed.

It is also important to consider the demographics of the recruitment sample. All the participants recruited to the study were men, ranging from 47 – 64 years old, with the average age being 58 years old. This sample size is representative of the demographics of the WRS client population, where the majority of the clients are men in their fifties. However it is important to acknowledge that by only having men recruited to the study I am only able to provide a male perspective of the experience of the WRS and that having women participants may have brought a different perspective to the experiences of the WRS and the stroke journey.

In terms of the process of interviewing, as previously discussed in chapter 4, as an experienced OT I am used to interviewing stroke patients as part of my clinical practice. However, it was important to explore the subjective experiences of the stroke survivors at the WRS and their stroke journey and not to slip into 'therapist' mode and try to seek information and formulate my own opinion through clinical reasoning. Instead it was important to ensure that I stayed in the role of researcher rather than clinician. In order to mitigate this happening, I ensured that I allowed myself ample preparation time prior to the interviews to get into the role of researcher and focus on the aims and objectives of the study and the interview schedule. Following the interviews I also ensured I had time set aside to reflect on the interview process and content of the discussion, including making any field notes and / or thoughts for the next interview. This was something that posed a challenge initially, being a structured process, but became more fluid and natural over time as I developed my skills, confidence and reflective practice as a researcher.

6.8.3 My influence as a researcher

Having previously worked clinically at the WRS, I initially told participants that I was an occupational therapist who had previously worked within the service in order to give them the background understanding to my initial interest in completing the research in this area of stroke. However, I was aware that not only did I need to be aware of my role as a researcher rather than a therapist within the interviews (as discussed above), but there also appeared to be an expectation of knowledge from the participant because they knew I was an occupational therapist. As an occupational therapist, participants would ask my advice on treatment or their recovery to date and future recovery trajectory. Therefore after the first couple of interviews I chose to introduce myself as a researcher rather than giving my clinical background as this allowed me to ask more open questions teasing out clarification from the participant as follow-up to things they had said. It is important to therefore acknowledge the pre-conceived ideas and assumptions that we make about someone and their role and consider this in terms of disclosure of clinical background within the research field.

6.8.4 Analysing and presenting the data

Although Smith et al (2009) state that the analysis process within IPA is not prescriptive, it was useful as a novice researcher to have guidance on the analysis stages as suggested by Smith and Osborn (2008). I used a process of thorough immersion and reiterative analysis of the interviews in order to gain a rich understanding of the participants' contexts and meanings attributed to their experience of attending the WRS. This was an evolving process where my depth of understanding was developed as I became more familiar and submerged in the data.

It has been important to demonstrate rigour, reliability and validity throughout the research process. Smith (1996) suggests that there should be internal coherence; this is in relation to whether the argument presented in the study is supported by the data and is internally consistent. I have endeavoured to demonstrate internal coherence through using rigorous analysis, where my themes have been derived from the data rather than categorising the data from prior assumptions or pre-determined categories (Dickson et al 2008). Sufficient data from the participants discourse should also be included in order to enable the reader to evaluate the interpretation (Smith 2011). For this reason, within the analysis process I have used representative verbatim quotes to back the identified themes within the findings, striving to provide an interesting narrative account of the participants' lived experiences of the WRS.

6.8.5 My journey as a researcher

Building confidence in my ability as a qualitative researcher has been an important part of the research journey for me. I started my DClinP as a qualitative research novice. Over the journey of my DClinP I have gained a better understanding and appreciation of the research process, but would not consider myself to be an expert. Initially I was very concerned that my data was too superficial, but as my research and interpretative data analysis skills have developed I realised that the interviews were rich with depth and meaning. What became more of an issue was deciding how to prioritise what to include as the salient themes of this study.

This has been a challenging journey, but an invaluable learning experience where I have learnt a lot about the research process and myself on the way. I feel that this experience has developed me as a person and made me richer as both a researcher and a clinician.

6.9 Summary

This discussion chapter has provided a discussion of the findings and key themes presented in chapter 5 and related them to the relevant research literature and government policy. The chapter has evaluated the research considering the implications for practice as well as reflecting on the research processes. I have also provided insight through a personal reflection considering my journey and development as a researcher through the process of the study.

To conclude this chapter, this study adds to the research literature on stroke through its unique insights into the world of the participants experiencing the WRS and the impact of this on the individual's stroke journey and recovery. These insights propose important implications for clinical practice, emphasising the benefits of holistic and client-centred rehabilitation. Clinicians need to work in partnership with the patient, providing them with the appropriate support and equipping them with the necessary skills, in order for patients to gain the maximum recovery from their stroke. This in turn provides the individual with the best opportunity to reach their full potential, returning to a fulfilled and meaningful quality of life. This study provides a novel qualitative and IPA focus on an individual work rehabilitation service adding to the existing predominantly quantitative body of research considering return to work post stroke.

Chapter 7: Conclusion

7.1 Introduction

This chapter will present a conclusion to the thesis. This will include a summary of what the findings of this study revealed and consider the unique contributions this research study adds to the existing research literature. Finally an over-arching summary will be provided.

7.2 What the findings revealed

This study aimed to explore the experiences of stroke survivors participating within a WRS; including the impact of the WRS on their stroke journey. Therefore my aim was to understand the world of the individual experiencing the WRS. This study has provided a unique and insightful understanding of the world of the individual experiencing the WRS exploring their meandering journey of recovery post stroke and the perceived impact of the WRS as a pivotal transition point in the individual's stroke journey providing a base back to "normalish life". The study revealed how the WRS impacts on the individual's life highlighting the importance of rehabilitation within a group environment, based on meaningful activity to give purpose and structure to their daily lives, preparing them for community reintegration and full participation back in society.

The importance and perceived benefit of the group environment that the WRS offers was highlighted by participants, including how the shared experience and peer support contributed to a sense of belonging as well as providing a process of self-evaluation, information and problem solving. The study revealed how the stroke impacted on the individual's sense of self identity and subsequently how the WRS contributed to the individual's process of adjustment and coming to terms, rebuilding themselves as a whole person after the stroke. Most noticeably the findings emphasised the perceived psychosocial benefits of the WRS environment contributing to the individual's overall sense of self-worth, wellbeing, recovery, and adjustment post stroke. These psychosocial benefits and the process of rebuilding themselves as individuals consequently impacted on the individual's changed perception of the world and their future, considering and embracing new avenues and new horizons.

An approach to rehabilitation based on the biopsychosocial model of healthcare, encompassing holistic client-centred practice, the use of meaningful occupation and purposeful activity as a treatment intervention and supported self-management are fundamentally at the core of

occupational therapy philosophy. The experiences of the individuals at the WRS provides an insight into how the core philosophy of occupational therapy can be used to its maximum benefit to meet the holistic needs of the individual. This study demonstrates the impact this had on the individual's physical, psychological and psychosocial recovery, providing true holistic client-centred rehabilitation 'back to life' and participation in extended activities enabling the potential for full community integration.

7.3 What the research contributes to knowledge

Existing research has explored the social consequences of stroke as well as the differing needs of young stroke patients highlighting the lack of tailored rehabilitation to meet the specific needs of the individual. Research specifically focused on vocational rehabilitation post stroke is sparse and the main area of focus instead has been on return to work as an outcome of stroke recovery. This body of research has considered the predictors and determinants of RTW post stroke, as well as some limited consideration of the sustainability of work post stroke and the role and experience of the employer. However, the existing research has not specifically considered the individual role of a vocational rehabilitation service in the process of RTW and the individual's stroke journey and recovery process; probably in part to the fact that these services are rare.

This study therefore sought to identify not only the experience of the individual, which has not commonly been considered to date by researchers investigating vocational rehabilitation and return to work post stroke, but also the unique contribution and impact a given vocational rehabilitation service can have on the individual's stroke journey and recovery process. The findings of this study have therefore presented a number of new personal perspectives providing novel and unique insights into the perceived positive experiences of attending a WRS and the impact of this on the individual's stroke journey, recovery and wider life.

Unlike the existing research which has explored the differing needs of young stroke patients highlighting the lack of tailored rehabilitation to meet the specific needs of the individual, as well as the inability to prepare the individual for life in the real world; this study alluded to a high level of satisfaction from the participants with the WRS rehabilitation intervention being successfully tailored to the individual needs and identified goals of the individual. This offers a different and unique perspective compared to the existing research literature which has consistently shown high levels of dissatisfaction and unmet needs (Kersten et al 2002, Ellis-Hill et al 2008, Cott 2004, Ellis-Hill and Horn 2004, Burton 2000).

The existing literature has also criticised the context of therapeutic activity and the rehabilitation environment as being substantially different from the reality of the individual's own social environments and consequently the inability to translate the skills from therapy into the individual's home and social life (Burton 2000). However the participants in this study conversely suggested that the WRS provided and achieved the balance of preparing them for future life with positive transference of the skills acquired at the WRS into their daily life.

The findings of this study appear to present the WRS as a unique rehabilitation service in successfully achieving meeting the needs of the individual, tailoring interventions through a client-centred approach, whilst also encompassing the added benefits to the individual of a group environment. The high levels of satisfaction reported by the participants of this study may be due to the fact that the WRS is an OT led service grounded in OT client-centred philosophy as discussed above.

