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Stroke survivors' experiences of upper limb dysfunction: a
longitudinal exploratory study

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Abstract

The experiences of stroke survivors have been researched quite extensively, in particular the effect that stroke can have on a person's life and sense of self, but how much upper limb dysfunction contributes to these experiences is not fully known. This study explores the impact that upper limb dysfunction, specifically, could have on people's lives after stroke, and their hopes and expectations for recovery of the upper limb.

Method: a longitudinal phenomenological study with a series of four semi-structured interviews at two-, six-, twelve-, and eighteen months post stroke with 13 participants recruited from a stroke rehabilitation unit. Data were analysed using thematic analysis and a modified form of framework analysis.

Results: Three main themes were identified in the data: The Altered Life; The Disrupted Self; The Experience of Recovery. Findings indicated that upper limb dysfunction after stroke, and the loss of two-handedness, can adversely affect the lives of stroke survivors, and this, in turn, can affect a person's self-esteem, self-image and identity. Stroke survivors initially viewed recovery of the lower limb as more important than the upper limb, but on returning home they recognised that the upper limb recovery was crucial in managing self-care and returning to meaningful activities and life roles. Therapy services, after hospital discharge, were short term and focused on mobility, not the upper limb, and stroke survivors were frustrated with the lack of information and advice. Participants wanted to be active partners with therapists, to self-manage recovery in their upper limb.

Conclusion: Therapists should be more aware of the impact that upper limb dysfunction can have on stroke survivors' lives and sense of self. Therapy, information and advice for the upper limb should be considered vital in rehabilitation, and models of services that capitalise on stroke survivors' desire to self-manage their recovery should be explored.

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Contents	Page
Chapter 1: Introduction and Background to the Thesis	1
1.1 Introduction	1
1.2 Background	3
1.3 Definition of Theoretical Terms	12
1.4 Chapter Summary	17
Chapter 2: Literature Review	18
2.1 Introduction	18
2.2 Method of Review	19
2.2.1 Search Strategy	19
2.2.2 Appraisal and Extraction of Themes	19
2.3 Themes and Subordinate Themes	29
2.3.1 Interrupted and Disrupted Life	29
2.3.2 Threat to the Self	31
2.3.3 Low Self-esteem	32
2.3.4 Altered Self-image and Identity	34
2.3.5 Loss	38
2.3.6 Recovery	40
2.3.7 Rehabilitation Priorities	44
2.3.8 Information and Advice	45
2.3.9 Experiences of Therapy	46
2.3.10 Personal Responsibility	49
2.4 Summary of the Literature Review	50
2.5 Development of the Research Questions	52
2.6 Methodological Choices Informed by the Literature Review	53
Chapter 3: Methods and Procedures	55
3.1 Introduction	55
3.2 Research Paradigm	55
3.3 Methodology	58
3.4 Study Design	61
3.4.1 Semi-structured Interviews	61
3.4.2 Development of the Interview Guide	64
3.4.2a Recruitment of Participants to the Focus Group	65
3.4.2b Focus Group Sample	66
3.4.2c Focus Group Data Collection Procedures	67
3.4.2d Data Analysis and Findings from the Focus Group	68
3.4.2e Consultation with an Expert in Hand Therapy	70

3.4.3	Interviewing Style	71
3.4.4	Sample	72
3.4.5	Ethical Issues and Procedures	73
3.4.6	Data Analysis	76
3.4.7	Rigour and Trustworthiness	84
3.4.7a	Researcher Reflexivity	88
3.4.7b	Transferability	91
3.5	Study Procedures	92
3.5.1	Participant Recruitment	94
3.5.1a	Inclusion Criteria	94
3.5.2	Data Collection	94
3.5.3	Data Analysis Procedures	96
3.5.4	Reflexive Account - Refining my Role as Interviewer and Co-constructor of Data	97
3.6	Chapter Summary	99
	Chapter 4: Findings	100
4.1	Introduction	100
4.2	Participants	100
4.3	Findings	103
4.3.1	The Altered Life	105
4.3.1a	Managing Self-care	108
4.3.1b	Meaningful and Valued Activities	110
4.3.1c	Life Roles and Relationships	115
4.3.1d	Summary of the Altered Life	119
4.3.2	The Disrupted Self	119
4.3.2a	Feeling Like a Child	120
4.3.2b	Feeling Devalued and Downgraded	122
4.3.2c	Disrupted Self-image	125
4.3.2d	Disrupted Identity	130
4.3.2e	Summary of the Disrupted Life	132
4.3.3	The Experience of Recovery	132
4.3.3a	Priorities, Hopes and Getting on With Life	133
4.3.3b	Experiences of Therapy	145
4.3.3c	Lack of Information and Advice	151
4.3.3d	Personal Responsibility for Recovery	153
4.3.4	Case Studies	155
4.3.4a	Bob	156
4.3.4b	Eve	160
4.3.4c	Jenny	165

4.3.4d	Summary of the Case Studies	169
4.4	Reflexive Accounts	169
4.4.1	Reflexive Account – the Personal Impact of the Interview Encounters	169
4.4.2	Maintaining my Role as a Researcher and my Distance as a Physiotherapist	171
4.5	Chapter Summary	172
	Chapter 5: Discussion	176
5.1	Introduction	176
5.2	The Importance of Two-handedness	176
5.2.1	The Importance of Two-handedness in Maintaining the Norm	180
5.2.2	Losing Two-handedness Can Bring Loss after Stroke	184
5.2.3	Losing Two-handedness Changes Life Roles	187
5.2.4	Summary of the Importance of Two-handedness	189
5.3	Transitions, Priorities and Hopes	190
5.4	Delivery of Therapy for the Upper Limb after Stroke	203
5.5	Opportunities for Self-management of the Upper Limb	210
5.6	Chapter Summary	215
	Chapter 6: Conclusions	216
6.1	Introduction	216
6.2	Final Conclusions from the Study	216
6.3	Implications from the Study	218
6.4	Limitations of the Study	219
6.5	Considerations for Further Research	221
	References	222
	Appendices	239
	Appendix 1 Focus Group Information Sheet and Consent Form	239
	Appendix 2 Quotations from Focus Group Data	242
	Appendix 3 Notes from a Consultation with Expert in Hand Therapy	244
	Appendix 4 Initial Interview Guide	246
	Appendix 5 Information Sheet and Consent Forms	248
	Appendix 6 Letter to Participants' GPs	253
	Appendix 7 Tables of Themes and Charts	254
	Appendix 8 Participant Summary	272
	Appendix 9 General Practitioners' Assessment of Cognition Test	275
	Appendix 10 Ethical approvals	277

Tables

Table 1: ICF Categories Affected by Upper Limb Dysfunction	10
Table 2.1: Articles Included in the Narrative Review	21
Table 2.2: Relationship between Extracted Themes, Subordinate Themes and Articles	28
Table 3.1: Focus Group Participants	66
Table 3.2: Focus Group Categories and Themes	69
Table 3.3: Steps in the Data Analysis Process	77
Table 4.1: Participant Details	101
Table 4.2: Themes and Subordinate Themes	104
Figure 1	93

Conference Poster Presentations from the Study

Purton J, Hunter SM, Sim J (2015) *Hopes and expectations for recovery of the upper limb: a qualitative study of stroke survivors' experiences*. Physiotherapy UK Conference, Liverpool

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Purton J, Perry N, Thompson G, Hunter SM (2010) *The upper limb after stroke: a focus group to explore areas of interest to stroke survivors*. UK Stroke Forum Conference, Harrogate

Chapter 1: Introduction and Background to the Thesis

1.1 Introduction

Each year in England 110,000 people have a stroke, most of whom will survive, and so currently there are thought to be 900,000 people living with the effects of stroke (NICE 2013). The World Health Organization (WHO 2015) defines stroke as an interruption of the blood supply to the brain either because a blood vessel is blocked by a clot or the vessel bursts. This then cuts off the supply of oxygen and nutrients causing damage to brain tissue. Blood flow to one side of the cerebral cortex is usually interrupted, typically resulting in motor and sensory disturbance of the contra-lateral side of the body, in addition to possible visual, communication and cognitive deficits. Thus a stroke can bring a sudden and profound disruption to a person's life. Approximately 70% of people will have altered arm and hand function and 40% will be left with a persistent lack of function in an upper limb (Intercollegiate Stroke Working Party [ISWP] 2012). This can lead to significant disability as the hand is a very specialised and versatile part of the human body critical to the performance of nearly all activities in which people engage (Trew and Everett 2005).

Rehabilitation of the upper limb after stroke can be challenging for both people with stroke and therapists because of the complex processes involved in controlling movement of the arm and hand (Yekutiel 2000). Functional recovery of the hand and arm after stroke is recognised as being much less frequently attained than that of the lower limb. Regaining good recovery in the arm and hand, which involves complex motor skills and dexterity, can be more difficult than regaining lower limb function, where walking can be achieved with more gross motor function (Raine et al 2009). Even if motor impairment of the upper limb improves to the same degree as that of the lower extremity, the minimal level of motor function that is sufficient for walking is quite inadequate for normal hand function. The lower limb can be considered functional if the patient can walk whereas the upper

limb is judged on much finer motor function and dexterity such as doing up buttons. A large number of stroke patients achieve a reasonable level of mobility but are left with a more or less useless hand (Yekutiel 2000).

Guidelines on stroke over recent years, such as the National Stroke Strategy (Department of Health 2007), NICE Guidelines on Long Term Rehabilitation After Stroke (NICE 2013) and the National Clinical Guidelines for Stroke (ISWP 2012), all agree that people with stroke need very tailored and flexible rehabilitation that should be available for as long as needed, yet they recognise that identifying the correct type and level of intervention is a challenge. This is never more so than in the NHS today where services are under pressure and, although acute services for stroke have improved greatly in the last decade, the emphasis is often on rehabilitation of walking to shorten the length of hospital stay. Services in the community are much less frequent compared to hospital treatment and are short-lived; therapy often remains focused on the lower limb; and people with stroke can feel that their upper limb is neglected (Sabari et al 2000, Wiles et al 2002, Cott et al 2007, White et al 2009). This may well be a contributory factor to the large number of patients who have a reasonable level of mobility after stroke but are left with a dysfunctional upper limb (Yekutiel 2000). It is understandable that regaining the ability to walk again is of great importance to people with stroke, and to therapists, as it provides the mobility and freedom to move around the home and community with a level of independence. However, this should not be the end goal of rehabilitation, as full independence is to have a full and meaningful life after stroke, and this requires more than just the ability to walk. As will be seen in the next section of this chapter, the arms and hands are vital to normal human function and therefore neglecting the upper limb can leave a person with a life of dependence and restriction.

This study is a longitudinal exploration of the experiences of upper limb dysfunction in people after stroke and so understanding the complexity of the upper limb and the vital role that the hands, in particular, play in the everyday lives of people is central to this

study. Therefore, the next section will present and explain the function of the arm and hand. This will then be followed by a brief overview of the pertinent issues related to rehabilitation of the upper limb and service provision after stroke.

1.2 Background

The hands, more than any other part of the body, play an integral role in an individual's life providing independence, competence and a sense of autonomy. The upper limbs are used in being productive, in employment and as a means of communication and intimacy (Meyer 2003). It is easy to take for granted the capacity to pick up objects and manipulate them, to gesture, to use the hands for support and balance, and for communicating affection and intimacy through touch (Rosenbaum et al 1996, Tubiana et al 1996, Champion et al 2009). The sensory and motor capabilities of the hand are highly developed and allow people to: interact with and control their environment; use tools (Chapman et al 1996); express themselves through such media as writing, music, arts and craft, and participate in sport and leisure activities and employment (Schieber 1996). Thus the hands are essential in nearly all of the valued activities and life roles in which people engage and consequently upper limb dysfunction as a result of stroke can have a significant effect on many aspects of people's lives.

The majority of tasks and activities that people perform with the hand require complex differentiated movements of the fingers and thumb in order to create the hand shapes necessary for grasping, manipulating, exploring, and gesturing (Tallis 2003). The thumb is a vital functional unit of the hand since without its opposable position to the fingers it would be impossible to grip and manipulate tools and objects (Trew and Everett 2005). All of this is possible because of the complex anatomical structure of the hand. There are 27 bones and 39 muscles that move the digits and joints of the hand and wrist (Hepp-Reymond et al 1996).

The hand is richly endowed with sensory cutaneous receptors, particularly in the skin of the tips of the fingers, and this allows the hand to become a sensory organ that can detect the texture, shape, volume, hardness and temperature of objects, and can judge the weight of an object held in the hand. The hand therefore works with the eyes as an organ of information (Lederman et al 1996, Tubiana et al 1996). This sensory function is as essential as the motor function in being able to sustain an appropriate level of force during power and precision grips and to manipulate objects with accuracy and the dexterity needed in the performance of tasks and activities (Carey and Matyas 2011). The hand can explore and 'see' in the dark or in places that are not accessible to vision (Tallis 2003). For example feeling for and identifying an object in a pocket or deep bag, or groping through the darkness of a bedroom at night.

Typically, most tasks that people perform require the cooperation of both hands (Wiesendanger 1996). Some activities require the same movement of both arms, for example in lifting a heavy object, whereas many others require the hands to work together but perform different movements i.e. to be bi-manual (Shumway-Cook and Woollacott 2007). For example, when taking the top off a bottle, the bottle is grasped with one hand and the bottle top is turned with the other. In all bi-manual activities the hands are performing different movements yet working cooperatively in a smooth and coordinated manner to achieve a goal. Many activities of daily living, such as dressing, using the toilet, preparing food and feeding require this bi-manual function of the hands, as do employment, leisure and creative activities (Champion et al 2009). Impairment of the hand, as in stroke, can therefore not only result in dependency on others but can also limit the scope of activities in which people can engage.

Of course, the hand cannot function without the action of the arm. The arm moves and controls the trajectory of the hand through space to reach for and locate objects, and positions and stabilises the hand so it can perform whatever task or activity is required (Wing et al 1996, Tallis 2003). It can transport the hand to accurately intercept moving

objects, such as catching a ball or preventing a falling object hitting the floor (Tallis 2003). The hand can reach any part of the body relatively easily, which is essential for personal hygiene, because of the mobility of the shoulder as well as that of the elbow and wrist. The arm can project the hand away from the body or move it closer. It brings the hand into the visual sight line, which is vital for most tasks. The hand functions efficiently only if the proximal joints of the arm are stable and yet mobile and this depends on muscle activity and control (Tubiana et al 1996). In addition, specialised sensory receptors in muscles, tendons and joints of the upper limb provide proprioceptive feedback about the position and movement of the arm and hand in space so that movements are coordinated and accurate (Trew and Everett 2005). This cooperation between the arm and the hand and the bi-manual actions of both upper limbs are only possible because of the neural control systems in the sensory and motor structures and pathways of the central and peripheral nervous systems (Shumway-Cook and Woollacott 2007). The proportion of the sensorimotor cortex devoted to arm and hand function is considerably greater than that devoted to other body segments such as the lower limb. Consequently, when a stroke occurs it very frequently affects the upper limb (Wing et al 1996).

The hands are more than just instruments of action. They are a means of interacting and relating to other people (Tubiana et al 1996). Dawson and Cole (2010) describe the hands as being articulate, in other words we speak through our hands and so they are very visible and essential in communication. The hands are used when meeting and greeting people: shaking hands, waving to catch another person's attention, beckoning another person towards them and embracing (Tallis 2003). They are subtly connected to speech in that they are often moving in tandem with the spoken words, making gestures that add meaning and physical expression. Gestures of the hands often mirror our emotions and can reflect our inner feelings, sometimes without the need for speech (Dawson and Cole 2010). People clap their hands to show appreciation of a performance, they can punch the air when watching their team score a goal, they can shake a fist at

someone when angry (Tallis 2003). The hands play an important role in more intimate relationships with others. A parent or grandparent will hold the hand of a young child to keep them close and protected or hold and cuddle a baby. A couple will hold hands to signify the closeness of their relationship and they will touch, embrace and caress (Tubiana et al 1996, Dawson and Cole(2010). After a stroke the hand can become immobile and unable to make gestures, to touch intimately; it becomes inarticulate and therefore can no longer 'talk'. This can have a subtle effect on a person's ability to communicate with others, posing a challenge to expression and intimacy. It could be even more profound for someone with dysphasia, a disorder of speech common after stroke, where losing the use of one hand to make gestures could add to the loss of speech rendering the person even more inarticulate (Tallis 2003). Because of their role in communication, the hands are a very visible part of the body and so a disfigured or non-functioning hand, as in stroke, is easily observed by other people. This can lead to a person feeling stigmatised socially and can lead to embarrassment, hiding of the hand and even avoidance of social interactions. Furthermore, the person could have issues with body image (Meyer 2003).

The upper limb plays an important role in mobility, balance and postural control. During normal walking the trunk twists about a vertical axis, with the shoulder girdle rotating in the opposite direction to the pelvis. The arms swing out of phase with the legs, so that the left leg and left side of the pelvis move forwards at the same time as the right arm and the right side of the shoulder girdle (Whittle 2007). The fluidity and efficiency of walking depends to some extent on this motion of the trunk and arms and it is thought that the movement acts as a counterbalance to the angular momentum and vertical ground reaction forces generated by the pelvis and leg, and this in turn is thought to minimise energy consumption during gait (Meyns et al 2013). Furthermore, although arm-swing is not essential for walking, it is thought that arm-swing may impart momentum through the trunk to the lower limbs making it less tiring and more energy efficient, particularly as gait

speed increases. The amplitude and speed of forward arm-swing increases in tandem with gait speed and this becomes even more necessary in order to run (Trew and Everett 2005). To walk efficiently outdoors in the community a person needs to be able to walk at a velocity of at least 1 metre per second. This is particularly important to cross roads safely (Whittle 2007). For a person with stroke, who may also have weakness in a lower limb, a dysfunctional upper limb may mean that walking becomes slower and more effortful, making accessing their community more challenging.

In the course of normal daily activities people experience countless perturbations to their balance. The centre of mass of the body is moved out of and back into the base of support in order to move forward. Whittle (2007) describes walking as a series of falls and recovery of balance. The ability to recover balance keeps a person upright and prevents falls. When balance is disturbed, equilibrium and righting reactions produce rapid movements at the ankles and hips, and if necessary a step is taken. In addition, the arms move away from the body to counteract the postural sway in order for a step to then be taken to recover balance. If recovery of balance is not successful, then the hands will reach for and grasp or press on a static object for support (Roos et al 2008). These movements are automatic and executed rapidly and therefore reaching and grasping can play a vital role in preventing falls. The ability to move both arms freely has been found to significantly improve the performance of participants in clinical balance tests (Milosevic et al 2011). It is also recognised that older people are more likely to use arm reactions to regain balance (Maki and McIlroy 2006) and will use a protective response to reach forward to arrest a fall, whereas younger adults will use the arms to recover balance (Roos et al 2008).

The upper limb is not only important in large disturbances to balance but can play a role in maintaining quiet stance. Finger-tip contact with a static object can reduce the effect of postural sway (Jeka and Lackner 1994). Light touch contact from the finger provides a feed-forward mechanism that activates postural muscles to control body sway.

Furthermore, it is thought that sensory information from light fingertip touch can compensate for diminished visual input and counteract postural sway. Light finger-tip touch can be even more effective in older people than in younger in that it compensates for the sub-clinical diminishing sensory and motor capacities in the lower extremities, a normal consequence of ageing (Baccini et al 2007). Therefore, in an older person with stroke, possibly with a visual defect and/or sensory and motor problems in the lower limb, a dysfunctional upper limb could add to difficulties in maintaining quiet stance and postural stability and lead to problems in maintaining balance and recovering from balance perturbations (Trew and Everett 2005). Not only could they be at increased risk of falls but they might also have an increased fear of falling, causing them to reduce their activities and become socially isolated (Hellstrom 1999).

In recognising the complexity of upper limb function and the role of the arm and hand in nearly everything that people do, it is easy to see how losing function in one arm and hand after stroke could be so disabling. This becomes even more evident when looking at the International Classification of Functioning, Disability and Health (ICFDH) Comprehensive Core Set for Stroke (Geyh et al 2004), a sub-set of the full World Health Organization's ICFDH (WHO 2001). This was developed through a consensus process of international experts on stroke to define the spectrum of problems that can occur in the functioning of stroke patients and should be taken into account when developing instruments or measures in assessing disability after stroke. The Core Set classifies and identifies the problems in function and the disability that can ensue after stroke and should be taken into account in assessment measures or instruments. It has categories of body functions, body structures, activities and participations, and environmental factors, each with a specific code that relates to a domain. For example, the activities and participation domain begins with a d, and in categories related to self-care the d is followed by the number 5. There are 51 categories in the component of 'activities and participation' in the Core Set, and a brief analysis of this, verified by a second independent researcher,

indicated that there are potentially 23 categories where normal function in both upper limbs could be required for a person to fully participate – see Table 1 (page 10). At first glance it is quite obvious how some of the categories could be affected, e.g. d440 fine hand use, d540 dressing, whereas in others it is less so, e.g. d760 family relationships. Interacting with and caring for children in a family, as parents or grandparents, can involve tasks that require bi-manual action of the hands, for example in dressing a young child, and contribute to the relationships with those children. A basic economic transaction - d860 - can be simply trying to retrieve cash from a purse or wallet to pay for goods in a shop, another bi-manual action. In view of information earlier in this section on the role of the hands in communication, it becomes more obvious how the categories of interpersonal interactions (d710), informal social relationships (d750) and intimate relationships (d770) could be affected. These ICFDH categories cover many other areas of a person's life, including work, leisure, and personal care, and so the extent of the disability that upper limb dysfunction could bring becomes evident.

Table 1: ICF Categories Affected by Upper Limb Dysfunction.

ICF Code	ICF Category	ICF Code	ICF Category	ICF Code	ICF Category
d170	Writing	d335	Producing non-verbal messages	d345	Writing messages
d430	Lifting & carrying objects	d440	Fine hand use	d445	Hand & arm use
d475	Driving	d510	Washing oneself	d520	Caring for body parts
d530	Toileting	d540	Dressing	d550	Eating
d630	Preparing meals	d640	Doing Housework	d710	Basic interpersonal interactions
d750	Informal social relationships	d760	Family relationships	d770	Intimate relationships
d845	Acquiring, keeping & terminating a job	d860	Basic economic transactions	d870	Economic self-sufficiency
d910	Community life	d920	Recreation & leisure		

In order to develop interventions and services that can support recovery of the upper limb after stroke, it is vital to try to understand the challenges faced by people with stroke and their priorities for recovery (Ch'ng et al 2008). Wolfe et al (2008) identified that one of the top ten priorities for stroke services research should be qualitative research identifying stroke survivors' priorities over time and in the longer term after stroke. Prigatano (2011) observed that individual's subjective experiences of stroke are often neglected or given cursory recognition, and yet there is much to learn from them that could improve care and rehabilitation. Furthermore, INVOLVE, a national advisory group that supports public

involvement in research, and is part of the National Institute for Health Research, states that involving members of the public should be an essential component in the development of research studies (INVOLVE 2015). This is supported in the draft of the UK Policy Framework for Health and Social Care Research which was recently out for public consultation (NHS Health Research Authority 2015). In particular, it is important that service users are listened to and should be involved in the ideas phase of research to ensure that priorities and research questions will be relevant to the needs of service users (INVOLVE 2015). Public involvement in research can also lead to better quality research as incorporating the perspectives of those who are on the receiving end of services and treatments could lead to better practical outcomes and it is more likely that the research will be implemented in clinical practice (INVOLVE 2013).

There are several examples of stroke research where service users have influenced the design of studies. In developing a study on the use of art therapy in stroke rehabilitation Ali et al (2014) changed the intervention to a group interactive one rather than a one-to-one intervention and added a qualitative narrative to the study. In an earlier paper Ali et al (2006) described how people with stroke were consulted to ensure the relevance of a study they were developing into the use of oxygen therapy and the usefulness of the outcome measures. McKevitt et al (2010) used focus groups of people with stroke to inform an interview guide in the development of a pilot ethnographic study about the personal costs of stroke. Sims et al (2013) have developed a patient and carer advisory group in stroke research as an on-going means of service user consultation and involvement. Therefore, consulting people with stroke at the design phase of a qualitative study could ensure that the most pertinent research questions and design are developed to identify the issues and challenges of living with a dysfunctional upper limb.

Fraas (2011) suggested that using a phenomenological approach to elicit the accounts of people with stroke could be an effective tool in guiding the development of more holistic services. The impairment and dysfunction of the arm and hand after stroke are well

reported, e.g. Barreca et al (2003), and after considering the importance of the upper limbs in nearly all that people do, and the ICFDH Core Set for Stroke (Geyh et al 2004) categories, the level of disability can be reasonably deduced; however, little is known about how this dysfunction and disability is perceived by people with stroke and what this means for them in their everyday lives. People's experiences and perceptions of stroke as a whole have been researched quite extensively, in particular the effect of stroke on the self and self-concept (e.g. Ellis-Hill and Horn, 2000), but how much upper limb dysfunction contributes to this is not known. Therefore, there is a need for qualitative, phenomenological investigation into the impact that upper limb dysfunction specifically could have on people's lives after stroke. By understanding people's subjective experiences, perspectives and reactions to dysfunction, and identifying their frustrations and priorities, services could become more tailored, individual and flexible (Prigatano 2011, Pringle et al 2008).

1.3 Definition of Theoretical Terms

This next section seeks to provide definitions and clarifications of the theories and terminology that are used in certain chapters within the thesis. This has been done to ensure clarity of understanding when referring to the theory within the literature review (chapter two) and the discussion (chapter five).

Recovery –can occur after stroke and can be defined as returning of capability to complete tasks and activities using strategies that were normal to the person before the stroke (Shumway-Cook and Woollacott 2007). This can be through spontaneous recovery, of which there is always some after stroke, also known as restitution (Lennon (2011), and through a process of neural plasticity: a re-organisation and modification of sensorimotor cortical structures, that can be stimulated by therapy, learning and experience (also known as remediation) (Dobkin and Carmichael 2005).

Compensation - can be used when further recovery is deemed unlikely. Compensatory strategies can be atypical approaches to meeting the requirements of a task to improve the mis-match between a person's impaired skills and the demands of the environment and to maintain or improve function (Shumway-Cook and Woollacott 2007). This could be through strategies within the person, e.g. using an unaffected limb or adopting a different posture, or through modifications to the environment and use of adaptive equipment, also known as substitution, e.g. grab rails in a toilet and walking aids (Dobkin and Carmichael 2005, Lennon 2011).

Adaptation -is an aspect of compensation. It can occur through alternative movement strategies, the use of adaptive devices, modifications to the environment, or the assistance of others (Dobkin and Carmichael 2005, Lennon 2011, Wolf and Baum 2011).

Occupations – are ordinary and familiar things that persons do every day to participate fully in a life that has meaning, independence and choice. They are purposeful and performed in situations and contexts that have meaning (Wolf and Baum 2011).

Participation – defined by the World Health Organization as involvement in a life situation. It is supported or limited by the physiological, cognitive, sensory and motor capacities of the individual, and by the environment (WHO 2002). It is also thought of as being able to do what one wants to do, go where one wants to go and have freedom in the choice of activities at the time one wants to do them, and is central to personal independence (Wolf and Baum 2011).

Adjustment – can be thought of as progress or movement towards acceptance of limitations in function and a return to activities and life roles in a modified form, or development of new ones, and as a consequence having a positive sense of well-being (Clarke 2003, Alaszewskiet al 2004).

The self - could be thought of as primarily a private domain, an inner realm of personal thoughts, values, strivings, emotions and desires (Elliott 2014). The self is not discovered in isolation, through looking inwards, but rather through connections to others and seeing oneself reflected through a social mirror (Harter 1996, Baumeister 1999, Christiansen 1999). It is the individual's perceived or imagined opinions of other people, who are significant and important to them, that construct their sense of self (Garner 2004). In everyday life a person will construct and move between several selves as differing roles are adopted, for example spouse, parent, friend, employee, and adjust behaviour in accordance with the situation and people being encountered (Harter 1996, Garner 2004, Swain 2004). The self could therefore be seen as the mechanism whereby the individual and social world intersect; however, aspects of the self may change as roles, life experiences, in particular illness and/or disability, and interactions with others change throughout life (Garner 2004, Niven 2006).

Self-concept - could be described as a composite image of who a person thinks they are, what they think they can achieve, what they think others think of them and what they would like to be (Burns 1979). It can also be defined as an inner realm of thoughts and values about the self-mediated through engagement and interaction with other people and situations, and the interpretation of how a person thinks other people view them (Elliott 2014). It encompasses personality traits and characteristics, the physical body, social roles and relationships (Christiansen 1999).

Self-esteem –is the evaluative aspect of self-concept and is the feelings and emotions that a person has regarding his or her self-worth (Harter 1996). Self-esteem is thought to be a developmental phenomenon that emerges through childhood experiences with significant others such as parents, siblings and peers. Children gradually become aware of their value to others, their competence and social acceptance, which together develop an overall sense of worthiness, but this can be responsive to situational and contextual influences and therefore fluctuate over time in both adulthood and childhood

(Oyserman2004). Therefore, the factors that contribute to overall self-esteem will be unique to each person. Low self-esteem is strongly correlated with depression, anxiety and an inability to cope with life, leading to mental illness in some (Oyserman 2004). Therefore, the desire to think well of oneself and to portray a competent image to others and have social approval and acceptance is a strong drive in most people (Christiansen 1999).

Self-image –can be thought of as the awareness of the body, its physical appearance and capability and is a focal point of social interaction (Leder 1990, Garner 2004, Fox and Wilson 2008). It is through the body that people move, think, communicate, inhabit life roles and generally live out their lives. Feeling positive about the body is important in establishing a positive sense of self (Leder 1990, Yuen and Hansen 2002). Goffman (1963), in his book *Stigma and Notes on the Management of Spoiled Identity*, observed that many people with a physical impairment will strive to maintain the appearance of being able-bodied rather than disabled and thus avoid the unwanted attention or gaze of others that Leder (1990) asserts arises from a disabled or disfigured body. To meet the stereotypes of being normal and socially acceptable is important in maintaining self-image and social identity.

Identity - is created more through roles and relationships in the social world, for example, mother, husband, physiotherapist (Christiansen 1999). Lawler (2014) asserts that identity can be associated with certain categories such as race and gender as well as roles and relationships and that a person will belong to many such categories. Identity can be distributed through many social environments and be multi-faceted. Therefore, individuals can feel they portray different identities depending on the social environment in which they find themselves, but all of which are part of a coherent self (Goffman 1963). Christiansen (1999), an occupational therapist, proposed that there is a close connection between doing and identity. Identity is closely connected to what people do: their actions and activities within the context of their lives. These occupations are embedded in the

relationships and roles that people inhabit and their perception of how they think they are viewed by others, and so the competent performance of actions and activities is essential in maintaining identity (Elliott 2014). Being able to act on and in the world around us enables the self to be expressed and an identity to be created (Christiansen 1999).

Life stories –are thought of as a means by which human beings can make sense of their life and create some kind of coherence and stability. This is achieved by people understanding their lives as an evolving narrative or life story (Christiansen 1999, Lawler 2014). Bruner (2002) and Swain (2004) describe how each person has a continuous inner dialogue and narrative account of his or her life making up a story of whom and what he or she is. This life story creates a link between the person we were, our thoughts and memories of our past, who we are now in the present moment and who we feel we are going to be in the future and our future plans (Ellis-Hill 2011). Bury (1992), in his work on the biographical disruption that can be brought about through chronic illness, asserts that as people our sense of self is a result of the life story or narrative we tell about ourselves to ourselves and to other people. Ellis-Hill et al (2008), in her work on the Life Threads Model, suggests that people build up a variety of stories that they tell about themselves and create with other people which she represents as threads in a greater 'rope' of life. Some threads are continuous throughout life, such as family roles; others will come and go as events that have a shorter time-scale in a person's life. It is these threads that bring continuity and coherence to life and build a sense of self that each person has through his or her experiences and through organising and reflecting on them. This brings continuity and integrity to a sense of self over time and gives life meaning; however, these threads can be broken by illness and disability thus interrupting and disrupting the continuity of a person's life story.

Loss – chronic ill-health and long term disability can result in a person experiencing loss in many areas of their life (Alaszewski et al 2004). Secrest and Thomas (1999) suggest that the life of a stroke survivor is grounded in loss and effort as they struggle with the

changes in their body after stroke and the loss of their pre-stroke, normal life. Salter et al (2008), in a qualitative meta-analysis of life after stroke, found that losses can be physical - losing independence and physical ability, social - social isolation or withdrawal, and psychological - changes to self-concept and identity.

Transition – is a process of passage from one level or state to another (Oxford English Dictionary 2016) and following the onset of a disability, such as stroke, a person has to make a life transition that encompasses changes in their body, their self, their daily life and the environment (Salter et al 2008). A stroke survivor has to negotiate a new self and identity as they try to rebuild a life after stroke and this can take place over many years (Pilkington 1999).

1.4 Chapter Summary

This chapter has presented the issue of upper limb dysfunction in the context of stroke and rehabilitation, and has explained the complexity of the function of the upper limbs and their vital role in normal human activity and participation, as illustrated through the analysis of the ICF Core Set for Stroke. It has provided the context for the thesis and established the need for exploration of the experiences and perceptions of upper limb dysfunction from the perspective of people with stroke. It has also provided a rationale for the consultation of service users in the development of the study, and identified definitions of the theoretical terms used within the thesis.

The thesis will continue with the next chapter which presents a narrative literature review of what is known about the experiences of stroke as a whole and provides further context for the research and development of the research questions.

Chapter 2: Literature Review

2.1 Introduction

This chapter comprises a narrative literature review. An initial search of the literature revealed that very little was written about experiences of upper limb dysfunction after stroke whereas much more was written about the experience of stroke as a whole. It was thought important to review this literature on stroke as it could inform the research questions for this study and provide context for the analysis of the findings from the study. As so little literature was available on the upper limb specifically after stroke a search was undertaken to see if any literature was available on experiences of injuries and arthritic conditions affecting the upper limb as a review of this might reveal knowledge of relevance to the development of this study.

There are several different ways of undertaking a literature review. A systematic review of qualitative literature requires more than one researcher to carry out a detailed and rigorous search to obtain all primary research on a topic by searching multiple databases, performing hand-searches of journals and catalogues and contacting authors of previously published research. In addition, data extraction and appraisal of selected papers follows standardised criteria (Aveyard 2007). These methods are designed to limit bias as this type of review is often focused on trying to answer a specific clinical question in health research and to come to a conclusion from the current research about interventions or management of a particular condition or symptom (Steward 2004). As there was only one researcher a true systematic review was not possible. Furthermore, the study was not attempting to answer a specific clinical question or to establish the efficacy of particular interventions or management of the upper limb after stroke, but rather was an exploration of people's experiences. Therefore, a narrative review was the approach taken so that a broad and coherent synthesis of the themes from as wide a range of literature as possible

could shed light on what is known about people's experiences of upper limb dysfunction after stroke and pathologies affecting the hand (Steward 2004, Green et al 2006).

2.2 Method of Review

2.2.1 Search Strategy

Although this was a narrative review, it was important to present as unbiased and objective view of the literature as possible so a search strategy was therefore developed to ensure a systematic search in the following databases that were most relevant to the study: CINAHL, the Cumulative Index of Nursing and Allied Health Literature; MEDLINE, medical literature; AMED, Allied Health and Medical literature; and PsycINFO, psychology -and psychiatry- related subjects. They were searched from January 1990 to April 2015 in order to find all relevant literature. Two searches were conducted. Firstly for stroke, where the key words for the search were: "stroke", "hemiplegia", "cerebrovascular accident", "survivor", "patient", "person", "people", "experience", "perception", "upper limb", "arm", "hand". Secondly for injuries and arthritic pathologies of the hand where the key words were: "hand", "injury", "trauma" and "arthritis". The electronic search was supplemented by hand-searching the reference lists of retrieved articles. The titles and abstracts of papers were scrutinised for suitability. The criteria for inclusion were: articles with stroke or injury/arthritis of the hand as their primary area of interest; participants aged 18 or over; articles written in English (there was no funding for a translator). Articles were excluded if stroke or hand injury/arthritis was not their primary area of interest.

2.2.2 Appraisal and Extraction of Themes

The search resulted in a broad range of 54 articles specific to stroke being included in the review, dated from 1993 to 2014. A much narrower range of only 9 articles were included on experiences of injuries and pathologies of the hand. This reflected the limited literature available on the topic. The literature covered research carried out in the United Kingdom, Europe, North America and Australia (see Table 2.1 page 21).

The purpose of this narrative review was not to present an in-depth critique of the literature; however, the key features of the papers are presented in Table 2.1 (page 21). The majority of the literature was of a qualitative methodology and the overall trustworthiness of this was considered in terms of credibility (explanations of sampling strategy, data collection and analysis, verification of data analysis, reflexivity of the researchers) and transferability (sufficient information about participants to determine relevance to this study). Those selected met the criteria apart from reflexivity, where only two studies – Eilertson et al (2010), and Secrest and Thomas (1999) - referred to this in their methodology. Six literature reviews were selected (see Table 2.1 page 21) and some of these had reviewed aspects of other papers included in this narrative review; however, those papers have remained in the review because of findings not discussed in the review articles but pertinent to this study. Five scholarly papers were included in this review because of the relevance of their content and the authority of the authors. In addition to the qualitative papers, three quantitative surveys were selected. Barker and Brauer (2005) in their survey of factors contributing to upper limb recovery was one of the few papers that directly investigated experiences of the upper limb. Ellis-Hill and Horn (2000) used a survey to determine change in identity after stroke and Martin et al (2002) followed up stroke survivors after discharge from hospital to investigate unmet needs.