Accordingly, the findings of this study have provided a unique insight into the less overt or hidden aspects and perceived benefits for individuals attending the WRS, suggesting that this type of rehabilitation is far from just a process for returning to work, but instead contributes to a far wider set of values and contributions in the individual's stroke journey, road to recovery and future life. This occupational therapy led rehabilitation environment appears to provide the appropriate fusion of client-centred professional practice incorporating partnership working and supported self-management, within a supportive environment fostered by peer support and access and signposting to appropriate resources and other services.

This study demonstrates the value of a qualitative and IPA approach providing an important contribution from the individual's perspective and lived experience, adding to the existing predominantly quantitative body of research literature on vocational rehabilitation and return to work post stroke.

7.4 Summary

This study has provided a rich and interpretive description, with new and novel exploratory insights, into the lived experiences of individuals attending the WRS. Three key conclusions can be drawn from the findings of this research study:

1. The WRS is a service embedded in the philosophy and principles of OT; consequently this provides a rich vocational rehabilitation experience demonstrating positive patient

outcomes due to a successful fusion of client-centred practice and meaningful activity within a group/peer environment.

2. The 'hidden extras' and unexpected outcomes of the WRS in terms of its perceived psychosocial benefits are considered by the participants to be as important to their recovery as the core treatment and rehabilitation.
3. The WRS provides rehabilitation beyond that of vocational rehabilitation to return to work. The philosophy and principles of the WRS combined with the hidden extras to support the individual to develop self-management strategies to prepare them for life post stroke.

Appendices

Appendix A Letter of approval for research governance



Solent Healthcare

**Southern Shared Primary Care
Research Management & Governance Service**

*2nd Floor Adelaide Health Centre
Western Community Hospital Campus
William Macleod Way
Southampton
SO16 4XE*

T: 023 8060 8925

E: shoredrmandg@scpct.nhs.uk

Monday, 21 June 2010

Miss Liz Cullen
Southern House
Otterbourne
Winchester
SO21 2RU

Dear Miss Cullen

Study: Stroke survivor and carer perceptions of the role of a work rehabilitation service
Research Ref: MWP/020/10

I am pleased to tell you that the above project has been approved by the Solent Healthcare.

R&D approval is separate from ethics approval and is also essential for the conduct of research within NHS trusts. It is subject to the following requirements.

- 1) It is a condition of the approval that the project is carried out according to Good Clinical Practice and within the guidelines of the NHS Research Governance Framework. You have responsibility for ensuring that you and any co-workers adhere to the protocol agreed by the ethics committee.
- 2) If there are any alterations to the protocol after the study has commenced, you must inform the Research Ethics Committee and the Trust Research Management & Governance (RM&G) Office.
- 3) It is my duty to remind you that as Chief Investigator you may be required to provide us with project monitoring and outcome information.

In the event that you have applied to have this study adopted onto the UKCRN Clinical Research Portfolio, we take this opportunity to remind you of your responsibility for uploading accrual data for our organisation should adoption subsequently be confirmed and we become a participating site.
(http://www.ukcrn.org.uk/index/clinical/portfolio_new/P_accrual.html)

Please do not hesitate to contact us should you require any additional information or support

Yours sincerely

Signed by Simon Drew, Research Governance Officer, on behalf of
Dr Raj Patel
R&D Lead



INVESTOR IN PEOPLE

Solent Healthcare is hosted by Southampton City Primary Care Trust
Solent Healthcare Headquarters, Adelaide Health Centre, William Macleod Way, Millbrook, Southampton SO16 4XE
Telephone: 023 8060 8900 Fax: 023 8053 8740 Website: www.solent.nhs.uk

Appendix B Letter of research sponsorship



Miss Liz Cullen
School of Health Sciences
University of Southampton
University Road
Highfield
Southampton
SO17 1BJ

17 September 2009

Dear Miss Cullen

RGO Ref: 6706

Project Title Stroke Survivor and Carer Perceptions of the Role of a Work Rehabilitation Service

I am writing to confirm that the University of Southampton is prepared to act as sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care (2nd edition 2005).

The University of Southampton fulfils the role of Research Sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the Principal Investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Research Governance Office on this basis.

I would like to take this opportunity to remind you of your responsibilities under the terms of the Research Governance Framework, and the EU Clinical Trials Directive (Medicines for Human Use Act) if conducting a clinical trial. We encourage you to become fully conversant with the terms of the Research Governance Framework by referring to the Department of Health document which can be accessed at:

<http://www.dh.gov.uk/assetRoot/04/12/24/27/041224>

In this regard if your project involves NHS patients or resources please send us a copy of your NHS REC and Trust approval letters when available.

Please do not hesitate to contact me should you require any additional information or support. May I also take this opportunity to wish you every success with your research.

Yours sincerely

Dr Martina Prude
Head of Research Governance
Tel: 023 8059 5058
email: rgoinfo@soton.ac.uk

Appendix C Professional indemnity and clinical trials insurance



Miss Liz Cullen
School of Health Sciences
University of Southampton
University Road
Highfield
Southampton
SO17 1BJ

RGO REF - 6706

17 September 2009

Dear Miss Cullen

Professional Indemnity and Clinical Trials Insurance

Project Title Stroke Survivor and Carer Perceptions of the Role of a Work Rehabilitation Service

Participant Type:	No Of Participants:	Participant Age Group:	Notes:
Patients	15	Adults	
Healthy volunteers	15	Adults	

Thank you for forwarding the completed questionnaire and attached papers.

Having taken note of the information provided, I can confirm that this project will be covered under the terms and conditions of the above policy, subject to written informed consent being obtained from the participating volunteers.

Insurance will only be activated when we have received a copy of the Ethics Committee approval and you must not begin your project prior to this. Please forward a copy of the Ethics Committee approval letter as soon as it is to hand to complete the insurance placement.

If there are any changes to the above details, please advise us as failure to do so may invalidate the insurance.

Yours sincerely

Mrs Ruth McFadyen
Insurance Services Manager

Tel: 023 8059 2417
email: hrm@soton.ac.uk

cc: File

Finance Department, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom.
Tel: +44 (0) 23 8059 5000 Fax: +44 (0) 23 8059 2195 www.southampton.ac.uk

Appendix D Ethics approval

IMI/STA/hph

09 March 2010

Miss Liz Cullen
Trainee Consultant Practitioner in Stroke
NHS Education South Central (NESC)
Southern House
Otterbourne
Winchester
SO21 2RU

National Research Ethics Service

SOUTHAMPTON & SOUTH WEST HAMPSHIRE
RESEARCH ETHICS COMMITTEE (A)

1ST Floor, Regents Park Surgery
Park Street, Shirley
Southampton
Hampshire
SO16 4RJ

Tel: 023 8036 2466

023 8036 3462

Fax: 023 8036 4110

Email: scsha.SWHRECA@nhs.net

Dear Miss Cullen

Study Title: Stroke survivor and carer perceptions of the role of a work rehabilitation service.
REC reference number: 09/H0502/110
Protocol number: 3

Thank you for your letter of 01 March 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		06 October 2009
REC application		01 October 2009
Investigator CV: Miss L Cullen		06 October 2009
Evidence of insurance or indemnity		17 September 2009
Letter from Sponsor		17 September 2009
Referees or other scientific critique report		25 June 2009
Summary/Synopsis	1	01 October 2009
Client First Interview Schedule	3	07 June 2009
Carer First Interview Schedule	3	07 June 2009
Client Follow-Up Interview Schedule	3	07 June 2009
Carer Follow-Up Interview Schedule	3	07 June 2009
Protocol	3	07 June 2009
Investigator CV: Dr M Donovan-Hall		
Investigator CV: Dr C Ellis-Hill		27 May 2009
Investigator CV: Dr P Kersten		02 March 2010
Participant Information Sheet: Client	4	25 February 2010
Participant Information Sheet: Carer	4	25 February 2010
Participant Consent Form: Client	4	25 February 2010
Participant Consent Form: Carer	4	25 February 2010
Letter of invitation to participant	4	25 February 2010
Reply Slip	4	25 February 2010
Response to Request for Further Information		01 March 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- **Notifying substantial amendments**

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0502/110

Please quote this number on all correspondence

Yours sincerely

 Dr Iain MacIntosh
Chair

Email: scsha.SWHRECA@nhs.net

Enclosures: "After ethical review – guidance for researchers" SL- AR2 for other studies

Copy to: Dr Martina Prude
University of Southampton

Mrs Clair Wright
The HIOW CLRN Shared RM & G Services

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix E Ethics amendment approval



National Research Ethics Service Southampton & South West Hampshire REC (A)

Building L27
University of Reading
London Road
Reading
RG1 5AQ

Tel: 0118 918 0567
Fax: 0118 918 0559

25 February 2011

Miss Liz Cullen
NHS Education South Central (NESC)
Trainee Consultant Practitioner in Stroke
Southern House
Otterbourne
Winchester
SO21 2RU