Table 2.1: Articles Included in the Narrative Review

No.	Authors	Year	Title	Sample	Method
1	Ammann et al	2012	Experiencing occupations with chronic hand disability: narratives of hand-injured adults	4	Narrative interviews
2	Banja	2011	Stroke rehabilitation and the phenomenological reconstitution of the self	N/A	Scholarly paper
3	BarkerandBrauer	2005	Upper limb recovery after stroke: the stroke survivors' perspective	19	focus groups, in-depth interviews
4	Barker et al	2007	Factors contributing to upper limb recovery after stroke: a survey of stroke survivors in Queensland Australia	220	survey
5	Bays	2001	Older adults description of hope after a stroke	9	in-depth interviews
6	Becker	1993	Continuity after stroke: implications of life-course disruption in old age	100	Semi-structured interviews
7	Bendz	2003	The first year of rehabilitation after a stroke – from two perspectives	15	Semi-structured interviews
8	Bonds Shapiro	2011	A story to create: stroke survivors' broken narrative	N/A	Scholarly paper
9	Burton	2000	Living with stroke: a phenomenological study	6	In-depth interviews
10	Bylund and Ahlgren	2010	Experiences and consequences for women with hand-arm vibration injuries	7	In-depth interviews
11	Cameron et al	2008	Optimizing stroke systems of care by enhancing transitions across care environments	N/A	Literature review

12	Cederlund et al	2010	Coping strategies in daily occupations 3 months after a severe or major hand injury	13	Semi-structured interviews
13	Ch'ng et al	2008	Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members	26	Focus groups
14	Chan and Spencer	2004	Adaptation to Hand Injury: an evolving experience	5	Semi-structured interviews
15	Chemnitz et al	2013	Consequences and adaptation in daily life – patients' experiences three decades after a nerve injury sustained in adolescence	15	Semi-structured interviews
16	Clarke	2003	Towards a greater understanding of the experience of stroke: integrating quantitative and qualitative methods	282/8	Surveys & semi-structured interviews
17	Connell et al	2014	Stroke survivors' experiences of somatosensory impairment after stroke: an interpretative phenomenological analysis	5	Semi-structured interviews
18	Cott et al	2007	Continuity, transition and participation: preparing clients for life in the community post-stroke	N/A	Literature review
19	Cox et al	1998	Coping with stroke: perceptions of elderly who have experienced stroke and rehabilitation interventions	39	In-depth interviews
20	Dowswell et al	2000	Investigating recovery from stroke: a qualitative study	30	Semi-structured interviews

21	Doyle et al	2014	Upper limb post-stroke sensory impairment: the survivor's experience	15	Semi-structured interviews
22	Eilertsen et al	2010	Recovering from stroke: a longitudinal qualitative study of older Norwegian women	6	Semi-structured interviews
23	Ellis-Hill and Horn	2000	Change in identity and self-concept: a new theoretical approach to recovery following a stroke	26	Cross-sectional comparison survey
24	Ellis-Hill et al	2000	Self-body split: issues of identity in physical recovery following a stroke	8	Narrative interviews
25	Ellis-Hill et al	2008	Using stroke to explore the Life Thread Model: an alternative approach to understanding rehabilitation following an acquired disability	N/A	Scholarly paper
26	Ellis-Hill et al	2009	Going home to get on with life; patients and carers experiences of being discharged from hospital following a stroke	33	Semi-structured interviews
27	Faircloth et al	2004	Sudden illness and biographical flow in narratives of stroke recovery	57	In-depth interviews
28	Fraas	2011	Enhancing quality of life for survivors of stroke through phenomenology	N/A	Scholarly paper
29	Grob et al	2008	The psychological impact of severe hand injury	N/A	literature review
30	Hilton	2002	The meaning of stroke in elderly women: a phenomenological investigation	5	Semi-structured interviews
31	Jones et al	2008	Reasons for recovery after stroke: a perspective based on personal experience	10	In-depth interviews
32	Kingston et al	2014	The experience of living with a traumatic hand injury in a rural and remote	15	Semi-structured

			location: an interpretative, phenomenological analysis		interviews
33	Kirkevold	2002	The unfolding illness trajectory of stroke	9	Semi-structured interviews
34	KvigneandKirkevold	2003	Living with bodily strangeness: women's experiences of their changing and unpredictable body following stroke	20	In-depth interviews
35	Kvigne et al	2004	Fighting back – struggling to continue life and preserve the self following a stroke	20	In-depth interviews
36	Lynch et al	2008	A qualitative study of quality of life after stroke: the importance of social relationships	15	Focus groups
37	Mangset et al	2008	'We're just sick people, nothing else': factors contributing to elderly stroke patients satisfaction with rehabilitation	12	Semi-structured interviews
38	Martin et al	2002	Outcome, functional recovery and unmet needs following acute stroke. Experience of patient follow up at 6 to 9 months in a newly established stroke service	179	Survey
39	Meyer	2003	Psychological aspects of mutilating hand injuries.	N/A	literature review
40	Murray and Harrison	2004	The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis	10	Semi-structured interviews
41	Olofsson et al	2005	'If only I manage to get home I'll get better' – interviews with stroke patients after emergency stay in hospital on their experiences and needs	9	In-depth interviews
42	Peoples et al	2011	Stroke survivors experiences of rehabilitation: a systematic review of qualitative	N/A	Systematic review

			studies		
43	Pilkington	1999	A qualitative study of life after stroke	13	Semi-structured interviews
44	Poltawski et al	2015	Assessing the impact of upper limb disability following stroke: a qualitative enquiry using internet-based personal accounts of stroke survivors	99	Internet based accounts
45	Pound et al	1998	A patient-centred study of the consequences of stroke	40	In-depth interviews
46	Prigatano	2011	The importance of the patient's subjective experience in stroke rehabilitation	N/A	Scholarly paper
47	Rittman et al	2007	Transition experiences of stroke survivors following discharge home	125	Semi-structured interviews
48	Sabari et al	2000	Reflections upon rehabilitation by members of a community based stroke club	10	Group observations
49	Salter et al	2008	The experience of living with stroke: a qualitative meta-analysis	N/A	Systematic review
50	Schier and Chan	2007	Changes in life roles after hand injury	3	Case-studies
51	Secrestand Thomas	1999	Continuity and discontinuity: the quality of life following stroke	14	In-depth interviews
52	Stamm et al	2014	Similar problem in the activities of daily living but different experience: a qualitative analysis in six rheumatic conditions and eight European countries	229	Focus groups
53	White et al	2009	Stroke patients' experiences with the Australian health system: a qualitative study	12	In-depth interviews

54	Wiles et al	2002	Patients' expectations of recovery following stroke: a qualitative study	16	In-depth interviews, Observations
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Themes were extracted from the papers by distinguishing and separating out findings and then grouping these together into main themes, some of which had subordinate themes, according to those that appeared to be on the same topic. The names of the themes were developed from the key findings in the text of the papers. The themes were: Interrupted and Disrupted Life; Threat to the Self, with sub-themes of Low Self-esteem and Altered Self-image and Identity; Loss; Recovery, with sub-themes of Rehabilitation Priorities, Information and Advice, Experiences of Therapy and Personal Responsibility. Table 2.2 (page 28) indicates the articles from where the themes and subordinate themes were extracted.

Table 2.2 Relationship between Extracted Themes, Subordinate Themes and Articles

Main themes	Subordinate themes	Articles (by number)
Interrupted and disrupted life		6, 7, 8, 10, 13, 14, 18, 20, 23, 24, 25, 27, 30, 10, 32, 33, 40, 47, 48, 49, 52
Threat to the self		2, 6, 8, 16, 18, 24, 30, 40, 47, 49
	Low self-esteem	1, 9, 10, 12, 13, 14, 20, 21, 23, 24, 30, 32, 34, 35, 40, 43, 45, 47, 49, 51, 52
	Altered self-image and identity	9, 10, 12, 13, 14, 15, 16, 19, 20, 21, 22, 24, 29, 34, 35, 39, 40, 44, 45, 46, 47, 49, 50, 51, 52
Loss		6, 10, 13, 14, 16, 19, 20, 22, 24, 28, 30, 36, 40, 43, 44, 45, 47, 49, 50, 51, 52
Recovery		1, 3, 5, 6, 7, 9, 10, 13, 14, 17, 18, 19, 20, 21, 22, 24, 26, 31, 33, 35, 37, 38, 41, 43, 44, 45, 47, 48, 49, 53, 54
	Rehabilitation priorities	2, 6, 7, 9, 13, 18, 24, 42, 48
	Information and advice	3, 11, 18, 26, 31, 37, 41, 42, 53
	Experiences of therapy	3, 4, 5, 7, 8, 9, 11, 13, 14, 15, 17, 18, 21, 26, 31, 32, 33, 37, 38, 45, 48, 53, 54
	Personal responsibility	3, 4, 7, 11, 31, 35, 41, 42, 48, 53

2.3 Themes and Subordinate Themes

2.3.1 Interrupted and Disrupted Life

A stroke is usually a very sudden event that occurs often without warning and can be overwhelming and catastrophic, resulting in physical and cognitive disability, loss of communication, fatigue and depression (Burton 2000, Bendz 2003, Department of Health [DH] 2007). So many critical factors of bodily function, perception and personality can be thrown into disarray and so it is not surprising that stroke can bring about a radical, fundamental and irrevocable change and a profound disruption to people's lives that pervades all aspects of their social world, making the future unpredictable and uncertain (Burton 2000, Dowswell et al 2000, Kirkevold 2002, Salter et al 2008). Hilton (2002) reports that the elderly women in their study reported sudden and significant bodily changes and disability after stroke that are difficult to come to terms with. One woman described the stroke as like a whirlwind in this respect. Becker (1993) reported that people with stroke unanimously agreed that stroke had brought a profound disruption to their lives, destroying the fabric of a predictable, everyday life.

In several of the studies on chronic hand injuries it was clear that the sudden and unexpected occurrence of the injury and the resultant loss of function in the hand had also disrupted people's lives in similar ways to that of stroke. In a study by Kingston et al (2014 p5), a comment by one participant was typical, as she expressed the view that her whole life had changed and that everything she had previously done was '*just memories*'. A woman in a series of three case studies by Schier and Chan (2007) explained how she felt that a big piece of her had been taken away as a result of her arm injury. Women in a study by Bylund and Ahlgren (2010) explained that they were living a different life to the one they had before their hand injury as all domains of life had been affected. Chan and Spencer (2004) observed that hand injury could bring about a sudden and immediate change to all areas of life.

Respondents in a study on stroke by Ellis-Hill et al (2000) described the change to life brought by stroke as having entered a new foreign world with no sense of return to their old life. Participants in studies by Ch'ng et al (2008) and Dowswell et al (2000) reported that their future plans were changed, their lives had come to a standstill and everything they previously liked to do had been lost. Their intended life story was interrupted or lost. The person they were in the past and hoped to be in the future was rendered discontinuous from who they were now in the present (Ellis-Hill and Horn 2000, Murray and Harrison 2004, Cott et al 2007). A participant in a study by Ellis-Hill et al (2000 p728) stated that the *'stroke had shattered her'* and she was now only half a person. Another participant in a paper by Dowswell et al (2000 p510) described the stroke as *'turning our life completely round'* and having *'ruined my life'*.

When a stroke occurs, individuals often experience a break in their internal narrative; the stories of who they are and how they had anticipated life would continue are disrupted. Ties to day-to-day activities and life roles are interrupted and in some cases severed (Bonds Shapiro 2011). Salter et al (2008), in their review of qualitative studies on living with stroke, found that some people felt a discontinuity and estrangement from the person they were before their stroke. Some of the threads of life are broken and the predictability of everyday life is lost, and they have entered a new and uncertain world of impairment and disability and a struggle to reconcile their post-stroke selves with their pre-stroke selves (Sabari et al 2000, Ellis-Hill et al 2008, Salter et al 2008). These life threads, or internal narratives, normally bring continuity and integrity to the sense of self over time and give life meaning, but when stroke occurs ideas of self are torn apart (Bonds Shapiro 2011).

Although there was strong agreement with the literature that stroke brings disruption and discontinuity, there were two papers by Faircloth et al (2004) and Rittman et al (2007) that cut across this notion. Both papers were based on the same participants who were older veterans of the USA armed services. They found that some of their participants saw

stroke in the context of the natural ageing process and therefore part of their continuing life-story. Most of their participants had other significant co-morbidities such as diabetes, cancer and osteoarthritis, and some had experienced a previous stroke, so stroke was subsumed into the overall effects of these other conditions as just another part of their health history and the disruption to life was mediated by this. In the other papers in this review participants were usually selected because stroke was their primary and often only illness and this, therefore, explains the significant impact it could have on people who were previously well and active.

2.3.2: Threat to the Self

Clarke (2003) found that many people after stroke found the resultant physical inactivity very difficult to deal with as they had been very active persons before their stroke and the activities they had engaged in were very much part of their sense of self and identity. Similarly, the cognitive difficulties some encountered challenged their ability to engage in work and leisure occupations and their perception of being a capable and competent person. Leder (1990) asserts that, in health the body and self are united and inseparable but the body is silent. Banja (2011) in his commentary agrees with this. The body is reliable, taken for granted and out of conscious awareness, but when an illness such as stroke occurs people become very aware of their impaired body. In some studies, many people reported a sudden disrupted embodiment, a separation of body and self, which leads to a change or loss of self (Ellis-Hill et al 2000, Rittman et al 2007, Banja 2011). Rittman et al (2007) reported two thirds of their 125 participants experiencing this disruption and change to the sense of self because of how they perceived their bodies after stroke. In other words, they became very aware of their body, it was no longer silent, but also felt distanced from it because it felt strange and unfamiliar to them, and was now an unreliable and unpredictable body and had changed how they could now live their lives (Murray and Harrison 2004, Salter et al 2008). They were forced to confront these bodily changes in order to engage in rehabilitation (Becker 1993) and had the daunting

challenge of integrating what remained from the pre-stroke self with their new post-stroke body to construct a coherent, post-stroke concept of self in order to claim purpose and meaning in their lives (Cott et al 2007, Banja 2011, Bonds Shapiro 2011). Hilton (2002) explained that the re-establishment of self was a journey from able-bodied to deterioration and decline, but then on to hardiness, resilience and re-engagement with the body to arrive at the destination of disabled and that disability was a condition to be lived with. Banja (2011) suggested that rehabilitation after stroke should enable people to reconstitute the post-disability self and, therefore, health professionals should take account of people's anxieties, beliefs, attitudes and sensibilities to assist them in re-constituting their worlds.

2.3.3 Low Self-esteem

Self-esteem, the feelings or evaluations a person has of their self worth, is strongly associated with psychological well-being (Fox and Wilson 2008, Keppel and Crowe 2000, Niven 2006) and lower self-esteem is related to poorer functional outcomes in stroke rehabilitation (Vickery et al 2008). The change from a reliable body to one that is unpredictable, with limitations in ability, and that requires great effort to function can bring a lack of self-confidence and low self-esteem (Murray and Harrison 2004). Ellis-Hill and Horn (2000) noted that some people after stroke described themselves as less capable, more dependent and helpless and, as a consequence, of less value. Many of the participants in the studies on hand injuries were of working age and losing competence and mastery over the work skills they previously held was difficult to bear as job roles had to change, and this lowered their self-confidence in the work-place (Amman et al 2012). Some with hand injuries were unable to carry on working and low self-esteem was a consequence. Lost status and professional identity, and concerns about providing financially for the family caused some with hand injuries to feel worthless (Chan and Spencer 2004, Schier and Chan 2007, Bylund and Ahlgren 2010).

Many papers on stroke reported that people had lost competency in the basic tasks of self-care and required assistance to complete these on a daily basis, leaving them feeling embarrassed, debased and degraded (Pilkington 1999, Kvigne and Kirkevold 2003, Rittmann et al 2007). Women in the study by Kvigne et al (2004) felt ashamed and stupid by their inability to manage their personal care. One man in the Pilkington (1999) study described feeling like a helpless little baby because he needed help and had to learn again some of the basic activities of daily living. People felt vulnerable, with a body that would not do what they wanted it to at a very basic level and this lack of mastery over their bodies resulted in feelings of helplessness and worthlessness (Pound et al 1998, Secrest and Thomas 1999, Burton 2000, Salter et al 2008). Ch'ng et al (2008) described participants as being emotionally upset at the loss of dignity they encountered. Doyle et al (2014) in their study on sensory loss in the upper limb recorded how loss of competency in upper limb function left people feeling worthless and vulnerable because of the help they needed with self-care activities.

Several of the papers on hand injuries reported participants having similar experiences when needing help with self-care tasks such as bathing, dressing, brushing teeth and feeding Schierand Chan 2007, Cederlund et al 2010, Bylund and Ahlgren 2010, Ammann et al 2012, Kingston et al 2014). Help frequently came from a spouse but in one study two participants reported that their young children were assisting them (Schier and Chan 2007). Being confronted with this level of dependence made people sad and angry (Ammann et al 2012), and affected self-esteem. Participants reported feeling degraded by asking for help (Cederlund et al 2010) and one man expressed feeling like a child because he was too afraid to have a bath when no-one was at home in case he got into difficulties (Chan and Spencer 2004).

In some studies, it was clear that stroke survivors were conscious of their bodies being conspicuous and subject to the gaze of others because of their visible impairments such as movement abnormalities, paralysis, contractures and having to use aids (Ellis-Hill et al

2000, Kvigne and Kirkevold 2003). Concerns over the reactions of others changed how people viewed their bodies and, for some, caused embarrassment, shame and discomfort; as a consequence they limited their social interaction (Dowswell et al 2000, Murray and Harrison 2004). In Rittman et al (2007), male stroke survivors described how their masculinity was challenged by their stooped postures and inability to walk normally, and they felt worthless and useless. Younger stroke survivors felt unattractive and self-conscious, and feared rejection by their peers resulting, for some, in emotional problems such as despair, depression, and even suicidal thoughts (Ch'ng et al 2008). Some stroke survivors felt stigmatised and degraded because they no longer conformed to society's perception of able-bodied (Ellis-Hill et al 2000).

2.3.4 Altered Self-image and Identity

The physical ability and appearance of the body are the foundation of a person's body image and part of self-image (Yuen and Hansen 2002). When stroke affects physical ability and appearance, the image people have of themselves may change (Secret and Thomas 1999, Prigatano 2011). Changes in the function and physical appearance of the arm and hand can lead to a person objectifying the hand. Poltawski et al (2015) found in the web-based diaries of stroke survivors that some people felt their upper limb was not part of their body but almost alien. Ellis-Hill et al (2000) reported similar findings with the hand becoming a separate entity from the person and rest of the body. In a phenomenological study of living with stroke a number of people expressed anger and frustration towards the hand that would not grip and function as previously (Burton 2000). Meyer (2003) and Grob et al (2008) both noted similar experiences in patients with mutilating hand injuries, noting that some people experience significant disruption to their body image as the hand is perceived as foreign or alien because of its appearance or changes in sensation. Pound et al (1998) observed participants slapping arms or legs that no longer had movement or feeling as if they had nothing to do with them. Disfigurement of the hand was a factor that could cause embarrassment. The hand is a very visible part

of the body due to its role in non-verbal communication and Meyer (2003) recognised that patients with disfigurement of the hand after injury can become acutely aware of others observing their hand; as a consequence they try to conceal the hand or indeed withdraw from social contact. Grob et al (2008) agrees with this suggesting that many patients have cosmetic concerns about the social acceptability of their disfigured hand.

Participants in a paper on hand injuries by Cederlund et al (2010) were concerned at the reactions of others to the appearance of their hand. Some reported that their family members found it hard to look at and touch their hand. Other papers reported people describing their hand as ugly and were hiding it because of embarrassment and to avoid unwanted attention and people staring (Bylund and Ahlgren 2010, Chemnitz et al 2013). In the focus group study on rheumatic hands by Stamm et al (2014) some described their hands as ugly and thick and, consequently, they held back from shaking hands with people. One person described being embarrassed when reaching out with the hand to pay for a bus ticket.

Many people have to adapt and make practical changes to the clothes they wear after stroke or conditions affecting the hand to make dressing easier in order to maintain some independence. Fastening buttons, laces, zips and putting on make-up and jewellery and styling the hair can be challenging if an upper limb is affected and bi-manual function of the hands is lost. Whilst making changes is very practical, it can limit a person's ability to express their personality and display the image they want to present to other people and to fit into and identify with the social world they choose to inhabit (Kvigne and Kirkevold 2003, Rittmann et al 2007). One person in the study on hand injuries by Cederlund et al (2010) described the type of clothing they could now wear as ugly. Perceived appearance factors and perceptions of social acceptance are strongly correlated with self-image (Garner 2004, Fox and Wilson 2008).

Changes in physical ability can have a major impact on body image (Kvigne and Kirkevold 2003). The inability to move and use the body according to socially accepted norms, or to

be reliant on visible aids, such as a walking stick or wheelchair, can challenge body image (Ellis-Hill et al 2000). Participants with stroke in Cox et al (1998) were very focused on their physical limitations and the consequent loss of activities that had occurred after stroke. Activities that require physical ability and skill can be very interwoven with body image and can be a source of satisfaction and achievement (Garner 2004), but if a person is no longer able to participate in them then their sense of pride in their body can be destroyed; this change in self-image can then lead to low self-esteem and depression (Pound et al 1998, Clarke 2003). Grob et al (2008) found this in patients with hand injuries, where the traumatic effect of the injury was compounded by the inability to work, and the loss of pride and satisfaction they previously had in their ability and skill was no longer available to them.

Often the skills and activities that people engage in are interwoven with not only their body image but also their sense of identity (Ellis-Hill et al 2000, Murray and Harrison 2004, Rittman et al 2007). They might be linked to occupations and hobbies through which people might describe themselves, such as gardener, musician, and as such are vital to their sense of self (Clarke 2003). Dowswell et al (2000) and Ellis-Hill et al (2000) identified that upper limb dysfunction prevented some from participating in tasks around the home, shopping, and highly valued hobbies and pastimes. A woman in the study by Poltawski et al (2015 p4) observed that the kitchen was 'the domain of the two-handed' and, therefore, trying to accomplish tasks associated with cooking was challenging. The loss of skill and ability can lead to frustration and often social isolation (Pound et al 1998, Murray and Harrison 2004). A participant in Cox et al (1998) described the loss of the ability to drive as losing empowerment, because of its association with freedom and independence. Clarke (2003) concluded that, if the disability from stroke prevents a person from engaging in an activity that is an important component of their identity, then their well-being is significantly affected.

The life roles people have are integral to their identity, and being able to give to others creates bonding in relationships and contributes to a sense of well-being (Prigatano 2011). They contribute to their concept of who they think they are, what they think they can achieve, and what they think others expect of them (Burns 1979). Women, in a study on stroke by Kvigne and Kirkevold (2003), felt they no longer had the strong, healthy body that had enabled them to work hard in fulfilling caring roles as a wife, mother and grandmother. Doyle et al (2014 p996) described a woman in their study describing herself as a 'lousy mum' because of being less active and more sedentary. Trying to maintain the female caring role of wife and mother within a family was essential to the women in the study by Kvigne et al (2004), and emerged as important in Pound et al (1998). The parent role was affected in the studies on hand injuries, particularly as the participants were adults with younger children. One participant found a threat to his identity as the active father coaching his son's soccer team. He could no longer throw and catch, and so playing sports with his children was impossible. Others were reduced from being the active parent to a passive observer of family activities (Schier and Chan 2007). They could no longer be a care-giver to their children in tasks such as preparing meals, bathing, changing nappies, and some felt grief at this inability to fully care for their children (Chan and Spencer 2004, Chemnitz et al 2013). For some men with stroke, the inability to work and provide financially for the family, to drive, and to carry out heavier domestic chores, threatened their masculine identity and traditional role and responsibility as protector and head of the household (Burton 2000, Dowswell et al 2000). This is echoed in other research where the disabilities encountered after stroke are a constant reminder to people of the family roles they can no longer fulfil in the same way as before their stroke (Pound et al 1998, Dowswell et al 2000, Murray and Harrison 2004, Ch'ng et al 2008). One participant in the paper by Dowswell et al (2000) commented on how the inability to use her hand in cooking resulted in her no longer taking on the identity of a helper in her family. This was typical of the women in a study by Eilertsen et al (2010), where the home and caring for family was central to their identity and fulfilment. Some patients reported

feelings of embarrassment because of their disability and inability to carry out previous roles (Dowswell et al 2000; Ellis-Hill et al 2000). A participant with upper limb dysfunction in Ellis-Hill et al (2000) described his embarrassment at having to standby while another woman helped his wife to lift heavy bags out of a shopping trolley, a task that was normally part of his role as a husband. He often felt judged by people who did not understand his physical disability and limitations and the effect on his identity as a strong man. People can have roles in other social networks as a result of leisure, community activities and friendships and when people can no longer fulfil them they can feel incompetent, isolated and sometimes abandoned by friends (Dowswell et al 2000). There is not only a loss of role but also a change in roles, disrupting family and social networks. People are changed from active contributors and doers to passive receivers (Burton 2000, Dowswell et al 2000, Salter et al 2008). The previously cared for become the carers, changing the balance in relationships (Schier and Chan 2007, Eilertsen et al 2010). Often the sick or invalid role subsumes all others and this change in status from giver to receiver is felt very deeply (Dowswell et al 2000). Re-defining contributions to family and community is difficult but returning to roles, even in a modified form, is strongly correlated with an improved sense of self and well-being (Clarke 2003, Rittmann et al 2007, Prigatano 2011).

2.3.5: Loss

Salter et al (2008) observed that people after stroke entered a world of loss, which could be in the areas of: physical ability; their social relationships; psychological changes to self-concept; losses in control of their lives, their independence and valued activities, as well as life roles. A participant in Dowswell et al (2000) explained how everything they had liked to do had gone. Secrest and Thomas (1999) described the world of stroke as grounded in loss and effort as people's concept of normality and taken-for-granted freedoms were gone and replaced by a daily struggle with their impaired body to regain some function. Pilkington (1999) described participants being sad, depressed, frustrated,

afraid and confused by the losses and restrictions they encountered in their everyday lives. Ch'ng et al (2008) reported great distress associated with losses in hobbies and activities that had previously been a source of achievement and pleasure. A participant in Hilton's (2002) study reports the great loss felt when she was forced to retire from work after a stroke. It affected her so badly that she could not attend a retirement party held for her. Similarly, in Poltawski et al's (2015) study, a woman, who was a professional musician, described the emotional impact that the loss of her ability to play her instrument had brought. Any activity that required assistance was a reminder of the losses incurred by the stroke (Becker 1993). Eilertsen et al (2010) noted stroke survivors grieving over their losses and the feeling that it was too late for many of the things they had wanted to do in life.

Loss was a significant factor in the lives of many people with hand injuries. In addition to the loss of roles and work, people expressed how the loss of function in their hand meant they no longer had the power and dexterity for many of their valued activities and hobbies. One person could no longer ride his motorbike because he could not steer with both hands, and another could no longer teach gymnastics (Schier and Chan 2007). Gardening, sewing, cooking, skiing were just some of the activities that were no longer possible (Bylund and Ahlgren 2010, Chan and Spencer 2004). Frustration and depression were common as a consequence and can be seen by one person's comment; *'this has shut me down'* (Chan and Spencer 2004, p132).

Another aspect associated with loss after stroke was social isolation. Physical disability, and the reactions of others to that disability, often affected the significant social relationships that people had before their stroke (Lynch et al 2008, Fraas 2011). Physical disability left some people virtually housebound or struggling to cope with access when outdoors and so unable to carry on with their previous social activities (Pound et al 1998, Rittman et al 2007, Fraas 2011). How other people reacted to the disabilities associated with stroke was a factor in several studies. Some people felt they were treated rudely or

dismissed and rejected by family members and friends who were embarrassed to be associated with them because of their disabilities, both visible and invisible (Clarke 2003, Lynch et al 2008, Salter et al 2008). For many this led to low self-esteem and feelings of worthlessness causing people to limit their social interaction, and avoid people and friends they knew before their stroke (Cox et al 1998, Clarke 2003, Murray and Harrison 2004). For others, they felt distanced from friends and family because it was difficult to explain their experiences to them, or friends and family withdrew from them because it was too uncomfortable trying to identify and relate to the person with stroke (Ellis-Hill et al 2000, Murray and Harrison 2004, Lynch et al 2008, Salter et al 2008). Furthermore, some people withdrew from their family and friends because they felt they were not able to contribute to their home and community and consequently did not want to be a burden (Dowswell et al 2000, Rittman et al 2007, Salter et al 2008).

2.3.6 Recovery

Recovery from stroke is hard work, as people are faced with the combined tasks of healing, regaining function, and re-forming and re-claiming their lives (Kirkevold 2002, Bonds Shapiro 2011). Ellis-Hill et al (2000) described this process as one of trying to create a new coherent sense of self. In many of the studies, participants discussed the impact of stroke in the context of their life before stroke. Progress and recovery were measured against their pre-stroke lives and valued roles and activities, not objective physical measures, and often their dominant thought and hope was one of getting back to normal (Pilkington 1999, Burton 2000, Wiles et al 2002, Bendz 2003, Ch'ng et al 2008, Salter et al 2008, Ellis-Hill et al 2009). Kirkevold (2002) and Eilertsen et al (2010) described the trajectory of stroke over the first year for patients. Initially, although radical bodily changes may have occurred, stroke was seen as a short-term problem where symptoms would quickly subside and a return to normal function would occur. The rapid improvement seen in the early weeks after stroke often led patients to anticipate, and have hope for, a full recovery (Burton 2000, Kirkevold 2002, Wiles et al 2002, Jones et al

2008). As time passed, and improvement occurred more slowly, their perceived time frame for recovery gradually lengthened and the awareness that disability may persist became apparent (Kirkevold 2002, Eilertsen et al 2010). Despite this slowing down of recovery, many patients did not give up hope of a full recovery and return to their previous lives and activities (Barker and Brauer 2005). This hopeful attitude to recovery was similar in people with hand injuries, as not all made a full recovery. Initially, people were expectant of a full recovery but as time progressed there was a gradual realisation of more lasting consequences from the injury (Chan and Spencer 2004).

Staying positive and self-motivated was identified as crucial by participants in the study by Cox et al (1998). Kvigne et al (2004) commented on their participants struggling to keep negative feelings away and to remain positive, and in Jones et al (2008) participants thought that their positive efforts and hope were vital to support recovery and overcome challenges. Kirkevold (2002) described how, six months after a stroke, the focus of patients shifted towards integrating the stroke into their lives to allow as many as possible of their valued activities to continue, or to find new ones to substitute for those no longer possible. For some patients, however, the slowing down of progress in recovery led to dissatisfaction, despondency and frustration, as they felt ill-prepared for it and it precipitated negative feelings as they reflected on their pre-stroke lives and the losses they had encountered (Burton 2000, Dowswell et al 2000). Some people were able to begin to adjust and adapt to the stroke by adapting their environment or the means of completing tasks and activities so that they could find some continuity with their previous life and, therefore, some continuity of their self (Poltawski et al 2015). Some were able to find new activities and routines to replace old ones and so regain some meaning and purpose to their lives (Becker 1993, Ch'ng et al 2008). This gave them some optimism and sense of control at the same time as keeping hope alive for more recovery (Salter et al 2008). In their longitudinal study, Eilertsen et al (2010) describe women recovering from stroke as only beginning to pick up the threads of their lives again in the second year

after stroke. This involves re-defining previously held ideas about who they were and what they could achieve, and letting go of hope for more recovery and accepting their disabilities. However, Jones et al (2008) were surprised by how many of their participants remained hopeful and optimistic about more recovery despite the severe level of disability some were facing and the predictions from therapists that more recovery was unlikely. They took hope from this re-adjustment and progress and took it as an indication that they could eventually make a full recovery, even after formal rehabilitation had ceased (Wiles et al 2002; Jones et al 2008).

In one of the few papers that directly explored patients' perspectives on recovery of the upper limb after stroke, participants commented on the enormous impact of loss of arm and hand function (Barker and Brauer 2005). One participant felt that poor arm function was more disabling than being unable to walk, commenting that there is much more a person can do when the arm recovers, even if sat in a wheelchair, whereas when the leg recovers all a person can do is learn to walk. Doyle et al (2014) noted that upper limb dysfunction permeated all aspects of life. A good recovery was perceived to be some return of the use of the hand to hold something and to have two hands functioning together, to do what a person wanted to do and to get on with life (Doyle et al 2014). Participants in Doyle et al's (2014) study emphasised how important it was to keep hope alive and to work hard on recovery, even when it was slow and there were setbacks. Barker and Brauer (2005 p1217) identified a theme of 'keeping the door open', in that participants in their study considered it important to remain optimistic and open to the possibility of further recovery even many years later. Connell et al (2014), in a study on sensory impairment after stroke, found that their participants persisted in trying to use the upper limb, but more often than not activities were completed by the non-affected arm. Striving for more recovery amidst trying to resume some sort of normal life was a challenge. Barker and Brauer (2005 p1218) described this as '*hanging in there*'; in other words, people felt that they had to persist and maintain hope. Recovery for many was

judged to be a return to valued hobbies or interests that would require some function of the upper limb (Bays 2001).

An important milestone for many people in their recovery was returning home from hospital after a stroke. It signified a move towards normality and regaining control over their lives (Kirkevold 2002, Olofsson et al 2005, Jones et al 2008). However, the happiness and relief on coming home was also mixed with anxiety and uncertainty when the consequences of their stroke were often only fully understood as they were faced with personal and practical tasks when they attempted to resume previous activities and roles (Kirkevold 2002, Olofsson et al 2005, Rittman et al 2007, White et al 2009, Eilertsen et al 2010). Facing the world they had lived in before with newly acquired physical, cognitive and emotional dysfunction forced people to confront their limitations, and consequently they were often more unhappy with their progress at home than they were when still in hospital (Becker 1993, Ellis-Hill et al 2009, Eilertsen et al 2010). None of the papers on stroke discussed the impact of the upper limb on their experiences of returning home after stroke and so it is difficult to conclude how much upper limb dysfunction contributed to these experiences. However, a study by Ammann et al (2012) on hand injuries could shed some light on this as their participants described feelings of frustration and helplessness on returning home and the full impact of the hand injury on their daily activities was realised. The artificial environment of hospital, where everyday tasks are completed for the patient, can give a false impression of the amount of recovery achieved.

Some patients had received little information about their ongoing care after hospital and this had made it difficult for them to plan for the transition home (Burton 2000, White et al 2009). The focus had been on regaining enough mobility to be discharged from hospital rather than enabling them to return to former roles or maximise their independence, which would require more arm and hand function. Several studies reported people feeling abandoned or disregarded by the healthcare system after returning home as services either reduced or ceased altogether (Sabari et al 2000, Martin et al 2002, Cott et al 2007,

Cameron et al 2008, Ch'ng et al 2008, Mangset et al 2008). However, often this was the time when they needed the most information and support and when the real work of rehabilitation in their own environment and context should begin (Olofsson et al 2005, Cameron et al 2008). Where services did continue after discharge home they were often concentrated in the first few weeks when patients were going through a period of re-adjustment and were not perhaps ready to take full advantage of the expertise on offer (Sabari et al 2000).

2.3.7 Rehabilitation Priorities

Several papers reported a difference between the goals set by health professionals and those seen as important by patients. For example, health professionals' main interest was in physical function, with predominantly short-term goals in improving basic activities of daily living such as dressing, feeding and toileting, whereas patients' goals were focused on trying to regain former roles and valued activities or to find new ones (Burton 2000, Sabari et al 2000, Bendz 2003, Cott et al 2007). Consequently, patients' goals were often broader in terms of regaining pre-stroke normality and identity and, therefore, more ambitious than those of the professionals (Becker 1993). Social, psychological and emotional needs of patients often went unrecognised and were not addressed (Burton 2000, Ellis-Hill et al 2000, Bendz 2003, Cott et al 2007, Ch'ng, et al 2008, Peoples et al 2011). In the review by Peoples et al (2011) participants felt that they wanted more psychological support, in particular re-assurance and encouragement about progress made and their worries acknowledged and listened to. Banja (2011) and Cott et al (2007) suggested that attending to this, as well as assisting people to gain as much function as possible, should be part of rehabilitation after stroke and would enable people to adjust to their post-stroke selves. Rehabilitation did not extend to restoring community living skills such as accessing transport, walking outdoors, buying a newspaper, shopping, managing money, or using the telephone (Sabari et al 2000). Dependence on others was often

assumed so domestic tasks that people may have previously done were not included in their rehabilitation.

2.3.8 Information and Advice

Communication between health professionals and patients was an area that was often fraught with difficulties for some patients, causing frustration and anxiety (White et al 2009). Getting the right information at the right time was seen as crucial to patients and carers and allowed them to feel empowered through understanding their stroke, to take an active part in their rehabilitation and recovery, and to be involved in decisions made about their care (Peoples et al 2011). Participants in Ellis-Hill et al (2009) found the lack of information distressing, particularly where it was related to advice about their recovery and the timing of services. Often, information was given at times when patients were either not ready to absorb it or did not know what questions to ask, but when they were ready the information was no longer available (Oloffson et al 2005, Mangset et al 2008). Some patients and carers perceived that staff were very busy with great workloads and so they did not want to bother them with their questions (Oloffson et al 2005; White et al 2009). Cameron et al (2008), in their review of transitions across care systems after stroke, observed that patients often felt that information was lacking during discharge from hospital to home, with the onus left on patients and families to pursue follow-up visits from consultants, therapists and general practitioners. White et al (2009) agree with this, as their participants felt inadequately informed about on-going care after discharge and as a consequence less able to participate in decisions about their treatment. Not all patients felt involved in the decisions being made about their future care and rehabilitation (Oloffson et al 2005, Jones et al 2008). However, Peoples et al (2011) pointed out diversity in the level of involvement in decision making that patients wanted. Some wanted shared decision making whereas others appreciated a more paternal approach from the healthcare professionals. This was the case in many other papers, where some stroke survivors and their carers regarded health professionals as those with the expert

knowledge, authority and responsibility for promoting their care and recovery; as a consequence, they adopted a passive role and wanted decisions to be made for them, and expressed surprise and frustration at having to make decisions for themselves. In contrast, others preferred an active role and resented the control they perceived that professionals had over the direction of their treatment (Barker and Brauer 2005, Oloffson et al 2005, Cott et al 2007, Jones et al 2008, Mangset et al 2008). Mangset et al (2008) concluded that those patients who expressed satisfaction with their care were those who felt that they were acknowledged as an individual, and who perceived that their autonomy was respected and that there was a dialogue and exchange of information with the professionals.

2.3.9 Experiences of Therapy

Therapy was often seen as essential for a good recovery and positive outcomes after stroke were often credited to the amount of therapy received (Wiles et al 2002, Bendz 2003, Barker and Brauer 2005, Ch'ng et al 2008). However, there was often a mis-match in expectations for recovery between stroke survivors and the therapists. Barker and Brauer (2005), in their study on stroke survivors' perspectives on upper limb recovery, found that patients believed therapists were knowledgeable about stroke and looked to them for guidance and encouragement, but conversely resented them when they were given predictions that they would never use their arm again. Wiles et al (2002), on the other hand, observed that physiotherapists were often reluctant to discuss recovery with patients or were cautious in their predictions about their expected level of recovery in order not to raise false expectations. Some participants in Jones et al (2008) wanted therapists to be honest with their predictions of progress as they sometimes thought that therapists' reassurance of them doing well was not said with real conviction; however, other participants valued the optimistic stance of therapists as this instilled feelings of hope and confidence. Despite this, many people ignored negative predictions and still

had high hopes of a full recovery and still believed that their physiotherapists expected them to make a good recovery (Wiles et al 2002).

Mangset et al (2008) found that many patients had a strong belief that more exercise and a better rehabilitation plan would improve their recovery. Engaging in active therapy and working towards meaningful goals of regaining lost activities fostered a sense of achievement and hope for some (Bays 2001, Ch'ng et al 2008). Wiles et al (2002) proposed that the over-optimistic expectations of some people may have resulted from a feeling that a positive outlook, determination and adherence to therapy was all that was necessary for a full recovery. It was apparent in some studies that therapists were caught in a dilemma around trying to meet patients' demands for realistic predictions of time-frames for recovery but then encountering dissatisfaction from patients who felt a less favourable prediction then affected their motivation and hope for recovery (Barker and Brauer 2005, Ch'ng et al 2008). The commentary by Bonds Shapiro (2011) on the disclosure of information by health professionals to stroke survivors points out that the outcome of stroke is unpredictable and not completely knowable, but patients were either not always informed of this by therapists or were misled by therapists' predictions that set specific expectations and time-frames. Therapists, therefore, have to tread a fine line between being honest and disclosing the reality of stroke recovery to patients without them then losing the effort and impetus to regain some recovery. The desire for more honesty in prognosis, without eliminating hope altogether, was also wanted by people with hand injuries (Chemnitz et al 2013).

Upper limb recovery was viewed as critical by patients but often they perceived it as a neglected issue by therapists and other health professionals, and the magnitude of their loss was therefore poorly understood (Barker and Brauer 2005). One patient in the study by White et al (2009 p 86) commented that, while he was in hospital, no therapist 'ever worked on my hand, never touched it'. Similarly, Doyle et al (2014) reported that priority was given to the lower limb, that balance and walking were the focus, with most

participants reporting that their arm was ignored by therapists. The losses in self-care and valued activities associated with arm impairment and a useless hand were enormous for many (Pound et al 1998; Barker and Brauer 2005). However, some participants in a number of studies were only focused on their lower limb and walking in the early stages after stroke and this was their priority as well as that of therapists (Kirkevold 2002, Jones et al 2008, Doyle et al 2014). Connell et al (2014) describes this as being the key focus to facilitate returning home. However, as well as Barker and Brauer (2005) and Doyle et al (2014), Connell et al (2014) found that many stroke survivors later questioned whether their arm might have recovered more if it had received as much attention from therapists as their leg had in the early post-stroke stage.

Patients valued therapy that was focused on achieving goals that were meaningful to them and where incremental progress was perceived (Sabari et al 2000, Bays 2001). Some participants in the study by Sabari et al (2000) felt that therapists were fixated on the underlying impairments of stroke without relating this to what people needed to do in their everyday lives. In his study, Burton (2000) reported that, for some participants, therapy seemed artificial and unreal because the context in which it took place was not at all similar to their home environments. Similarly, in studies on hand injuries, the focus of therapy were not always where people thought it should be. Work occupations, activities and roles that were meaningful and significant to people were not always incorporated into rehabilitation (Chan and Spencer 2004, Kingston et al 2014).

Stroke survivors were generally satisfied with the hospital phase of their care but some were unhappy with the service provided after discharge home, although this was attributed to a lack of resources in services and not individual therapists (Martin et al 2002, Kirkevold 2002, Jones et al 2008, Ellis-Hill et al 2009). The transition to out-patient or community therapy often led to disappointment in patients as the amount and duration of treatment was significantly reduced or it ceased altogether, and there was concern that this would affect their recovery (Wiles et al 2002, Cameron et al 2008, Mangset et al 2008,

White et al 2009). Contrary to this, Ellis-Hill et al (2009), in a study of people's experiences of transition from hospital to home, found many participants feeling very supported when there was preparation for discharge and continuity of services afterwards, particularly where services were flexible and adapted to people's needs. There was dissatisfaction when there was no continuity between services, or people were discharged with little warning. Cameron et al (2008), in their review of the literature on transitions in stroke care, agree with this and observed that services were often mis-timed and not available to support people in transition from hospital to home and from out-patient to community therapy. Where therapy was available after discharge, there was often a delay in its commencement, it was much less frequent compared to hospital treatment, and it was not continued long enough for patients to maximise their recovery and accomplish achievable functional goals (Sabari et al 2000, Wiles et al 2002, Cott et al 2007, White et al 2009). This was particularly a concern with regard to upper limb recovery as it was often after patients had returned home that they were ready to give their attention more fully to their arm; but if therapy was no longer available, or thought by therapists to be no longer appropriate, then the potential for further recovery was lost (Barker et al 2007). Some patients felt un-prepared for the reduction in therapy they encountered in the community, as they were used to their days being structured around therapy sessions as in-patients, and little information was given to them about this prior to discharge. In-patient physiotherapists were often reluctant to discuss this change as they had no control over the amount of out-patient or community therapy that would be available, as this was often situated in a different NHS organisation, and there was little communication between the services (Wiles et al 2002).

2.3.10 Personal Responsibility

In many of the papers, it was clear that stroke survivors wanted to be an active partner with therapists in their recovery and in setting the direction of therapy, and wanted overcoming problems to be a two-way process (Kvigne et al 2004, Jones et al 2008,

Peoples et al 2011). An essential ingredient in this was that therapists should teach people how to exercise independently outside of formal therapy sessions and be available for advice on how to progress activities (Bendz 2003; Barker and Brauer 2005). Exercise was seen by stroke survivors as the main means to recovery in the upper limb, in particular by practising regularly and intensively (Barker and Brauer 2005). Participants in the survey by Barker et al (2007) wanted advice about how to keep moving ahead in their recovery. This did not necessarily mean regular therapy but rather having access to further intermittent and timely intervention to provide them with the knowledge, skills and confidence to drive their own recovery forward. White et al (2009) found that stroke survivors felt they should be able to re-enter rehabilitation if they experienced further recovery, identified new goals, or their social situation changed. Olofsson et al (2005) found that most people took responsibility for their progress in recovery but wanted some means of keeping in contact with health professionals, mostly for advice, encouragement and re-assurance that recovery was progressing as expected. A stroke survivor in Sabari et al (2000) suggested that therapists should be available to patients every two to three months rather than on a short-term weekly basis. One example in their study showed how the lack of access back into therapy was a barrier to a patient who, during early rehabilitation, was not shown how to get in or out of a car as it was not then relevant; but later, when he wanted to be able to do this, rehabilitation was not available. A more flexible, longer-term therapy service would allow people to access information and guidance when they were ready to engage with it and as it became relevant to them in their life (Sabari et al 2000, Barker and Brauer 2005, Cameron et al 2008, White et al 2009).

2.4 Summary of the Literature Review

This narrative review has brought together findings from a wide range of literature on people's experiences of stroke; the themes from those findings reveal that stroke has the potential to disrupt a person's life significantly, and can pervade all aspects of that life and

interrupt their life story. The impairments and disabilities that can result from a stroke greatly challenge a person's independence and their competence and capability in many of the tasks, activities and roles that make up everyday life. The consequence can often be an altered sense of self with low self-esteem and changes in self-image and identity. As so little was available in the stroke literature on the effect of upper limb dysfunction, literature on injuries and pathologies of the hand was reviewed. There was a very limited range of this literature available; however, it did reveal some similarities with stroke. There was significant disruption to peoples' lives, in particular with regard to work and family life and, as a consequence, low self-esteem and changes in image and identity as people could no longer fulfil life roles in the same way.

Another aspect where there were some similarities in the literature was in the area of loss. Life after stroke was described as being grounded in loss: loss of valued activities in hobbies and leisure; loss of roles and loss of social interaction and relationships. To a lesser degree, people with hand injuries encountered losses in work, hobbies and family roles.

The literature on stroke indicated that stroke survivors find that recovery from stroke is hard work, and that people's perceptions change as they move from optimism of a full recovery to realising the longer-term nature of recovery and the possible limitations to the extent of that recovery. People recovering from hand injuries had similar experiences. Stroke survivors found information and advice during recovery often to be lacking and not available when needed. Both stroke and hand-injured participants wanted therapy and for it to be focused on their goals and valued activities rather than on impairments and function. Some people wanted more clarity from therapists in predictions of recovery, but others did not want time limits on recovery as this could impact on motivation and keeping hope alive. This was also the perspective from hand-injured participants. From the limited findings in the stroke literature, it was apparent that therapy for the upper limb after stroke was less frequent than for the lower limb. Generally, there was dissatisfaction with

the short-term nature of therapy for stroke in the community. This was a barrier to people who wanted to take responsibility for their recovery but felt they needed access to support and advice.

2.5 Development of the Research Questions

The purpose of carrying out the narrative literature review was to inform the development of the research questions for this study. The review has revealed that a great deal is known about the overall experience of stroke but little is known about how much upper limb dysfunction contributes to this experience. The literature on injuries and pathologies of the hand began to shed some light on this by showing how much an injury or pathology of just the hand alone can affect a person's life. However, the nature of the condition in comparison to stroke and the limited literature meant that transferring the findings to stroke and drawing any significant conclusions was not possible; this confirms the need for this study to explore peoples' experiences of upper limb dysfunction after stroke. As much of the literature on stroke as a whole had revealed the impact of stroke on the self, it was important that this was explored in relation to the upper limb, and so the focus of the research was on stroke survivors' perceptions and what upper limb dysfunction meant to them. Therefore, the first research question for this study was:

1. What are stroke survivors' perceptions of their upper limb dysfunction after stroke and what are the meanings they ascribe to them?

The literature review revealed that individuals' experiences of recovery from stroke is complex and can change over time as they begin to realise it is a long-term process. Furthermore, twelve of the studies in this literature review have investigated the experiences of stroke over time (Table 2.1 [page] 21] studies 6,7,9, 22, 24, 27, 33, 34, 35, 37, 43, 54), but only three have followed people for longer than a year (Kvigne and Kirkevold 2003, Kvigne et al 2004, Eilertsen et al 2010,). Therefore, it was deemed important for this study to explore the experience of upper limb dysfunction over a longer

period of time to see if people's perceptions changed. Thus, the second research question was:

2. Do stroke survivors' perceptions of the impact of their upper limb dysfunction change over time?

The review revealed peoples' experiences of rehabilitation and their priorities after stroke, and this study, therefore, sought to explore this in terms of the upper limb after stroke and what people saw as their goals in the longer term. Consequently, the third research question was:

3. What are stroke survivors' goals in the long term in regard to their upper limb?

2.6 Methodological Choices Informed by the Literature Review

In addition to informing the development of the research questions, the literature review has also influenced some of the methodological decisions made in this study. While reviewing the literature on people's experiences of stroke, and also on injuries and pathologies of the hand, it became apparent that qualitative research was by far the most appropriate and effective paradigm to identify such experiences. As can be seen in Table 2.1 (page 21), out of the 54 papers reviewed, 42 were qualitative research studies, two were qualitative systematic reviews and the remaining four literature reviews included a large proportion of qualitative studies. Furthermore, phenomenology was overtly stated as the methodology of choice in eight of the studies where various aspects of living with, and experiences of, stroke were explored (Table 2.1 [page 21]) studies 9, 17, 30, 31, 34, 35, 40, 51). For example, Kvigne and Kirkevold (2003) and Kvigne et al (2004) adopted a phenomenological methodology in their research studies as they considered this the most effective way of ascertaining how the bodily changes that can occur after stroke can affect a person's lifeworld. Similarly, Murray and Harrison (2004) selected interpretative phenomenology because of its emphasis on the lifeworld of participants and how people make sense and meaning from their experiences of being a stroke survivor. Hilton (2002),

in her study on the meaning of stroke in elderly women, used phenomenology because it can be a means of grasping and comprehending people's experiences with stroke and identifying some commonalities. From reading these studies it became apparent that phenomenology would be an appropriate methodology from which to explore and interpret not only the experience of upper limb dysfunction after stroke, but also to identify the perceptions and meanings that people ascribed to it and how it affected their lives.

Table 2.1 (page 21) also shows that 34 of the studies in the literature review used some form of interview as the means of data collection. These were narrative, in-depth or semi-structured interviews and allowed the researchers to explore issues in depth and detail with individual participants. This suggested that interviewing participants would be the optimal choice in this phenomenological study in order to explore the three research questions with participants in sufficient depth. Furthermore, using a semi-structured interview guide would, as found by Dowswell et al (2000) and Murray and Harrison (2004), allow for a consistency of approach and enable all three research questions to be addressed, while, at the same time, allow for exploration of issues of importance to the participants.

The rationale for the research paradigm, methodology and procedures that were implemented to answer the three research questions will be discussed further in the next chapter.

Chapter 3: Methods and Procedures

3.1 Introduction

The purpose of this chapter is to discuss the methodology selected for the study, the theoretical paradigm that underpins it and the methods used. The study was qualitative, phenomenological and longitudinal in nature with stroke survivors participating in a series of four in-depth, semi-structured interviews during the first 18 months after their stroke. Participants had to have upper limb dysfunction as a consequence of the stroke and have the ability to communicate their experiences verbally. The research paradigm, methodology, design, sampling, ethical issues, data collection and analysis, and the procedures undertaken to ensure the trustworthiness of the findings will be explained.

3.2 Research Paradigm

In the previous chapter it was explained that the aim of the research was to explore stroke survivors' experiences of upper limb dysfunction during the first eighteen months after stroke and the research questions were:

1. What are stroke survivors' perceptions of their upper limb dysfunction after stroke and what are the meanings they ascribe to them?
2. Do stroke survivors' perceptions of the impact of their upper limb dysfunction change over time?
3. What are stroke survivors' goals in the long term in regard to their upper limb?

A qualitative paradigm was considered to be the most appropriate means of addressing the aim of the study and answering the research questions. Hansen (2006) suggests that qualitative research is social research as it is concerned with how people experience their lives and the meanings and interpretations they ascribe to their lives. Finlay and Ballinger (2006) also state that qualitative research is concerned with how people make sense of

the world and experience events. This cannot be detached from the social context that people live in, the actions of others around them, and the situations and events that make up their lives. Qualitative research is typically inductive rather than deductive, in that it aims to investigate and explore phenomena, rather than predict and explain, and to provide detailed descriptions and analysis of the substance of human experience (Willig 2008). In relation to this study, therefore, a qualitative paradigm would enable exploration of peoples' experiences of upper limb dysfunction after stroke and, in terms of chronic illness, it would provide insight into 'what it means and how it feels to live with' this dysfunction (Willig 2008 p8).

The philosophy that underpinned this qualitative study was an interpretive and relativist one. This approach assumes there is no single reality or truth but many possible perceptions or interpretations of reality, which could change over time and will be influenced by social context (Finlay and Ballinger 2006). Human experiences and interactions are too complex to be reduced to a set of variables, as in quantitative research (Howitt and Cramer 2008). The ways in which people interpret and make sense of their experiences cannot be separated from historical, social and cultural influences, and are, therefore, relative to the situations people find themselves in. People are able to make sense of their place in the world, and therefore, in this study, the interpretive and relativist approach enabled investigation of the meanings and perceptions of people who have upper limb dysfunction after stroke and their long term goals. It was recognised that individual participants would interpret their experiences within the context of their everyday life and relative to and influenced by the situations, events and people around them

This interpretive and relativist approach, centred in the notion of multiple realities, stands in contrast to the positivist philosophy that lies behind quantitative research. Scientific methods are employed to investigate natural phenomena, such as disease in health research, with the underlying assumption that there is a single, stable reality, and that

phenomena exist whether we study them or not, and can be observed and measured objectively (Hansen 2006). This positivist philosophy relies on researchers being objective and unbiased, the need to control variables that could skew data, and the use of standardised reliable and valid measures (Coyle 2002). However, in qualitative research, it is accepted that the researcher is an integral part of the data generation process, and the knowledge and understandings produced are partial and context driven (Finlay and Ballinger 2006).

Qualitative research is being used increasingly in health care research as there is recognition that the positivist perspective that explains the objective reality and properties of the pathology, signs and symptoms of illness, is not sufficient to explain the lived experience of illness (Nicholls 2009). It is now widely recognised that grasping and understanding this lived experience is needed if the aim of person-centred, high-quality care is to be achieved (National Institute for Health and Care Excellence [NICE] 2012). In the case of this study, while the physiological and pathological process of stroke and symptoms, such as muscle weakness and altered sensation and muscle tone in the upper limb, may be similar for all participants, their perceptions and experiences of these may be very different. Quantitative objective measures of impairment, function and activities of daily living, could have been collected but they would not have fully explained participants' perceptions of the impact of impairment and dysfunction on their everyday lives and what it means for them in the context of the social world in which they are situated (Finlay and Ballinger 2006). Neither would those measures have been able to fully grasp the changing and evolving perceptions of the impairment and dysfunction over time, nor the goals that individuals may have in relation to their recovery and adjustment to residual disability. Furthermore, as Hansen (2006) observes, qualitative research is particularly suited to understanding issues and relating them to their wider contexts, and the professional background and knowledge of the researcher enables the findings to be situated within the theory, clinical practice, and health policy and guidelines. Therefore,

the participants and researcher together were co-creating knowledge (Denzin and Lincoln 2008). The influence of the researcher on the research process will be discussed in more detail in Section 3.4.7 Rigour and Trustworthiness (page 84).

To summarise, it was hoped that, by taking this qualitative approach, participants' experiences would be investigated in depth, and this would enable greater insight into the impact of upper limb dysfunction and provide new knowledge and perspectives that could inform clinical practice and service provision. In the next section, the rationale for using the qualitative methodology of phenomenology will be discussed.

3.3 Methodology

The aim of phenomenology is to 'describe the lived world of everyday experience' (Finlay 2011 p10). It gives insight to and understanding of the human condition and experiences. Phenomenology was formulated by the 20th century German philosopher Edmund Husserl who was 'interested in the world as it is experienced by human beings within particular contexts and at particular times' (Willig 2008 p 52). Husserl was concerned with phenomena as they appear in a person's consciousness rather than in abstract facts about their nature. In other words, it makes no sense to think of the world of objects and subjects as separate from our experience of them, as all reality is made up of objects and events as perceived by someone's conscious experience (Willig 2008). Therefore, 'nothing could be spoken about or witnessed if it did not come through someone's consciousness' (Giorgio and Giorgio 2008 p26). So it is not surprising that different people can experience what appears to be the same phenomenon in very different ways. Phenomenologists believe that by creating data with people who have experienced a particular phenomenon, a composite description can be assembled of the essence of the experience for all participants (Creswell 2007). Therefore, in the context of the research questions in this study it was considered that, by using the methodology of phenomenology the essence of living with a dysfunctional upper limb after stroke would emerge as participants talked about their lived experience. This phenomenological

approach could then contribute to a greater understanding of the effect that a dysfunctional upper limb can have on people with stroke, and is congruent with the increasing use of phenomenology in health research to provide a greater understanding among health professionals of the patients' perspective of ill-health or disability (Hansen 2006).

Phenomenologists recognise that human beings experience the world through their bodies (Polit and Tatano Beck 2014). Embodiment acknowledges peoples' physical ties to their world as they think, see, hear, feel, move and are conscious. It also recognises that lived experience, or the lifeworld, has four aspects to it: lived space, or spatiality; lived body, or corporeality; lived time, or temporality; and lived human relations, or relationality (Finlay 2011). This is particularly relevant to investigating the experience of upper limb dysfunction after stroke. Physical impairment can limit how a person moves and uses their body, how they sense their body and the space and environment around them, and these things can have an effect on the nature of their relationships. Furthermore, stroke is usually a sudden event that happens in a particular time in a person's life and can change how they view their past life and anticipate the life that lies ahead in their future (Ellis-Hill 2000). Finlay (2011) argues that a person's sense of self arises out of their experience of their body and their relationships with others, and, therefore, the body, self and world are intertwined. Consequently, the methodology of phenomenology was considered to be the most effective way of gaining access to the lifeworld of stroke survivors with upper limb dysfunction.

There are diverse forms of phenomenology. However Creswell (2007) and Willig (2008) agree that they broadly fall into two categories: descriptive and interpretive. This study is in the interpretive category. Descriptive phenomenology remains true to Husserl's philosophy of careful portrayal of phenomena as lived by people. The primary aim is to be as true as possible to the participants' accounts of their experience and to achieve a credible description of the phenomenon of interest (Polit and Tatano Beck 2014). A key

aspect of this is bracketing, where all past knowledge and pre-conceived beliefs and opinions of the researcher about the phenomenon under investigation are bracketed and held to one side in an effort to see the data as they truly are (Finlay (2011)). However, interpretive phenomenology, also known as hermeneutic phenomenology, which was founded by Martin Heidegger, a student of Husserl, stresses the importance of interpreting and understanding human experience rather than just describing it (Creswell (2007)). Hermeneutics presupposes the researcher's prior knowledge and understanding and asserts that it is not possible to bracket this knowledge and understanding. The researcher and the participant are engaged together in coming to an understanding of the phenomenon, but researchers should be reflexive about how their previous experience, knowledge and assumptions might have impacted on the research (Finlay 2009). In this study, the researcher's professional and academic knowledge of stroke and clinical experience as a physiotherapist came to the fore during the final stage of analysis, where the data were mapped against theory, health policy and guidelines, clinical practice, and service provision. This was done in order to fully explain, understand and situate the participants' experiences of upper limb dysfunction after stroke in this wider context. Other qualitative methodologies were considered. Ethnography would not have been suitable as the aim of the study was to explore individual lived experience rather than the interactions and shared values, beliefs and patterns of behaviour of stroke survivors in particular settings and locations, which is the purpose of ethnography as described by Creswell (2007). Similarly grounded theory, which was developed in sociology research in the 1960's by Glaser and Strauss (Polit and Tatano Beck 2014), was not adopted as the study was about explaining and understanding the experiences and perceptions of living with upper limb dysfunction rather than trying to arrive at concepts and categories to generate a theory that might explain this.

In summary, a phenomenological methodology was considered the most appropriate means of answering the research questions. It facilitated the emergence of perceptions

and meanings of living with a dysfunctional arm after stroke. In the next section, the study design including the rationale behind the methods used for data collection and analysis will be explained and discussed.

3.4 Study Design

3.4.1 Semi-structured Interviews

In this study it was important that participants were engaged in a way that encouraged them to express freely, in their own language, their thoughts and feelings on having a dysfunctional upper limb after stroke. In qualitative studies language becomes both the means of data collection and the data themselves (Green and Thorogood 2009). It is the vehicle through which participants' perceptions and meanings of their experiences in their everyday lives can be expressed, and an understanding of them arrived at. Willig (2008) describes the type of data collected in qualitative research as naturalistic. In other words, the design of a study should not summarise or categorise the data at the point of data collection. The design should minimise any reduction or processing of the data and should engage the participant in a process of data gathering that creates a comprehensive record of their words and actions. Furthermore, the design of a phenomenological study should generate data through an encounter between the researcher and participant, where the meanings of a phenomenon can emerge through dialogue and language (Finlay (2011)). Therefore, it was decided that interviews with individual participants was the most effective method of achieving this. Interviews are one of the most common forms of data collection in qualitative research and phenomenology (Hansen 2006, Green and Thorogood 2009). It was thought that through engaging on a one-to-one basis with the researcher, participants would have the opportunity to express their thoughts and feelings; in addition through putting these thoughts and feelings into words, they could find fresh interpretations and be able to make further sense of their experiences and perceptions (Howitt and Cramer 2008). Furthermore, these

conversations enabled the researcher to enter into the participants' world and have access to their experiences and perceptions.

Research interviews are a particular type of conversation where the direction of the conversation is determined by the type of data required by the researcher (Creswell 2007). Interviews can be classified by the level at which the researcher directs the interview and the topics covered. Broadly speaking, it is recognised that in phenomenological research there are two types of interview: unstructured, also referred to as in-depth; and semi-structured (Hansen 2006, Finlay 2011). Semi-structured interviews were chosen for this study rather than unstructured. It was considered important to this study that participants would be directed to keep their focus on their upper limb dysfunction after stroke rather than their wider experience of stroke. An interview guide of topics and open-ended questions, which is the typical format in semi-structured interviews (Willig 2008), helped the researcher to get at the more specific impact of upper limb dysfunction on participants' everyday lives. Participants might have found it more difficult to dissociate the upper limb from other areas of dysfunction while talking about their experiences in unstructured interviews, where the researcher may ask an introductory question and then allow participants to talk freely about their experiences (Polit and Tatano Beck 2014). This, in fact, became apparent during the focus group that was conducted to inform the interview guide for the first interviews, and is reported on in section 3.4.2 (page 64). In that instance, the participants strayed very easily into talking about their wider experiences of stroke, and it required strong direction from the facilitator to keep the focus on the upper limb. This confirmed the need for semi-structured interviews as the vehicle by which the data required to answer the research questions could be obtained. Using non-standardised, open-ended questions maintained the focus of the interview but gave flexibility in the order in which questions were asked, enabled the researcher to follow participants' experiences, and to prompt and probe for more depth

and clarification (Silverman 2001, Hunt and Smith 2004). The development of the interview guide follows in Section 3.4.2 (page 64).

Bringing together focus groups of participants with upper limb dysfunction after stroke could have been an alternate method of data gathering from a greater number of participants (Stewart et al 2007). There may be advantages to this in that a group of participants may spark off different views and perceptions that individual participants may not have thought of previously (Hansen 2006). However, a group setting can be counter-productive and prove a barrier for some participants. Uncertainty about the reactions of others in the group when sharing experiences, or being over-shadowed by more assertive group members, can prevent some participants from sharing the full extent of their thoughts and feelings (Lewis 2003). Furthermore, there may have been less time and opportunity for participants to fully articulate their perceptions of their individual lived experiences, which was the primary aim of this study.

The second and third research questions in this study were to explore whether participants' perceptions of the impact of their upper limb dysfunction would change over time, and also what their goals would be in the longer term for their upper limb. Therefore, it was necessary for this study to be longitudinal in nature and for participants to be interviewed more than once over an extended period of time. The fact that the study was being completed as a part-time PhD enabled data to be collected over an 18-month period of time. This period allowed any changes in participants' experiences and goals over time to emerge. Ideally, an even longer time period would have been advantageous to explore changes in perceptions and goals, as it is recognised that recovery after stroke and adjustment to disability can occur over many years (DH 2007). However, this was not possible within the time restrictions of this PhD, although it is potentially an area for further investigation. Another advantage of this longitudinal study was that some familiarity and rapport was built between the researcher and participant over time, and this may have provided more detail and depth in subsequent interviews. Also, participants had time to

reflect on their responses in previous interviews and then build on these in subsequent ones.

It was important in the study that upper limb impairment was clearly established in participants by the time of the first interview, and that it was not transitory and, therefore, likely to resolve quickly with minimal impact in the longer term. Therefore, the first interviews took place at two months after the stroke had occurred. This also ensured that participants were medically stable and able to fully participate in an interview.

Subsequent interviews were at six months, twelve months and eighteen months after the stroke. It was considered that this was sufficient time between interviews to explore any changing perceptions and experiences with participants.

3.4.2 Preliminary Phase – Carer and Service User Consultation to Develop the Interview guide

The more general experiences and perceptions of stroke that were explored in the literature review in Chapter Two were the starting point for the topic areas of an interview guide, but, in order to be able to develop questions that would be the most salient and of interest to stroke survivors, it was decided to consult the users of a Stroke Association support group with the aim of ascertaining their views and insights into upper limb dysfunction. The National Stroke Strategy (DH 2007) suggests that stroke survivors should be consulted and involved in the development of research and, as explained in the introduction and background to the thesis in Chapter 1, the National Institute for Health Research recommend active patient and public involvement in all stages of research (INVOLVE2015). It was considered that the experiences of service users with stroke could provide insight into living with a dysfunctional arm and would ensure that the most appropriate and relevant topics and questions would be included in the interview guide. This would ensure that the outcome of the research would be relevant to service users and, therefore, more likely to inform clinical practice (INVOLVE 2013). The clinical background and perspective of the researcher in this study, as a physiotherapist, may not

have been enough to ensure that the interview guide was fully relevant to participants and would elicit meanings beyond what may have been expected. As stated in the literature review the goals of people with stroke can differ from those of health professionals (Burton 2000, Sabari et al 2000, Bendz 2003, Cott et al 2007) and so consulting service users was seen as an essential process in the development of the data collection process.

It was decided, therefore, as a preliminary phase of the research, to conduct a focus group with the Stroke Association support group members. Focus groups are a means of generating complex information at a low cost and in a minimum amount of time and are a useful way of exploring a phenomenon about which little is known, as in the case of this study where people's experiences of upper limb dysfunction have not been fully explored (Kroll et al 2007, Stewart et al 2007). Furthermore, an exploratory focus group in the preliminary phase of a study is a useful means of developing items for inclusion in an interview guide (Barbour 2007). Permission to approach the support group members was sought from the Regional Coordinator of the Stroke Association and ethical approval was gained from York St John University Ethics Committee. A copy of this is in Appendix 10: Ethical Approvals (page 277).

3.4.2a Recruitment of Participants to the Focus Group

In order to recruit participants to the focus group, the researcher attended one of the monthly support group meetings to explain the purpose of the consultation and the focus group. An information sheet was given out to those people with stroke who had some upper limb dysfunction and there was opportunity during the support group meeting to answer any individual's questions about the research. Consent forms were handed out to those people who expressed an interest in participating. The information sheet and consent forms are in Appendix 1 (page 239). A total of eight people showed an interest in participating. They were given a further three weeks to consider this and were then contacted by the researcher by telephone to confirm their participation. Two people were

unable to participate due to other commitments. Completed consent forms were collected from the remaining participants on attendance at the focus group.

3.4.2b Focus Group Sample

A volunteer sample of six stroke survivors with upper limb dysfunction at various stages of post stroke recovery attended the focus group. A group of six participants was considered to be an acceptable number for the focus group. Smaller groups run the risk of being dominated by one person, whereas this is less likely to occur in larger groups (Fallon and Berman Brown 2002, Peek and Fothergill 2009). Larger groups can be difficult to manage and not all participants may get the opportunity to contribute. Table 3.1 (below) shows the age, sex, time since stroke, side of the body affected by the stroke, and dominant hand. Participants have been given pseudonyms to protect their anonymity.

Table 3.1: Focus Group Participants

Name	Sex	Age	Time since stroke (months)	Affected side	Dominant hand
Jack	Male	77	24	right	right
Keith	Male	78	31	left	right
Frank	Male	77	33	left	right
Ted	Male	65	43	right	right
Colin	Male	72	64	left	right
Kevin	Male	67	24	left	right

All participants were male, and this may have had an influence on the data generated in the focus group discussion, as women are considered to be more able to express their emotional reactions to experiences, whereas men may report more concrete, factual

information (Stewart et al 2007). Unfortunately, the members of the support group at that time who had upper limb dysfunction, and were able to communicate and, therefore, to participate in a focus group discussion, were predominantly male. The two people who initially showed an interest in the focus group but then were unable to participate were female.

3.4.2c Focus Group Data Collection Procedures

The focus group was held at the same location as the usual drop-in group, and on the same day and time as the drop-in group. This meant that the participants were in familiar surroundings, as it was thought this would put them at ease, and, furthermore, they had no additional travel or time commitment to make. Participants sat round a large table so they could all see and hear one another easily. A topic guide of open-ended questions was used to stimulate the group discussion and participant interaction so that the conversation could flow and move in a direction determined by the participants but yet stay focused on the topic (Bowling 2002, Pope and Mays 2006, Stewart et al 2007). As each question was discussed, several large pieces of paper with the question printed in large font were distributed around the table so that all participants could see the question. This acted as a prompt and reminder to keep everyone focused on the topic being discussed at that point (Kroll 2007). The questions were:

- What was important to you when you first had your stroke and has this since changed?
- How soon after your stroke did the difficulty in moving your arm and hand become an issue?
- What are your thoughts about the therapy you have had for your arm and hand?
- How does your arm and hand affect your life and the activities you like to do now?
- How do you see the recovery of your arm in the future and what information have you been given about this?

- Please add anything else that you think is important with regard to your arm and hand.

The researcher acted as the facilitator, introducing the questions and ensuring that everyone in the group had an opportunity to share their experiences, and that the conversation was not dominated by any one individual, which can happen in a focus group (Bowling 2002, Kroll et al 2007). The facilitator role should be one of encouraging and showing a genuine interest in people's thoughts and experiences (Stewart et al 2007). This is crucial in drawing out important contributions and providing rich data. An observer was also present to make field notes on any non-verbal communication between group members, such as significant facial expressions or gestures, to augment the transcript taken from the audio recording and to enhance the data analysis (Kidd and Parshall 2000, Barbour 2007).

3.4.2d Data Analysis and Findings from the Focus Group

The focus group discussion was audio-recorded and transcribed verbatim. The observer's notes of facial expressions and non-verbal gestures supplemented this (Stewart et al 2007). The data were analysed using thematic analysis. This process of data analysis is explained more fully later in this chapter in Section 3.4.6 Data Analysis (Table 3.3 Steps 1-6 page 77). The data were coded using the computer software package NVivo 8 and organised into categories and themes. Four main categories were identified in the data: self care, valued activities, therapy and recovery. The categories and themes that were extracted from the categories, with some examples of participant quotations, are presented in Table 3.2 (page 69). More participant quotations are in Appendix 2 (page 242).

Table 3.2: Focus Group Categories and Themes

Category	Theme	Quotation
Self-care	Mobility	<i>'we'll go for a little walk ... out of the ward and the first thing in front of me is the stairs. You automatically go like that [gesturing as if he is going to grab the hand rail with his right hand] but you can't because you've got your stick so you've got to get hold of it, have your stick in this hand [gesturing with left hand] 'cause I find it difficult holding the stick.'</i>
	Toileting	<i>'one thing that hit me was I've also got a colostomy – two handed job – only one hand.'</i>
	Feeding	<i>'with me it became more important when you couldn't eat with being left handed to start off with my right hand, which I do now, but of course more food goes on floor down here.'</i>
Valued activities	Driving	<i>'Biggest thing we've found is we can't manage to drive anymore ... i was never a car driver I was a motorcyclist.. '</i>
	Leisure	<i>'I used to play bowls - it stopped me bowling for quite a while.' 'Can't play cricket'. 'I used to swim'</i>
Therapy	Amount	<i>'I had to wait 6 weeks before I'm onto the physio staff from leaving hospital'.</i>
	Information	<i>'no you're told to just keep exercising that's all, erm keep using it and hope it'll come good.'</i>
Recovery	Motivation	<i>'If I don't exercise one day I start from scratch the next, you go back a bit.' 'You know you've got to use or lose it.'</i>
	Attitude	<i>'I can't describe how It turned my life upside down. Still learning, constant learning curve I suppose, I don't know I can't describe it.'</i>
	Priority of arm or leg	<i>'My leg, my leg Well I couldn't get around if I couldn't balance on my leg. This [raises his left hand] I could concentrate on later. It wasn't too bad at least I could pick things up.'</i>

The findings from these themes indicated areas that could be explored in future interviews and sensitised the researcher to these four areas self-care, valued activities, therapy and

recovery (see Table 3.2 above). These data were not added to the data for the main study but were used solely to inform the interview guide and sensitise the researcher.

3.4.2e Consultation with an Expert in Hand Therapy

In addition to consulting service users, an occupational therapist specialising in hand therapy was consulted for her opinion on areas that should be explored with participants. This was also done as a preliminary phase of the research. Her area of expertise was not in stroke but in hand trauma and pathologies, such as rheumatoid arthritis. This provided a perspective from an expert in hand dysfunction, within a different therapy discipline from that of the researcher, on the impact it could have on a person's life and occupations, in its broader sense. A record of the consultation is in Appendix 3 (page 244). This provided additional topic areas around body image to explore with participants, such as feelings about the appearance of their arm and hand, their ability to dress and adorn their body, and also about significant life roles they have and how they may be affected by a dysfunctional hand.