Dear Miss Cullen

Study title: Stroke survivor and carer perceptions of the role of a work rehabilitation service.
REC reference: 09/H0502/110
Protocol number: 6706
Amendment number: Amendment number 1 20110110
Amendment date: 01 February 2011

The above amendment was reviewed at the meeting of the Sub-Committee held on 18 February 2011.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides		
Participant Consent Form		
Participant Consent Form		
Participant Information Sheet; Carer PIS for retrospective interviews	5	10 January 2011
Participant Information Sheet; Client PIS for retrospective interviews	5	10 January 2011
Protocol	4	10 January 2011
Notice of Substantial Amendment (non-CTIMPs)	Amendment number 1 20110110	01 February 2011
Covering Letter		27 January 2011

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Letter of agreement from service manager regarding recruitment changes		10 January 2011
Interview Schedules/Topic Guides	Carer retrospective interview schedule	10 January 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/H0502/110:	Please quote this number on all correspondence
---------------	--

Yours sincerely

Miss Megan Walmsley
Committee Co-ordinator

E-mail: scsha.swhreca@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr Martina Prude

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Southampton & South West Hampshire REC (A)**Attendance at Sub-Committee of the REC meeting on 18 February 2011**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Paul Diprose	Consultant Anaesthetist	Expert
Dr Iain MacIntosh	Consultant Paediatric Intensive Care	Expert

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix F Letter of invitation to participate



Solent Healthcare

Community Neurological Rehabilitation Team
Work Rehabilitation Service
Unity 12
9 – 19 Rose Road
Southampton
SO14 6TE

Tele: 023 80 716502/3
Fax : 023 80202659

www.solent.nhs.uk

The role of a work rehabilitation service in the stroke patient's rehabilitation recovery and experiences following a stroke.

Ethics Number: 09/H0502/110

Dear Sir / Madam,

I am Liz Cullen, a Doctorate in Clinical Practice student at the University of Southampton. As part of my research I am carrying out a study looking at the role of the Work Rehabilitation Service with Stroke patients. The Work Rehabilitation Service and the Therapy Services Manager are in support of this project and therefore have kindly agreed to send out these invitation letters on my behalf. I would like to ask you to read through the information sheet to see if you would be interested in taking part in the study. I would like to speak to people who have had a stroke and their relative/friend to look at what are your experiences of the Work Rehabilitation Service.

If, after reading the information sheet you are interested in taking part, then please complete the reply slip and post it back in the pre-paid envelope provided. If you have any further questions about the study then please do not hesitate to contact me – Liz Cullen on 07799861364.

Thank you for your time,

Liz Cullen
Trainee Consultant Practitioner in Stroke

Sue Stephenson
Therapy Services Manager



Solent Healthcare is hosted by Southampton City Primary Care Trust
Solent Healthcare Headquarters, Adelaide Health Centre, William Madeod Way, Millbrook, Southampton SO16 4XE
Telephone: 023 8060 8900 Fax: 023 8053 8740 Website: www.solent.nhs.uk

Appendix G Participant information sheet

DClinP Research Protocol
Stroke survivor and carer perceptions of the role of a work rehabilitation service.
09/H0502/110



CLIENT PARTICIPANT INFORMATION SHEET FOR INTERVIEWS

Ethics number: 09/H0502/110

Participant Information Sheet

The role of a work rehabilitation service in the stroke patient's rehabilitation, recovery and experiences following a stroke.

You are being invited to take part in a study. Before you decide whether you would like to take part in the study it is important for you to understand why the research is being completed and what it will involve. Please take the time to read the following information carefully and feel free to talk to others about the study if you wish.

What is the purpose of the study?

The purpose of the study is to gain an understanding of the role of the work rehabilitation service in the rehab, recovery and experiences following a stroke.

Why have I been invited?

You have been approached to take part in this study as you are a stroke client currently receiving input from the Work Rehabilitation Service.

Do I have to take part?

No. It is up to you to decide whether or not you take part. If you do, you will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. If you choose not to take part in the study it will not affect your intervention from the Work Rehabilitation Service or your medical care.

What will happen to me if I take part?

If you decide to take part you will be asked to take part in two interviews. One at the beginning of your work rehabilitation and one near the end of the programme. You will need to complete the reply slip and return it in the pre-paid envelope, this is required so you can be contacted. You will be contacted and asked where you would

Document DClinP_Research_Protocol 20100225 V04
Author Liz Cullen

1 / 4

like the interviews to take place either in your home environment or at the Work Rehabilitation Service.

Each interview will cover aspects such as your experience of the Work Rehabilitation Service following your stroke. Each interview will last approximately 1 hour. You have the right to withdraw from the study at any point without giving any reason.

The interviews will be audiotaped to help the researcher remember what has been said, only the researcher will listen to the tape. Your consent will be required in order to record the discussion which is one of the reasons why you will need to sign the consent form.

When the tapes are transcribed each of the interview participants will be given a number to ensure anonymity and confidentiality. As the study will be written up for publication, any identifying comments will be altered to maintain confidentiality.

Expenses and payments

You will be reimbursed for your travel expenses if you have to travel to the interview outside of your scheduled treatment time. You will be issued with an expenses claim form and a stamped addressed envelope on the day of the interview.

What do I have to do?

You need to complete the reply slip and return it in the pre-paid envelope. The researcher will contact all respondents to check that they meet the selection criteria (– anybody with a diagnosis of stroke who is currently attending the Work Rehabilitation Service (WRS) and does not have severe communication problems which would prevent them from being able to participate in the interviews). If you meet the criteria you will be asked to choose where you would like the interview to take place – in your home environment or at the Work Rehabilitation Service. If you choose to have the interview at the Work Rehabilitation Service you will need to travel to the venue where the interview is taking place, if you are not able to attend via your own transport we can arrange transport for you. If you do not meet the selection criteria, the reasons why (as stated above) will be explained to you by the researcher.

What are the other possible disadvantages and risks of taking part?

The only disadvantage to taking part is the inconvenience to you of taking part in the interview and possibly travelling to the Work Rehabilitation Service if you choose to have your interview there.

What are the possible benefits of taking part?

There is no direct benefit to you for participating in this study; however the results of the study will be used to inform future research into stroke rehabilitation and Work Rehabilitation Services.

What happens when the research study stops?

Feedback sessions will be arranged involving a presentation by the researcher to provide initial feedback and findings to all participants. The findings will be published in a research journal and presented at national conference so that the work can influence future research and practice.

What if there is a problem?

Any complaint about the way you have been approached or treated during the study will be addressed. If you have a concern or a complaint about this study you should contact Susan Rogers, Head of Research & Enterprise Services, at the School of Health Sciences (Address: University of Southampton, Building 67, High field, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 7942; Email: S.J.S.Rogers@soton.ac.uk)

Will my taking part in the study be kept confidential?

Yes. All the information regarding your participation in this study will be kept confidential. Your interview will be audio taped and transcribed; however, no names will be used in the transcription as all participants in the study will be allocated a number in order to ensure anonymity. The write up of the study for publication will include quotes from the interviews; however, no identifying descriptions will be included so as to ensure anonymity. The tapes and transcripts from the interviews will only be used by the researcher and will be kept in a locked cabinet. If you wish to withdraw from the study, you may leave at any time without giving any reason.

What will happen if I don't want to carry on with the study?

If you wish to withdraw from the study, you may leave at any time without giving any reason and if you want your interview can be omitted from the data analysis.

What will happen to the results of the study?

The study will be written up for publication and presented at conferences, however as previously stated no names or identifying descriptions will be included to ensure anonymity.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Southampton and South West Hampshire Research Ethics Committee.

Contact details

For further questions please contact the researcher **Liz Cullen** on 07799861364.

Thank you for taking the time to read this information sheet, please keep it for future reference.

Appendix H Participant reply slip

DClinP Research Protocol
Stroke survivor and carer perceptions of the role of a work rehabilitation service.
09/H0502/110

UNIVERSITY OF
Southampton
School of Health Sciences

PARTICIPANT REPLY SLIP

Ethics number: 09/H0502/110

I am interested in taking part in the following study:

'The role of a work rehabilitation service in the stroke patient's rehabilitation, recovery and experiences following a stroke.'

Name:

.....

Date:

.....

Please could you include your address, telephone number and e-mail address if you have one so that I can contact you:

Address:

.....

.....

Telephone number(s):

.....

E-mail address:

.....

Please return this slip in the stamped addressed envelope attached, or if you prefer, e-mail Liz Cullen on eac1b06@soton.ac.uk

Thank you,

Liz Cullen

Document DClinP_Research_Protocol 20100225 V04
Author Liz Cullen

1 / 1

Appendix I Participant consent form

DClinP Research Protocol
Stroke survivor and carer perceptions of the role of a work rehabilitation service.
09/H0502/110

UNIVERSITY OF
Southampton
School of Health Sciences

CLIENT PARTICIPANT CONSENT FORM

Ethics number: 09/H0502/110

Title of research study:

'The role of a work rehabilitation service in the stroke patient's rehabilitation, recovery and experiences following a stroke.'