The information gathered from the consultations with the service users, and the expert in hand therapy, were added to that of an initial literature review on experiences of stroke to construct the interview guide. A copy of the interview guide is in Appendix 4 (page 246). The topic areas can be broadly summarised into: personal appearance and their feelings about this, personal care, communication, valued activities, life-roles, recovery, therapy, and advice and information. This provided a guide for the semi-structured interviews with participants, and, as the researcher had been sensitised by the experiences of the service users in the focus group, the interviews were not fully open as may be expected in some phenomenological research. However, it was a guide and not a rigid structure, and this did, therefore, allow the researcher to follow participants' leading and areas of significance for them, and also to probe for more information where necessary. Furthermore, as explained in section 3.4.1 (page 61), the experience of conducting the focus group highlighted that some structure and direction was needed to enable participants to

dissociate the issues around the upper limb from the general issues of stroke, and for a novice researcher this also was helpful.

As the process of data collection and analysis progressed over the longitudinal course of the study, the interview guide evolved to reflect the data accruing from the participants in previous interviews. The process therefore became an iterative one as is so often the case in qualitative research (Creswell 2007, Willig 2008, Green and Thorogood 2009), with the interview guides for individual participants at six, twelve and eighteen months being influenced to some extent by the preceding interview.

3.4.3 Interviewing Style

When using an interview design, the interviewer becomes the most important data collection tool and, therefore, researchers need to consider the style in which an interview should be conducted (Hansen 2006). As in the case of the researcher in this study, many health professionals receive training in and have experience of interviewing. The skills in clinical interviewing of building rapport and trust, putting people at ease, being non-judgemental in both verbal and non-verbal language, and active listening are also essential to build relationships with participants in research. However, for this study other skills useful in clinical interviewing would not be useful in this type of research (Green and Thorogood 2009, Finlay 2011). It was important that questions were put to participants in an open-ended way to allow them time and control in answering the question. This was very different from the closed questions frequently used to obtain a case history in a clinical interview. Furthermore, in clinical history-taking, the interviewer may have prior assumptions about the categories of information that would come forward, but in this case the researcher had to remain open to whatever was identified in the data, while being mindful that the focus of the study was on the upper limb. In addition, it was vital that the researcher allowed for pauses and periods of silence in the interview where no-one was speaking and did not move on to successive questions too quickly. This gave participants time to reflect on the question asked or the answer they had just given and sometimes

provided space for them to reveal more (Finlay 2011). To develop and maintain this interview style the researcher listened to the early interview recordings and reviewed transcripts to improve technique.

So far in this section on study design, the methods used in data collection have been discussed. The next section will go on to explain the decisions made on sampling and sample size.

3.4.4 Sample

Qualitative data requires in-depth analysis and interpretation and, therefore, large sample sizes are not easily managed (Morse et al 2001). In contrast to quantitative research, the purpose is not to have a large randomly selected sample from which results can be generalised to the wider population. The sample should be purposive and therefore should be those people who can give information-rich data that can provide a full understanding of the topic under investigation (Hansen 2006). In the case of this study, the sample was taken from a population of adult stroke survivors, who had experienced a stroke within the previous two months, and who had been identified by a physiotherapist as having impairment of function in their upper limb causing limitation in spontaneous use in functional everyday tasks. The sample size should be large enough to ensure sufficient breadth, i.e. participants that reflect the range of people that are relevant to the topic, and small enough to allow in-depth data analysis (Bramley and Eatough 2005, Wain et al 2008). In this longitudinal study, where data were collected from each participant up to four times, a sample size of 14 to 16 was considered sufficient and also manageable within the limits of a PhD. This provided adequate breadth – in that similar numbers of male and female participants, a mixture of people with affected dominant and non-dominant upper limbs, and severity of stroke, could be recruited – but allowed for depth of analysis to give insight into the experience of upper limb dysfunction after stroke. However, recognising that mortality in people who have had a stroke could be an issue, the option to recruit more participants during the study remained open.

The decisions made about study design regarding data collection and sampling raised certain ethical issues that had to be considered and managed, and these are discussed in the next section.

3.4.5 Ethical Issues and Procedures

Following a successful methodological scrutiny by Keele University Independent Peer Review Committee ethical approval was sought from and granted by East Yorkshire and North Lincolnshire Research Ethics Committee. Copies of the approvals from both committees are in Appendix 10 (page 277).

As there was no intervention in this study, one could have assumed that there would be no potential for physical harm to participants; however, there was the possibility that engaging in the interviews could provoke emotional distress. The interviews were directed at asking people to explain their experiences of stroke and their arm dysfunction and reflect on their perceptions of this. Therefore, there was the potential that this could have evoked difficult memories for them and powerful, unresolved feelings (Roberts 2002, Nunkoosing 2005). Thus, it was important that the researcher was sensitive and non-judgemental and alert to any verbal or non-verbal signs of distress, and also could signpost or refer people on to support services if necessary. Additionally, as most of the interviews were conducted in participants' homes, it was recognised that there was potential to disrupt their normal routines and require a commitment of time from them. Therefore, all participants were contacted by telephone to arrange interviews at a time of their choosing and convenience.

It is essential that people approached to participate in a research study are given sufficient information about the methods of the study and the data collection procedures so that they can make an informed decision about whether or not to take part. In addition, they should have the opportunity to clarify any queries they may have with the researcher and be allowed a period of time to consider their decision and perhaps discuss it with family or friends (Morse and Richards 2002, Hansen 2006). Therefore, in this study all potential

participants were given both oral and written information about the study, and then one week in which to consider their participation before they were asked to give consent. A copy of the information sheet and the consent form are in Appendix 5 (page 248).

Research interviews may be a potential area for exploitation as participants may perceive the relationship between themselves and the researcher as unequal, in that the researcher will have more knowledge of the research methods and procedures.

Therefore, it was regarded as vital that the researcher should maintain respect for the participants' views by adopting a non-judgemental attitude that would enable participants to freely express their opinions and feelings. It was hoped that, by conducting the interviews with sensitivity and care, and allowing people opportunity to reflect and talk freely about their perceptions and experiences, this would be a positive process for participants (Hansen 2006, Green and Thorogood 2009). Furthermore, participants were re-assured that they could withdraw from the study at any time without having to give an explanation. In addition, re-assurances were given that withdrawal would not have an impact on any current or future treatment for their stroke, thus allaying any feeling of coercion to participate (Lewis 2003).

It is recognised that there is potential for deteriorating health or mortality within stroke survivors (DH 2007), and so there was the possibility of causing distress to a participant, or a family member, by an untimely or insensitive contact from the researcher in the event of a change in the participant's condition. To avoid this, all participants' GPs were informed by letter (see Appendix 6 page 253) of their participation in the study and the researcher then contacted the GP prior to any appointments being made for interviews. In the event of a death or a participant becoming too unwell to continue in the study, the data already collected was retained and used in the study.

Maintaining the privacy of a participant and confidentiality of their data is a key ethical criterion in any research study (Willig 2008, Green and Thorogood 2009). In this study,

potential participants were identified through a local collaborator, who was a physiotherapist and was involved in the care of some of the participants. However, it was made clear to participants that none of the information disclosed in an interview would be disclosed to the local collaborator. Data from the interviews were only discussed with the researcher's supervisory team. The only time it was anticipated that confidentiality could be at risk was if there were concerns about the safety and wellbeing of a participant. The researcher, having undergone training in safeguarding of vulnerable people, was aware of local policy and procedures for reporting any such concerns. Similarly, with the consent of the participant, the researcher had access to appropriate clinicians in the event of any issues arising requiring medical intervention. The interviews that were held in the rehabilitation facility were conducted in a private room where the conversation could not be overheard. In the case of interviews taking place in participants' homes, the researcher followed the lead of the participant as to where in the home it was situated and who might possibly overhear (French et al 2001).

Procedures were put in place to ensure all audio recordings and transcripts were kept in a secure place only accessible to the researcher (Morse and Richards 2002). To maintain anonymity and confidentiality, participants were allocated a code used on all transcripts and tables and charts, and a pseudonym in the thesis. Identifying features of the location of the research were removed (Hansen 2006). Furthermore, it was not deemed necessary for the researcher to have access to the participants' medical records beyond the need for their contact details, demographic information and the NIHSS score.

Ensuring the safety of researchers whilst out in the field is another aspect of research ethics (Creswell 2007). Procedures must be in place whereby a researcher can inform others of their location and time of departure and expected time of return. In this study the Keele University Lone Worker Policy was followed. The researcher informed the research office of the times and locations of interviews and carried a mobile phone to raise an alert if safety was a concern. Researchers can encounter disturbing and emotional situations

when gathering data and there should be arrangements for de-briefing and support afterwards (Willig 2008). In this study there was opportunity within regular supervision sessions to discuss any such occurrences. Also, throughout the study, ethical issues were regularly discussed so that appropriate and justifiable decisions were reached. The next section will move on from considering the ethical issues to discuss the theoretical approach to the analysis of the data.

3.4.6 Data Analysis

This section will explain the rationale behind the methods used to analyse the data in this longitudinal study in which each participant was interviewed at two months, six months, twelve months and eighteen months post-stroke. Table 3.3 on page 77 identifies the steps taken in the data analysis process.

Table 3.3: Steps in the Data Analysis Process

Step 1	Adopting a phenomenological attitude to be open to all possibilities in the data.
Step 2	Listening to the interview several times, referring to any field notes, to remember the interview as a whole.
Step 3	Reading and re-reading the transcript several times.
Step 4	Annotating the transcript where recurring themes are identified.
Step 5	Coding the transcript to label the themes and to look for similarities between them.
Step 6	Clustering of similar themes into a table of themes for every interview with each participant.
Step 7	First supervisor analyses a sample of three transcripts from each interview point.
Step 8	Supervision meetings to discuss and review data analysis and development of tables of themes.
Step 9	Collating the data into charts, for each interview point of two-, six-, twelve- and eighteen months post-stroke, of super-ordinate themes across all participants.
Step 10	Supervision meetings to discuss and review development of charts.
Step 11	Mapping of data to concepts, theory, policy and service provision.

Two approaches guided the analysis at different stages. The first was thematic analysis, to identify the themes emerging from the transcript of each interview, and the second was a modified form of framework analysis, to manage, organise and interpret the data within and across all participants (Creswell 2007). The decision to use a form of thematic analysis was arrived at very early in the design of the study; however, the decision to use a modified form of framework analysis was taken at a later stage when it was recognised that the large amount of data generated from this longitudinal study would need a structure that would facilitate data to be viewed and summarised across and within all participants but yet still grounded in the transcripts.

The purpose of analysing qualitative data is to reflect the complexity of the phenomena studied but also to transform it into a structure that allows the meaning of the data to emerge (Green and Thorogood 2009). Furthermore, in health research, bringing interpretation and structure to the data can situate and explain participants' experiences and perceptions within the wider context of theory, policy, guidelines, clinical practice and service provision (Hansen 2006). There are no universal rules for analysing qualitative data and this can make it challenging for a novice researcher, as in the case of this study (Hansen 2006, Polit and Tatano Beck 2014). However, Creswell (2007) suggested that there are three central steps followed by all qualitative researchers and these were followed in this study: first to prepare the data; second to reduce it into themes through a process of coding and condensing codes; and finally to represent the data in tables and discussion.

In this study, the first process was to prepare the data by transcribing the interview recordings (this was done through a transcription service – see page 96). It is important that transcripts fully reflect the conversations that took place so that none of the meaning and nuances intended by participants is lost (Legard et al 2003, Green and Thorogood 2009). Therefore, transcription was verbatim i.e. it documented what was spoken word for word, in any local dialect, slang or idioms that were used. Pauses, hesitations, laughter or any expressions of distress were noted. However, it was acknowledged that transcripts cannot provide access to the non-verbal elements of communication that occur in an interview so inevitably some information is lost and, therefore, there will always be some element of reduction in the data. A verbatim transcript of an interview is not the same as the participant's delivery in real time. Nevertheless, the aim in transcription was to lose as little as possible in the transforming of the data and to produce a rich description. Field notes were also made during and immediately after the interview so that any points of emphasis, mood, tone and body language could be noted to add to the depth of the words spoken and the creation of meaning from the data (Hughes 1994, Artur and Nazroo 2003).

The next stage of analysis was to reduce the data in the transcriptions into themes through a process of coding, where transcripts were annotated to identify codes, and memos were written to record initial observations, thoughts and impressions about the data (Creswell 2007). Transcripts were read several times over and interview recordings listened to again so that the full sense of the interview could be remembered as a whole before it was broken down into parts [steps 2 and 3] (Srivastava and Thomson 2009). Willig (2008 p 55), in a discussion of phenomenology, suggests that, at this stage researchers should ensure they are 'truly present to the phenomenon as it manifests itself in a particular instance'. To do this, a phenomenological attitude must be adopted in which all past knowledge about the phenomenon, both lay and expert is acknowledged by the researcher and put to one side, so that the meaning of the participants' experiences can be identified [step 1]. The reflexive process that was undertaken in this study is discussed in section 3.4.7a (page 88).

As the purpose of this study was to explore the experiences and perceptions of upper limb dysfunction after stroke, it was considered appropriate to use thematic analysis. Green and Thorogood (2009) and Hansen (2006) acknowledge that thematic analysis is often used in health research as it is useful in answering questions about the salient issues for particular groups of people; so, in this study it was particularly suited to identifying the experiences and perceptions that are most important to stroke survivors with upper limb dysfunction. Themes are identified by a researcher looking for recurring patterns of interest in the transcript. Sections of the data that correspond to particular themes are marked and given a label, i.e. a code that might be derived from a term used by a participant, or a descriptive label (Smith and Osborn 2008). In the case of this study, this was done by initially annotating each transcript in the margins [step 4]. For example, the label 'toileting' was used to annotate areas of the transcript where participants talked about issues and feelings they had about the effect their arm dysfunction had on accessing and using the toilet [step 5]. Themes can be suggested by the research

questions – these are known as ‘a priori’ themes – but also, more commonly in phenomenological research, themes are identified inductively from the data as the researcher adopts the phenomenological attitude, as described above, and scrutinises the transcript for themes that truly represent the participants’ experiences (Willig 2008). Only two ‘a priori’ themes were used in this study: one was around the long-term goals participants had with regard to their upper limb, and the second was whether their perceptions of their upper limb dysfunction would change over time. All other themes were identified as each transcript was read and interview recordings were listened to.

As Polit and Tatano Beck (2014) note, thematic analysis is seldom a tidy linear process. Iteration is often necessary where the researcher keeps going back to the transcript with themes in mind, checking that they are an accurate representation, and, in some instances, where data analysis begins before data collection with all participants is complete. Analysis of early data, therefore, will influence later data collection. In this longitudinal study, where each participant was interviewed up to four times, the interview guide that was developed for the first interviews at two months after stroke was modified as interviews were conducted and analysed and then more interviews conducted.

At some point, order and structure has to be brought into the analysis to reduce the data and make it more manageable (Hunt and Smith 2004, Smith and Osborn 2008). This is the final step of the analysis process as suggested by Creswell (2007) and it involves thinking about the themes in relationship to one another. This is an approach used in interpretive phenomenological analysis to enable a researcher to move on from just describing phenomena to bringing some interpretation (Willig 2008, Green and Thorogood 2009). In this study, interviews were analysed one by one. The integration of data between and within participants was left until the later stage in this process, where a modified form of framework analysis was applied. This is discussed later in this section. The initial themes in each transcript were viewed for similarities and relationships to one another and clustered together. For example, the theme ‘toileting’ was clustered together

with themes of 'dressing', 'washing/bathing and grooming', and 'feeding' into a theme of 'self-care'. From this a table of themes for each transcript was developed, which noted the themes, key words or phrases that illustrated each theme, and the relevant page and line number from the transcript [step 6]. An example of a table of themes can be seen in Appendix 7 (page 254). This structure enabled the continuing iterative process of going back and forth between analysis and the original data. Furthermore, the table indicates that the themes arrived at were grounded in participants' words, thus maintaining the rigour of the process and providing a transparent audit trail which is considered to be good practice in qualitative designs (Hunt and Smith 2004, Smith and Osborn 2008). In addition to this, a sample of three transcripts from each interview point was reviewed by the researcher's first supervisor. These were then discussed and reviewed at regular supervision meetings [steps 7 and 8].

The next stage in this process of bringing order and structure to the data was to move on to use a modified version of framework analysis, to look across all participants at each of the four data collection points of two, six, twelve and eighteen months post-stroke, and to look longitudinally throughout all of the data points. It was at this point that the amount of data identified from the four data collection points with each of the participants seemed daunting for this novice researcher to manage, and the framework approach provided a process that could guide a systematic and rigorous analysis of data, both across and within participants, from the initial thematic analysis through to the development of an interpretive account of the phenomenon of upper limb dysfunction after a stroke (Furber 2010, Smith and Firth 2011).

Framework analysis was developed in the 1980's by social policy researchers at the National Centre for Social Research, who described it as a method that involves summarising and classifying data within a thematic framework (Ritchie and Spencer 1994). It was specifically developed in the context of applied policy research that is commissioned to meet specific information needs and provide outcomes that may shape

social policy, for example in health, education, or crime and justice (NIHR RDS 2009, Srivasta and Thomson 2009, Furber 2010, Smith and Firth 2011). Commissioners of such research want to see the steps by which the results have been obtained from the data (Ritchie and Spencer 1994) and it is frequently carried out by a research team, in a short time-scale, so efficient and specific processes are needed that can be viewed, discussed and operated by individuals within a team (Ritchie et al 2003). Over the last decade, this method has been increasingly used in healthcare research to produce practice-oriented findings where the views and experiences of patients with particular conditions are increasingly sought and valued in the shaping and delivery of services (DH 2007, Green and Thorogood 2009, NIHR RDS 2009, Furber 2010, Smith and Firth 2011). It was selected for this study for several reasons: firstly, to facilitate a structure whereby the themes identified in the tables of themes from each transcript could be summarised across and within participants. The processes in the framework approach allow a researcher to move back and forth across and within data until a coherent interpretive account is identified. Secondly, it would aid interpretation of the data in the light of theory, policy, guidelines, clinical practice and service provision, and to make this interpretation of participants experiences, by the researcher, transparent (Smith and Firth 2011). Thirdly, it would ensure that all relevant data from the transcripts were captured and easily accessible to the researcher's supervisor, whereby confirmation of the themes and interpretation could be verified (Ritchie et al 2003). A criticism of the framework approach is that it could be a more linear method and thereby limit the creation of understandings and interpretations that could be identified from the data. An alternative method could have been using a mind-mapping, or concept-mapping, technique whereby themes and concepts linked to a central topic are identified in visual forms as branches and inter-connections from the central topic. This is thought to stimulate memory and creative thinking (Buzan and Buzan 2009, Wheeldon and Faubert 2009). However, it was considered that the framework approach would still allow for creativity of thought as the researcher moved back and forth in an iterative manner between the tables of themes and

the charts but, at the same time, have an overview of the data within each participant and across the participants (Smith and Firth 2011).

There are five key stages in framework analysis: familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation. The first and second stages of familiarisation and identifying a thematic framework are very similar to the iterative thematic analysis described above. The only difference was that, in framework analysis, each theme is numbered in a framework so that during the next stage of indexing every transcript can be annotated with the theme number according to where that theme appears in the text (Ritchie and Spencer 1994). In this study, indexing of the transcripts was not done because the decision to use a modified form of framework analysis was taken after tables of themes had been developed. Key words or phrases from the transcript with their page and line numbers, which were in the table of themes from every interview with each participant, were deemed sufficient to move to the next stage of charting. This was the modification of the process, but the remainder of the analysis followed the next three stages of framework analysis. The fourth stage is charting, which involves re-arranging the data either case by case or by category and theme into a chart, thereby summarising it. This allows a researcher to view the range of data across cases under categories and themes (Ritchie et al 2003, Furber 2010). In this study, charts of themes were drawn up from the tables of themes from each of the four interview points of two, six, twelve and eighteen months post-stroke [step 9]. For example, for the data from the two month post-stroke interviews, a chart labelled Self-care was constructed. The themes of 'toileting', 'washing/bathing and grooming', 'dressing' and 'feeding' were labels for the columns and two more columns labelled 'perceptions' and 'meanings' were added. This meant not only that the participants' descriptions of their difficulties in these areas could be summarised in key words or phrases, but also the perceptions and meanings they ascribed to these things could be captured in the chart. The charts were discussed and reviewed at regular supervision meetings [step 10]. The ordering of the participants

vertically down the left hand side of a chart was kept the same in all charts so that the whole data set for each participant could be viewed easily (Ritchie and Spencer 1994). Examples of the charts can be seen in Appendix 7 (page 254).

The final stage in framework analysis of mapping and interpretation involves analysis of the key characteristics of the charts to synthesise and interpret the data further (Srivastava and Thomson 2009, Furber 2010). The themes in each chart are reviewed to look for relationships between them in terms of any concepts or typologies and also links to theory, policy, or service provision [step 11]. For example, in this study a link could be made from the data in the charts on self-care to theory on self-esteem. It also enabled participants' experiences in self-care to be analysed and situated in the context of health policy, guidelines, clinical practice and service provision. It was important that the original transcripts were referred to during this mapping and interpretation stage to ensure that any links and conclusions arrived at remained grounded in the original data (Smith and Firth 2011). This process then provided a whole picture of the data across each interview point and longitudinally in this study. It also allowed individual cases of particular interest to be more thoroughly scrutinised (Ritchie and Spencer 1994, Furber 2010).

This section has discussed the theoretical concepts and strategies that guided the data analysis in this study. The next section will explain the processes used to ensure the design of the study was rigorous and therefore the findings could be considered trustworthy.

3.4.7 Rigour and Trustworthiness

Rigour and validity can be contentious terms in qualitative research as some would argue they are more relevant to quantitative research, where the design of a study should eliminate bias and maintain objectivity for it to be seen as valid and reliable, and therefore provide findings that can be generalised to a wider population (Sim and Wright 2000, Finlay 2011, Polit and Tatano Beck 2014). In qualitative research, and in particular

phenomenology where the researcher becomes the instrument of data collection through interaction with participants, complete objectivity is not possible nor desirable (Willig 2008). Similarly, the theoretical and professional background of the researcher can be brought to bear on the data analysis and interpretation of the findings (Sim and Wright 2000). Creswell (2007) also argues that validity is not a useful term in qualitative research as it is in quantitative research. For example, interviews are temporal, located and an interaction between a participant and researcher, and what emerges are data that is the product of that interpersonal and social context (Finlay 2011). Therefore, it is unlikely that an identical conversation would ensue if the participant was interviewed by a different researcher. Nevertheless, despite these issues, there is agreement that certain principles of good practice in qualitative research can ensure rigour in the design and the findings thereby considered trustworthy (Hansen 2006, Tong et al 2007, Green and Thorogood 2009, Polit and Tatano Beck 2014). Lincoln and Guba (1985) proposed that there are four criteria that should be applied to qualitative research to ensure a rigorous design and the trustworthiness of the findings. They are credibility, dependability, confirmability and transferability. These criteria are commonly applied to qualitative research today and so were used to guide the design of this study (Finlay 2011, Polit and Tatano Beck 2014).

Credibility refers to having confidence that the data and its interpretation are a believable picture of the phenomenon. It replaces the quantitative criterion of internal validity and several factors were considered in the design of this study to ensure its credibility (Finlay 2011). Firstly, the purposive sampling strategy reflects the population of people affected by stroke and upper limb dysfunction, in that there are both male and female participants, those with dominant and non-dominant affected upper limbs, and the older age of participants is typical. This, and the description of the participants in Table 4.1 (page 101), should enable others to decide if the findings of this study are relevant to their patients and situations. The consultation with members of the Stroke Association support

group and the discussion with the occupational therapist specialising in hand therapy ensured that the interview guide used in the first interviews at two months post-stroke would be resonant with people's experiences and thus the data emerging from the interviews would likely be credible. In addition, the guide for each subsequent interview with a participant was developed from the table of themes from the previous interview, thus ensuring that it was grounded in their experiences. Furthermore, the steps used in the development of the tables of themes and the framework analysis charts with the key words and phrases from the transcripts, with their page and line numbers, demonstrate that the analysis was grounded in the raw data and there is transparency in how the data were being managed and interpreted (Tong et al 2007, Finlay 2011).

Dependability, which is analogous to reliability in quantitative research, relies on having confidence in the decisions made during the analysis process. Tong et al (2007) suggest that more than one person should analyse data so that description and interpretation of the data is plausible and justified. In this study, the researcher analysed all transcripts but a sample of three transcripts from each of the two-, six-, twelve- and eighteen month interviews was analysed by the PhD lead supervisor. This was followed by discussion to resolve any differences of opinion and the researcher then revisiting transcripts to ensure that all relevant themes were included. As analysis developed, decisions taken during the charting, mapping and interpretation of the data were discussed with the supervisory team.

The credibility and dependability of a study can be enhanced through participant checking (Hansen 2006, Tong et al 2007). A summary of the findings from the data from the whole study was mailed out to each participant and they were given the opportunity to discuss the findings with the researcher in reference to their recollection of their interviews (a copy of the summary is in Appendix 8 (page 272)). Only two participants chose to do this and both confirmed that the findings resonated with their experiences. Another factor thought to improve credibility and dependability of a study's findings is triangulation, whereby more

than one method of data collection is used (Hansen 2006). However, in a phenomenological study such as this, it was not feasible. The only other relevant method of data collection possible would have been to conduct focus groups with the participants but the limitations of this method were discussed earlier in section 3.4.1 (page 61). Furthermore, the practicalities of bringing together participants, who were recruited into the study over a period of seventeen months and, therefore, at different stages of their recovery, and at different geographical locations, was not realistic within the confines of this PhD.

Analysis by more than one researcher and participant checking also contribute to confirmability, the third criteria considered vital by Lincoln and Guba (1985) to ensure rigour and trustworthiness. Confirmability can be likened to objectivity and limiting bias in quantitative research (Finlay 2011). Transparency in the management of the data through the tables of themes and framework charts and the decisions taken in the analysis, as described in the results chapter, provide an audit trail, which adds to the credibility of this study. There is another procedure that not only contributes to confirmability but also credibility and dependability, and that is researcher reflexivity. It has already been highlighted in section 3.4.3 (page 71) that, in phenomenology, and in particular in semi-structured interviews, the researcher enters into the social world of the phenomenon under investigation and is the data collection instrument (Sword 1999, Patton 2002). The researcher is the conduit through which participants' voices are heard and their experiences interpreted (Gergen and Gergen 2003). Therefore, in qualitative research it is recognised that a researcher's social and cultural background, professional knowledge and experience may influence both the collection and analysis of the data. To acknowledge these factors it is widely accepted that a researcher should engage in a reflexive process whereby these issues are explored in an effort to bracket them. Bracketing is an essential part of a researcher adopting a phenomenological attitude whereby the researchers have an awareness of how their background and professional

knowledge will influence how they create understanding. Therefore they need to be as open as possible to hearing and seeing beyond what they may expect, so that the data generated are a more accurate reflection of the phenomenon, and also to consider where and when the professional knowledge and experience should be applied in data analysis (Morse and Richards 2002, Hansen 2006, Howitt and Cramer 2008, Finlay 2009). In this study, the researcher undertook a reflexive process before and during data collection and analysis and recorded this in a reflexive log. Issues that arose were discussed with the supervisory team and are considered below. This section is therefore written in the first person.

3.4.7a Researcher Reflexivity

It was important for me to consider myself in relation to the participants and to the topics likely to be discussed in the interviews (Finlay 2002, Gough 2003). There were two issues I was most concerned with: firstly, how might participants view me in terms of my social class; and secondly and possibly more importantly, would my professional background as a physiotherapist influence the direction the interviews might take? Before recruitment to the study began, I anticipated that participants might be mostly from a lower socio-economic background. The risk factors for stroke, such as smoking and a diet heavy in saturated fats, are associated with particular lifestyle factors more prevalent in people from that background (DH 2007). The concern was that participants might assume me to be middle class because of my role as the researcher and might feel some hesitancy in explaining their experiences and perceptions to me, and moderate the language they would normally use, in case I was unable to appreciate their values and social roles. This might have resulted in depth and nuances in the data being lost (Hughes 1994). However, I grew up and continue to have family and friends in a typical working-class area and, in my professional work as a physiotherapist, I have encountered many people from lower socio-economic groups. Therefore, I felt I would be comfortable with participants from that background and be able to adapt my interactions with them to place them at

ease and to encourage them to talk to me quite naturally. Interestingly, the participants that were recruited to the study were not all from this socio-economic group and it became evident that age was the common causal factor in their stroke. Other issues about my social and cultural background that could have influenced interactions participants were my gender, ethnicity, values and beliefs. However, I reflected on my years of clinical work, where I had communicated effectively with people of all ages and backgrounds, and concluded that this was sufficient preparation for me to be open and non-judgemental during my interactions with participants (Ahern 1999).

The second issue for me was my professional background as a physiotherapist and the influence this would have on data collection and analysis (Finlay and Ballinger 2006). My interest in this area of research stemmed from my clinical background working with people with stroke before moving into lecturing as a physiotherapist, and this had inevitably influenced the research questions. The focus of the research, though, was not to explore people's experiences of physiotherapy, although it was recognised that this might emerge as people talked about their future goals. The dilemma for me was whether or not to reveal my profession to participants. It was possible that this might divert their focus from the wider aspects of their upper limb dysfunction to discussing the medical and, more specifically, physiotherapy management, and possibly seeking advice from me regarding their treatment, which would be outside of the ethical boundaries of the study (Bondi 2005). This was discussed with my supervisors and the decision taken to identify myself as a researcher, and only to reveal my professional background if people asked me directly. Interestingly, only three of the 13 participants asked me this question and, for those that did ask, I found that the interview guide enabled me to maintain the direction of the interview towards the research questions. Conversely, however, it was important that my professional knowledge and experience came to the fore in the later stages of data analysis where mapping of the data to clinical practice, health policy and guidelines, and service provision provided a more meaningful interpretation of participants' experiences

and perceptions within this wider context (Morse et al 2001; Dean et al 2006; Larkin et al 2006).

Another issue I considered was managing the potential for a power imbalance between me and participants. As well as the issue of social position and class, there was the influence of the knowledge held by me as the researcher (Finlay 2003). I had designed the study and asked the questions and so I may have been perceived by participants as more influential in terms of expertise and authority and this could have created a barrier between us (Gough 2003). However, I was mindful that each participant was the expert when it came to his or her experiences and that was how I tried to position myself when conducting the interviews and analysing the data. Furthermore, I was careful to avoid the use of any professional jargon or words that participants may not understand and thus reinforce a perception of me as the expert and create a barrier to communication (Sword 1999). It was important to ensure that the voice of the participants was heard and not overshadowed by me (Denzin and Lincoln 2008, Nairn et al 2005). I considered that holding interviews in surroundings familiar to the participants, such as the rehabilitation ward and their homes, would make people feel more relaxed and in control and therefore help to redress any power imbalance (Finlay 2003).

The final concern for me was my interview technique. As a physiotherapist, I had routinely interviewed countless patients during my clinical work but I was aware that, in phenomenological semi-structured interviews, some different skills were needed (Britten 2006). A clinical interview is possibly more similar to a quantitative, structured interview, as it is led by the clinician, who will have certain questions to be asked, many of which will be closed questions, often in a certain order according to a patient's condition. Open-ended questions are used, but they are typically very directed by the physiotherapist and brought to a conclusion quickly. The aim is to identify the physical problem as promptly as possible in order to select an appropriate intervention (Britten 2006, Green and Thorogood 2009). I recognised, therefore, that I had to monitor how I posed questions to participants.

I did not want to be directive or leading, but rather to ensure that questions were open-ended and that I avoided conveying any prior assumptions I may have had. In addition, I had to allow participants the time to reflect and think before speaking in order to give a full response, and also to use probing questions to get more information and depth where necessary (Silverman 2001, Britten 2006, Smith and Eatough 2006). To do this, firstly, I was able to draw on previous experience of facilitating focus groups both in my professional life as a lecturer and when consulting people from the Stroke Association during the development of the interview guide. Secondly, when drafting an interview guide I thought carefully about the structure and language I should use in questions to make sure they were open-ended and did not embody certain assumptions on my part. I also listened to recordings of previous interviews and read through the transcripts to pinpoint any times where my technique fell short so that next time I interviewed a participant I could pursue those topics further, if necessary. In summary then, by considering these issues through a reflexive process the confirmability, dependability and credibility of the design and findings of the study were enhanced. Further extracts from the reflexive journal are included in section 3.5.4 (page 97) and Chapter Four: Findings, section 4.4 (page 169)

3.4.7b Transferability

The final one of the four criteria identified by Lincoln and Guba (1985) is transferability. This is a similar concept to external validity in quantitative research (Finlay 2011). It is the degree to which the results of a study can be generalised to settings or samples other than those studied. In qualitative research, rather than generalising to a wider population it is more relevant to think of the applicability of findings to other settings or groups (Polit and Tatano Beck 2014). Wain et al (2008 p 1368) suggest that 'people who share similar events share an "essence"' indicating that the findings from qualitative studies, where rigorous and robust procedures have been used, can be learnt from and applied to similar people. The rigorous design of this study, the transparency of the procedures in data

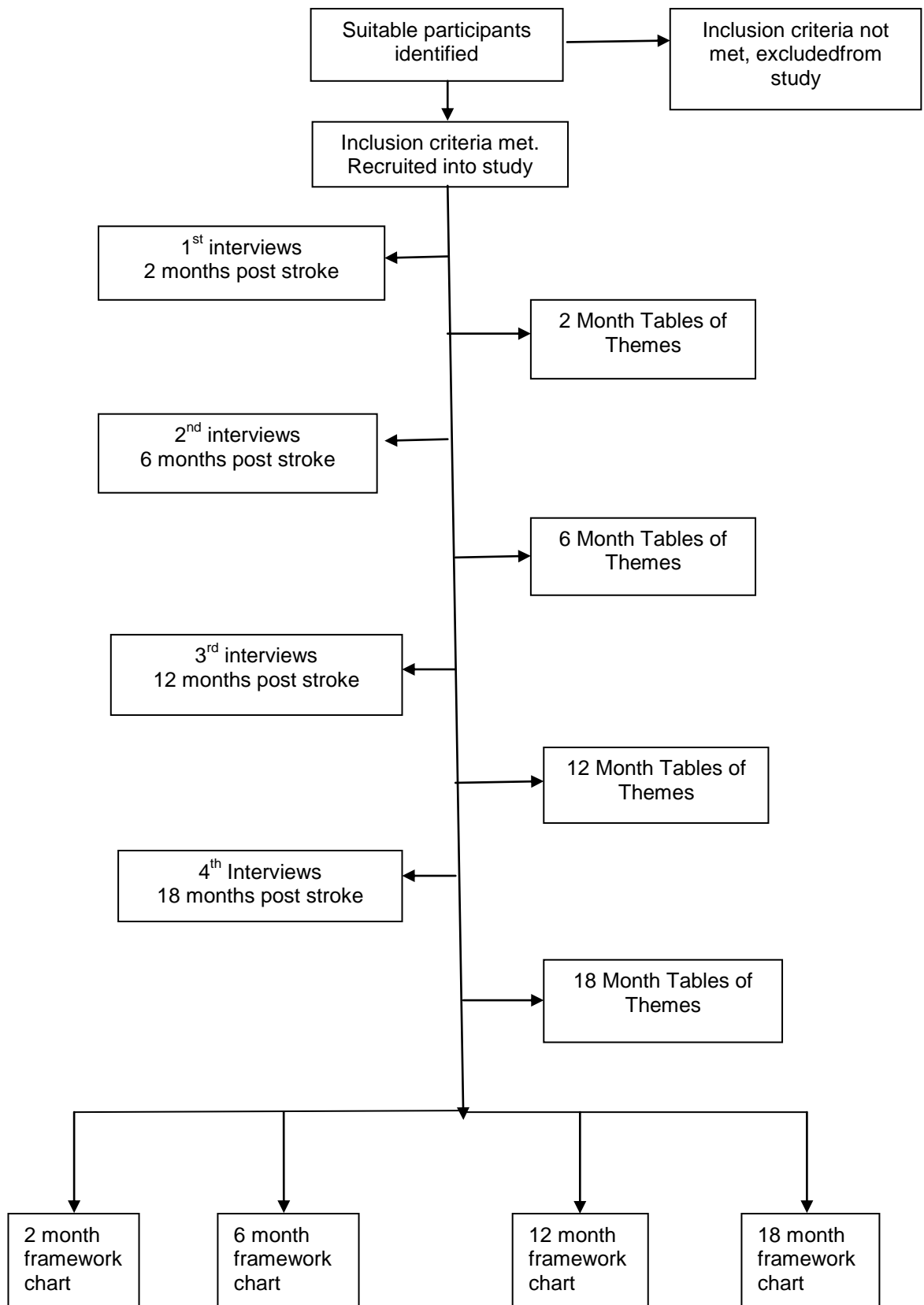
collection and analysis, and the reflexivity of the researcher, all confirm that the findings are trustworthy and therefore could be transferable to other stroke survivors with upper limb dysfunction.

This section has discussed the rigour in the design and the trustworthiness of the findings thus bringing section 3.4 Study Design to a close. The next section, 3.5 will describe the procedures of the study.

3.5 Study Procedures

Figure 1 illustrates the process of recruitment and selection of participants, and the data collection and subsequent data analysis and development of the tables of themes for each interview point at two, six, twelve and 18- months post-stroke.

Figure 1: Process of Data Collection and Analysis Followed in the Study.



3.5.1 Participant Recruitment

Following ethical approval, described previously in section 3.4.5 (page 73), participants were recruited from a stroke rehabilitation unit. Suitable people, who met the inclusion criteria, were identified by a local collaborator, who was a physiotherapist working in the unit. The local collaborator gave potential participants a letter from the researcher containing information explaining the purpose of the study and the semi-structured interviews for data collection. After a period of one week, during which participants had time to read the information, or have it read to them by a family member or healthcare worker, the researcher visited them individually to provide any further clarification and, if they were willing, to complete a consent form. Copies of the information sheet and consent forms are in Appendix 5 (page 248). Participants' GPs were informed by letter of their recruitment into the study, as was the consultant in charge of their care.