Name of researcher: Liz Cullen

	Please initial box
1. I confirm that I have read and understand the information sheet dated DClinP_Research_Protocol 20100225 V04 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	
3. I understand that the interviews will be tape recorded and transcribed for the specific purpose of this study.	
4. I understand that although no names or identifying comments will be included, that quotations may be used in the write up of this study.	
5. I agree to take part in the above study.	
6. I am happy to take part in two interviews – an initial and follow-up interview.	

.....
Name of Participant

.....
Signature

.....
Date

.....
Name of Researcher

.....
Signature

.....
Date

2 copies – 1 for participant, 1 for researcher

Document DClinP_Research_Protocol 20100225 V04
Author Liz Cullen

1 / 1

Appendix J Interview schedules

Client first interview schedule:

- Background to the stroke:
 - How long ago did you have the stroke?
 - How long were you in hospital?
 - How has the stroke affected you?
 - What was life like before the stroke? E.g. six months prior to the stroke.
- Work Rehabilitation Service:
 - How did you hear about the Work Rehabilitation Service?
 - What do you know about the Work Rehabilitation Service?
 - What do you expect will happen at the Work Rehabilitation Service?
 - What do you hope to achieve by coming to the Work Rehabilitation Service?
- What are your hopes for the future?
- Is there anything else that you feel it would be important for me to know about?

Client follow-up interview schedule:

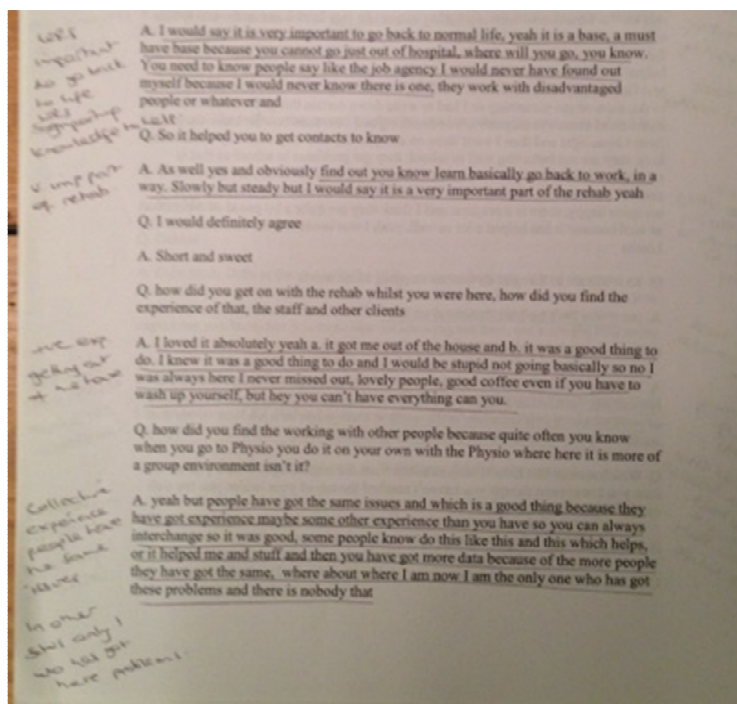
- I saw you X months ago how is life now?
- How have things changed?
- What impact does the stroke have on your life now?
- What have you achieved by coming to the Work Rehabilitation Service?
- In the previous interview you said you expected X,Y,Z from the Work Rehabilitation Service - what are your thoughts on these?
- What are your views on work rehabilitation?
- How did you get on with work rehabilitation?
- Have you or do you hope to return to your previous job and hobbies or take up new ones?
- What are your hopes for the future?
- Is there anything else that in your opinion I should have asked you?

Client retrospective interview schedule:

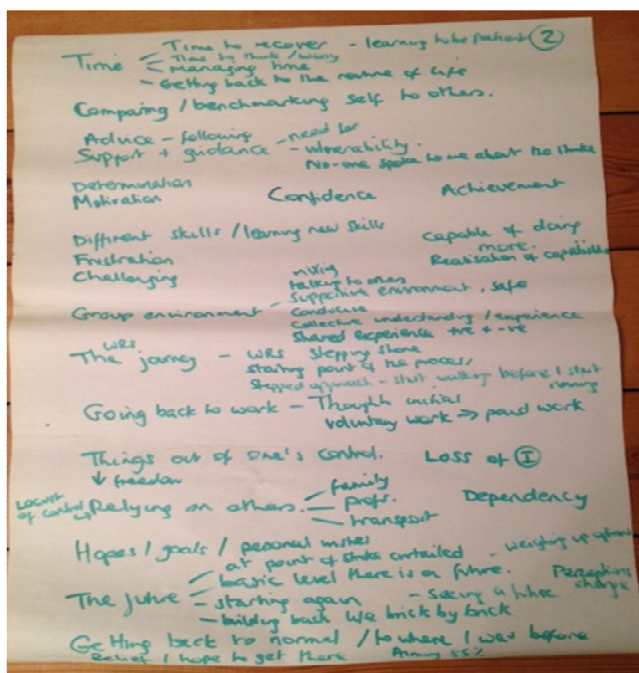
- Background to the stroke:
 - How long ago did you have the stroke?
 - How long were you in hospital?
 - How has the stroke affected you?
 - What was life like before the stroke? E.g. six months prior to the stroke.
 - What impact does the stroke have on your life now?
- Work Rehabilitation Service:
 - How did you hear about the Work Rehabilitation Service?
 - How did your expectations of the Work Rehabilitation Service change from the time that you started to the time that you finished your treatment?
 - What have you achieved by coming to the Work Rehabilitation Service?
 - What are your views on work rehabilitation?
 - How did you get on with work rehabilitation?
 - Have you or do you hope to return to your previous job and hobbies or take up new ones?
- What are your hopes for the future?
- Is there anything else that you feel it would be important for me to know about?
- Is there anything else that in your opinion I should have asked you?

Appendix K Example of data analysis process

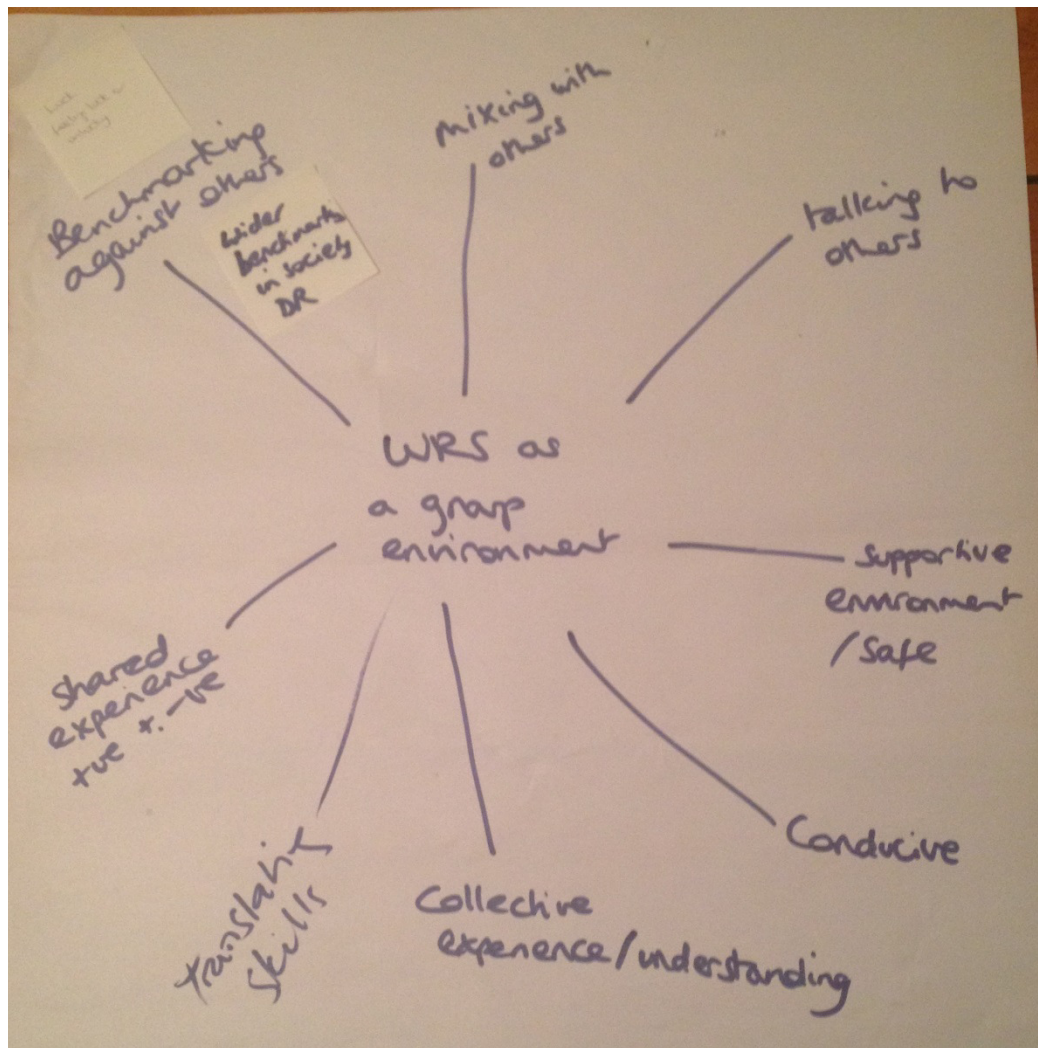
Example of an annotation of a transcript – Identifying meaningful elements, including paraphrasing of text, own thoughts, use of language etc:



Example of a flipchart which was used to map out emerging patterns and themes and start to cluster similar themes:



Example of initial clustering of a theme:



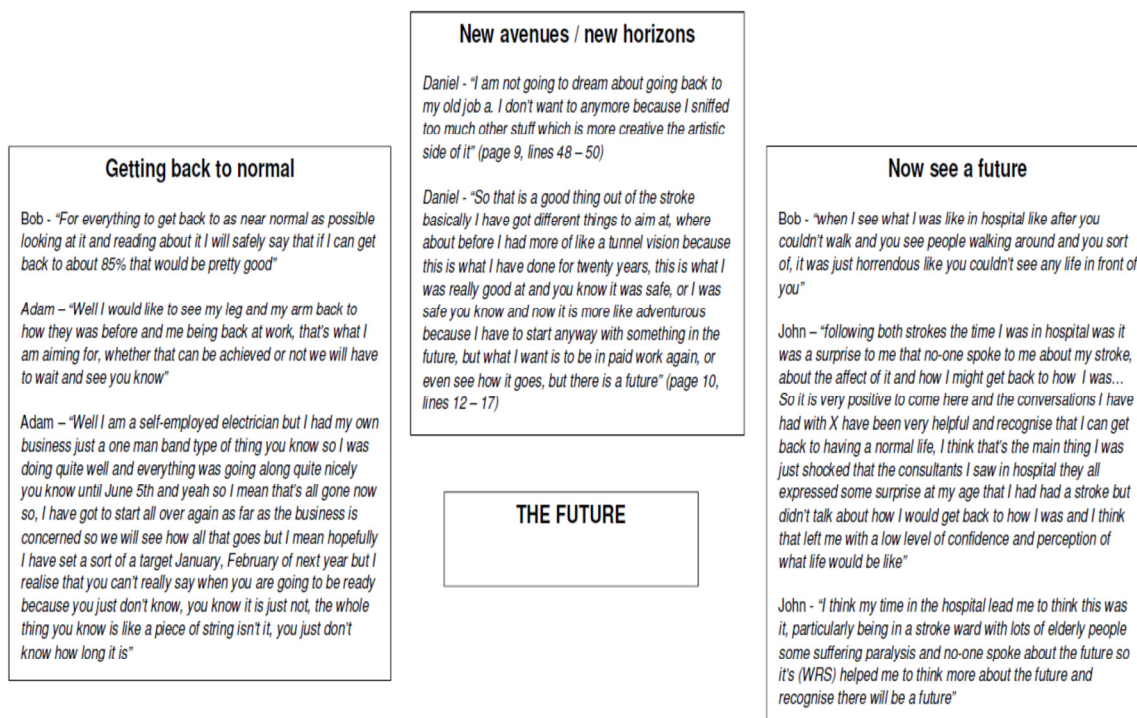
Example of developing themes:

<u>Current Themes</u>							
Theme	WRS	The future	The journey	Time	Luck	Rebuilding the whole person	Expectation of others
Sub Theme	1. Perceptions of rehabilitation 2. Shared experience 3. Psychosocial benefits	1. Now see a future 2. Getting back to 'normal' 3. New avenues / horizons		1. Time to recover 2. Structure in life			1. Employer 2. Other people
Sub, sub Theme	1. Confidence 2. Learning new skills 3. Sense of achievement 4. motivation						

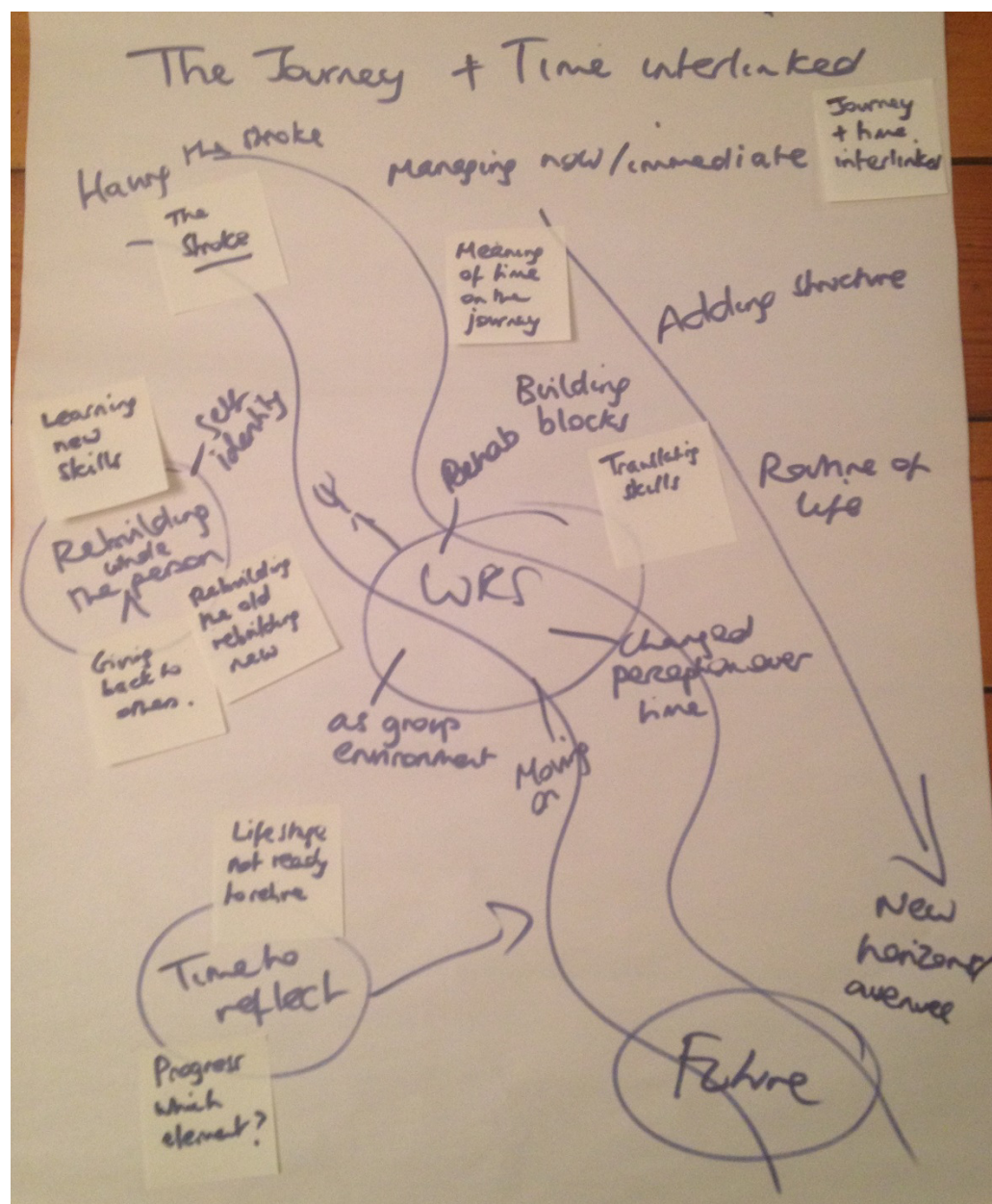
Proposed themes going forward

Theme	WRS	Psychosocial benefits	The journey	The future	Rebuilding the whole person
Sub Theme	1. Perceptions of rehabilitation 2. Shared experience	1. Confidence 2. Learning new skills 3. Sense of achievement 4. Motivation	1. Time 2. Structure in life /meaningful activity 3. WRS as a transition on the journey to recovery	1. Now see a future 2. Getting back to 'normal' 3. New avenues /horizons	1. Self-identity 2. Luck 3. Expectation of others

Example of initial clustering of quotes for a theme and subthemes:



Example of building up the themes into a picture of the individual's stroke journey:



Example of developing major themes and sub- themes:



List of References

- Alaszewski, A., Alaszewski, H., Potter, J., Penhale, B. (2007) Working after a stroke: Survivors' experiences and perceptions of barriers to and facilitators of the return to paid employment, *Disability and Rehabilitation*, 29 (24) pp1858 – 1869.
- Alaszewski, A., Alaszewski, H., Potter, J. (2004) The bereavement model, stroke and rehabilitation: a critical analysis of the use of a psychological model in professional practice, *Disability and Rehabilitation*, 26 (18) pp1067 – 1078.
- Bandura, A. (1997) The nature and structure of self-efficacy, in Bandura, A. (Editor) *Self-efficacy: the exercise of control*, New York, WH Freeman and Company.
- Bloor, M., Wood, F. (2006) *Keywords in qualitative methods: a vocabulary of research concepts*, London, Sage.
- Bogdan, R., Taylor, S.J. (1975) *Introduction to qualitative research methods: a phenomenological approach to the social sciences*, New York, Wiley.
- Boger, E.J., Demain, S.H., Latter, S.M. (2015) Stroke self-management: A focus group study to identify the factors influencing self-management following stroke, *International Journal of Nursing Studies*, 52 pp175 – 187.
- Boschen, K.A., Tonack, M., Gargaro, J. (2003) Long-term adjustment and community reintegration following spinal injury, *International Journal of Rehabilitation Research*, 26 pp157 – 164.
- Bosworth, H., Horner, R., Edwards, L., Matcher, D. (2000) Depression and other determinants of values placed on current health state by stroke patients: Evidence from the VA acute stroke study, *Stroke*, 31 pp2603 – 2609.
- British Society of Rehabilitation Medicine (2000) *Vocational rehabilitation – the way forward – Report of a working party (Chair, A.O. Frank)*, London, British Society of Rehabilitation Medicine.
- Burton, C. (2000) Living with stroke: A phenomenological study, *Journal of Advanced Nursing*, 32 (2) pp301 – 309.