3.5.1a Inclusion Criteria

Participants had to be 18 years old or over and sufficiently articulate to engage in conversation and report their experiences (Morse et al 2001; Morse and Richards 2002). Therefore, those with significant dysphasia or cognitive problems were excluded from the study. The General Practitioners' Assessment of Cognition test, a common test used in local clinical practice, was available to screen participants where cognitive impairment was suspected (Brodaty et al 2004). A copy of this is in Appendix 9 (page 275). In addition, non-English speaking people were excluded as there was no funding for an interpreter service. It was important that the upper limb dysfunction was a direct result of a stroke and so those people with stroke who had previous conditions affecting the upper limb, such as arthritis, were also excluded.

3.5.2 Data Collection

Semi-structured interviews were conducted at two months, six months, twelve months and eighteen months after the stroke. It is well recognised that the location of an interview can have an impact on the data gathered (Silverman 2001, Hansen 2006, Finlay 2011). Being

in comfortable, familiar and private surroundings can put participants at ease and facilitate a less formal and more interactive experience with the researcher. In this study, the majority of interviews took place in participants' homes and so participants appeared to be relaxed and in control and therefore more willing and ready to share their experiences and feelings. However, some participants were still in a rehabilitation facility at the interview two months after their stroke and this might have been less than ideal. However, having been there for two months, the environment was quite familiar to them and using a private room provided a comfortable and safe environment for them to talk freely. The interview guide developed from the focus group with members of a Stroke Association support group and the consultation with the occupational therapist expert in hand therapy was used for the two-month interviews. At the first interview all participants were given an information leaflet about the local Stroke Association Information, Advice and Support Service from which support and counselling could be accessed in the event of any distress ensuing from participating in an interview. In addition to this, a Stroke Association support worker visited the rehabilitation unit regularly to provide information, advice and support. Before arranging subsequent interviews, the researcher confirmed with a participant's GP that his or her condition had not changed. This prevented any distress being caused through an untimely phone call in the event of their condition having changed. The duration of each interview was on average 40 minutes.

In order to carry out a full analysis of the data it was necessary to audio-record each interview so that a transcript could be produced. The alternative to this of making copious written notes would have been a distraction to both the interviewer and the participant and would have interfered with eye contact and non-verbal communication, which are important in developing rapport (Willig 2008). Some people can feel uncomfortable and inhibited when being recorded; however, by using a small, unobtrusive, digital recorder participants soon became less aware of it and relaxed (Finlay 2011). To enhance the data from the audio- recording, some written field notes recorded notable changes in a

participant's mood or body language during the interview, but this was kept to a minimum. The initial impressions of the interview and the key things to remember were noted by the researcher immediately afterwards and memos were made from these in NVivo 9 and used in the initial data analysis alongside the transcription (Hansen 2006). Anything notable that had been said before or after the voice recorder was switched on or off was also written down. This added to the richness of the data collected.

In addition to the qualitative data, it was decided to note demographic information of age and sex, and the affected arm and hand dominance. This was so these factors could be explored in terms of the perceptions and meanings of the upper limb dysfunction. Also, it was deemed important that some measure of stroke severity should be recorded to provide the overall context for each participant's experiences, and so the National Institutes of Health Stroke Scale score (NIHSS 2010), which is a measure of neurological deficit and stroke severity, was taken from each participant's medical notes. This was preferable to carrying out tests of impairment or functions of the upper limb before the first interview as these could have influenced the direction of the interview and made the relationship between participants and the researcher seem more clinical. It was considered very important that the interviews should follow participants' perceptions and experiences and not be focused on just function and impairment which may not have been meaningful to them.

3.5.3 Data Analysis Procedures

Audio recordings of the interviews were sent to transcribers for verbatim transcription. This was funded by two research grants from York St John University and the Chartered Society of Physiotherapy Research Foundation (see footnote¹). Audio-recordings of the interviews were listened to and transcripts were read and re-read several times over, and field notes were consulted. Transcripts were scrutinised and annotated for recurring

¹ Faculty of Health and Life Sciences, York St John University; Physiotherapy Research Foundation – Scheme A

themes and categories. These were then coded using the computer package NVivo9. From this coding, a table of themes was developed for each interview and charts of themes were drafted for each of the four interview points (see Appendix 7, page 254). This allowed data to be viewed more easily across and within all participants; for themes and subordinate themes to be identified; and to enable mapping of the data to theory, policy, guidelines, clinical practice and service provision. Independent analysis of a sample of interview transcripts from each interview point was undertaken by the PhD first supervisor and development of the tables of themes and framework charting and mapping was discussed at regular supervision meetings. In addition, a summary of the findings from the analysis of all the data was sent to all participants to give them the opportunity to meet with the researcher to comment on the findings with regard to whether or not this resonated with their experiences.

3.5.4 Reflexive Account – Refining my Role as Interviewer and Co-constructor of Data

On listening back to recordings of the first two interviews with participants at two months post-stroke, I noticed some flaws in my technique that may have been barriers to people fully expressing their experiences and perceptions. I was not always posing open-ended questions and, at times, not allowing participants sufficient time to pause and reflect when answering questions. I also recognised during interviews that I was not comfortable with pauses and silences, and so, in places, I was jumping in with prompts before a participant had time to fully consider and reflect on his or her answer. The recordings also highlighted to me a habit I have of saying 'right' or 'OK' after a participant has responded to a question. This may have given participants the impression that what they said was sufficient as an answer and I did not wish to hear anything further, therefore, creating a barrier to expanding the topic any further. On reading the transcripts of these two interviews I saw opportunities where I could have asked participants more probing questions to elicit more information from them. This was also pointed out to me by my

supervisor, who analysed the transcripts independently. I was, therefore, not fully realising my role as a co-producer of data and, rather than being a conduit through which the participants' experiences can be identified I was a barrier (Denzin and Lincoln 2008). Fortunately, while reflecting on my limitations as a novice researcher I was interviewed by a colleague from the counselling academic subject area in my faculty. The interview was not related to my research but was, in fact, part of an educational study he was conducting. As the interview progressed I realised that he was using a 'reflecting back' technique and paraphrasing what I had just said back to me for confirmation, and this often stimulated me to elaborate further on my answers. This reminded me of some counselling training I had undertaken many years ago, where this technique was recommended, and so I revisited some of the theory and techniques from this (Bedi et al 2005). Clearly, I was not in a counselling situation with participants, but found some of the points helpful in conducting subsequent interviews. In particular, I used the 'reflecting back' technique at times to paraphrase the participants' words back to them. This, I think, signalled to them that I was actively listening and was acknowledging their experiences or the way they saw a situation, and how they felt about it. This led them to elaborate further on points and open up opportunities for me to probe for more information. I became more aware of my body language, adopting an open posture, and tried to remain calm and relaxed. Instead of saying 'right' and 'OK' I used prompts such as 'mm' and 'uh uh' to encourage further conversation. I tried to stay 'in the moment' with each question or topic and to avoid thinking about the next question while the participant was still talking about the current one, reminding myself that the interview guide was a 'guide' and to be flexible to where the interview moved to, while being mindful of the overall aim of the research.

I recognised that I needed time to prepare for each interview and to adopt a phenomenological attitude. I spent some time sitting quietly in my car outside the location of the interview before meeting the participant, to clear my head of activities, experiences and thoughts that may have arisen previously in the day, and of any expectations I may

have had of the forthcoming interview so that I was open to whatever was said and brought forward by the participant. I reminded myself of the interview techniques I needed to use in order to enhance the dialogue with participants to elicit the fullest account of their experiences and perceptions (Gergen and Gergen 2003). It was important to continue to analyse and reflect on my interviewing technique throughout the study as this enabled me to continue to improve and develop into a more effective researcher and co-constructor of data.

3.6 Chapter Summary

This chapter has discussed the methodology of the study. The qualitative approach and phenomenological methodology, and semi-structured interview design were argued to be the most appropriate for answering the research questions. The conduct of the research, including the sampling, participant recruitment, ethical issues, data collection and analysis has shown that the findings and their interpretation were trustworthy. The next chapter, Chapter 4, will discuss the findings from the study.

Chapter 4: Findings

4.1 Introduction

The previous chapter discussed the design and procedures of this phenomenological study and this chapter follows on from this to present the findings that were identified from the data analysis. It will describe the participants who were recruited and the themes that were identified from the two-, six-, twelve- and eighteen- month post-stroke interviews. The chapter is constructed around the themes, rather than the four data collection points, allowing the results to be viewed across all participants over the course of the four interviews. A longitudinal approach to the data is also presented in this chapter, where case studies are used to explain the changing perceptions and experiences of some participants over the course of the eighteen-month period of data collection.

4.2 Participants

Sixteen people were recruited into the study from a local stroke rehabilitation unit. The recruitment period lasted for ten months, which was longer than initially anticipated. There was a period of two months within this in which recruitment was halted owing to staffing and management changes within the unit. Three people were withdrawn from the study before the data collection period commenced: one because of deteriorating health, and two because of personal reasons. In all, thirteen people participated in the study. They are identified by a pseudonym to maintain anonymity (Table 4.1, page 101).

Table 4.1: Participant Details

Participant	Age	Side of stroke	Dominant hand	NIHSS score	Living arrangements, activities & interests, important life roles
Ada *	74	L	R	5	Widow, lived alone before stroke, moved to daughter's home after, cooking and dancing, deceased after 3 rd interview.
Barbara	67	L	R	2	Married, lived with husband and daughter, looking after the home.
Alan	62	L	R	12	Lived alone before stroke, moved in with partner afterwards, driving, grandfather.
Cath *	84	L	R	8	Widow, lived alone, deceased after first interview.
Doris	84	L	R	2	Widow, lived alone, reading, community group.
Eve	65	L	R	8	Married, husband worked away part of each week, dancing, swimming, looking after the home.
Jenny #	76	R	R	4	Widow, lived alone, gardening, looking after home.
Lily	77	L	R	3	Married, looking after home.
Bob	70	R	R	6	Married, musician, conductor, composer.
Meg	80	L	R	16	Married, looking after home
Colin	71	L	R	14	Married, driving, looking after home, DIY, grandfather.
Gordon	62	R	R	N/A	Lived alone, partner visits, semi-retired maintenance fitter, DIY.
Harry	86	L	L	15	Married, driving, looking after home

R = right, L = left , * participants deceased before end of study, # participant distressed at two-month interview

Eleven participants completed all four interviews at two, six, twelve and eighteen months after stroke. Unfortunately, two participants died before completing all four interviews and another participant was unable to finish the two-month interview as she became very distressed when talking about her experiences and so the interview was terminated early (see Table 4.1 page 101). Concerns about her emotional state were reported to the stroke unit where she subsequently received support and she was able to participate fully in later interviews.

Table 4.1 (page 101) gives the following information about the people who participated in the interviews: age on recruitment into the study, sex, side of the body affected by the stroke, dominant hand, and the National Institute of Health Stroke Scale (NIHSS) score on admission to hospital, where available. It was anticipated that, with purposive sampling, there would be equal numbers of males and females, and the sample would, theoretically, provide a good variety of views and opinions relevant to upper limb dysfunction after stroke. The age of participants ranged from 62 to 86 years. This is typical of most stroke survivors in that stroke is much more common in people over 60 (Stroke Association 2015). Eight women and five men were recruited and this is less typical in that the incidence of stroke in men is 25% higher than in women (Stroke Association 2015). This imbalance was as a result of the period of suspension in recruitment and the availability of participants who met the inclusion criteria. Pragmatic decisions had to be taken to ensure sufficient numbers were recruited and interviews could be completed in the available time to complete the PhD. However, it should be noted that there are currently more women than men living with stroke in the UK, as women generally live longer than men (Stroke Association 2015), so the sample did provide a relevant variety of views and opinions.

Table 4.1 (page 101) shows that ten participants with right cerebral hemisphere strokes, and consequently left-sided hemiplegia, entered the study. It was anticipated that this would occur as dysphasia is much less common in those stroke survivors because the areas associated with speech are located in Broca's and Wernicke's areas in the left

hemisphere of the cerebral cortex – the ability to enter into conversation in an interview was an essential inclusion criterion in the study. A consequence of this is that there were more people in the study with their non-dominant hand affected by stroke. However, one of the ten participants with left-sided hemiplegia was left-handed and three participants with right-sided hemiplegia who were not dysphasic in the study, giving a total of four participants with their dominant hand affected.

The NIHSS is a measure that quantifies and categorises the level of overall impairment after stroke (Schlegel et al 2003) and Table 4.1 (page 101) indicates that four patients were considered to have had a mild stroke (NIHSS score of 1–4) on admission to hospital, seven a moderate stroke (NIHSS score of 5–15) and one a moderate to severe stroke (NIHSS score of 16–20). It should be noted that motor function of the arm is only one of eleven items in the scale and assesses the ability of the patient to hold the arm up against gravity for 10 seconds, not the functional ability of the hand. Of the four participants in the mild stroke category only two, Doris and Lily, had some useful hand function. All other participants in the study reported having either no movement or minimal gross movements of the hand.

4.3 Findings

Table 4.2 below shows that three main themes were identified in the data: The Altered Life, The Disrupted Self and The Experience of Recovery. Each of these main themes had subordinate themes which are shown in Table 4.2 below.

Table 4.2: Themes and Subordinate Themes

Main Themes	The Altered Life	The Disrupted Self	The Experience of Recovery
Subordinate Themes	Managing Self-care	Feeling Like a Child	Priorities, Hopes and Getting on with Life
	Meaningful Activities	Feeling Devalued and Downgraded	Experiences of Therapy
	Life Roles and Relationships	Disrupted Self-image	Lack of Information and Advice
		Disrupted Identity	Personal Responsibility for Recovery

The themes and subordinate themes will be presented in three sections. The first two will present findings from across all the participants: the first will present the findings in the main theme of The Altered Life; and the second the main theme of The Disrupted Self. The third section will present the main theme of The Experience of Recovery, and this encapsulates the longitudinal nature of some of the data showing the changing perceptions of participants over the course of the four interviews. It will also present three case studies selected to show how certain factors either facilitated or hindered recovery, adjustment or adaptation to upper limb dysfunction.

Participants have been given a pseudonym. The sources of quotations can be identified by the pseudonym and a number that indicates the relevant data point from which it was taken: two months post-stroke = 2, six months post-stroke = 6, 12 months post-stroke =

12, 18 months post-stroke = 18. Therefore, for example, a quotation from an interview with Ada at twelve months post stroke will be identified as Ada (12).

It was clear from the findings in this study that the two main themes of The Altered Life and The Disrupted Self were occurring at the same time in participants' lives and were closely intertwined. Upper limb dysfunction had significantly altered how participants were able to live their lives and as a consequence of this they were experiencing some significant disruption to their sense of self. The Altered Life will be explained first in order to understand how this related to The Disrupted Self.

4.3.1 The Altered Life

The findings showed that the life participants were leading after their stroke was very different from their life before stroke. Their upper limb dysfunction had been a significant factor in this and had permeated all areas of their lives. It had affected their ability to manage their self-care, to participate in valued activities and to fulfil life roles. Jenny at two months post-stroke was beginning to find out how much she needed her arm and hand if she was to regain her past life.

Jenny (2): *'It just won't do what I want it to do ... it just won't work like I want it to work.'*

Interviewer: *'And how do you feel about that, what do you think about that?'*

Jenny: *'Well it's my right hand, and I'm right handed so I feel shattered really. I've got to have this [pointing at affected dominant hand] back quick to carry on with my life. I never thought it would be so difficult being without your hand'*

She used the term '*shattered*' not to describe fatigue but rather that her life, as she previously knew it, was now broken and in pieces, and this realisation affected her so deeply that she became very tearful and the interview had to be suspended. Her

experience resonates with some of the literature on stroke, where others have also described their lives as shattered or broken (Ellis-Hill et al 2000).

Colin, who was at home at two months post-stroke and could walk independently around the home, referred at that point to things stopping, as though his life had been put on hold, particularly by needing help with self-care and his inability to drive, both of which he attributed to his weak left hand. His wife did not drive, so many of their normal everyday activities were suspended and they had become more dependent on their family.

Colin (2): *'Everything stops, everything you used to do you can't do ... you've even someone to wash yourself ... Days like today we just jump in the car and visit the coast, all that stops ... can't drive. We used to go out every day, to garden centres, or just have a run around you know, just go off for enjoyment, we can't do it now. It means everything stops and you've to rely on your family.'*

Interviewer: *'I want to know what having the problem with your arm and hand, what has that meant for you?'*

Colin: *'It changes everything, changes your whole way of life, and it's very difficult, very difficult'*

This was not just the experience of people at two months but persisted longer for some.

Ada (12): *'Well I can't do the things I want to do, I'm just limited to what I can do you know, it annoys me.'*

Interviewer: *'And how much does your arm and hand contribute to the feeling of not being the person you were before?'*

Ada: *'Terrible'*

Interviewer: *'Really?'*

Ada: 'Yes'

Interviewer: '*Why is that then, why is your arm and hand such an important part of it?*'

Ada: '*Because you need both hands, don't you ... to get on with life, and you just cannot ... and as I say I miss my dancing, I miss my cycling. I used to cycle all over. I've done it all my life.*'

Ada's life was significantly altered as by six months post-stroke she had gone from living in her own home, very happily alone, to living with her daughter in a busy family house. She became tearful as she reflected on this major change. Her upper limb dysfunction meant she had lost her independence and her periods of solitude, which she enjoyed.

'Just horrible ... just awful ... just to think I can't be on my own.' Ada (6)

Gaining mastery over the tasks that are integral to everyday life and significant for a person develops a sense of competence and capability (Mruk 1999). Daily life is made up of routine self-care tasks such as dressing and feeding oneself, and also of tasks that are part of occupations and activities such as work, hobbies and roles in families and the wider community. Having the skill and ability to complete tasks successfully develops a sense of competency in those areas and of being a capable person. Nearly all the tasks that individuals typically perform require cooperative, bi-manual movements of both hands; in other words, as Ada pointed out, people need both hands. It was clear from the data in this study that dysfunction of one upper limb after stroke had left many participants without the competence to be independent in self-care and the capability to carry out the activities in their lives that they valued the most, and the life roles that were important and meaningful to them. Thus the three sub-themes in this main theme are: Managing Self-care; Meaningful Activities; Life Roles and Relationships

4.3.1a Managing Self-care

The loss of strength, manipulation and dexterity in an arm and hand left many participants unable to manage many of the aspects of their daily lives that were vital to them. This left many feeling they were no longer the competent people they were before their stroke.

Within the category of self-care it was evident that using the toilet, dressing, feeding, washing and bathing were challenging for all participants at two months post-stroke, leaving many needing assistance with these very personal, intimate tasks. For example, Ada describes very clearly the problem she, and other participants, faced when using the toilet with only one functioning arm. Ada was able to walk to the toilet independently, using a stick, but once inside she was no longer independent. She had to use her unaffected hand on her stick or grab rail for support, because of lower limb weakness and reduced balance, and therefore, she no longer had a useful hand to pull down and pull up clothing and to clean herself.

Interviewer: 'What aspects of your personal care are you having difficulty with because of your arm and hand?'

Ada (2): 'wiping my bum, 'cos I need to hold on and I can't hold on with that [pointing to her affected hand] and I need that hand to do it [pointing to her unaffected hand]'

The result was that she needed assistance with this most personal of tasks. This is seemingly a simple task that people are competent of carrying out alone and in private. Similarly, losing movement in one arm and hand meant that many participants needed help with bathing and washing as a person needs full use of both arms and hands to reach all parts of the body. The intrusion of other people into the normally private sphere of some self-care activities was hard to accept and left individuals feeling exposed, embarrassed and vulnerable. Meg, at six months post-stroke, had become weary of carers coming in and out of her home to help her but recognised that she needed them.

Barbara was embarrassed that her daughter had to help her with bathing. Alan described his very strong feelings of embarrassment when carers were helping him to bathe. His vulnerability and the invasion of his privacy came over very strongly, almost as if he was being violated by needing this level of care.

'I can't do what I used to do like have a bath on my own, you get embarrassed when they strip you and things like that and you've got other people coming in and stripping you.' Alan (12)

Several participants were distressed and embarrassed by their inability to maintain their own cleanliness. Eve described how she could go to the toilet on her own but, like Ada, had to hold on to the grab rail with her unaffected hand and so was unable to reach behind her body with her other hand to clean herself fully afterwards. So she had to pull up her clothes and wait until the carers came to do this for her. She mentioned it at all four interviews and so this was clearly a real issue for her. She not only was very embarrassed but also explained the effect on her mood.

'I get really angry with myself, get angry with other people.' Eve (12).

Using cutlery to feed oneself is a task that normally requires two hands to use a knife and fork to cut up food, move it around and off the plate and up to the mouth. Cath, at two months post-stroke, explained how her routine of dining out in a restaurant once a week with her son had been altered. She described *'chasing peas around the plate'* and how having just one functioning hand made it very messy to eat and so she had decided to withdraw from that situation. Meg too was embarrassed by her continuing struggle to feed herself with only one hand without spilling food.

'He [her husband] brought chops in other night and he'd forgotten to cut it up and I says "oh" but it's so... I'm so messy. Oh I'm quite upset about it. I'm embarrassed.' Meg (18)

Gordon described how his partner had to cut up his food and this made him *'feel low'*.

Many participants described feelings of helplessness when they talked about the assistance they needed with self-care. The effect of this loss of competence and mastery over these basic self-care tasks was summed up very graphically by Harry at two months post-stroke. His life was very different now as he was so dependent on others

'I feel like, these people who collect butterflies, I feel like one of them pinned to a board ... only if the master comes in and takes the pin out and moves you can you do anything.' Harry (2)

This subordinate theme indicates that having a dysfunctional upper limb can lead to dependence in self-care, and this in turn is a cause of embarrassment and can leave people feeling incompetent and vulnerable. Furthermore, it was apparent that this had a profound effect on how participants viewed themselves, in particular their self-esteem, and this will be explained in the other main theme of the Disrupted Self, which comes later in this chapter.

4.3.1b Meaningful and Valued Activities

All participants reported that their upper limb dysfunction had affected their capability in activities that were valued and meaningful and an important part of their lives prior to their stroke. Many people had regarded themselves as being very capable and skilful in certain activities such as cooking, housework, gardening and DIY but after their stroke they had lost the strength, dexterity and skill in their arm and hand and so no longer had the two hands that they had depended upon to carry out these activities. Furthermore, as well as taking pride in their capabilities, it was clear that many participants found great pleasure in their valued activities; losing capability meant losing this pleasure and participants were left feeling bored and purposeless. Ada had spent much of her time before her stroke cooking and baking, particularly for other people, and there was both pride and great sadness in her voice as she described what she had been capable of but was no longer.

'Well there are two neighbours next door. They're both on their own, young men. So I do dinners and what have you and put them in freezer and pass them over for them. I do, er, corned-beef hash, shepherds pies and things like that. I don't think I'll be able to make dinners like I used to do. You've got to cut up the veg and everything.' Ada (2)

At six months post-stroke, Ada explained that she *'can't even crack an egg'* because of the dysfunction in her hand, and described how reading and watching television were no substitute for cooking which in her words *'gave me something to live for'*.

Meg, too, missed the domestic activities that were a large part of her life and this made her angry. She had taken pride and satisfaction in her efficiency prior to the stroke describing, at six months post-stroke, how she used to *'wash and iron in the same day'* (Meg 6). She had to use a stick in her unaffected hand to aid her balance in walking and to use that hand to steady her balance in standing; this left her without a useful hand to pick clothes up and put them in the washing machine.

'I want to go in the kitchen ... I still haven't got my balance properly. I get so mad because I think I'll bring something out and put it in the washer, but I still can't.'

Meg (18)

Gordon, who had previously done all his own DIY tasks, explained how he could no longer do a simple thing like hitting a nail with a hammer. Harry described his frustration in not being able to do the heavier domestic tasks that had previously been his responsibility as having gone from being *'left-handed to no-handed'* (Harry 12). This perhaps emphasises how much people depend on having two hands and how when one hand is affected it can feel as though both hands are useless. This could be even more so when the dominant hand is affected, as in Harry's case. Harry, like many other participants, found it very frustrating and felt guilty that he was relying on others to do the tasks of which he had been previously very capable. Alan's description of how he felt when another person did

a small DIY task for him and his partner illustrates how difficult it was for him to watch another person doing a task that he would previously have been perfectly capable of completing. He clearly felt incapable and of no use when he and his partner had to rely on another person, and so he withdrew himself from the situation.

'My mate had to have a look at that clock on the wall. I couldn't because I haven't got the use of my left arm ... I just sat in the kitchen out of the way ... felt terrible. I feel guilty – we've got to rely on other people.' Alan (18)

For two of the men in the study, losing skill in their hand threatened their livelihoods. Gordon had worked as a maintenance fitter before his stroke and, although he could walk normally and was in that respect fit for work, he had limited function in his dominant hand as he explained that he could not even use a spanner; and during the six-month post-stroke interview, as he looked ahead to possibly returning to work, he reflected that he would *'only be good for sweeping up'*. Not only was his income threatened but his comment reveals how his upper limb dysfunction made him feel he had not only lost his skill but had also been relegated to a lower status. Unfortunately, by the next interview at 12 months post-stroke his status had deteriorated even further in that his employment had ended because of his loss of skill. He observed *'Well you feel a bit lost'*, giving a sense of how much his job had been part of the purpose of his life, and he was unsure now of how to fill this void.

Bob was a musician, and this was both a hobby and a means of paid employment. He played the piano, church organ and bass recorder, and was also an orchestral conductor and music teacher prior to his stroke. He had little function left in his dominant right hand and this greatly affected his capability and skill as a musician. This was of great concern and sadness to him, more so than just losing his income, and dominated all four interviews. Music was clearly his life and to lose the dexterity and skill in his hand to play his instruments was devastating for him.

'It's very sad ... I used to be a pretty good pianist, I mean I've been living in music all my life. It is a bit depressing, you know. I mean that's my job isn't it, music ...'

Bob (6)

He went on to explain, again with some sadness, how before the stroke he was so accomplished as a musician that he could play the bass recorder at the same time as conducting the recorder group, but after the stroke he had to put it to one side and only conduct.

'I just simply put it [bass recorder] to one side and just direct.' Bob (6)

In a later interview he reflected on the frustration he felt about his lost skill.

'Without wanting to blow my own trumpet I was a good performer and I would take the difficult parts myself. And now I'm just thinking of last Tuesday when I was conducting, erm, somebody else had to take the difficult part and I thought "I could have played that perfectly well" but in fact somebody else had to and she was having difficulty with it.' Bob (12)

Jenny had enjoyed gardening, particularly growing plants from seeds, but was worried that she would no longer be able to transplant seedlings as she did not have the delicate, precision grip in her right hand. She attended a pensioners' club where craft activities were popular, but her right hand excluded her from much of this.

'Like the craft things, I sit and watch a lot, where I would like to join in. I feel in my brain my hand wants to do it, but it can't. I don't like it.' Jenny (18)

Eve reflected that her life was now *'non-existent'* as all she did was sit in the chair and watch television. She had enjoyed swimming and ballroom dancing before her stroke but felt that she would need two hands to return to those activities.

'cause you can't really jive with just one hand – it's two hands.' Eve (6)

'Well I can't move this arm, so I'd be going round in circles. It's getting in and out of the pool...I could jump in but getting out up the steps with just one hand?' Eve (12)

She explained how housework and shopping were also a big part of her life before stroke but like Meg she had to use a walking stick in her unaffected hand. As she had little movement in her affected arm and hand this restricted her activities in the home and she was too fearful to walk unaccompanied outdoors, and so many activities were lost to her. Eve observed, sadly, at six months post-stroke that you *'have to get used to losing things'* and at twelve months post-stroke the tone in her voice expressed how angry she felt about how much her life had altered.

Eve (12): It's very difficult when you haven't got a choice of what you want to do or where you want to go.'

Interviewer: 'So you feel it's the frustration with your arm and hand that has changed your mood and how you are....?'

Eve: 'I do feel absolutely hopeless and helpless ... It has changed my life. Do you know I wouldn't wish this on my worst enemy?'

Eve's experiences around the effect of her upper limb on her mobility will be explored further in a case study later in this chapter.

Harry explained how he had enjoyed reading the newspaper everyday but this was now spoilt by the lack of function in his left hand. He described how frustrating it was to try to hold and turn the pages of a large broadsheet newspaper with only one hand, this being his non-dominant hand. It had become a daily fight he could not win.

'I fight a page for about ten minutes and still can't do it.' Harry (2)

Jenny and Barbara also commented on how difficult it was with one hand to turn the pages of a book without losing their place. Ada, despite her age, had been a cyclist before her stroke but was too fearful of cycling again, not just because of a weaker leg but because she could not steer the bicycle and make hand signals with just one hand. She missed the freedom and pleasure that cycling had given her. She also missed dancing, which had been a regular part of her life

Ada (12): *'I get fed up of sitting looking at that box [television]'*

Interviewer: *'What else do you miss?'*

Ada: *'...to go shopping in the village on my bike. I used to have bagfuls of shopping on the handlebars. I used to enjoy that.'*

Interviewer: *'Oh you were still cycling before you had your stroke were you?'*

Ada: *'Yeah, and dancing ... used to go three or four times a week ... modern sequence and modern dancing, you know, I used to like them all.'*

This subordinate theme indicates that having a dysfunctional upper limb can lead to people losing the capability to engage in activities that were once so integral to their lives and meaningful to them before their stroke. It also appears to rob them of some purpose and pleasure in life. Furthermore, it was apparent that participants' experiences caused changes in how they viewed themselves and so there was a strong link from this subordinate theme to the other main theme of a Disrupted Self as self-esteem and self-image were affected. This will be explained in that main theme of the Disrupted Self later in this chapter.

4.3.1c Life Roles and Relationships

The roles that participants held were another area of normal life that was altered by their upper limb dysfunction. It was often associated with the valued activities in which people were no longer capable. Lack of movement and control in the arm and hand was a

contributory factor to some being unable to drive and, for several of the men, this was a responsibility as a husband or partner that they could no longer fulfil. This, along with their inability to complete the heavier domestic tasks around the home due to weakness and lack of movement in their upper limb, and also the need to have their spouse help them with self-care, was disrupting the balance and roles within their relationships.

'It annoys me. It should be the other way round. She should be dependent on me. It's how we've always lived. It's changed it.' Colin (6)

Interviewer: *'What other things are there in life where you want to just get up and do something?'*

Colin (18): *'Well [wife] has to cut the grass you know and it's hard work, I'm thinking I'm sure I could do that you know.'*

Interviewer: *'How does that make you feel?'*

Colin: *'... doesn't feel right. No. Well it's my job. Well it's tiring her out.'*

For Alan, there was a sense of him no longer being the one in the relationship who was more "in charge" because of his need for help in self-care.

'She looks after me like a nurse. I feel guilty that I can't do this and I can't do that. It's changed the way we sort of get on. Well I was number 1, now I'm number 2.'

Alan (6)

This is similar to other research on stroke where men felt that their traditional male role as protector and head of the household was challenged and disrupted (Burton 2000, Rittmann et al 2007, Ch'ng, et al 2008). Relinquishing domestic chores to other family members caused friction in some relationships. Barbara described at 12 months post-stroke how hard it was for her to have to sit and watch her daughter and husband do the tasks she had previously done as the wife and mother. Eve described the frustration and

irritation between her and her husband, who was possibly feeling the additional burden of these extra tasks, which is not uncommon in family members who have had to take on extra responsibilities previously held by the person with stroke.

'I feel as though I want to be saying "you don't do it like that, you do it like this". He would get annoyed and say "well do it your bloody self then".' Eve (6)

Other important roles in family life as a father and grandfather had altered. Colin and Harry had been fathers to whom their grown-up children looked for help with DIY tasks; however, these roles had reversed and now the children were doing those tasks for their fathers. For Alan, being unable to drive had limited his contact with his grandchildren who lived a distance away from him. Harry talked about being unable to do DIY tasks for his family and mend the punctures in his grandchildren's bicycles, and he worried that the family now just saw him as *'the old fella in the room downstairs'* (Harry 6), and not as their father and grandfather. Colin and his wife helped with caring for grandchildren, but he was frustrated that he could not play with them or lift them up in the same way because of his arm dysfunction. Eve became very tearful during the six-month post-stroke interview as she explained her worries about possibly harming her granddaughter because of the lack of control she had over the involuntary spasticity in her hand.

'If she puts her little hand in mine and mine grips hold of it, well I could really hurt her.' Eve (6)

Her words produce a powerful image of how her role had altered: the small child's hand in the large hand of the grandmother, who could now become a source of harm rather than protection and safety. Eve was anticipating the birth of another grandchild but was sad that she would not be able to bathe, dress and change nappies with this one as she had with her granddaughter. She described at twelve months post-stroke how her upper limb dysfunction had altered how she could live out her role as the grandmother. All she could see were the things she could no longer do with her grandchildren.

'I can't be left to babysit when she's in bed because if she started to cry I can't get upstairs to her. I wouldn't feel safe holding the baby. I can't hold her hand or anything 'cause with the stick being in this one [unaffected hand], I can't hold on to her, so we can't go out for little walks. We don't play games like we used to ... I can't get down and sit on floor with her because I can't get up with just one hand.'

Eve (12)

As will be shown in the case study about Eve, later in this chapter, her inability to use her arm to maintain her balance prevented her from going upstairs in her home and so she would not be able to attend to a grandchild crying in the bedroom upstairs. Having to use a walking stick in her unaffected hand prevented Eve from holding her granddaughter's hand when walking. The dysfunction in her arm and hand had altered significantly her role as a grandmother.

Bob, a musician, composer and conductor, considered his role as vital in his life as both an occupation and hobby that brought him recognition in the musical circles he moved in. At six months post-stroke, he explained how hard it was for him to consider that this role might have to come to an end because of his inability to play his instruments. Before his stroke this was not something he had seriously considered.

'It's a bit depressing because that's my job you know, my work. Although I'm 71 now so I suppose it's time I ought to retire anyway [laughs]. The funny thing is I'm thinking of people like [person's name] who used to be the cathedral organist and he's still a brilliant organist, brilliant musician and he still plays recitals on the organ regularly... he's 94 and so, er... people sort of keep going forever, pretty well, musicians. I thought I would be able to choose for myself when I wanted to retire rather than have it chosen for me. That's the point.' Bob (6)

For Bob, being a musician was not only a role but also was very much at the heart of his identity and, therefore, closely connected to the main theme of the Disrupted Self. This

altering of roles affected other participants in similar ways, again showing the link between the main themes of The Altered life and The Disrupted Self. This will be further explained later in the next section.

4.3.1d Summary of the Altered Life

The findings in this main theme of The Altered Life and the subordinate themes have shown how much upper limb dysfunction had affected the lives of the participants. The experiences of the participants have shown that people need two hands working together to get on with their lives and, when this is lost through stroke it can alter the fabric of an individual's life in many different ways. Instead of the competent and capable people they were before their stroke, they can become dependent and unable to fulfil the roles they had. The findings highlight the importance of two-handed function, with both upper limbs working together.

4.3.2 The Disrupted Self

As was seen in the literature review chapter, everyone has a sense of self, of who they think they are. This is formed through personal life experiences and interaction with the environment and others throughout life. This sense of self, therefore, can be affected by life experiences and stroke is one of those experiences that can have a significant effect on how a person feels about him or herself (Burns 1979, Berndt and Burghy 1996, Ellis-Hill 2011). The findings from this study indicated that upper limb dysfunction had not only altered people's lives but had disrupted participants' sense of self. The consequences of the changes in peoples' lives and the feelings associated with losing competence in self-care and the capability to carry out meaningful activities and life roles brought a change in this inner realm of thoughts and values about themselves. For many, this picture of the self did not live up to the one they previously held of themselves. In particular, there were changes in self-esteem, self-image and identity, all of which are important aspects of a person's perception of who and what they are.

4.3.2a Feeling Like a Child

As individuals move through childhood into adulthood they become competent in self-care tasks but, for many of the participants in this study, needing assistance with self-care because of their upper limb dysfunction, changed their perception from one of being a competent adult to feeling more like a child again. Doris and Barbara described being *'treated like a child'* (Doris 2) and *'feeling like a baby'* (Barbara 2) when having help with bathing and using the toilet. Eve described the frustration of losing the ability to choose when to shower or use the toilet, having to wait until carers arrived, and how being at the convenience of others made her feel less of an adult and more like a child having to wait for an adult to accompany her to the toilet.

'Having a bath and a shower, being told when I can have one and when I can't ... you sort of feel as though you've got no choices... you feel like a kid.' Eve (2)

Needing help with using cutlery and feeding was particularly difficult and evocative of childhood.

'Well [wife] will cut it up for me, and I drop a lot, I feel a bit of an idiot, you know you have to cut your own food up, and a bit like a baby, you're dropping food all over the place.' Harry (12)

This was even more evocative of childhood in social situations. It is not unusual to see young children having help with cutting up and managing food, but it is unusual to see this with adults and, therefore, can cause bystanders to take more notice of this. Ada described being embarrassed in that she felt she had become more visible and conspicuous, and subject to the gaze of other people around her. This is not an uncommon phenomenon, in that people can feel that their impairments and disabilities make them stand out (Kvigne and Kirkevold 2003). Alan explained his discomfort at feeling he was being noticed and conspicuous when needing help to get food on his plate

at a buffet table during a social occasion, similar to the way in which an adult will put food on a child's plate.

'I had to go up to the table, I could hold my plate but my partner had to put food on the plate. Just feels like everyone in there's watching you.' Alan (12)

There were findings that showed the efforts participants went to in order to avoid having food cut up for them in social settings.