List of references

- Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4 (2) pp167 – 182.
- Care Quality Commission (2011) *Supporting life after stroke: a review of services for people who have had a stroke and their carers*, London, Care Quality Commission
- Catalano, T., Dickson, P., Kendell, E., Posner, T. (2003) The perceived benefits of the chronic disease self-management program among participants with stroke: A qualitative study, *Australian Journal of Primary Health*, 9 (2/3) pp80 – 89.
- Chamberlain, M.A., Moser, V.F., Ekholm, K.S., O'Connor, R.J., Herceg, M., Ekholm, J. (2009) Vocational rehabilitation: an educational review, *Journal of Rehabilitation Medicine*, 41 (11) pp856 – 869.
- Charmaz, K. (2001) Grounded Theory, in Smith, J.A., Harré, R., Van Langenhove, L. (Editors) *Rethinking Methods in Psychology*, London, Sage Publications.
- College of Occupational Therapists (2010) *Code of Ethics and Professional Conduct*, COT.
- Coole, C., Radford, K., Grant, M., Terry, J. (2013) Returning to work after stroke: Perspectives of employer stakeholders, a qualitative study, *Journal of occupational rehabilitation*, 23 pp406 – 418.
- Corbin, J., Strauss, A. (1987) Accompaniments of chronic illness: changes in body, self, biography and biographical time, *Research in the Sociology of Health Care*, 9 pp249 – 81.
- Corr, S., Wilmer, S. (2003) Returning to work after a stroke: an important but neglected area, *British Journal of Occupational Therapy*, 66 (5) pp186 – 192.
- Cott, C.A. (2004) Client-centred rehabilitation: client perspectives, *Disability and Rehabilitation*, 26 (24) pp1411 – 1422.
- Cracknell, E. (1993) To do is to be, *British Journal of Occupational Therapy*, 56 (11) p391.
- Cynkin, S., Robinson, A.M. (1990) *Occupational therapy and activities health: towards health through activity*, Little, Brown, Boston.

- Daniel, K., Wolfe, C.D.A., Busch, M.A., McKevitt, C. (2009) What are the social consequences of stroke for working aged adults? A systematic review, *Stroke*, 40 pp431 – 440.
- Denzin, N.K. (1995) Symbolic Interactionism in Smith, J.A., Harré, R. Van Langenhove, L. (Editors) *Rethinking Psychology*, London, Sage.
- Department of Health (2014) *The NHS Outcomes Framework 2015/16*, London, Department of Health.
- Department of Health (2013) *Cardiovascular Disease Outcomes Strategy*, London, Department of Health.
- Department of Health (2008a) *High Quality Care For All NHS Next Stage Review Final Report*, London, The Stationary Office.
- Department of Health (2008b) *Common core principles to support self-care: A guide to support implementation*, London, Department of Health.
- Department of Health (2007) *National Stroke Strategy*, London, Department of Health.
- Department of Health (2005a) *National Service Framework for Long Term Conditions*, London, Department of Health.
- Department of Health (2005b) *Supporting people with long-term conditions. An NHS and social care model to support local innovation and integration*, London, Department of Health.
- Department of Health (2001) *National Service Framework for Older People Executive Summary*, London, Department of Health.
- Department of Health (2000) *National Service Framework for Coronary Heart Disease*, London, Department of Health.
- Department for Work and Pensions (2012) *Disability employment support: fulfilling potential*, London, The Stationary Office.

List of references

Department for Work and Pensions (2004) *Building capacity for work: a UK framework for vocational rehabilitation*, London, Department of Works and Pensions.

Department of Work & Pensions (2002) *Pathways to work: Helping people into employment*, London, The Stationary Office.

Department for Work and Pensions, Department of Health, Health and Safety Executive (2005) *Health, work and wellbeing: caring for our future*, London, Department of Works and Pensions.

Deshpande, P., Turner-Stokes, L. (2004) Survey of vocational rehabilitation services available to people with acquired brain injury in the UK, in Tyerman, A., Meehan, M.J. (Editors) *Vocational assessment and rehabilitation after acquired brain injury: inter-agency guidelines*, London, British Society of Rehabilitation Medicine/Royal College of Physicians, pp35 – 40.

Dibb, B., Ellis-Hill, C., Donovan-Hall, M., Burridge, J., Rushton, D. (2013) Exploring positive adjustment in people with spinal cord injury, *Journal of Health Psychology*
DOI:10.1177/1359105313483158.

Dickson, A., Allan, D., O'Carroll, R. (2008) Biographical disruption and the experience of loss following a spinal cord injury: An interpretative phenomenological analysis, *Psychology and Health*, 23 (4) pp407 – 425.

Disler, P. B., Pallant, J. F. (2001) Vocational rehabilitation, *BMJ*, 323 (7305) pp121–123.

Doolittle, N. (1991) Clinical ethnography of lacunar stroke: implications for acute care, *Journal of Neuroscience Nursing*, 23 pp235 – 240.

Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A., Hearn, J. (2000) Investigating recovery from stroke: A qualitative study, *Journal of Clinical Nursing*, 9 pp507 – 515.

Ellis, G., Mant, J., Langhorne, P., Dennis, M., Winner, S. (2010) Stroke liaison workers for stroke patients and carers: an individual patient data meta-analysis, *Cochrane Database of Systematic Reviews*, (5).

- Ellis-Hill, C., Payne, S., Ward, C. (2008) Using stroke to explore the Life Thread Model: An alternative approach to understanding rehabilitation following an acquired disability, *Disability and Rehabilitation*, 30 (2) pp150 – 159.
- Ellis-Hill, C.S., Horn, S. (2000) Change in identity and self-concept: a new theoretical approach to recovery following a stroke, *Clinical Rehabilitation*, 14 pp279 – 287.
- Ellis-Hill, C.S., Payne, S., Ward, C. (2000) Self-body split: issues of identity in physical recovery following a stroke, *Disability and Rehabilitation*, 22 (16) pp725 – 733.
- Frank, A.W. (1993) The rhetoric of self-change: Illness experience as narrative, *Sociological Quarterly*, 34 pp39 – 52.
- Festinger, L. (1954) A Theory of Social Comparison Processes, *Human Relations*, 7 pp117 – 140.
- Gilworth, G., Phil, M., Cert, Ad., Sansam, K.A.J., Kent, R.M. (2009) Personal experiences of returning to work following stroke: An exploratory study, *Work*, 34 pp95 – 103.
- Giorgi, A., Giorgi, B. (2008) Phenomenology. In Smith J.A. (Editor) *Qualitative Psychology: A Practical Guide to Research Methods* 2nd Edition, London, Sage Publications.
- Glozier, N., Hackett, M.L., Parag, V., Anderson, C.S. (2008) The influence of psychiatric morbidity on return to paid work after stroke in younger adults, *Stroke*, 39 pp1526 – 1532.
- Gobelet, C., Luthi, F., Al-Khodairy, A., Chamberlain, M. (2007) Vocational Rehabilitation: A multidisciplinary intervention, *Disability and Rehabilitation*, 29 (17) pp1405 – 1410.
- Hackett, M.L., Glozier, N., Jan, S., Lindley, R. (2009) Psychosocial outcomes in stroke: the POISE observational stroke study protocol, *BMC Neurology*, 9 (24) pp1 – 12.
- Hannerz, H., Ferm, L., Poulsen, O.M., Holbaek Pederson, B., Anderson, L.L. (2012) Enterprise size and return to work after stroke, *Journal of Occupational Rehabilitation*, 22 pp456 – 461.
- Hannerz, H., Holbaek Pedersen, B., Poulson, O.M., Humle, F., Anderson, L.L. (2011) A nationwide prospective cohort study on return to gainful occupation after stroke in Denmark 1996 – 2006, *BMJ Open* 1e000180.

List of references

Hatano, S. (1976) Experience from a multicentre stroke register: a preliminary report. *Bulletin of the World Health Organization* 54: 541– 53.