Lily (2): *'Well I've just tried to get things cut up and then just use a fork with my right hand but it's not always convenient.'*

Interviewer: *'So when is it inconvenient?'*

Lily: *'Well I mean, I've been out a couple of times to eat but I've managed to get food that was easy to manage with a fork.'*

It seemed important to feel more "normal", perhaps as an adult would be, and so feel less conspicuous. However, this did limit their choice of food, and, as Meg explained, made her feel different from her friends. To avoid having her husband cut up her food, she could not enjoy her preferred choice of food and so join in with the same experience as her friends.

'We went to the local pub with our friends, they ordered steak and I thought "oh I'll have scampi, that'll be easier"'. Meg (18)

Interestingly, it was not just self-care activities that left participants feeling like a child again. Alan, at 12-months post-stroke, explained how shop assistants would help him get money out of his wallet in the same way they might with a child, and Harry compared his attempts at writing with his non-dominant right hand to that of his grandchild.

'The four-year-old writes better than I do' Harry (6)

This subordinate theme emphasises just how vital the bi-manual function of the hands is as people develop through childhood to become competent, independent adults. This two-handedness can so easily be eroded away by a dysfunctional hand, returning people back to the dependency of childhood.

4.3.2b Feeling Devalued and Downgraded

It was apparent that the embarrassment and vulnerability that people experienced when needing help with self-care also had an effect on their self-esteem causing some to feel that they were of less value and worth than before their stroke. Self-esteem is part of self-concept and was defined in an earlier chapter as the feelings or evaluations that people have regarding their self-worth (Niven 2006). The lack of mastery over self-care because of upper limb dysfunction, feeling like a child again and an inability to carry out valued activities and fulfil roles had a great impact on many participants. Cath and Eve both described *'feeling degraded'* while being helped with self-care, particularly when it was a male nurse assisting.

Interviewer: *'How do you feel about having help with some of those personal things?'*

Eve (2): *'It's a bit degrading ... when a male nurse comes to you for to clean you [after using the toilet] you think "Oh no, this is not right".'*

Doris admitted *'feeling like a beached whale'* and said *'your self-esteem plummets a bit'* (Doris 2). Their bodies did not conform to what would be accepted as normal adult behaviour, and so their use of the word degraded indicates that they felt of less value or status as a consequence. Stroke survivors in a study by Ellis-Hill et al (2000) expressed similar feelings of being downgraded because they no longer conformed to society's view of being able-bodied. Many participants in this study frequently described themselves as *'inadequate'*, *'useless'*, *'helpless'* and *'hopeless'* when describing their inability to manage self-care, indicating that they viewed themselves as of less worth than prior to their stroke.

This is Colin at two months post-stroke talking about needing help with dressing because of his weak left arm and hand.

Interviewer: *'so has it changed how you view yourself as a person needing help with those personal things?'*

Colin (2): *'Yeah I feel ... you feel... you feel useless. You've got to ask people to help you "get me this, get me that" just makes you feel inadequate.'*

These feelings persisted for many participants.

Interviewer: *'How do you feel in yourself when you have someone cutting up your food for you?'*

Barbara (6): *'You feel useless; you ought to do it for yourself'*

Alan, at six months post-stroke, was struggling with feelings of being of less value, particularly in the eyes of other people. He explained that his partner now looked after him *'like a nurse'* because of his dependency in self-care.

Alan (6): *'Everyone is saying ... "look I feel sorry for her looking after him. What's she doing with a bloke like that?"'*

Interviewer: *'In what way has your arm and hand changed how you feel about yourself?'*

Alan: *'Right, before I used to look as though I was a first class person, now I'm sort of like a second class citizen. It downgrades you.'*

His self-esteem had not improved at the twelve-month post-stroke interview as he still needed some help with self-care, and he was not able to carry out the general DIY and domestic chores he had before his stroke.

Alan (12): *'Because I can't do things and I feel like ... I'm not a whole person.'*

Interviewer: *'So your arm and hand particularly make you feel that you're not a whole person?'*

Alan: *'Yes'*

Interviewer: *'Why?'*

Alan: *'Because... I feel half a person 'cause I can only do half the things I used to do. I can't do what I used to do.'*

He explained how he felt when shop assistants had to help him get money out of his wallet when shopping.

Alan (12): *'It makes you feel mad and you want to scream and say I want to do it myself.'*

Interviewer: *'What does that mean in terms of how you view yourself as a person?'*

Alan: *'Like a second class citizen'*

Alan's words are a reminder of the fact that we use our upper limbs in almost everything we do and so losing function in an arm and hand can leave someone feeling they are not a full person, but have become half a person and furthermore of less worth than they were before their stroke. It is interesting that the terms used to describe the impairment that stroke brings are hemiplegia or hemiparesis i.e. paralysis or weakness of half or one side of the body, but from Alan's experience it is possible that upper limb dysfunction alone could leave an individual feeling like a 'hemi-person'.

Ada described how she felt when she was confronted with the extent of her upper limb dysfunction during an activity with the occupational therapist while still in hospital.

'I tried baking here [in Occupational Therapy kitchen] and believe me I was a mess, absolutely a mess. If I go home and do my meat and potato pies and apple pies like this, nobody will eat them.' Ada (2)

It is interesting that she described herself as a mess rather than she made a mess, and she was clearly concerned that her cooking would not be good enough for other people and be rejected and so felt she may be rejected. Cooking for others was so integral to her life and her identity, as will be discussed in a later section, that any negative comment about food she had prepared could be perceived by her as a negative view of her as a person. Harry made his feelings about himself very clear with regard to needing help with self-care and also being unable to fulfil his role in the family. At twelve months post-stroke, he felt *'a bit of an idiot'* when needing help with feeding and both at two and at eighteen months post-stroke described himself as *'a useless old bugger sitting in a chair.'* The findings in this theme and the previous one of Feeling like a Child indicate how participants' self-esteem had been disrupted because of their upper limb dysfunction and altered lives. They were feeling much less of a competent adult and, as a consequence, of less value and worth as a person. Their altered life had also resulted in changes to self-image, which is explained in the next section.

4.3.2c Disrupted Self-image

The presentation and appearance of the body is strongly related not only to self-esteem but also to self-image (Garner 2004). The findings in the study indicated that there were two issues that were affecting self-image for the participants. Firstly, they were unable to dress and present or adorn their body in their preferred way, and secondly, the cosmetic appearance of their arm and hand was a concern.

The subordinate theme of Managing Self-care in the main theme of The Altered Life explained how a dysfunctional upper limb can make dressing very challenging. This was a difficulty encountered by all participants at two months post stroke and persisted for

many throughout the eighteen-month period of the study. Fastening buttons, zips, underwear, pulling up trousers, putting on socks, tying shoelaces and neckties all require bi-manual activity of both hands working together and great dexterity, and as a consequence many participants had made changes to the type of clothing they wore to make dressing easier, often wearing looser fitting garments with fewer fastenings. Although this was very practical, it meant that their preferred style of dressing was no longer an option. This comment by Meg shows how wearing looser fitting clothes was not consistent with the smarter image that many participants had of themselves and that they preferred to present.

'I don't like it because I've always been what you call a smart person and I like the clothes to fit, you know, properly.' Meg (18)

Alan indicated that he felt dirty and, interestingly, for him his usual attire before the stroke had enabled him to fit in and blend in socially with those around him, whereas at this point he clearly felt uncomfortable and different having to wear looser trousers that did not have buttons and zips and so were easier to put on. This shows how wearing clothing appropriate to the social setting is important for a person's confidence and self-image.

'sometimes I feel scruffy when I go out ... seeing everybody else smartly dressed and I'm sort of there in a pair of tracksuit bottoms... not wearing proper trousers... I feel out of place a bit.' Alan (12)

Bob complained that he no longer felt he was dressed properly because he could not tie a necktie. This had always been a feature of his daily dress and the image he liked to present when he went out. People express themselves through the type of clothing they wear and this enables them to present an image that they feel represents who they are and is appropriate socially to the setting they are in (Yuen and Hansen 2002). Putting on jewellery, styling hair and manicuring nails all require dexterity in both hands as they work together. Many of the women no longer had the dexterity to adorn their body with

jewellery and make-up or to manicure nails and style their hair, which had been important aspects of their self-image before their stroke. Lily explained how she had been almost ambidextrous before her stroke but now could not apply nail varnish to her right hand because she had lost the fine control in her left hand. The head and face are the most noticeable parts of the body because generally we look at people's faces when we meet and talk to them so hairstyle and (for women) make-up can be very important in a person's presentation. Ada was embarrassed with her hairstyle and felt she now looked 'a mess' (Ada 12) and would never have left the house before her stroke with her hair as it was now. Meg talked about how she could not 'tidy' herself up by doing her make-up and hair and wear smart clothes, and this affected the younger image she liked to present to the outside world.

'I'm not impressed ... I used to like to dress up ... and I never looked my age.' Meg
(12)

Eve admitted that her appearance made her feel inferior while she was still in hospital and later, at six months post-stroke, this feeling persisted as she was still restricted in her choice of clothing, and was unable to style her hair and wear make-up.

The cosmetic appearance of the affected arm was also a cause of dissatisfaction with self-image for some and caused them to hide the arm away.

Interviewer: *'Are you conscious of your arm and hand and how it looks?'*

Ada (2): *'Yes I keep it under the covers'*

Interviewer: *'Why is that?'*

Ada: *'I don't really know I just think oh gosh it's ugly, so I lay the covers over it.'*

Meg, at six months post-stroke, was aware that the posture of her arm was affecting the fit of her clothes, particularly around her shoulder and upper arm.

'My clothes are sort of all lop-sided with this arm. My clothes never look right.' Meg (6)

By eighteen months this seemed to be getting her down and now she was trying to camouflage her arm by draping a scarf over her shoulders.

'I'm so fed up with my clothes. They're always dragging down, that's why I put a scarf on.' Meg (18)

Concealing the arm and hand was a phenomenon in studies by Ellis-Hill et al (2000) and Kvigne and Kirkevold (2003) where people were embarrassed and uncomfortable about their body no longer conforming to the norm. This was clearly a strong emotion for Ada, as she thought her arm was ugly and should be hidden away. Hiding or disguising the affected body part is an attempt to melt into the background and to avoid the gaze of other people. Alan, too, was very aware of how different his arm was compared to others.

'I feel a bit embarrassed because you see everybody else out, are showing their two hands, you know, and things like putting their hands in their pockets. I can't even put my hand in my pocket.' Alan (6)

When Alan mentions people showing their two hands it highlights how visible the hands are when we encounter people. After the face, they are possibly the most noticeable part of the body because individuals gesture with them while they talk, and sometimes use gestures instead of talking. Alan tended to gesture only with his right hand. It is interesting, also, that Alan noticed people putting their hands in their pockets, a common occurrence, sometimes to retrieve an object, sometimes just to rest the hand or keep it warm, and sometimes as part of a behavioural posture or stance. This brought home to him the visibility of his dysfunction and difference to others.

The physical ability of the body can be a factor in self-image. Not only were participants no longer capable of carrying out their valued and meaningful activities because of their

upper limb dysfunction (as explained in the main theme of The Altered Life), but this change in their physical capabilities had affected the self-image of some. Barbara explained how before her stroke she was always busy with activities around her home but now she had to sit and watch her daughter doing them, and as well as being frustrated, she thought she had become a lazy person, rather than the efficient housekeeper she was before. Lily described herself before the stroke as *'a very quick person ... very active ... I was always doing things'* (Lily 6) and this she said was the perception of others *"you're always so busy"* (Lily 6). Dysfunction of her hand had caused her to become *'slow'* at activities, and this was very frustrating for her as she compared herself to others.

'I went to the supermarket and went in the toilet and a woman came in after me, and I'd been in there a bit and I was getting my clothes down to get on the loo and next I heard her washing her hands... and I hadn't even got my clothes down... I was always a very quick person.' Lily (6)

At twelve months post-stroke she described herself as an *'invalid'* because of this slowness and thought that this was how her friends now saw her. Colin had seen himself as a capable and competent person before his stroke but this comment shows he clearly felt reduced to feeling he had to beg for help.

'That's all part of the frustration of not living a normal life. Because I'm putting on people, I used to do it all myself, I wouldn't have been begging people to look after us.' Colin (2)

The loss of function in one arm and hand had not only altered these participants' lives but had left them with a different image of themselves and this, combined with low self-esteem, was disrupting their picture of the self. Self-image is intertwined with identity and the next section will explain how losing capability in valued and meaningful activities and life roles also affected peoples' identity.

4.3.2d Disrupted Identity

Christiansen (1999) suggests that a person's identity is closely linked to their occupations, in the wider sense of valued activities and life roles, and this was very much the case for participants in this study. Identity can be defined by the labels a person may assign to him or herself, or feel that others assign to him or her (Baumeister 1999). Bob, for example, described himself as a musician at the first interview and described how he had '*lived in music all my life*' (Bob 2), but clearly this was challenged by his upper limb dysfunction, as he talked about his ability to play the bass recorder and organ as a good performer in the past tense. He still had that identity as a musician, but no longer the identity of being a good performer as a musician.

'I was a good performer and I would take the difficult parts myself... I can't play any instrument with my right hand now so my organ playing is not as good as it used to be.' Bob (12)

Alan, at six months post-stroke, was very conscious of his identity as a man and changes in his upper limb function threatened this. He described how his upper limb dysfunction meant it was easier for him to sit down on the toilet rather than stand as a man would normally do when passing urine. If he stood, he would have to use his unaffected hand to support his balance, thus leaving him without a useful hand to complete the task. While this was very practical in his home, in more public toilets it was important to him to struggle to use the urinals in the same way as other men.

'Like yesterday we went into a pub for a cup of coffee and I had to go to the bathroom. Because it was the gents, I only had [his female partner] with me, I had to go on my own. I can't normally stand up and I had to stand at the urinals instead of sit on the toilet.' Alan (6)

Stroke can challenge a man's masculinity, as in a study by Rittman et al (2007), where having a stooped posture and abnormal gait affected the male identity of being upright

and strong. In this case, with Alan, it was his upper limb as well as his lower limb that were important in maintaining his masculine identity. This shows how important it is to have two functional upper limbs to be able to use the toilet independently when weakness in a lower limb necessitates a walking aid.

Ada saw herself as a cook, and this identity had grown from necessity during her childhood in a large family. However, at six months post-stroke she was clearly very upset at losing her skill. She recounted how during a recent family bereavement she was frustrated because she would normally have looked after the family by cooking and providing food. Now, others were doing this for her and the emphasis she put on the word 'me' illustrates how she saw this as an affront to her identity.

'My sister came at the weekend and brought me a chocolate cake.' Ada (6)

Her sister had taken over her identity of the cook in the family. She became quite emotional as she talked about this and went on to describe herself as 'useless' and 'stupid', illustrating how losing the valued activities that provide identity can also affect self-esteem. Jenny, similarly became distressed during the two-month post-stroke interview as she explained how she had been the carer for her husband for many years, and looked after the home single-handedly. She realised that this part of her had gone and now she was the one needing help and care.

Having a life role in the family provided identity for many participants. They were still a spouse, parent or grandparent but, as highlighted in the section on Life Roles and Relationships, how they could now live out this role was changed, thereby disrupting their identity. Eve no longer saw herself as the reliable and protective grandmother who could be left alone to take care of her grandchildren. Colin was no longer the strong, playful grandfather who could pick up his grandchildren, and Harry was not the grandfather who could fix bicycles. Colin, Alan and Harry were no longer the strong husbands who could

take care of the heavy domestic tasks in their homes and drive their wives wherever they wanted to go.

4.3.2e Summary of the Disrupted Life

The findings in this main theme of The Disrupted Life and the subordinate themes have shown how much having a life altered by upper limb dysfunction can bring about a disruption to an individual's sense of self. The experiences of the participants have shown how vital it is to have two upper limbs that can work together to provide the competence and capability to live a life and, when this is not the case, how a person's view of him- or herself can change for the worse. The literature review identified how stroke as a whole can affect the sense of self, but the findings from this study bring to light how upper limb dysfunction can be a significant factor in this. Thus, paying attention to the rehabilitation of the upper limb and helping to restore some degree of two-handedness could be vital in helping people retain their self-esteem, self-image and identity after stroke.

In the next section, the findings from the third main theme of The Experience of Recovery will be presented. There are three subordinate themes: Hopes, Priorities and Getting on With Life; Therapy; and Information and Advice.

4.3.3 The Experience of Recovery

The background to this study explained the theory behind recovery, physical adaptation and psychological adjustment. A person's perception of stroke, as a whole, can change over time as they recover but also adjust and adapt to the changes in their body at the same time as trying to construct a new post-stroke life, although not all are successful in doing this (Ellis-Hill et al 2008). The second and third research questions in this study were directed at exploring this in the context of the upper limb. The longitudinal design of the study, with each participant interviewed four times over an 18-month period after stroke, provided an opportunity to do this. When asked about their long term goals for their upper limb it was apparent that participants did not have specific goals, but rather they talked more about their general expectations and hope for more recovery and their

experiences of health services in that process of recovery. The first subordinate theme of Priorities, Hopes and Getting on with Life is presented first and is subdivided into the four interview points of two, six, twelve and eighteen months post-stroke to illustrate the change in participants over time.

4.3.3a Priorities, Hopes and Getting on with Life

Two Months Post-stroke

At this stage, those participants still in hospital were focused on getting home and were hopeful of a good recovery and a return to their normal life. This was not unexpected as often it is only when people are back in their normal environment and they realise the extent of their disability that they can begin the process of adjustment and adaptation (Olofsson et al 2005). Interestingly, the five participants who were already at home at this stage were also optimistic about their recovery; however, most had only been at home a very short time before the interview. The priority for nearly all participants was overwhelmingly to regain the ability to walk or to improve their walking. This was particularly so for those who were still in hospital at this point and were unable to walk independently. A comment by Meg was typical of how walking was seen as crucial to achieving more independence.

Interviewer: *'What do you think is your priority for getting better? What's important to you at the moment?'*

Meg (2): *'Walking, because I'd like to get out of the chair and walk across there [pointing to the wash basin] and walk back.'*

Ada, Doris and Jenny saw walking as the key to discharge and seemed to equate walking with freedom and choice.

Interviewer: *'So is there anything more important to you than your arm and hand, in terms of getting better?'*

Ada (2): *'Being able to walk out and go wherever I want.'*

Doris and Jenny wanted to return to living alone in their own home, as they had done before their stroke. Doris had made more recovery in her arm and hand than in her leg and this probably explained her priority to improve her walking, whereas Jenny, who had little recovery in her upper limb, recognised that her priority could change from walking to her upper limb once she was at home if she was to remain independent.

Interviewer: *'So you feel that your leg and foot are more important than your arm at this stage?'*

Jenny (2): *'At this stage it is, because I can do things with my left hand. I can eat with it, I can make cups of tea, I can do what I need to do at the moment, but not for long.'*

Alan and Harry were both happy to ignore the upper limb at this point and concentrate on walking. Alan explained that he felt he could work on his arm later. Harry wanted mobility. He compared his feelings about his arm and hand to a broken down car. This perhaps showed not only frustration but also anger with his lack of function.

'I'm ignoring them. ... It's not working so, I mean a bit like a car, if it won't work you get out and slam the door!' Harry (2)

The lower limb was not the priority for all, though. Three of the participants who were discharged from hospital and living at home at two months post-stroke had a different attitude to their upper limb. Bob, the musician, considered that upper limb recovery was just as important as that of his lower limb. He needed both hands to play his instruments and also to drive. Colin also saw upper limb recovery as central to returning to a normal life. Gordon acknowledged that while in hospital he was more concerned with recovery in his leg but this had improved considerably and now, like Colin, he saw his arm and hand as vital to his independence and return to work as a maintenance fitter.

There was a much hope in many participants at this point for a full recovery in the arm, despite their prioritisation of the lower limb. The anticipation was that it would be within a short period of time and people seemed to want to set milestones at certain points in time by which they would have recovered. Alan stated that six months was his time scale for full recovery and Harry was also optimistic, despite the fact that, as stated earlier, he was ignoring his arm.

'I fully expect the arm to work properly soon.' Harry (2)

Not all anticipated recovery to come so quickly, although they still talked in terms of months rather than years. Jenny, who was interviewed in the summer, expected *'by autumn I'll be fine'* (Jenny 2) but Meg, interviewed in January, anticipated *'this hand won't be right by Christmas'* (Meg 2). Colin recognised that the rate of recovery in his arm was much slower than his leg and so his time-scale for full recovery was longer. He based his expectation on advice from health professionals and another stroke survivor's experiences.

'About two to three year ... some say 18 months – one of the physios. My son knows somebody who had a stroke like this, and 18 months they were back to normal.' Colin (2)

Bob was less optimistic because of the prediction he had been given by the physiotherapist whom he saw as *'the expert'*.

'He said "I don't think you'll ever be able to play the piano very well with your right [affected] hand"' Bob (2)

Nevertheless, he hung on to some hope as he stated *'Well I want to prove [physiotherapist's name] wrong.'* (Bob 2)

Six Months Post-stroke

By six months post-stroke, all participants were discharged from hospital and living in their own homes, apart from Ada who was living with a family member. Doris and Jenny, who lived alone, were adapting physically by employing cleaners and gardeners, using adaptive gadgets and equipment in the kitchen and bathroom. They were unperturbed by their outward appearance and changes they had made to the type of clothes they now wore or their hairstyles. They were more concerned about being able to continue to live alone. Jenny used the phrase *'I get by'* several times during the interview, which indicated that perhaps her quality of life was not ideal but this was compensated for by continuing to be able to live alone. Colin, too, was trying to adapt but finding adjusting to this psychologically was more challenging.

'You've to stop worrying about stuff and get on with it. ... I tell myself all the time "stop moaning and get on with it".' Colin (6)

Despite the signs of some adjustment and adaptation, it was apparent from the results that the issues with low self-esteem, changes in self-image and identity had heightened during the period from the two month interview to this point. The full impact of their upper limb dysfunction and loss of competence and capability in many areas of their lives was fully recognised by participants because of the months they had now been at home. The challenges faced in self-care and valued activities and the changes in roles and relationships were fully realised. It was during these six-month interviews that the words *'useless'* and *'hopeless'* were used the most frequently by participants to describe how they felt.

By this six-month point, priorities had changed for many and having function in both upper limbs was seen as essential in being able to return to valued activities. All participants had now been discharged from hospital, and the reality of their inability to manage self-care independently and participate in valued activities was now clear to them. Going

home from hospital is seen as a crucial point at which people often begin to grasp the extent of their disabilities as they try to recover their self-care and valued activities (Olofsson et al 2005). It is not surprising, therefore, that this was the experience of the participants, particularly when both upper limbs are involved in nearly all of the tasks and activities that people normally engage in.

'Get this hand going ... definitely. I think it's coming home and trying to do things here and I can't do them ... I'd love to, you know, but even to bake a cake, a simple thing, there is no way I could do it.' Ada (6)

However, for some, walking remained their priority. Alan and his partner were contemplating marriage and he wanted to walk down the aisle, and Meg wanted to be able to walk to the shops. Harry declared he was still *'not bothered'* about his arm and hand as he saw walking as the key to competence in self-care.

'I feel if you're walking then the rest of you will improve with it. ... I need to get to the toilet and shower and shave myself' Harry (6)

This prioritisation of recovery of walking over the upper limb is recognised in other research on stroke (Kirkevold 2002; Jones et al 2008) and is understandable. Walking is a fundamental part of human behaviour and is commonly equated with independence. Using a wheelchair for mobility can make a person seem more dependent as it can be a barrier to access to the home and external environment, and can necessitate dependence on others to assist with transfers to beds and chairs and to propel the wheelchair. Harry's comment belies the fact that if he made it into the bathroom independently he may not necessarily be able to shower and shave independently because of his upper limb dysfunction, as the findings in this study have shown.

As time progressed, participants' perceptions of recovery of the upper limb were changing. They still had hope but the temporal milestones for recovery were being moved

further away. They were seeing a slowing down in the rate of recovery. These comments from Lily at six months post-stroke were typical and showed that some participants were not prepared for this slowing down.

'I seemed to make such good progress to begin with, and then it seems to have slowed up ... it's been a lot slower than I thought it would be. I expected it would continue, yes, but it's not.' Lily (6)

Several participants had been given lengthy time-scales for recovery in terms of years by doctors; this was changing expectations but keeping hope alive for some.

'The consultant, I don't see him anymore now, but he said it could take up to two years to come so I keep hoping.' Jenny (6)

Many participants were holding on to the advice and experiences of other stroke survivors to help them make sense of their experiences and to keep hoping that in time more recovery would come. Gordon admitted he had initially expected his arm to recover within four months of the stroke but now was looking much further ahead.

'Her [his partner's] uncle had a stroke and took him two and a half years before he got full use of his hand.' Gordon (6)

For some people, however, the slowing down of the rate of recovery and the less positive experiences of others were causing hope to fade.

Ada (6): *'When I was in hospital I thought "Ah well I'm going to get better" but now I'm just down to rock bottom, thinking there's no future.'*

Interviewer: *'What has made you think that?'*

Ada: *'Well it's took so long to get this far ... as I say I keep trying and I just can't do ... even to lift a plate. I'm frightened to death if I put it in that hand it'll drop.'*

Alan explained how he was disheartened and '*knocked for six*' by hearing about another stroke survivor who had not recovered arm function even after three years. It was evident that trying to keep hope for more recovery alive was a struggle for some participants. The shifting of temporal milestones further away was possibly a means of doing this in the face of a slowing down of recovery and hearing about the experiences of other stroke survivors.

Twelve Months Post-stroke

At twelve months post-stroke, there was little change in most participants as the losses in competence in self-care and valued activities and changes in roles were largely the same as at six months. Low self-esteem and issues with self-image and identity were still prevalent. It was clear that some were trying to come to terms with their situation, but for those needing help with self-care this was more difficult.

'I don't feel my daughter should have to do it for me ... you know well if she's used to that I can get used to her you know.' Ada (12)

Psychological adjustment seemed to occur when things had improved or physical adaptation was successful, such as in the case of Bob, who was making adaptations so he could continue with his hobby and profession in music. This will be discussed in more depth in the case study to follow. Colin, too, was more positive, because he was driving again, albeit in an adapted car, which was not too much to his liking; however, he could again fulfil his role as a husband in providing transport for his wife.

By this 12-month point there were changes in priorities, in that all participants now were concerned about their upper limb and were realising how vital their arm and hand were for them to resume self-care, activities and roles.

Eve (12): 'Well if I can only use my arm I'd be able to do a lot more for myself'

Interviewer: *'What sort of things are you thinking about that you'd be able to do for yourself?'*

Eve: *'Well I'd be able to dress myself and undress myself properly, and then I'd be able to have a shower ... on my own. Yeah I'd be able to walk down the street and get on a bus ... and then playing with my granddaughter.'*

Jenny admitted that up to that point her leg was more important so that she could walk to the local shops but now she wanted a normal hand to do more gardening. Meg had fallen several times and realised how essential her affected arm was to assist in maintaining her balance and for function.

'Sometimes I just wish I could save myself with this hand. ... It would help if I could walk like I do [with stick in unaffected hand] and I could use my hand for something' Meg (12)

Harry was no longer ignoring his arm. He was still unable to walk at this point, but felt he would be more competent in feeding himself if he had two functioning hands.

Participants' comments were very revealing as they reflected back at this point, twelve months after stroke, on what they had anticipated about recovery of their upper limb when in the early stages of their stroke. This could highlight either the lack of relevant information available or that people cannot fully interpret and retain information in the early days after a stroke.

'I thought I'd get home and start doing all the things I did before.' Eve (12)

'I mean silly me, naïve me thought it would come back automatically. My walking was coming on in hospital and this [pointing to her affected hand] would follow.'

Jenny (12)

Although reality had not lived up to expectations there was still hope, particularly where improvement had occurred.

'Now if I can improve it next year like I've improved it first year, no problem. ... As long as I got progress then I can't complain can I?' Colin (12)

Eighteen Months Post-stroke

At 18 months post stroke, Doris, Jenny, Bob and Colin continued to adjust and adapt.

Colin described an experience he had when dining during a recent cruise.

'Waiter came up and cut all my meat up every night, brilliant, absolutely brilliant.'

Colin (18)

He explained that he did not feel *'different or awkward'* because there were many other disabled people on the holiday. This had put his experience of stroke into context and normalised his upper limb dysfunction. He went on to explain how his attitude to needing help had changed. This was in contrast to how he felt at two months post-stroke when he saw himself as *'putting on people'* and *'begging people to look after us'*, indicating that he had made further psychological adjustment to his situation.

'You just accept you need help, when you need it you've got to accept it.' Colin

(18)

Others, too, had made some psychological adjustment by this point. Harry, who still required significant help with all aspects of his self-care, described how he coped with it now.

'I just relax and let it happen. If you accept it, it gets better.' Harry (18)

Lily, who at 12 months post-stroke was concerned that she was slow and labelled herself as an invalid, now reflected that she was *'the same person as before, just slower.'*

However, many participants were still dealing with low self-esteem and changed self-

image and identity. Alan described himself as a '*second-class citizen*', Barbara still felt '*like a baby*' because she needed help with bathing, as did Eve who described feeling '*useless*'.

The focus on regaining more recovery in the upper limb continued at 18 months post-stroke. For Barbara and Meg their upper limb was just as vital as their lower limb in resuming valued activities.

'To be able to use them [hands]more, and walking about ... probably be able to do some cooking.' Barbara (18)

Harry seemed to have given up hope of walking again, but wanted more upper limb function in his dominant left hand, which was affected by the stroke. He wanted to write and sign his name with his left hand, and type more quickly on a computer (he had been able to touch type with both hands before the stroke) so he could take back some of his previous domestic administrative responsibilities from his wife and regain some of his role as a husband.

'Yeah, like re-taxing the car ... and house insurance and stuff like that. Yeah, she does everything.' Harry (18)

By this stage, participants seemed to be moderating their expectations of how much more recovery was possible. Some still had hope for improvement but not necessarily full recovery.

'I can grip some things ... I can zip me coats up ... so I think if I can do that I am going to do other things.' Barbara (18)

'It won't properly get back to the way it was but I'm hoping it will get three quarters of the way there.' Alan (18)

Some, though, had accepted that more recovery was unlikely. This was not necessarily based on the amount of function they had regained. Lily had good function in her hand but sensation had not fully returned and she thought it might not recover fully.

'I still have to watch it else I catch it ... I'm very clumsy I find ... it's not as sensitive. It probably won't ever really [recover].' Lily (18)

Bob had little useful function and had seen minimal improvement; he now agreed that the physiotherapist's prediction that he would not play his instruments again was correct.

'I'd love to think in a year's time I could use this hand, but in practice I don't think I will. I thank him for being honest you know, I mean sometimes you've got to agree and realise that there's something you can't do.' Bob (18)

Others, though, took hope and optimism for a full recovery from the improvements they had made.

'Yeah 'cause I'm improving all the time, very slowly but I am improving. ... I am hopeful – I don't know how long it'll take.' Gordon (18)

Summary

These findings show that there were some changes in participants' perceptions over time and in their hopes and expectations during the eighteen-month period of the study. For many, the altered life they encountered after their stroke changed little, with many continuing to need assistance with self-care and being unable to resume valued activities and life roles. Those participants who were more successful in regaining some of these things were those who had some motivation to do so, either from living alone (Doris, Jenny and Gordon) or from a very significant valued activity (Bob). For many of the others, the disruption to their sense of self continued alongside the little changes to their altered life. Also, it seemed that being able to put their experiences of stroke into the context of others experiences helped to make their experiences seem more normal, as in

the case of Colin's experience on the cruise ship, and in the case study on Bob that follows. Psychological adjustment appeared to be much harder for those who continued to need significant help with self-care.

It is interesting that the recovery of walking was the first and most important priority early after their stroke, and this concurs with other research (Kirkevold 2002, Connell et al 2014, Doyle et al 2014). However, the findings showed that this shifted to the upper limb as time passed and people returned to their homes and recognised how vital their upper limb was in self-care, valued activities and life roles. It is clear from these findings that participants' hopes for recovery changed over time, with optimism for a good recovery being very strong in the first few months, even though they were more focused on recovery in the lower limb at this point, but this then moderating over time. These findings appear to confirm other research on people's hopes for recovery and the trajectory of stroke more generally (Burton 2000; Kirkevold 2002; Wiles et al 2002; Jones et al 2008), but this is the first time attitudes to recovery in the upper limb have been identified. It would appear that some people set themselves certain points in time by which they expected full recovery, but these were getting further away as recovery slowed down and time passed. It seemed that this shifting of these temporal mile-stones was a way of keeping hope alive for them. The resilience of some in maintaining hope even in the face of little recovery is striking, but might be a hindrance to them eventually adjusting and adapting in the longer term. They would have to give up hope for recovery and learn to live with the dysfunction in their arm and hand, and find ways to adapt to it in order to either resume activities and roles or find new ones. Some of the time-scales that people set were influenced by the opinions of health professionals and the experiences of other stroke survivors but, as the next sections will show, access to health professionals and advice and information were often limited, particularly out in the community.

4.3.3b Experiences of Therapy

The findings revealed that therapy was short-lived for most of the participants and was mostly directed at recovery or improvement of walking. This accorded somewhat with participants' priorities in the first two months but later, as individuals began to see the importance of their upper limb, this did not coincide with therapist's priorities, or therapy had discontinued altogether.

Two Months Post-stroke

All participants saw therapy, and in particular physiotherapy, as crucial to their recovery and there was mostly satisfaction with the amount of physiotherapy they had received while in hospital. Doris described her experience of therapy as '*excellent ... the department is wonderful.*' She was very happy with the therapy for her arm and hand.

'With the first bits of physio I had, I was made to use the hand and arm and it's paid off.' Doris (2)

But not all were as pleased as Doris, particularly when it came to how much of the therapy had been directed towards recovery of their arm in the early stages.

'Well had, er ... physio about two to three times a week, but it wasn't anything to do with hands and legs ... Had to sit still and put a ring through what looked like a traffic cone. ...I didn't think much of it at all to tell you the truth.' Harry (2)

The comments are not surprising in light of the priority given to the lower limb by many participants, as explained in an earlier section, but could indicate that Harry had expected some treatment to be directed at his upper limb even though he had admitted he was ignoring it. A study by White et al (2009) found similar experiences in their participants, who reported that hospital therapists had paid little attention to their arm and hand. Colin, who was at home at two months post-stroke, saw his upper limb as a priority but was very dissatisfied with his treatment. His comments indicate that his expectations of

physiotherapy differed from that of the professionals. He clearly felt that he needed physical help to move his arm and hand.

'I have physios come every week but they don't do anything. All they do is talk to me. They give me exercises and advice ... they don't do hands on. She said the only people that get hands on are sports injuries.' Colin (2)

Colin was looking to a family member, who was a physiotherapist, for more 'hands on' treatment for his upper limb. He reflected on his short time in hospital after the stroke where he felt the priority was on his lower limb to improve his mobility and so facilitate discharge.

'They just get you out of there.' Colin (2)

Six Months Post-stroke

For most participants, it was after discharge from hospital that dissatisfaction with therapy grew. For many participants, therapy was either discontinued or was very infrequent by six months post-stroke. Ada and Alan described how they felt isolated and abandoned after having only been visited twice by the community physiotherapist.

'Well ... they've got rid of me ... I'm on my own now [became tearful].' Ada (6)

'I feel cut off.' Alan (6)

There was a feeling here that therapists would not only have provided the therapy but, through that, they would have also been a source of support and encouragement to people in their recovery from stroke. Several participants had received six weeks of therapy once discharged home, but this was mostly directed towards their lower limb and walking. Meg explained how this approach was justified to her by the physiotherapist, giving her the impression that she could not have treatment for both her lower limb and her upper limb and had to choose which was more important.

'But then they ask you "what would you rather have – your hand or your walking"'.

Meg (6)

Meg was fortunate that she was given a further six weeks of physiotherapy, but the focus remained on her lower limb.

'They seemed to think that, er, get me walking and then concentrate on your hand.' Meg (6)

Unfortunately, physiotherapy stopped before any work could be done on her hand. Eve, Jenny and Bob reported similar experiences, with an occupational therapist visiting them rather than a physiotherapist.

'OT came weekly and took me for walks to get me going but other than that they didn't do a lot.' Jenny (6)

It would seem that the priorities of the physiotherapists and occupational therapists were at odds with those of the participants. When therapy was available, the focus for therapists remained on walking, whereas the participants' concerns were turning to their arm and hand, but this was not being acknowledged by the therapists. There could be several reasons for this, including limited resources for therapy, and so therapists were directing this resource at improving walking as they saw it as more important to people.

Many participants had no means of referring back to therapy for advice or support. Meg and Jenny were given resting splints for their hand early after their stroke but had no means of referral back to occupational therapy for adjustments. Lily reported that the physiotherapist had visited to review progress, but did not prescribe any exercises for her hand but rather told her to *'just use it'*. This was similar to Gordon who described having *'a flying visit'* from a physiotherapist who gave him an exercise sheet. He had followed the exercises and made good improvement in his upper limb and, being unsure of what to do next, devised his own exercises to promote further recovery, but he was uncertain if

they were correct as he had no follow-up treatment. This shows how a therapy service that has no means of individuals referring back into therapy or a therapy review process could be holding recovery back in some people.

Harry waited six months after discharge from hospital before community therapy even began. Barbara, Bob and Colin had been referred to a local gymnasium after six weeks of physiotherapy. Colin declined to attend as there was no physiotherapy provided at the gym and, therefore, in his eyes no expertise to aid his recovery. Bob was limited in how frequently he could attend by the cost of travel. Furthermore, the gym equipment available could only improve gross movements of his arm and not the movement and dexterity in his hand and fingers, which were of more importance to him as a musician.

Twelve Months Post-stroke

By 12 months post-stroke, therapy had stopped for all participants, apart from Harry, and there was dissatisfaction, with many feeling unsupported, ignored and abandoned by therapy services.

'It's as if I've been let down. You're out of hospital that's it, you know, do your own thing ... it's just as if I've been deserted, that's it.' Ada (12)

'Once you've come out of hospital you're out of their care now and they're not bothered about you then. Yeah, that's it, you look after yourself and that's it.' Eve (12)

Gordon felt that therapy services should do more, but he thought that *'they just write you off'*. Clearly, once therapy has stopped, the opportunity for more recovery in the upper limb is very limited. Physiotherapy had recently re-started for Harry because his wife *'had been pestering everybody'*. However, he was concerned that his priorities were being ignored as treatment was focused on his balance and walking. The therapists possibly saw this as more important, whereas for him recovery in his upper limb was becoming

more vital, perhaps because he felt that walking was no longer an achievable goal, whereas some function in his upper limb might enable him to do some activities, albeit from a wheelchair.

'Well you feel you've been left out in the cold. All the time seems to be taken up with what they want to do.' Harry (12)

Eighteen Months Post-stroke

At 18 months post stroke, the situation with therapy had changed little. Eve had been reviewed by a physiotherapist but no further treatment was given.

'Well nothing happened 'cause I couldn't move my arm so she couldn't do anything with it.' Eve (18)

Unfortunately, this review had not coincided with Botulinum toxin injections administered by a hospital doctor to reduce spasticity in her arm. She reported that he advised her to *'get the carers to try and pull your arm down a bit.'* There appeared to be no coordination between the doctor and physiotherapist. With the spasticity reduced, there may have been some underlying movement in Eve's arm and, therefore, some potential for further rehabilitation. The consensus from all participants, apart from Doris, was surprise that there was so little therapy available for stroke survivors. They all expressed a desire for more physiotherapy for their upper limb, as they saw it as the key to further recovery. The comments by Alan were typical.

'I reckon a bit more physio on this [pointing to his hand] and I'd be able to use it a bit more. I feel gutted, you know because they came for about three months and they suddenly stopped.' Alan (18)

Several participants had wanted physiotherapy to be very *'hands on'* to facilitate movement initially so they could then achieve more function with the arm. Colin's comments mentioned earlier in this section were similar to those of Eve.

'Well if they came and did it with me, you know, because the arm's too strong [spasticity] for me to try and lift up, I can't do anything with it.' Eve (12)

At this point, as participants looked back on their experiences of therapy, some felt that they would have had more recovery in their upper limb if more treatment had been available and had commenced from the beginning.

'I'm sure it would have made a difference if I'd had therapy in hospital. They should have done more, should have been more helpful, even though they are busy ... it's not very good for a professional health service. I'd have got better quicker.' Gordon (18)

Jenny explained that she had interpreted the little attention that was paid to her upper limb by therapists as meaning that natural, spontaneous recovery would occur. It was only after she was able to walk outdoors and little had changed in her arm that her attention turned to it, but by then therapy had stopped. Barker and Brauer (2005) found that the participants in their study had later questioned whether more recovery might have occurred in their upper limbs if more had been done in the early stage after stroke. Bob had improved his grip strength, but in order to play his musical instruments he needed dexterity in his fingers. He admitted that this would have been his aim if given the opportunity, whereas the prediction from the physiotherapist, and then the lack of ongoing therapy, pushed him towards a more compensatory approach.

'I would have said to the physiotherapist, "look I'm not bothered about the strength of the arm, I'm more concerned about the ability to do that sort of thing" [moving the fingers individually on his unaffected hand].' Bob (18)

These results show how limited therapy services reportedly were for these participants especially in the community after discharge from hospital. It would seem that the duration of therapy was too short to enable more attention to be directed at the upper limb, and so

it was often disregarded and ignored by therapists, who focused on the lower limb, despite the on-going hope participants had for more recovery in their arm and hand. Therefore, there may have been missed opportunities for people to gain further recovery, particularly if therapy for the arm and hand was not starting in the early stages after stroke. In other words there was no restorative option for people; their only choice was one of adapting by compensating with their affected upper limb, such as in the case studies of Bob and Jenny that come later in this chapter. This next section will show that this disregard for the upper limb often extended into information and advice to participants about their arm and hand being limited.

4.3.3c Lack of Information and Advice

The NICE guidelines on long term rehabilitation after stroke (2013) and the National Clinical Guidelines on Stroke (ISWP 2012) are clear that, in order for stroke survivors to set realistic goals, they need to be well informed and included in decision making about their care. The results from this study indicate that this was not the case for some participants with regard to their upper limb. At two months post-stroke, Cath recounted how disappointed and angry she was when she asked a physiotherapist how long it would take for her upper limb to recover. *“How long is a piece of string?”* was the reply. It is understandable that a patient might ask such a question and the response to it underlines the difficulty in making predictions about recovery and, therefore, the reluctance of health professionals to talk honestly about this with patients. This is a point that will be picked up again in the case study on Bob later in the chapter. Eve explained that there was little opportunity to ask doctors questions while in hospital.

Eve (2): ‘Because the very first time I met my doctor it wasn’t “oh hello I’m doctor so and so and I’ve come to talk to you about your stroke”, you didn’t know who he was so you couldn’t talk to him because you didn’t know what you wanted to say.’

Interviewer: *'So what point did you feel you would have felt ready to sit down and have that conversation?'*

Eve: *'Oh about an hour after I'd met him.'*

It seems the doctor had turned up unexpectedly and was gone before she had time to gather her thoughts and ask pertinent questions. She also complained that the physiotherapists used medical jargon that she did not understand. Harry and Gordon complained of being discharged with no information about if and when therapy would commence in the community. They may, of course, have been given this information but not remembered it.

Once discharged from hospital, it seemed that participants were in a vacuum when it came to information and advice about their upper limb. Many had looked for more from the hospital consultant or their GP, but they were dissatisfied with the lack of interest shown in their upper limb.

'He [hospital consultant] hasn't said anything about my arm yet.' Eve (6)

'No the hospital has finished with me. Actually it was a waste of time going – they take your blood pressure, take your weight ... I mean they don't tell you nothing.'

Gordon (6)

'The doctors [GPs] when I see them, they never mention it [the arm].' Jenny (12)

Participants wanted information and advice from therapists about their arm and hand, but they had little access to them. Eve described how therapy just stopped without any warning or explanation, leaving her without the information she needed to continue her recovery.

'I try different things but I don't know if I'm doing right or wrong.' Eve (12)

These results show how desperate the participants were for information and advice about their upper limb and its potential for recovery. The lack of contact and advice from therapists and doctors had created a vacuum that some participants were trying to fill with their own ideas about treatment. The next section will show how participants recognised their responsibility in managing their upper limb and wanted support from therapy to enable them to be active in driving recovery forward.

4.3.3d Personal Responsibility for Recovery

All participants acknowledged that they had a large part to play in their recovery. There was recognition that they had to follow advice from therapists about exercises and activities, where it had been given, and should try to maintain a positive attitude and to remain motivated.

'If you're not prepared to do as you're told then you won't get anywhere ... No need to be negative about things, you've got to try and be positive about things.'

Lily (2)

'If I keep making myself do things that they've told me ... Well it's me that's got to make these things work.' Barbara (6)

Several participants were devising their own exercises and buying equipment. Harry, at twelve months post-stroke, had purchased a muscle stimulator for his arm and hand after his wife had read about it; however, the physiotherapist showed little interest in this, continuing to direct attention to recovery of the lower limb, leaving him and his wife to work out how best to use it. Meg's husband had bought her a small pedal machine that she could use for her arms as well as her legs, but again the physiotherapists apparently paid little attention to her efforts with this. At each interview, Gordon described how he was working hard on his arm despite the lack of therapy and advice.

'Well muscles are painful. I'm trying to build it, I don't know whether I'm building up right things or not.' Gordon (6)

However, not all were as self-motivated from the beginning. Alan was more passive at six months post-stroke and was pinning a lot of hope on a forthcoming appointment with the consultant and expecting more help with his arm. Unfortunately, the consultant showed no interest in his arm and so, at 12 and 18 months post-stroke, Alan's attitude had changed. His comment of *'show me exercises to do'* was typical. Participants wanted exercise prescription, guidance about upper limb functional activities they could practise, and encouragement and confirmation that they were doing the right things to promote more recovery.

'Well if somebody gave me instructions I could do them at home.' Lily (12)

'... you just need that little bit of pushing behind you, for somebody to say "Yes you've done that right, yes it is getting better".' Ada (12)

All participants were realistic and recognised that there were not the resources for continuous long term therapy, but they wanted access to regular review, and advice. Several participants had been prescribed exercises early after their stroke, some of which had been effective and some not, but had received no follow-up to help them move forward.

'... and I've accomplished that [touching her index finger with her thumb] so what else can I do?' Ada (6)

'I slosh it about in water, which I was told to do in [hospital]... just somebody to talk to about it now and again.' Jenny (18)

Gordon thought group work could be more a more cost-effective way of providing support and therapy in the longer term. Stroke survivors themselves could be a good resource and encouragement for one another.

'I think a group therapy would be better. You can see how well other people are doing and they can see how well you are doing, and while you are doing it, have a chat. You have got to be with other people who have had a stroke.' Gordon (6)

The results in this last section indicate that these participants did not want to be passive recipients of therapy, but rather active in partnership with therapists. They wanted to take responsibility for their upper limb recovery and work with the therapists to solve the problem of their upper limb dysfunction, and they were ready to put in the effort required so they could be more independent and more useful in their lives. Unfortunately, the hope many had for more recovery, as seen in a previous section, and the positive attitude and responsibility demonstrated by participants was undermined by the lack of services. Comments from Harry sum up very well how participants felt their hope and desire to be more active in their recovery was apparently disregarded by services and a wasted opportunity for people to become less dependent on services in the longer term.

'Well I mean there'll be a lot of people like me around and, er ... well, they should see it as wasting assets ... there aren't enough resources for people in our situation.' Harry (6)

The findings in this section would support the recent increase in awareness of the benefits of self-management in long term conditions, such as stroke, both for service users and also for more effective use of resources. The participants in this study could potentially have benefitted from this to help them drive forward their recovery and adjustment and adaptation to upper limb dysfunction.

4.3.4 Case Studies

Three case studies have been included in this results chapter. The three participants were selected because it was an opportunity to further illustrate the changing perceptions of upper limb dysfunction over time, and each case study had specific issues that

warranted further explanation around the role of the upper limb in individuals' lives. The case study on Bob reveals how particular valued activities can be central to people's lives and identity and can therefore drive adjustment and adaptation and also, the influence that predictions about levels of recovery can have on this. Eve was chosen because her experiences highlight the effect that upper limb dysfunction can have on balance and walking and the limitations it can bring to a person's life. Finally, Jenny was selected because of her hopeful attitude to recovery, while appearing to negotiate with the time-scales for such recovery, and yet at the same time adapting to her dysfunction so she could continue to live alone.

4.3.4a Bob

Bob was a musician, who played the piano, church organ and bass recorder. He also conducted orchestras and composed music. Music was both a hobby and, as he described it, his profession, so his upper limbs were vital to him continuing with this. Bob was right-handed and the stroke had left him with a right hemiplegia. At two months post-stroke, he had little useful movement in his arm and hand and so he referred to his ability as a musician frequently in the first interview, which was held in his home. Being a musician was a strong identity of his, and even at two months post-stroke Bob was working out ways in which he could still carry this on, albeit in an adapted way. It appeared that a prediction by a physiotherapist, given during his time on the rehabilitation ward, about the expected level of recovery in his arm was having a significant effect on him.

'He said "I don't think you'll ever be able to play the piano very well with your right hand." He said "you might be able to play one or two notes here and there but I really can't see you being a pianist with your right hand".' Bob (2)

Bob saw the physiotherapist as *'the expert'* and although he stated that he wanted to prove him wrong, this seemed to influence his desire to adapt and be able to continue

playing in a limited way, rather than wait and hope for a full recovery. Thus, he was beginning to move down the road of a more compensatory strategy rather than a restorative approach.

'I agree but it's, erm ... I don't think it will ever be as good as it used to be, erm, I think it will be a lot better than it is now but I can't really see me, erm, playing the piano as I used to.' Bob (2)

Bob described how he had *'lived in music all his life'* and clearly to continue with this was a strong motivation for him, despite the dysfunction in his upper limb. Even at this early two-month post-stroke stage he had worked out a way of playing the church organ with one hand and one foot, and this was his explanation of how he played the piano for a service in the hospital chapel while still an in-patient.

'When you are playing a hymn for the church service you usually play the soprano, alto with your right hand, the tenor and base with your left hand, well by putting the tenor an octave higher you play three parts with one hand.'

At the six-month post-stroke interview, Bob introduced his music into the conversation from the very beginning, indicating how central music was to his life. Some movement and strength had returned to his arm but there was little improvement in his hand and so he was continuing to adapt and compensate so he could continue to play. He admitted that his inability to play fully was *'a bit depressing because that's my job you know, my work'*. He had received six weeks of physiotherapy and occupational therapy after discharge from hospital and had then been referred to a local gym where the focus was on his lower limb as there was little equipment that would assist any recovery in his upper limb. He referred to the prediction of the physiotherapist about recovery of his upper limb and, again, stated he would like to prove him wrong. However, he appeared uncertain and somewhat conflicted in his attitude to whether his upper limb would recover, so the

overriding drive to continue to play was making him adapt and compensate for his dysfunctional upper limb.

'I could have decided okay, I'd like to be able to get the use of both hands and then I'd start playing the organ again ... but if I did that it may be never, but at least a year or two, and so I'd rather keep on playing the organ and keep on being involved in music, even if I got just the left hand ... I mean eventually it would be lovely if I could use my right hand, I'm not saying I wouldn't be able to, but I don't want to wait until the right hand's working because that may never happen.' Bob (6)

Bob had returned to conducting a recorder group, although he could no longer play the bass recorder and conduct at the same time as he had done before. He had adapted to using a computer mouse in his left hand so he could continue to compose music. This adaptation to continue to play was evident at the twelve- and eighteen-month interviews and clearly was a successful strategy. He reported at the final interview that he had been to Yokohama in Japan with the recorder group to play one of his compositions. He had re-written some music for the recorder group so he could play in a limited way.

'We all played the same notes it's just that I was playing the ones you could do with one hand and it meant some of the people had to play different notes.' Bob (18)

He also reflected about his life in general:

'I don't think there's anything else that I used to do that I can't do, with difficulty and slower.' Bob (18)

Bob repeated the physiotherapist's prediction again at both the twelve- and eighteen-month interviews and at eighteen months agreed that the prediction had been accurate. He was about to purchase a one-handed bass recorder, which possibly indicated that his

adaptation to using predominantly his left hand was complete. He admitted that since the stroke he had not really tried for more recovery in his right hand.

'I tend to go the easy way and use my left hand, brush my teeth with my left hand, do everything with my left hand ... I don't try to use it very much.' Bob (18)

It is interesting in this case that the combination of a prediction of a poor recovery, no on-going therapy for his upper limb and a strong desire to continue in music may have led to Bob adopting an adaptive, compensatory approach to his recovery from stroke. The prediction of the physiotherapist could have been accurate and, therefore, the compensatory approach could have been the best one for Bob. Alternatively, this prediction may have caused him to give up on the effort to work and pay attention to the recovery process. However, with such a short period of therapy available to Bob, the prediction could have been a self-fulfilling prophecy. Although Bob did continue relatively successfully with his career in music, he may have been robbed of the opportunity for more useful function in his upper limb, which would have been of great value to him as a musician. As recovery from stroke can be unpredictable, physiotherapists should perhaps exercise more caution in giving such definite prognoses in the early days of recovery.

In addition to adapting well physically to his upper limb dysfunction Bob seemed able to adjust psychologically. A possible reason for this became apparent at the six-month post-stroke interview, when he appeared to find context for his stroke and how to cope with it from his father who had been paraplegic.

'He [his father] didn't feel embarrassed ... he was like "hey I'm doing the best I can". I'm annoyed that it's happened but not embarrassed ... I'm trying my best to make things work.' Bob (6)

When Bob was asked about his feelings about the effect upper limb dysfunction had on him, his response at all four interviews was that he was *'annoyed'* or *'irritated'*, but it did

not appear to have affected his self-esteem or self-image. The example of his father may well have helped him with adjusting and adapting and moving forward into a meaningful post-stroke life. He seemed happy to ask for assistance from other people when necessary. At twelve months post-stroke he described how, while attending a music conference, a fellow attendee assisted him with donning his ankle splint and carried his tray of food at the self-service restaurant. Later, at eighteen months, he explained how a fellow diner at a dinner party had cut up a steak for him.

'I'm not embarrassed because it [stroke] could happen to anybody couldn't it? I'm very grateful that people are just kind. I'm still the same person, just can't use the right side of my body.' Bob (18)

There was, however, some sadness in Bob, as seen in the earlier section on identity, that the recognition he previously had for his skill as a musician was gone and, although he still saw himself as a musician, this perhaps had affected his self-image and identity as an accomplished musician. Nevertheless, the motivation to continue in his music, combined with the example of his father's experiences as a paraplegic, seemed to have enabled Bob to adapt physically and adjust psychologically to his upper limb dysfunction in the eighteen-month period after the stroke. Bob had managed to regain the purpose and meaning that music gave to his life. Bonds Shapiro (2011) suggests that finding purpose and meaning again is crucial in re-adjustment after stroke.

4.3.4b Eve

Unfortunately, Eve was less able to move forward with her life, as she found her upper limb dysfunction a hindrance to nearly all areas of her life. At each of the four interviews over the eighteen-month period there was no evidence of her re-gaining any of the aspects of her life that were meaningful before her stroke. The main factor in this was the spasticity and loss of voluntary movement in her upper limb. While in hospital, at the two-month post-stroke interview, Eve was clear that improving her walking was her priority but,

by the six-month interview, this had changed. She had returned home, and the challenges inherent in trying to do meaningful activities in her normal environment had been realised, which is often the case for stroke survivors after discharge home (Olofsson et al 2005).

'Well I use my arms more than my legs so I feel as though my arm's more important for the things I need to do.' Eve (6)

Before her stroke Eve took full responsibility for looking after the home she shared with her husband, and so her day was filled with domestic tasks of cleaning, laundry, cooking and shopping. In addition, she had hobbies of ballroom dancing and swimming. Unlike Bob, she was not adapting or compensating by trying to do tasks with only her unaffected right arm because she was fearful of falling. She had to use her right hand to hold a walking stick when standing or walking and she was too fearful to let go of the stick to use her right hand for tasks. Therefore, although she could walk into the kitchen, for example, she was very limited in the things she could do once there. Furthermore, carers attended her four times a day, mainly to assist with toileting and showering as she was too afraid to let go of the grab rail because of the frequent, sudden involuntary movements of her hand due to spasticity.

'My hand might catch the arm-rest [of the raised toilet seat] and it just grips onto the arm so I have to undo the hand and push it away, you know.' Eve (6)

The lack of spontaneous movement and the involuntary movements in her left arm resulted in her being too fearful to use the stairs and so she slept downstairs in an armchair, and this fear prevented her from doing valued activities. Eve recognised only too well the role of the upper limbs in maintaining balance, as highlighted in the first chapter. She really wanted the independence to use public transport again, but realised that she could not use her left arm and hand to steady herself and cope with disturbances

to her balance, and her right hand was occupied in supplementing her weaker leg through a walking stick.

'I just need for it [the arm] to get better, you know so I can start doing normal things, doing my housework and being able to go and catch a bus ... I mean I daren't even go to the bus stop to get on a bus 'cause I think, well nine times out of ten you can be walking down the bus to get a seat and the driver will set off. Now if he sets off I could go straight down, I've only got one arm to stop me falling so ...'

Eve (6)

At twelve months post-stroke the situation had not improved. Eve was still sleeping downstairs and had not regained any of her valued activities, and her role as a grandmother, as explained in the earlier subordinate theme of Life Roles and Relationships, was deeply affected. She put all of this down to the inability to use her left arm. She was too fearful to walk outdoors for the same reasons she gave for not using public transport. Her left arm was no use to her as an aid to her balance, and furthermore if she fell she could not use it to get back up from the ground.

Interviewer: *'So if your arm was better, do you think you'd be ... [Eve interrupts]'*

Eve(12): *'Oh I'd be a lot better ... yes yeah. I'd be able to exercise more, I'd be able to take myself down the street for a walk and back you know but at the moment I can't because I think if I slip and fall there's no way I could get up on my own, and what do I do, lie in the middle of the road screaming and shouting for some help and that, you know. Not everybody's going to hear you are they?'*

At the final interview at eighteen months post-stroke she explained that she had still not walked outdoors, let alone travelled on a bus, and her life within her home was just as restricted and frustrating, largely because of her upper limb.

Interviewer: *'So thinking about your arm and leg, which of those do you think is more crucial to you becoming more independent?'*

Eve (18): *'My arm. I was just saying to my neighbour next door this morning, "I'll never sit down again once I get out of this chair properly, that'll be it, you know". I mean I can't even Hoover up you know ... I can't mop anywhere ... I'm frightened to dust in case I fall over. I can't do anything with that arm [pointing to her affected left arm] to hold to anything so ...'*

Throughout all four interviews Eve frequently used the words *'helpless'*, *'hopeless'* and *'useless'* to describe how she felt about herself. Eve was trying to adjust to her situation and cope with this low self-esteem by focusing on the practicalities of her life and some of the benefits.

'I can't fasten a button so everything has to go over my head - ... everything's sort of T shirts and what have you - ... I mean I'm comfortable just like this.'

However, at six months post-stroke it was clear that the level of assistance she needed with self-care was not easy for her to adjust to psychologically. She admitted she had become depressed and was prescribed medication but decided not to take it and rather try to come to terms with her circumstances, despite her feeling embarrassed in the presence of the carers, as this quotation shows.

'Well it's just one of those things you have to put up with ... I mean I couldn't wash myself properly with just one hand ... It's a bit embarrassing sometimes but you just have to put that at the back of your mind and get on with it ... I'd rather have a shower and not think about what they're doing ... It's just one of those things you have to get over isn't it ... we all get embarrassed at some point in our lives and you either have to live with it or don't live with it, well I choose to live with it.' Eve (6)

At twelve months post-stroke, it was a real struggle emotionally for her to live with her level of dependence and the disruption to her life. The restriction her upper limb had brought was arousing powerful emotions in her, such as frustration, and also causing friction between her and her husband, who seemed to lack understanding of the full effect of her upper limb dysfunction.

'It is very difficult when you haven't got a choice of what you want to do or where you want to go, you know, so I can get really angry, really quick ... I snap at [husband] all the time you know, and I don't normally. I think he thinks I should be able to do more with it [her affected arm]. I should be able to do different things, I should be able to carry my plate back into the kitchen but this hand won't hold anything, you know. It has changed my life, yeah, yeah. Do you know I wouldn't wish this on my worst enemy?' Eve (12)

At the final interview at eighteen months post-stroke, Eve expressed her feelings very graphically in response to a question about what might improve her arm and her quality of life. This illustrates very well her frustration with her upper limb dysfunction and its effect on her life as a whole.

'Well I don't know, you know ... apart from chop the blooming thing off. I'd rather they amputate it. Well I mean if it's here it's not doing any good, so might as well not have it if you can't use it.' Eve (18)

As was explained in the first chapter, the upper limb has a vital role in maintaining balance and Eve's case study illustrates the effect in stroke when one of the upper limbs cannot contribute to this role. When there is weakness in a lower limb after stroke, and a dysfunctional arm and hand, balance is greatly compromised and, as in the case of Eve there is a real fear of falling. The functional hand is occupied in using walking aids to maintain balance rather than its normal use in holding and manipulating tools to complete activities, thus rendering the person more dependent. This emphasises how recovery of

the upper limb is as important as the lower limb in the recovery of mobility and independence if people are to live as full and meaningful a life as possible, and to adjust and adapt after stroke.

4.3.4c Jenny

Jenny's case has been included because similar to Bob she appeared to adapt and adjust to her upper limb dysfunction over the course of the eighteen months. The difference between her and Bob however, was her optimism and hope for more recovery in her upper limb, whilst at the same time having to adapt and compensate because of her desire to remain living alone and independent after the stroke. At two-months post-stroke Jenny became very distressed during the interview as she foresaw needing assistance with self-care on her return home. Nevertheless, she was hopeful that with hard work – *'I'll blooming work hard'* - and determination she would be back to normal in a few months.

At six months post-stroke, although she reported that the recovery in her arm and hand had not happened within a few months as she anticipated, she was still hopeful of this occurring within an additional few months. She declared that she was now 90% independent and the last 10% of independence was down to the dysfunction in her hand.

'I can say to myself in the New Year, come spring, I'll be able to do everything. Well the gardening and, er, more housework and it'll come. If I can get the hand moving everything else will come.' Jenny (6)

Jenny always seemed to need to set specific points in time by which recovery would have occurred. Her hand was vital to her. To have full strength and dexterity was the key to her being fully independent in her home and to doing the activities that she valued. She appeared to base her continuing hope for recovery of the hand on information from the hospital consultant.

'He said it can take up to two years to come right ... I'm hoping it'll be quicker than that. In fact he wrote to the GP and said I've a very good attitude and I'm determined - just having it in my mind that it's going to do [improve].' Jenny (6)

Despite this optimism and hope for more recovery in her arm, Jenny was adapting the way she did tasks by using adapted gadgets in her unaffected left hand, and employing a cleaner and gardener. Her emotional adjustment appeared to be lagging behind her physical adaptation, as at times during the interview when she talked about her strategies for coping she became a little tearful.

Interviewer: *'What do you think about not being able to do those things that you used to do yourself because of your hand?'*

Jenny (6): *'All right I suppose ... well I go out of the room and leave them [the cleaners] to it, erm ... it was... something you've been doing for all those years and the thought of somebody else coming to do it because you can't [becomes tearful]... that was difficult.'*

This highlighted that emotionally she was struggling with the changes her upper limb dysfunction had brought to her lifestyle, and this is not surprising as six months is a short period of time in which to make such major adjustments. Unfortunately, despite her hope and desire for more recovery, therapy had ceased by six months post-stroke. She had only received occupational therapy and this had been focused on her lower limbs to improve her walking out in the community. Jenny had apparently been given no advice regarding exercises or activities that she could continue with to aid recovery in her upper limb.

At twelve months post-stroke, Jenny's adaptation to her upper limb continued with friends and family purchasing gifts of more gadgets and adapted tools for the kitchen and garden.

Emotionally, she appeared to be more resilient as her adaptation was enabling her to feel in control.

'Oh yes I'm still running my life ... Well you have to be [resourceful] ... you know I could have curled up in a corner and gone ... but it's not going to beat me I can assure you.' Jenny (12)

Hope for more recovery in her arm and hand was beginning to fade, but there was still a glimmer as she referred back to the consultant stating that it could take up to two years. It is interesting that Jenny's point in time for recovery had moved further away yet she was still hopeful. At this interview she reflected back on what her expectations of recovery had been from the start and how the direction of therapy had influenced her to be hopeful.

'Well at the time I felt okay about it because my leg was fine you know and I was getting about on my own ... and it was only after that I thought "well hey up [what about my arm]", but they'd [therapists] done their time... 'cause they'd hundreds more to look after than me. I mean silly me, naive me thought it would come back automatically ... with my leg I was doing exercises, but nobody, even at the hospital they didn't give me anything to do with my hand other than that [pointing to a hand splint] and I had another thing that put electric currents through ... but then it was maybe one of those things that none of them picked up on at the hospital that it was gonna go as it did. I just thought I'd go home, I'd learn to catch up with my walking 'cause that was coming in the hospital and this [her arm] would follow.' Jenny (12)

Jenny's explanation for her hope and expectation for recovery shows how an individual can fill a void in information with their own interpretation of circumstances. From Jenny's perspective, it could be seen as perfectly logical that the lack of attention to her arm from the therapists was because they expected it to recover spontaneously without any treatment.

By eighteen months post-stroke, there was no further improvement in her arm and hand and Jenny was accepting that more recovery was probably unrealistic. However, she did reiterate that the consultant had told her at six months that it could take up to two years and she added '*and it's [the arm] always the last [to recover], so I lived in hope. I mean I still do.*' Here, again, Jenny is holding on to a point in time by which recovery will come. Later, she added that she had a more realistic goal to be able to pick up light objects between her thumb and index finger, but not necessarily with great precision. Emotionally and psychologically she seemed more accepting of her dysfunction.

'Yes I've accepted it now, got used to it. I think when I came home and I got back to my own way of living and, er, you think "how will I do it?" you know, and I can do it this way and you just do it.' Jenny(18)

She acknowledged that the desire to live independently in her own home was the driving force for her to adapt and adjust.

'Oh no it's pushed me I can assure you! Because I live on my own and if you don't learn how to do things what do you do?' Jenny(18)

Jenny's case shows that people after stroke can be resilient in their hope for more recovery in their upper limb even in the face of little support from health professionals. She seemed to use specific points in time, negotiating them further away as recovery slowed down, as an aid to keeping that hope alive. The misinterpretation by Jenny that the lack of treatment for her arm and hand meant that spontaneous recovery would occur may apply not only to Jenny but to other people with stroke, particularly where more specific information is lacking. It may be that people fill the gaps in information with their own pre-existing assumptions and suppositions.

4.3.4d Summary of the Case Studies

Therapy, as seen in the subordinate theme of Experiences of Therapy, had not continued for long for the participants in these case studies, and little of the treatment was directed at the upper limb. This may well have been a factor for the compensatory path that Bob and Jenny adopted, as they both had powerful factors that drove them to find adaptive ways of continuing with their valued activities and lifestyle. However, for Eve the lack of therapy for her upper limb was possibly a contributory factor in her inability to adjust and adapt because of her fear of falling.

4.4 Reflexive Accounts

There follows, in this next section, two reflexive accounts of the personal impact and challenges encountered in the interviews and interactions with participants in the process of collecting and analysing the data.

4.4.1 The Personal Impact of the Interview Encounters.

When developing the study I had anticipated that there was the possibility of participants experiencing some distress as they reflected on and described their experiences, and provision was made for this in the ethical issues and procedures (see page 73). However, I was somewhat unprepared for the effect that this might have on me as the researcher. The strength of feelings and emotions that came across from some participants did provoke some reactions in me. I was concerned that through the interview process some participants were recalling difficult memories and unresolved feelings and thus becoming quite vulnerable emotionally. This was expressed in sadness and tears in some and, for other people, anger at their situation. In the earlier interviews at two months, I found this disturbing and questioned the ethics of being the cause of such distress, and was unsure how to respond to participants and how much of my feelings to reveal to them. As a novice qualitative researcher this brought home to me the nature of this type of research, in that the researcher and the participant enter into an interaction in an interview and it is

this that produces data (Finlay 2003). However, participants are thinking, feeling human beings and so such interactions can be rich in emotions (Bondi 2005). It is one thing to recognise this in theory, but quite another to encounter and deal with this in practice. I acknowledged that I would have to manage my emotions so that I could conduct interviews and remain neutral without seeming aloof and untouched by the participants' experiences (Denzin and Lincoln 2008). A key strategy in this was recording my thoughts and feelings and then discussing them in meetings with my supervisors. Considering again, with them, the procedures and support that were in place for distressed participants reassured me that the study was ethically sound. Ahern (1999) suggests that having support and de-briefing should be a key component in research. I found that discussing my emotional responses helped me to find the right balance in conducting interviews. I could express to participants an understanding and acceptance of their emotions and feelings, without being too emotional or appearing to be distant and indifferent to them. It was important that participants would feel comfortable with me, and so either extreme of response from me could have provoked discomfort in them and a barrier to disclosing the full extent of their experiences and feelings to me. Furthermore, it could have discouraged them from participating in subsequent interviews.

As I conducted more interviews, and later analysed them, I began to reflect on my previous clinical practice as a physiotherapist. As I began to see how much upper limb dysfunction had altered participants' lives and affected their self-esteem, self-image and identity, I was saddened by how little I had understood this in my patients. I had worked in a neurological rehabilitation unit before moving into an academic role and had treated many stroke patients. Looking back, I recognised that I had been more concerned with function in basic activities of daily living and with mobility than with people's life roles and meaningful activities. I had little understanding of how their upper limb dysfunction would restrict them and so affect their view of themselves. At the time I understood that many would need assistance with self-care and would be limited in how they could dress, but at

the time saw this only in terms of function and dependence rather than the wider impact on their self-esteem and self-image. I was not alone in my understanding and views and was typical of my colleagues and practices. The literature review chapter in this thesis has shown that there is limited research on the effect of upper limb dysfunction so it is no surprise that my clinical practice had such limitations. Also, I had predominantly worked with in-patients, and the full impact of their upper limb dysfunction had possibly not been realised by them until they returned home, as was the case with many of the participants in this study. When I look back on my practice, with the knowledge I have now, I regret that I did not do more to promote recovery of the upper limb in my patients. However, I cannot go back and change this, but I can ensure that the knowledge from this study is disseminated to clinicians and may change their practice. Furthermore, in my current role in education I can pass this knowledge on to student physiotherapists and influence their future practice.

4.4.2 Maintaining my Role as a Researcher and my Distance as a Physiotherapist

In the previous chapter, in the section on researcher reflexivity (section 3.4.7a page 88), I explained the decision to identify myself as a researcher and not disclose my professional background as a physiotherapist in order to prevent this influencing the focus and direction of interviews. Although this was an appropriate strategy in terms of conducting the interviews, there were occasions when I found this challenging professionally. This was particularly so when participants were explaining the limitations they had in the movement of their arm and hand and, as a physiotherapist, I could see that they possibly had potential for improvement, and would benefit from more physiotherapy when often, by this point, it had been discontinued. Similarly, there were occasions in conversations when it was clear that participants lacked information and advice about their stroke and their upper limb, and as a physiotherapist, and an academic, I could have provided some of this. At times I left interviews feeling quite conflicted about my role, and this became even harder as I did subsequent interviews and had got to know more about participants'

lives. Logically, and ethically, I understood that my role was that of a researcher, and to move into any kind of clinical role was unprofessional. It was outside the bounds of both the ethical approval for the study and my professional liability. Nevertheless, emotionally, I often found myself frustrated by the inability to use my professional expertise and knowledge to help the participant. I had to remind myself that my primary obligation to the participants was to convey and disseminate their experiences to a wider audience (Gergen and Gergen 2003) and entering into a clinical therapeutic relationship would inevitably change the relationship I had with them as a researcher, and subsequently adversely influence any data obtained.

In the earlier section 4.3.3b Experiences of Therapy (page 145) it is clear that participants were, on the whole, critical of physiotherapy services and, in some instances, critical of individual physiotherapist's attitudes. As a novice researcher this was, again, an area where I had to distance myself from my professional background as a physiotherapist in order to maintain a neutral stance with participants and not offer any opinion. In particular, it was hard to hear the accounts where the focus of therapy was on mobility and opportunities for treatment of the upper limb were overlooked.

The experience of negotiating my way around the nuances of the researcher and participant relationship, acknowledging the boundaries and dealing with my emotional responses, has been challenging. At times it has felt messy and, as Finlay (2002) described, like negotiating my way through a swamp of dilemmas and decisions. However, I feel I have made steps forward from being a novice researcher and am further on in my journey of being a qualitative researcher.

4.5 Chapter Summary

The results from this study could be considered quite wide ranging in terms of participants perceptions and experiences. The key findings are:

- Upper limb dysfunction can lead to a person's life being significantly altered after a stroke. Losing the ability to use both hands together, cooperatively, in completing tasks can affect all areas of a person's life. People can lose competence in managing their self-care, and needing assistance in these private areas of life can lead to feelings of embarrassment and vulnerability. Losing the ability to carry out tasks and activities that are valued and meaningful to a person can leave them without purpose and meaning in their life. In addition, losing capability and skill in such activities caused sadness and frustration. It can also rob them of the pleasure and satisfaction they had previously gained from these activities, leaving them bored and with little purposeful activity in their lives. Furthermore, upper limb dysfunction can affect the life roles and relationships that are significant to people. Losing capability in tasks and activities can mean a person cannot fulfil all the aspects of a life role, such as a spouse or grandparent, in the same way as before their stroke. This can bring sadness but also change the balance in important relationships.
- This altered life can disrupt how an individual can view him or herself. Needing assistance with self-care can leave individuals feeling more like a child than a competent adult and can make them feel of less value and worth. The inability to engage in valued activities and life roles can then disrupt self-image and identity.
- Psychological adjustment and physical adaptation to upper limb dysfunction is possible in the 18 months period after stroke for some but not all. Having an overriding purpose in life, such as continuing to live alone or a significant valued activity, and the return of some function, can be an aid. However, where significant help with self-care is required, valued activities are not resumed and life roles changed, then it is more challenging.

- Recovery of the upper limb was less of a priority than recovery of walking for stroke survivors, and some health professionals, early after stroke. The upper limb continued to be disregarded by health professionals but not by the stroke survivors, who came to see how vital it was in regaining a meaningful life and for their self-esteem, self-image and identity.
- Therapy services after discharge from hospital were inadequate and focused on mobility only and not on the upper limb. Participants were not prepared for this. They wanted more access to therapy for their arm and hand, and in particular physiotherapy, as they saw this as vital for more recovery.
- Stroke survivors found there was a reluctance to discuss expectations of further recovery of the upper limb and thought that insufficient time was given to them to ask questions while in hospital. After discharge home there was a lack of access to information and advice from doctors and therapists about the rate of recovery after stroke and this caused confusion and misinterpretation in what to hope for and expect in recovery of the upper limb.
- Participants wanted to be active partners with therapists in their rehabilitation. They wanted exercise prescription and advice about activities that would foster more recovery. They did not expect therapy to be continuous in the longer term, but rather to have regular review of their upper limb and access back into services.