Herbert, C.C.M., Powell, G.E. (1989) Insights and progress in rehabilitation, *Clinical Rehabilitation*, 3 pp125 – 130.

Hinckley, J.J. (2002) Vocational and social outcomes of adults with chronic aphasia, *Journal of Communication Disorders* 35 pp543 – 560.

Hofgren, C., Bjorkdahl, A., Esbjornsson, E., Stibrant-Sunnerhagen, K. (2007) Recovery after stroke: cognition, ADL function and return to work, *Acta Neurologica Scandinavica*, 115 pp73 – 80.

Holloway, I. (2008) *A – Z of Qualitative Research in Healthcare*, 2nd Edition, Chichester, Wiley-Blackwell.

Holloway, I., Wheeler, S. (2010) *Qualitative research in nursing and healthcare*, 3rd Edition, Chichester, Wiley-Blackwell.

Howes, H., Benton, D., Edwards, S. (2005) Women's experiences of brain injury: An interpretative phenomenological analysis, *Psychology and Health*, 20 pp129 – 142.

Howitt, D., Cramer, D. (2011) *Introduction to Research Methods in Psychology*, 3rd Edition, London, Pearson.

Jones, F. (2006) Strategies to enhance chronic disease self-management: how can we apply this to stroke?, *Disability and Rehabilitation*, 28 pp841 – 847.

Jones, F., Mandy, A., Partridge, C. (2008) Reasons for recovery after stroke: A perspective based on personal experience, *Disability and Rehabilitation*, 30 (7) pp507 – 516.

Jones, F., Riazi, A. (2011) Self-efficacy and self-management after stroke: a systematic review, *Disability and Rehabilitation*, 33 pp797 – 810.

- Kersten, P., Low, J., Ashburn, A., George, S., McLellan, D. (2002) The unmet needs of young people who have had a stroke: results of a national UK survey, *Disability and Rehabilitation*, 24 (16) pp860 – 866.
- Kirkevold, M., Bronken, B.A., Martinsen, R., Kvigne, K. (2012) Promoting psychosocial well-being following a stroke: Developing a theoretically and empirically sound complex intervention, *International Journal of Nursing Studies*, 49 pp386 – 397.
- Knapp, P., Young, J., House, A., Forster, A. (2000) Non-drug strategies to resolve psychosocial difficulties after stroke, *Age and Ageing*, 29 pp23 – 30.
- Koch, L., Egbert, N., Coeling, H., Ayers, D. (2005) Returning to work after the onset of illness: Experiences of right hemisphere stroke survivors, *Rehabilitation Counseling Bulletin*, 48 (4) pp209 – 218.
- Larkin, M., Watts, S., Clifton, E. (2006) Giving voice and making sense in interpretative phenomenological analysis, *Qualitative Research in Psychology*, 3 pp102 – 120.
- Leng, C.M. (2008) Description of a return to work occupational therapy programme for stroke rehabilitation in Singapore, *Occupational Therapy International*, 15 (2) pp87 – 99.
- Lennon, S., McKenna, S., Jones, F. (2013) Self-management programmes for people post stroke: a systematic review, *Clinical Rehabilitation*, 27 (10) pp867 – 878.
- Leonard, V.W. (1994) A Heideggerian phenomenological perspective on the concept of the person In Benner, P. (Editor) *Interpretative Phenomenology: Embodiment, Caring and Ethics in Health and Illness*, Thousand Oaks, Sage.
- Lindmark, B., Hamrin, E. (1995) A five year follow-up of stroke survivors: motor function and activities of daily living, *Clinical Rehabilitation*, 9 pp1 – 9.
- Lindstrom, B., Roding, J., Sundelin, G. (2009) Positive attitudes and preserved high level of motor performance are important factors for return to work in younger persons after stroke: A national survey, *Journal of Rehabilitation Medicine*, 41 pp714 – 718.

List of references

- Lock, S., Jordan, L., Bryan, K., Maxim, J. (2005) Work after stroke: focusing on barriers and enablers, *Disability and Society*, 20 (1) pp33 – 47.
- Maclean, N., Pound, P., Wolfe, C., Rudd, A. (2002) The concept of patient motivation: A qualitative analysis of stroke professionals' attitudes, *Stroke*, 33 pp444 – 448.
- Maclean, N., Pound, P., Wolfe, C., Rudd, A. (2000) Qualitative analysis of stroke patients' motivation for rehabilitation, *British Medical Journal*, 321 pp1051 – 1054.
- Mason, J. (2002) *Qualitative Researching*, 2nd Edition, London, Sage.
- McLeod, J. (2001) *Qualitative methods on counselling and psychology*, London, Sage.
- Medin, J., Barajas, J., Ekberg, K. (2006) Stroke patients' experiences of return to work, *Disability and Rehabilitation*, 28 (17) pp1051 – 1060.
- Meyer, A. (1922) *The Archives of Occupational Therapy*, cited in Turner, A. (1997).
- Mitchell, J.M., Adkins, R.H., Kemp, B.J. (2006) The effects of aging on employment of people with disabilities, *Rehabilitation Counseling Bulletin*, 49 (3) pp157 – 165.
- Murray, C.D., Harrison, B. (2004) The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis, *Disability and Rehabilitation*, 26 (13) pp808 – 816.
- National Audit Office (2010) *Progress in improving stroke care*, London, Department of Health, The Stationary Office.
- National Audit Office (2005) *Reducing Brain Damage: Faster access to better stroke care*, London, National Audit Office.
- NHS England, Care Quality Commission, Health Education England, Monitor, Public Health England, Trust Development Authority (2014) *NHS five year forward view*, London, NHS England.
- O'Brien, A.N., Wolf, T.J. (2010) Determining work outcomes in mild to moderate stroke survivors, *Work*, 36 pp441 – 447.

- O'Neill, K., Wolf, T.J. (2010) Development and pilot-testing of a work readiness battery, *Work*, 36 pp423 – 430.
- Onsworth, T., Shum, D. (2008) Rehabilitation between executive functions and productivity outcomes following stroke, *Disability and Rehabilitation*, 30 (7) pp531 – 540.
- Packer, M., Addison, R. (Editors), (1989) *Entering the Circle: Hermeneutic Investigation in Psychology*, New York, New York Press.
- Piaget, J. (1969) *The psychology of the child*, cited in Cynkin, S., Robinson, A.M. (1990)
- Pope, C., Mays, N. (2000) Qualitative Methods in Health Research, in Pope, C., Mays, N. (Editors) *Qualitative Research in Healthcare*, London, BMJ Books.
- Radcliffe, E., Lowton, K., Morgan, M. (2013) Co-construction of chronic illness narratives by older stroke survivors and their spouses, *Sociology of Health and Illness*, 35 (7) pp993 – 1007.
- Radford, K., Crompton, A., Stainer, K. (2013) Commissioning vocational rehabilitation after stroke: Can the Cinderella services get to the ball? A qualitative study, *Journal of Health Services Research and Policy*, 18 (Suppl. 1) pp30 – 38.
- Redfern, J., McKeivitt, C., Wolfe, C.D.A. (2006) Development of complex interventions in stroke care. A systematic Review, *Stroke*, 37 pp2410 – 2419.
- Robinson-Smith, G., Johnston, M., Allen, J. (2000) Self-care, self-efficacy, quality of life, and depression after stroke, *Archives of Physical Medical Rehabilitation*, 81 pp460 – 465.
- Roding, J., Lindstrom, B., Malm, J., Ohman, A. (2003) Frustrated and invisible – younger stroke patients' experiences of the rehabilitation process, *Disability and Rehabilitation*, 25 (15) pp867 – 874.
- Rothwell, P.M., Coull, A.J., Giles, M.F., Howard, S.C., Silver, L.E., Bull, L.M., Gutnikov, S.A., Edwards, P., Mant, D., Sackley, C.M., Farmer, A., Sandercock, P.A., Dennis, M.S., Warlow, C.P., Bamford, J.M., Anslow, P. (2004) Change in stroke incidence, mortality, case-fatality, severity and risk factors in Oxfordshire UK from 1981 to 2004 (Oxford Vascular Study), *Lancet*, 363 pp1925 – 1933.

List of references

Rotter, J.B. (1966) Generalised expectancies for internal versus external control of reinforcement, *Psychological Monographs*, 80 (1) 609 American Psychological Association.

Royal College of Physicians (2012) *National Clinical Guideline for stroke*, 4th Edition, London, Royal College of Physicians.

Royal College of Physicians (2009) *National Sentinel Stroke Audit 2008 Report for England, Wales and Northern Ireland*, London, Royal College of Physicians.

Royal College of Physicians (2008) *National Clinical Guideline for stroke*, 3rd Edition, London, Royal College of Physicians.

Royal College of Physicians (2007) *National Sentinel Stroke Audit 2006 Report for England, Wales and Northern Ireland*, London, Royal College of Physicians.

Ryan, R.M., Deci, E.L. (2000) Intrinsic and Extrinsic Motivations: Classic Definitions and New Directions, *Contemporary Educational Psychology*, 25 pp54 – 67.

Saeki, S., Ogata, H., Okubo, T., Takahashi, K., Hoshuyama, T. (1993) Factors influencing return to work after stroke in Japan, *Stroke*, 24 pp1182 – 1185.

Saeki, S., Hachisuka, K. (2004) The Association between stroke location and return to work after first stroke, *Journal of Stroke and Cerebrovascular Diseases*, 13 (4) pp160 – 163.

Saeki, S., Toyonaga, T. (2010) Determinants of early return to work after first stroke in Japan, *Journal of Rehabilitation Medicine*, 42 pp254 – 258.

Schachter, S. (1959) *The psychology of affiliation*, Stanford CA, Stanford University Press.

Seale, C. (1999) *The Quality of Qualitative Research*, London, Sage Publications.

Shames, J., Treger, I., Ring, H., Giaquinto, S. (2007) Return to work following traumatic brain injury: trends and challenges, *Disability Rehabilitation*, 29 pp1387 – 1395.

Silverman, D. (2005) *Doing Qualitative Research*, 2nd Edition, London, Sage Publications.

Smith, J.A. (2011) Evaluating the contribution of interpretative phenomenological analysis, *Health Psychology Review*, 5 (1) pp9 – 27.

Smith, J.A. (2007) Hermeneutics, human sciences and health: linking theory and practice, *International Journal of Qualitative Studies on Health and Well-being*, 2 pp3 – 11.

Smith, J.A. (1996) Semi-structured interviewing and qualitative analysis, in Smith, J., Harré, R., Van Langenhove, L.V. (Editors) *Rethinking methods in psychology*, London, Sage Publications, pp9 – 26.

Smith, J.A., Forster, A., House, A., Knapp, P., Wright, J.J., Young, J. (2008) Information provision for stroke patients and their caregivers, *Cochrane Database of Systematic Reviews*, (2).

Smith, J.A., Harré, R., Van Langenhove L. (1995) Idiography in Smith, J.A., Harré, R., Van Langenhove, L. (Editors) *Rethinking Psychology*, London, Sage.

Smith, J.A., Osborn, M. (2015) Interpretative Phenomenological Analysis, in Smith, J.A. (Editor) *Qualitative psychology: a practical guide to research methods*, 3rd Edition, London, Sage Publications pp25 – 52.

Smith, J.A., Osborn, M. (2008) Interpretative Phenomenological Analysis, in Smith, J.A. (Editor) *Qualitative psychology: a practical guide to research methods*, 2ⁿ Edition, London, Sage Publications pp53 – 80.

Smith, J.A., Flowers, P., Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*, London, Sage.

Stroke Association (2015) *Stroke Newsroom Press Release*, [Online] 12 May 2015, <http://www.mynewsdesk.com/uk/stroke-association/pressreleases/stroke-rates-soar-among-men-and-women-in-their-40s-and-50s-1151403>

Stroke Association (2012) *What is a stroke?*, London, Stroke Association.

Stroke Association (2010) FAST Public Awareness Campaign

Stroke Association (2007) FAST Public Awareness Campaign

List of references

Stroke Unit Trialists' Collaboration (2013) Organised inpatient (stroke unit) care for stroke, *Cochrane Database of Systematic Reviews 2013* Article first published online: 11 Sep 2013 DOI: 10.1002/14651858.CD000197.pub3

Tanaka, H., Toyonaga, T., Hashimoto, H. (2011) Functional and occupational characteristics associated with very early return to work after stroke in Japan, *Arch Phys Med Rehabilitation*, 92 pp743 – 748.

Taylor, S.E., Lobel, M. (1989) Social comparison activity under threat: Downward evaluation and upward contacts, *Psychological Review*, 96 (4) pp569 – 575.

Teasdale, T.W., Engberg, A.W. (2005) Psychosocial consequences of stroke: A long term population based follow up, *Brain Injury*, 19 pp1049 – 1058.

Teasell, R., McRae, M., Finestone, H. (2000) Social Issues in the Rehabilitation of Younger Stroke Patients, *Archives of Physical Medicine and Rehabilitation*, 81 pp205 – 209.

Topping, A. (2010) The Quantitative – Qualitative Continuum, in Gerrish, K., Lacey, A. (Editors) *The Research Process in Nursing*, 6th Edition, Oxford, Blackwell Science.

Treger, I., Shames, J., Giaquinto, S., Ring, H. (2007) Return to work in stroke patients, *Disability and Rehabilitation*, 29 (17) pp1397 – 1403.

Trygged, S. (2012) Return to work and wellbeing after stroke – a success story?, *International Journal of Therapy and Rehabilitation*, 19 (8) pp431 – 438.

Turner, A. (1997) The philosophy and history of occupational therapy, in Turner, A., Foster, M., Johnson, S.E. (Editors) *Occupational Therapy and Physical Dysfunction*, 4th Edition, London, Churchill Livingstone, pp3 – 25.

Tyerman, A., Meehan, M.J. (Editors) (2004) *Vocational assessment and rehabilitation after acquired brain injury: inter-agency guidelines*, London, British Society of Rehabilitation Medicine/Royal College of Physicians.

- Van Velzen, J. M., Van Bennekom, C. A. M., Edelaar, M. J. A., Sluiter, J. K., Frings-Dresen, M. H. W. (2009) Prognostic factors of return to work after acquired brain injury: A systematic review, *Brain Injury*, 23(5) 385 – 395.
- Vestling, M., Ramel, E., Iwarsson, S. (2013) Thoughts and experiences from returning to work after stroke, *Work*, 45 pp201 – 211.
- Vestling, M., Ramel, E., Iwarsson, S. (2005) Quality of life after stroke: Well-being, life satisfaction and subjective aspects of work, *Scandinavian Journal of Occupational Therapy*, 12 pp89 – 95.
- Vestling, M., Tufvesson, B., Iwarsson, S. (2003) Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction, *Journal of Rehabilitation Medicine*, 35 pp127 – 131.
- Wade, D.T., Halligan, P.W. (2004) Do biomedical models of illness make for good healthcare systems? *British Medical Journal*, 329 pp1398 – 1401.
- Wade, D., Langton-Hewer, R. (1987) Functional abilities after stroke: measurement, natural history and prognosis, *Journal of Neurology, Neurosurgery and Psychiatry*, 50 pp177 – 182.
- Wagner, E.H., Austin, B.T., Davis, C., Hindmarsh, M., Schaefer, J.K., Bonomi, A. (2001) Improving chronic illness care: Translating evidence into action, *Health Affairs*, 20 pp64 – 78.
- Widen Holmqvist, L., von Koch, L. (2001) Environmental factors in stroke rehabilitation: Being in hospital itself demotivates patients, *BMJ*, 322 pp1501 – 1502.
- Wilkinson, A., Whitehead, L. (2009) Evolution of the concept of self-care and implications for nurses: a literature review, *International Journal of Nursing Studies*, 46 pp1143 – 1147.
- Williams, G. (1984) The genesis of chronic illness: narrative re-construction, *Sociology of Health and Illness*, 6 (2) pp175 – 200.
- Willig, C. (2008) *Introducing qualitative research in psychology: adventures in theory and method*, 2nd Edition, Maidenhead, McGraw Hill Open University Press.

List of references

Wills, T.A. (1981) Downward comparison principles in social psychology, *Psychological Bulletin*, 90 (2) pp245 – 271.

Wolf, T.J., Baum, C., Connor, L. (2009) The Changing Face of Stroke: Implications for Occupational Therapy, *American Journal of Occupational Therapy*, 63 pp621 – 625.

Wolfe, C.D., Rudd, A.G., Howard, R. (2002) Incidence and case fatality rates of stroke subtypes in a multi-ethnic population: the South London Stroke Register, *Journal of Neurology, Neurosurgery and Psychiatry*, 72 pp211 – 216.

World Health Organization (2001) *International classification of functioning, disability and health*, Geneva, ICF.

Wozniak, M.A., Kittner, S.J., Price, T.R., Hebel, J.R., Sloan, M.A., Gardner, J.F. (1999) Stroke location is not associated with return to work after first ischaemic stroke, *Stroke*, 30 pp2568 – 2573.

Yardley, L. (2015) Demonstrating Validity in Qualitative Psychology, in Smith, J.A. (Editor) *Qualitative Psychology: a practical guide to research methods*, 3rd Edition, London, Sage Publications, pp257 – 272.

Yardley, L., Marks, D.F. (2004) Introduction to research methods in clinical health psychology, in Yardley, L., Marks, D.F. (Editors) *Research Methods for Clinical and Health Psychology*, London, Sage Publications.

Yardley, L., Murray, M. (2004) Qualitative analysis of talk and text: Discourse and narrative analysis, in Yardley L., Marks, D.F. (Editors) *Research Methods for Clinical and Health Psychology*, London, Sage Publications.

Yerxa, E.J., Clark, F., Frank, G., Jackson, J., Parham, D., Pierce, D., Stein, C., Zemke, R. (1989) An introduction to occupational science, a foundation for occupational therapy in the 21st century, in Johnson, J., Yerxa, E.J. (Editors) *Occupational science: The foundation for new models of practice*, New York, Haworth, pp1 – 18.