In conclusion, the findings indicate that having upper limb dysfunction is much more than just losing function. The loss of competence and capability can be wide-reaching and alter many aspects of a person's meaningful life and disrupt their sense of self.

Furthermore, these results could indicate that health services, in particular therapy services, do not fully recognise this effect and are insufficient to meet the needs of stroke

survivors. In the following chapter, the implications of this research will be discussed in more depth and in the context of other research and national policy and guidelines.

Chapter 5: Discussion

5.1 Introduction

This chapter will discuss the findings from this study in the context of the literature on stroke in general and the literature on hand pathologies. Bringing together the literature on stroke and hand pathologies has not been considered before in other literature, but situating the findings of this study in this way will allow further insight, specifically, into the effect of upper limb dysfunction after stroke. The chapter will also discuss the findings in the context of national guidelines and implications for clinical practice. The chapter will begin with a discussion on the effect that upper limb dysfunction had on participants' lives and the impact on their sense of self and this will then be followed by a discussion on experiences of recovery and therapy.

5.2 The Importance of Two-handedness

Upper limb dysfunction had meant the loss of two-handedness for the participants in this study and this had altered how they were able to live their lives. This comment from a participant summed up the effect it had on participants; *'You need both hands, don't you, ... to get on with life'* Ada (12). The life they had after stroke was very different to how it had been before their stroke. Some of the literature on stroke identifies that stroke can bring about a fundamental change to a person's life pervading many of the areas that make up the fabric of a predictable and ordered life (Becker 1993, Burton 2000, Dowswell et al 2000, Kirkevold 2002, Salter et al 2008). The findings in this study have shown that upper limb dysfunction can be a significant factor in this change and can have wide-reaching consequences for a person, altering many areas of their life as indicated by the findings in the subordinate themes of Managing Self-care, Meaningful and Valued activities, and Life Roles and Relationships. Certainly for many participants in this study there was a sense of their lives being altered and interrupted by their upper limb dysfunction.

The participants' experiences in this study do confirm other literature on stroke in general. For example a lady in the study by Hilton (2002) expressed how stroke had been like a whirlwind changing everything, and studies by Dowswell et al (2000) and Ch'ng et al (2008) found that stroke had changed how people viewed their future, as their plans and anticipation of how life would unfold had to change. However it is the literature on hand injuries that support the findings in this study and show how significant the dysfunctional hand could be in altering life after stroke. Women in a study by Bylund and Ahlgren (2010) found they were living a very different life as all domains of their lives had been affected by their hand injury, as it had for those in Chan and Spencer's study (2004). A person in a paper by Kingston et al (2014) summed it up by saying that everything she had done before her injury was now just a memory. Their hand injuries were altering their lives at many different levels such as managing self-care and participating in meaningful activities in the home and in their work. In addition, it was affecting their perception of themselves with low self-esteem being common, as they felt less competent and capable in activities and life roles. These were people who had no other disabilities other than their hand injury, and yet were having similar experiences to the participants with stroke in this study. This emphasises the important role of the hands in the activities that make-up every-day life, as explained in the first chapter, and confirms the findings in this study that losing two-handedness after stroke is a significant factor in the changes stroke survivors' encounter in their life after stroke. Upper limb dysfunction needs to be addressed in rehabilitation if people are to rebuild a life after stroke. It could be as important as the recovery of walking for many people. Indeed, if walking is not recovered then recovery of the upper limb could become more important as there are many tasks and meaningful activities a person could engage in from a wheelchair if they had some function in their upper limb.

The findings in this study bring to light how the loss of two-handedness can alter significantly the way in which individuals can manage their self-care; a vital area of

everyday life. Upper limb dysfunction had rendered participants incompetent and incapable in the most basic and private tasks that people engage in and had resulted in low self-esteem. The literature review identified that low self-esteem can be a problem after stroke (Ellis-Hill and Horn 2000, Murray and Harrison 2004) and confirms that it can be associated with loss of competence in self-care (Pound et al 1998, Secrest and Thomas 1999, Burton 2000, Salter et al 2008). This study, however, highlights how the focus on mobility that most participants experienced in rehabilitation after their stroke, both as in-patients and out-patients, is inadequate to address the self-care needs of stroke survivors. Increased mobility may enable a person to transfer between bed, chair, toilet etc. and enable freer movement around their environment, without the need for a wheelchair, and therefore facilitate an earlier discharge from hospital, but it is not enough to enable people to regain a greater level of independence in self-care, and to maintain a good level of self-esteem, if they have a dysfunctional arm and hand. Ellis-Hill and Horn (2000), in their study on change in identity and self-concept after stroke, reported their respondents describing themselves as less capable and less dependent after their stroke, but they only reported on the side of weakness and the mobility levels of their participants and not any upper limb problems. However, this study adds to those findings in that it is the loss of two-handedness that will make people feel incapable as they will be dependent on others when using the toilet, bathing or dressing. Furthermore, the dependence that upper limb dysfunction can bring means a loss of privacy and the intrusion of other people into the normally private sphere of self-care activities. Therefore, individuals can feel embarrassed and vulnerable, and losing privacy in these personal and intimate tasks can change how a person might perceive him or herself, and how they think those people who assist them might now view them, and so, as was found in this study, self-esteem can be adversely affected. This change in circumstances in self-care, brought about by the loss of two-handedness, interrupts the flow of a normal, predictable life, and, as Ellis-Hill et al (2008) suggests in the Life Threads Model, this can alter a person's sense of self-worth and value, compared to how they felt about themselves prior to their stroke. They may

look ahead into the future and be very uncertain about who they may become as a consequence of their upper limb dysfunction. Kvigne and Kirkevold (2003) reported in their study stroke survivors finding their bodies had become unreliable, rather than their normal and reliable bodies, and so were vulnerable and dependent, and women in Kvigne et al's study (2004) described feeling uncomfortable and exposed to the view of others when being helped by carers. Burton (2000), Pound et al (1998), Secret and Thomas (1999) and Salter et al (2008) all report in their papers that a lack of mastery over self-care activities can leave people feeling vulnerable, and Pilkington (1999) and Kvigne and Kirkevold (2003) both agree that individuals are embarrassed when needing help with self-care. None of that research, however, delved into the specific functional deficits that caused the lack of competency in self-care, whereas the findings from this study bring to light that dysfunction in the upper limb can be a main factor. More recent research on sensory loss in the upper limb after stroke, published after data collection in this study was completed, adds strength to the findings in this study as vulnerability was reported in some of their participants who struggled with self-care tasks as a consequence of sensory loss in the hand (Doyle et al 2014). It is in the literature on hand injuries where more similarities with this study can be found. Participants in Schier and Chan (2007), Bylund and Ahlgren(2010), Ammann et al (2012), Kingston et al (2014) and Cederlund et al (2010) all reported loss of competence in self-care, and with that embarrassment and low self-esteem because of the help individuals required. This literature emphasises the findings in this study that the upper limb can be more crucial than the lower limb in maintaining independence in self-care and, therefore, a positive self-esteem, as the injuries in these studies were limited to the upper limb as participants had normal lower limb function.

As stated in the literature review low self-esteem is associated with depression and depression is common after stroke, and both low self-esteem and depression are related to poorer outcomes in rehabilitation (Vickery et al 2008). The National Clinical Guidelines

on Stroke, 4th edition, (Intercollegiate Stroke Working Party 2012) suggest that there is a link between low self-esteem, depression and engagement in therapy. Furthermore, the guideline states that depression itself is associated with motor impairments and activity limitation. The findings in this study could indicate that motor impairment of the upper limb and the resultant low self-esteem, experienced by many of the participants in the study, could be a cause of depression, particularly if as in the case of these participants, their upper limb impairment and activity limitation is ignored in therapy. It seems, therefore, that attending to the upper limb in rehabilitation in an attempt to restore some function could be a factor in reducing post-stroke depression. Indeed, in the NICE (2013) Guideline on Stroke Rehabilitation: Long Term Rehabilitation after Stroke, recommendation 1.10 on self-care recommends that occupational therapy should be available to assist people in recovery of self-care tasks, through either a restorative or compensatory approach.

5.2.1 The Importance of Two-handedness in Maintaining the Norm

The findings in this study illustrate how important the hands are in enabling individuals to conform to socially acceptable norms and to maintain their normal social interactions. Outward appearance of disability has been consistently linked to feelings of being conspicuous and a barrier to social interaction (Murray and Harrison 2004) and Dowswell et al (2000), in their study investigating recovery from stroke, report people feeling ashamed of their disabled body and concerned about the reactions of others, and so withdrawing from social contact. Some people in social settings will strive to make their impairment less visible and appear able-bodied, rather than disabled (Goffmann 1963, Christiansen 1999). Lower limb impairments can be more easily disguised, for example, whilst seated at a table during a meal with family or friends, whereas upper limb impairments would be more visible because of the normal activity of both hands in using cutlery in a normally acceptable manner. In some social situations individuals may feel uncomfortable and embarrassed when able to use only a fork, or if assistance is needed

to cut up food, and a consequence of this could be avoidance of such social occasions and social isolation, as was found in the participants in this study, and also in the study by Poltawski et al (2015) where a participant in a blog on the impact of the upper limb after stroke reported withdrawing from eating out socially.

Another factor in maintaining the norm is the way in which individuals dress and adorn their bodies, and, as the participants in this study reported, being two-handed can be vital for people to present themselves socially in their preferred style, and in what they might consider socially appropriate. The findings in the study showed that this is not just important in social interactions, but is a crucial aspect in a person's self-image and in maintaining a positive self-esteem. Often in rehabilitation, functional activities of daily living are the priority and people are taught by occupational therapists how to dress more independently through compensatory strategies of wearing clothes that are looser fitting with fewer fastenings, and adorning the body with make-up and jewellery is not usually an important consideration. Looser fitting clothes can also make it easier for carers to assist with dressing. However, this study shows that, while needing less assistance to dress might have a positive effect on self-esteem, this could be outweighed by the dissatisfaction a person might feel about their appearance and self-image, and as a consequence lower their self-esteem, and in some cases lead to withdrawal from social situations. A person's appearance is a focal point in social interactions and the desire to present a positive image is crucial for self-esteem (Leder 1990, Garner 2004, Fox and Wilson 2008) and so this should be acknowledged in rehabilitation. The findings on self-image and self-esteem in this study support what others have found. Kvigne and Kirkevold (2003) explained how the women in their study felt being well dressed was part of looking well and attractive, and therefore made them less conspicuous and more socially acceptable, but the authors did not specifically link this to upper limb function. However it is in the literature on hand injuries where the link with hand function and self-image becomes more apparent. A participant in Cederlund et al (2010) was very

dissatisfied with her appearance. She described the problems she had with fastenings on clothes, and therefore described the type of clothing she could now wear as ugly. This confirms the findings in this study, where many participants were very unhappy with their clothing and appearance, and also demonstrates how the literature on hand injuries can inform and add to the literature on stroke.

As explained in the first chapter, the hands play an important role in social interactions when meeting and communicating with people and are, therefore, very visible. However, as found in this study, people with impairment and/or disfigurement of the hand may hide it away or camouflage it, in order to maintain social acceptability and to avoid feeling conspicuous (Meyer 2003). The literature on hand injuries supports the findings in this study. Participants in Stamm et al (2014) described their rheumatic hands as thick and ugly and shied away from shaking hands with people as they would be more conspicuous. Meyer (2003) and Grob et al (2008) both agree that people with hand injuries can be very concerned about the cosmetic appearance of the hand and its social acceptability. This study showed that the function of the hand can be important in maintaining identity in social situations, as in the case of Alan. His efforts to use a urinal in a public toilet, and the awareness that he could not put his hand in and out of his pocket, as other men often do, to store and retrieve items or just to rest it, illustrated how important it was for him to try to present a masculine identity. This has similarities to the men in a study by Rittman et al (2007), who felt their stooped postures after stroke challenged their masculine image.

The loss of two-handedness can have consequences in how stroke survivors view themselves as normal adults. Becoming competent and independent in self-care tasks is synonymous with growing up and moving into adulthood, so it is not surprising that needing assistance in these areas caused participants to feel they were more like a child than a competent adult. Indeed Pilkington's paper (1999 p 339) explores a link between helplessness and feeling like a child after stroke, where a participant describes feeling *'just like a little baby, a helpless baby now'*. However, the study does not extend to fully

exploring the effect that the upper limb might have had on this, whereas this study has explored this relationship and illustrates that upper limb dysfunction could be a significant factor at the root of these feelings. It is in studies on hand injuries where similar experiences can be found and directly attributable to the hand. In Chan and Spencer (2004) a man with a hand injury expressed feeling like a child because he was too afraid to have a bath when no-one was at home in case he got into difficulties. This confirms the findings of this study that having two upper limbs that can work together is vital for people to feel they are normal, competent, adults.

It was interesting that one participant in the study reported '*feeling like half a person*' (Alan) because he could only do half the things he did before, and again this illustrates the full effect that upper limb dysfunction after stroke can have on a person. This is similar to that which Ellis-Hill et al (2000 p728) found, where one of their participants also described feeling like '*half a person*'. Occupational science makes a connection between the activities that individuals participate in, identified by Hammell (2004) as 'doing', and their perception of themselves as a fully competent and capable person, and so could explain the full extent of losing two-handedness, and how vital it is to have two upper limbs working together for an individual to 'do' and, therefore, feel they are a whole, normal person.

The findings in the study highlight how having mobility in the lower limbs may enable a person after stroke to access the community socially, but this alone may not be sufficient for individuals with stroke to interact socially. Losing two-handedness can have a significant impact on whether a person feels they conform to socially acceptable norms and their self-image may be adversely affected. Furthermore, this may prove to be a barrier to stroke survivors interacting socially and they may, therefore, withdraw from their community.

5.2.2 Losing Two-handedness Can Bring Loss after Stroke

Upper limb dysfunction can fundamentally change the day to day structure of everyday life for stroke survivors as they lose activities that bring purpose and meaning in life. The participants in this study were very aware of the meaningful activities that they could no longer participate in because they no longer had bi-lateral hand function. As Wolf and Baum (2011) explain, it is the ordinary and familiar things that persons do every day that have purpose and meaning for them. Being able to participate in meaningful activities, or being able to 'do', brings purpose and fulfilment, and enables a person to see a possible future with structure and activity (Hammell 2004). As the findings in the study show, losing meaningful activities can bring frustration, boredom and sadness. Salter et al (2008) observed that people after stroke enter a world of loss as they lose their independence and abilities to participate in life as before their stroke, and lose control over their lives. Secretst and Thomas (1999) describe the world of stroke as grounded in loss as people's concept of normality and taken for granted freedoms are gone. People lose choice over what they want to do and where they want to go. Bourland et al (2011) found that a loss of valued activities left a void or emptiness in the lives of their participants. None of the above studies had explored in any great detail the specific impairments that can lead to loss of activities but the findings in this study suggest that upper limb dysfunction could be a significant cause of loss of activities and could be at the heart of loss after stroke.

Ellis-Hill et al (2008) describe the activities people engage in as the threads that make up a person's life story, and the participants' experiences in this study demonstrate how losing two-handedness is an important factor in these threads being broken, and the discontinuity in a person's life after stroke. Christiansen (1999) suggests that it is these occupations that are part of a person's life story and their purpose in life. Lawler (2014) explains that when these are affected the internal narrative or life story of a person, which brings continuity and integrity can be disrupted and altered. Losing the dexterity, strength

and skill in the upper limb, and being unable to work with both hands, could mean losing the meaning and purpose in life and possibly interrupting and altering a person's life story. As explained in the first chapter, loss after stroke can be physical, social and psychological (Salter et al 2008). The participants' loss of two-handedness was physical, but it also had psychological consequences for them, as they lost the physical activities and skills that had contributed to their self-image and self-esteem. Day-to-day, routine occupations are a vital part of a person's life story and through them they build an image of who they think they are (Christiansen 1999, Hammell 2004). For example, the experiences of several of the women in the study, who had taken pride in their skilful, quick and efficient bodies, that allowed them to care for their homes and family before their stroke, was similar to the women in the study by Kvigne and Kirkevold (2003). They too had expressed satisfaction with their hard-working and strong bodies that allowed them to take care of their homes and children, but after stroke had become unreliable and demanding, changing how they saw themselves.

Christiansen (1999) suggests that the activities and occupations that people engage in can not only contribute to self-image but can also be the bedrock of a person's identity. The competent and capable performance of activities and the perception that others might view them positively as a consequence are essential for a person to maintain a sense of their own identity (Elliott 2014). Therefore, what was evident in the literature about people encountering changes in their sense of identity after stroke would now seem logical in the light of the findings from this study. The studies that referred to changes in identity after stroke had linked this to valued activities but had not fully explored the causes for the limitations in those activities (Ellis-Hill et al 2000; Clarke 2003, Murray and Harrison 2004; Rittman et al 2007). The experiences of the participants in this study indicate that upper limb dysfunction can be a significant factor in the loss of identity after stroke. Several of the participants in this study gave themselves labels by which they seemed to be defined e.g. cook, musician, and this supports Baumeister's (1990) assertion that this is how

people find identity. However, if that identity is associated with a meaningful activity, which is then lost after stroke because of upper limb dysfunction, then the sense of identity they get from that activity is going to be changed or lost after stroke.

Not all activities that people engage in are purposeful or productive, but some might be just for pleasure, as in leisure pursuits and hobbies. In the 'Doing, Being, Belonging and Becoming' model of occupation (Hammell 2004) these types of occupations are situated more in the 'being' construct, and can be associated with their identity, although clearly in some there will be an element of 'doing'. It was evident in participants' experiences that much of the pleasure had gone out of their lives as they were no longer able to 'be' as they had been in their previous past-times. The pleasure from reading, and being absorbed in the newspaper or a book, was tainted by the struggle to turn the pages, the feeling of freedom from riding and steering a bicycle, the experience of playing a musical instrument, or dancing to music with a partner, were gone. There was a sense of participants being bored and frustrated as they had lost occupations that gave them meaning and pleasure, and allowed them to 'be' in the moment of pleasure. Ch'ng et al (2008), reported great distress in stroke survivors where there were losses in hobbies and activities that had previously been a source of achievement and pleasure for people, but this study brings to light how important bilateral hand function will be in enabling individuals to regain these activities.

The literature on hand injuries supports the findings in this study that upper limb dysfunction could be at the heart of the losses encountered after stroke. Several studies explained the losses in meaningful activities that people encountered in their lives after hand injury, many similar to the activities of the participants in this study. A woman in Chan and Spencer (2004 p131) reported that '*everything had changed*' in her life. She was unable to cook and clean, or to continue with her craft hobbies, which were important to her. A man in Schier and Chan (2007) could no longer play sports, and in Chemnitz et al (2013) playing musical instruments was not possible for several people. Women with

vibration hand injuries in Bylund and Ahlgren (2010) had to give up work and reported shortcomings in their ability to complete household tasks. In fact, one person's description in Chan and Spencer (2004 p132) of the effect on his life resonated strongly with the participants experiences of loss and life being interrupted, or put on hold, as he stated, referring to his hand injury, *'this has shut me down'*. For stroke survivors to rebuild their lives, and maintain a coherent and positive sense of self, it is vital, therefore, that the dysfunctional upper limb is not ignored. It could be just as important as mobility, or even more so, for people to regain purposeful, meaningful and pleasurable activities.

5.2.3 Losing Two-handedness Changes Life Roles

The findings in this study revealed the impact of upper limb dysfunction on the life roles that people held, and their relationships. The loss of two-handedness meant that this was an area of life that had changed, and that they could no longer get on with in the same way as before their stroke. Often integral to these changes were the valued and meaningful activities that participants could no longer do because they did not have two hands functioning together. These activities conformed to quite stereotypical male and female roles, which are more common in the older generation, and affected the balance in spousal relationships, as responsibilities and tasks had to be relinquished to a spouse, who they then became more dependent upon. Christiansen (1999) suggests that the life roles people inhabit are intertwined with their identity and this was evident in the study, where the men felt they could not complete the domestic tasks typical of a husband, and the women could not fulfil the typical tasks of a wife. Their experiences correspond with those of other stroke survivor's. Several papers record men feeling their role was challenged by the effect of the stroke on their physical capabilities (Burton 2000, Dowswell et al 2000, Ellis-Hill et al 2000, Rittmann et al 2007, Ch'ng, et al 2008), and Eilertsen et al (2010) and Kirkevold (2002) report women feeling their role in the home and caring for family was changed.

A person's perceived status within a relationship and the wider family can be affected by upper limb dysfunction. They will continue to be a spouse, parent or grandparent but how they will inhabit that role could change as a consequence of losing two-handedness. In the 'Doing, Being, Belonging and Becoming' model of occupation, Hammell (2004) explains that an essential part of belonging and connectedness in a relationship is associated with the contribution a person feels they bring to that relationship. Prigatano (2011) agrees that helping one another in relationships creates bonds and connectedness. Upper limb dysfunction, therefore, has the potential to adversely affect that belonging and connectedness in people with stroke, as they can no longer complete the tasks and responsibilities associated with their role. This was very evident in some participants, who felt their status had changed and they now had less control in relationships, and had become useless, rather than useful, to their families. This confirms other research, both on stroke and hand injuries, where it is reported that these changes are felt deeply and difficult to accept (Pound et al 1998, Dowswell et al 2000, Schier and Chan 2007, Eilertsen et al 2010).

Of course life roles also bring pleasure into individual's lives, and in this study this was very evident in the relationships between grandparent and grandchild, where participants were very sad about the way their upper limb dysfunction had affected how they could 'be' with their grandchildren. They were no longer the playful, caring, safe grandparent they had been, as they could not interact with the children in the same way as before their stroke, and so had lost that giving and receiving of pleasure, which is an important element in building bonds in relationships (Hammell 2004, Prigatano 2011). There were similarities in the study on hand injuries in the study by Schier and Chan (2007), where a father was distressed at being unable to throw and catch balls, and ultimately gave up coaching his son's soccer team. Other studies on hand injuries showed the sadness in parents at the realisation of how much their impaired hand was affecting their ability to care for their children and to 'be' a parent (Chan and Spencer 2004, Chemnitz et al 2013).

Roles and relationships are part of the 'threads of life' (Ellis-Hill et al 2008) and therefore upper limb dysfunction after stroke has the potential to break some of these threads. Stroke survivors could struggle to reconnect with their families, as they have lost the tasks and activities that helped them to belong. Roles and relationships bring continuity to a person's life (Ellis-Hill 2011) but upper limb dysfunction will not only affect roles and relationships in the present, but how individuals can live them out in the future might be very different to that which they expected before their stroke. In the 'becoming' construct of the 'Doing, Being, Belonging and Becoming' model of occupation, Hammell (2004) explains that all individuals envision a future self, the person they expected to become as they live out the roles and relationships that are important to them. Losing two-handedness after stroke, therefore, has the potential to disrupt their vision of the person they will be in the future, as they realise that the contribution they can bring to those roles and relationships will change.

5.2.4 Summary of the Importance of Two-handedness

The discussion in this part of the chapter has brought to the fore how a dysfunctional upper limb after stroke, and the consequent loss of two-handedness, can affect many areas of a person's life. Bilateral arm and hand function are vital in activities of everyday life, but further than this the effect of being unable to manage self-care, and participate in meaningful activities, and life roles and relationships, can permeate through into a person's sense of self, disrupting their identity and self-image, and causing them to have low self-esteem. The findings from the study, discussed in the context of the literature on hand injuries and pathologies, has brought new knowledge to the existing literature on stroke and brought to the fore how much the upper limbs are needed for a person to live a life of meaning with a positive self-esteem, self-image and identity that gives a coherent concept of the self. Upper limb dysfunction after stroke can alter a person's life bringing loss and change, and disrupting the self. The study has shown that it can bring discontinuity to the threads of life because of its effect on meaningful activities, and life

roles and relationships. The adverse changes in self-esteem, self-image and identity brought about by the loss of two-handedness have the potential to disrupt how a person may view him or herself in the present and what they may become in the future.

The findings from the study confirm the brief analysis of the ICFDH Core Set for Stroke (Geyh et al 2004) in the first chapter of this thesis, where it was suggested that bilateral upper limb function could be essential for participation in certain categories of activities that make up normal life. The loss of two-handedness resulted in many of the participants in this study feeling helpless and vulnerable in several of the categories related to self-care: d510 washing oneself, d520 caring for body parts, d530 toileting, d540 dressing, and d550 eating, and furthermore their embarrassment had consequences for them in d750 informal social relationships. The findings also confirm that upper limb dysfunction after stroke can be a barrier to participation in those categories that could be linked to meaningful activities and life roles: d430 lifting and carrying objects, d475 driving, d630 preparing meals, d640 doing housework, d750 informal social relationships, d760 family relationships, d845 acquiring and keeping a job, d870 economic self-sufficiency, d920 recreation and leisure, d910 community life. The ICFDH Activity and Participation categories are deemed as being universal to normal human functioning (WHO 2002) and, therefore, the experiences of the participants in this study demonstrate that upper limb dysfunction, and losing two-handedness, can alter this human functioning, bringing a life of loss and change, with less meaning and purpose. This demonstrates how important it is for upper limb impairments and dysfunction to be addressed in rehabilitation. Recovery of mobility is important but these findings suggest that upper limb function could be just as vital to individuals with stroke if they are to recover some of the meaning and purpose to their lives and to rebuild a coherent sense of self.

5.3 Transitions, Priorities and Hopes

In the previous sections it was seen that upper limb dysfunction had a significant effect on participants' meaningful lives and their sense of self. This next section will discuss the

changes that occurred in peoples' perceptions and experiences of recovery as they went through the transition from hospital to home, their hopes and expectations for recovery, and their adjustment and adaptation to their upper limb dysfunction over the 18 month period of the study.

The findings of the study at two months post-stroke correlated well with the literature on stroke. Those participants who were still in hospital were very concerned about returning home. By this stage therapy was well underway and, similar to participants in Kirkevold's study (2002), their attention was beginning to focus on returning home. Returning home is an important transition and milestone in recovery after stroke as it can symbolise a hope of return to a normal life (Jones et al 2008). Olofsson et al (2005) described this yearning to come home as overshadowing everything else and this did seem to be the case for many participants in this study. Upper limb recovery was less of a priority than the lower limb. Regaining or improving walking was seen as the key to them being discharged from hospital and being able to live again in their own home. These findings are very similar to that of Kirkevold (2002) and Connell et al (2014) where being able to walk independently was seen as the milestone that needed to be achieved in order to return home and thus the main priority for stroke survivors. Even though many participants described their frustration and embarrassment at needing help with self-care while in hospital, and it was clear that their self-esteem was suffering as a consequence, this was not enough to make the upper limb either equally or more important than the lower limb. This resonates with Doyle et al (2014) in their study on experiences of sensory impairment in the upper limb where their participants' attention only turned to their upper limb once they had achieved some recovery of walking. There is no doubt that walking achieves a degree of independence in being able to move around the environment without the need for assistance and, therefore, will enable people to live in their homes and community more easily. It is an activity that is achieved very early in life and seen as an important milestone in childhood and a vital part of being a more autonomous person. However, as

the findings in this study have shown, it will not necessarily bring complete independence as two-handedness is crucial in most of the activities people engage in.

What was noticeable in this study was the difference in priorities at two months between those still in hospital and four of the five participants living at home. They had achieved their goal of returning home and could walk independently around their home, and so could turn their attention to their upper limb. Also, they were confronted with the life they had led before their stroke and the tasks and activities that they wanted to and needed to do at home, whereas in hospital they were in an unreal situation where more was done for them so masking the need for upper limb function.

It was interesting to note that although some participants were ignoring their arm, and many did not prioritise it at two months post-stroke, they did have expectations at this point that their arm and hand would recover, and they would return to their normal activities, and for this to occur within a relatively short period of time of months. Hope for a return to normal is a common theme in the stroke literature, where people measure recovery in terms of their normal valued activities (Burton 2000, Eilertsen et al 2010). Eilertsen et al (2010) reports individuals, in the first two months after stroke, seeing their stroke as transitory in nature with symptoms subsiding relatively quickly. Bendz (2003) also found similar attitudes and this does agree with some participants in this study who regarded upper limb recovery as something that would be achieved within months. Harry for example expected his arm to recover fully, even though he was paying little attention to it. Conversely there were two participants who saw recovery as taking much longer if at all and this had been influenced by information they had received from physiotherapists and other people with stroke. They were the only two who seemed to have been given some specific information. Colin was still expecting a return to normal but over a much longer time scale of years rather than months, but Bob was less optimistic because of the physiotherapist's prediction that he would not be able to play the piano again. Playing instruments were a much valued activity for him as a musician. However, Bob was

holding on to some hope as he stated he wanted to prove the physiotherapist's prediction to be incorrect.

Having hope for more recovery is a theme in several studies, e.g. (Bays 2001, Wiles et al 2002, Ch'ng et al 2008, Salter et al 2008, Doyle et al 2014), and Bob's attitude is similar to the people in Barker and Brauer (2005 p1217) where they saw *'keeping the door open'* to more recovery in the upper limb as essential, even when, like Bob, this cut across the predictions of health professionals. Some in that study resented the negative predictions because of their power to shatter hope and so chose not to listen to them in the hope that they would not always be correct, and it seemed that Bob was hopeful of this too. Wiles et al (2002) also found some of their participants choosing to ignore negative predictions by physiotherapists and maintaining high hopes of a full recovery. Bays (2001) found having hope to be the key to the person being able to move forward and see a possible future for themselves and find some inner strength to engage in rehabilitation. Hope can be an anchor that a person uses to ground themselves in the present but then allows them to see how they may be in the future (Salter et al 2008). Bonds Shapiro (2011) explains how the stories people with stroke tell themselves can influence their attitudes to recovery. They can be the beginning of a negotiation with him or herself as they try to reconcile who they were in the past with who they hope to become in a particular point in the future and, therefore give them the motivation to continue to strive for more recovery (Ellis-Hill et al 2000). Again there are similarities to participants in Barker and Brauer (2005 p1218) who used the expression *'hanging in there'* to describe their persistence in not giving up hope.

Having hope for regaining sensation in the hand was a strong message from participants in Doyle et al (2014) as this kept them working hard for more recovery, and for the participants in this study it could have been helpful for them to have hope for a full recovery at two months after their stroke. As Bays (2001) observed, this could have given them the impetus to engage in rehabilitation. However, apart from a few participants, this

hope for a full recovery did not seem to be based on information from health professionals. According to several participants, information about their upper limb was lacking in the two months after their stroke, with little time or opportunity for responding to questions and concerns about the upper limb, and there was an avoidance of discussing expectations for recovery. Ellis-Hill et al (2009) noted how distressing this lack of information about recovery was for people with stroke. The reluctance by therapists to discuss recovery was something that Wiles et al (2002) also found, often because therapists did not want to raise false hope for recovery, but this ignores the need in stroke survivors for information (Jones et al 2008). It is possible that the participants had filled the void left by the lack of information with their own assumptions. The assumption of a full recovery could have been influenced by the rate of recovery participants may have already experienced in the first two months. This is usually quite rapid and unless informed otherwise participants could have expected this rate of recovery to continue. Burton (2000) and Kirkevold (2002) found this assumption about rate of recovery in the people with stroke in their studies and interestingly it was also the case with people after hand injuries (Chan and Spencer 2004). Furthermore, the lack of attention to the upper limb by the therapists, at this early stage, could have been interpreted by some as meaning that recovery would just spontaneously happen at some point.

As discussed in the literature review chapter, the outcome of stroke can be unpredictable and will vary between people as there are many factors at play that can influence it; therefore, to expect health professionals to be specific about expected time-frames for recovery is unreasonable. However, as Bonds Shapiro (2011) suggests the participants could have been given this more honest information about the reality of stroke, and it may have helped Bob to be more optimistic and to continue to strive for more recovery rather than adopting the compensatory approach he took so early after his stroke, and the others to retain some hope and impetus for engagement in therapy, which would be vital at this early post-stroke point. Treading this fine line of honesty and maintaining hope was also

wanted by people with hand injuries and so it shows how important and vital recovery of the hand is to people and their need for information (Chemnitz et al 2013).

There could of course be another interpretation of participants hope for a full recovery. They may well have received information about their arm and hand but had either chosen to ignore it or had forgotten. By ignoring the information participants may have been able then to hold on to hope and so were behaving in a way not uncommon in other stroke survivors who have been noted to maintain high hopes for a full recovery in the face of very negative predictions (Wiles et al 2002, Barker and Brauer 2005, Jones et al 2008). Communication between health professionals and people with stroke can be a difficult area to get right, particularly early after stroke (White et al 2009). Stroke survivors may not be ready to fully understand and remember information when it is given for many reasons, such as poor memory, post-stroke depression or just feeling overwhelmed by the sudden dramatic changes in their body and circumstances (Oloffson et al 2005, Mangset et al 2008). When participants in the study were ready for information it was given in medical terms they did not understand and it may also have been that they perceived the staff as being too busy to bother with their questions as in the case of others with stroke (Oloffson et al 2005, White et al 2009). Peoples et al (2011) points out that some people prefer to remain quite passive in the early stages after stroke, allowing the health professionals to take control, and therefore do not seek or want information and this may have also been the case for some of the participants.

At six months after stroke all participants were living at home and it was evident that this transition and settling in to living at home was not an easy one. Cott et al (2007) comments on how challenging the transition home from hospital can be with regard to meeting self-care needs of people with stroke and, although they do not refer directly to the upper limb in their paper, the experiences of these participants indicate how difficult self-care could be with upper limb dysfunction when living alone. As Oloffson et al (2005) observed, it is often in the transition from hospital to home where the realisation of the

impact of stroke becomes apparent, and this seemed to be the case for many participants, forcing them to acknowledge how important upper limb recovery was going to be. Becker, as far back as 1993, recognised how crucial this transition was for bringing to light the full effect of stroke on as stroke survivors were faced with the reality of their limitations and how different their life might now be. A more recent study on people with hand injuries by Ammann et al (2012), where participants complained of feeling frustrated and helpless on their return to home, as the effect of their hand dysfunction was being realised, confirms the findings in this study in that the significance of upper limb dysfunction comes to the fore in the transition home from hospital, and so explains why upper limb recovery can become more of a priority for people with stroke at that stage. As in other literature on stroke, the participants were concerned about returning to activities and roles that were valued and meaningful to them before their stroke. Bendz (2003) found people with stroke wanted to get back to their usual self and Sabari et al (2000) observed that stroke survivors wanted to get back to the activities that had provided a good quality of life before their stroke.

It was not surprising that low self-esteem continued to be an issue as now close family members were assisting some with self-care or paid carers were coming in regularly. Similarly, the changes in self-image and identity would be expected at this point as people had encountered the challenges in valued activities and life roles and they were beginning to affect their view of themselves. However, for some participants this transition to home was enabling the process of adaption to begin. This was particularly so in two participants where their desire to continue to live alone in their own homes, with minimal help, was driving their adaptation. Alison Bonds Shapiro (2011), herself a stroke survivor, comments how important it is for people to find solutions to the functional problems they find after stroke in order to adapt and reform their life after stroke. It takes time for the process of adapting to begin, and it is only as individuals are recovering from the shock of having had a stroke, and the apprehension and fear is subsiding, that they can begin to

solve the functional problems they are confronted with (Ch'ng et al 2008, Williams and Murray (2013). By using adapted equipment and having help with some of the heavier domestic tasks participants were solving their 'problem' of continuing to live alone. Some seemed more adjusted psychologically at this point to their circumstances, and this was partly because they were able to put their experiences into the context of their age, and what you would expect at that point in life, and so were adjusting expectations and finding more fulfilment in pursuits that were less active but still important, such as reading and using the internet. Clarke (2003) found in her participants that, if people could adjust their expectations and continue with some interests that were important to them, then their well-being was less affected. Jenny, however, by her comment that she was '*getting by*', and by the tearfulness she showed as she talked about having help come into her home, indicated that her life was not as ideal as she would have liked. She had to make more adaptations because of a greater degree of dysfunction. Similarly, Colin's comments about trying not to moan about his circumstances and to get on with life could suggest a struggle psychologically.

Walking was still a priority for some, particularly to walk outdoors and in more public settings as seen by Alan who wanted to marry his partner and walk her down the aisle. It was to be expected that Harry would still be focused on walking as he was very much chair-bound at six months after his stroke. His feeling that '*the rest will improve*' once he had achieved walking showed how much importance he gave to this and could explain his indifference to his arm and hand. He clearly wanted to walk to the bathroom in his home but it may not, at that point, have occurred to him that his upper limb might be a barrier to him being independent once in there.

The moderating of participants' hopes and expectations for a full recovery in their arm and hand was not surprising at this point after stroke. They seemed to be unprepared for the general slowing down of the rate of recovery they were experiencing by six months after their stroke and, as a consequence, some were feeling much less hopeful as well as

adjusting their time-scale for recovery of their upper limb. There was a sense of them having to re-negotiate with themselves their expectations for recovery and to push further into the future their picture of themselves with a recovered arm and hand (Salter et al 2008). This gradual realisation by people that recovery would not continue at the same rate was noticed in studies by Kirkevold (2002) and Eilertsen et al (201) and the discouragement and despondency in some participants in this study corresponds with other literature (Burton 2000, Dowswell et al 2000). The lack of therapy had meant that participants had no-one to discuss their concerns with or to re-assure them that the slowing down of the rate of recovery is part of the normal trajectory of stroke (Kirkevold 2002). The National Clinical Guidelines for Stroke (ISWP 2012) recommend that all people with stroke should have a six month review and this would be an opportunity to discuss concerns but unfortunately none of the participants had a six month review. They are not alone in this as the Post-stroke SSNAP audit (2014) found that services that could offer this review were very limited across the country.

It would seem that the disinterest in the upper limb and lack of information extended to the hospital consultants. Some patients had been to a follow up appointment with a consultant but were very disappointed that there was less concern with progress with their arm and hand than with their mobility. People in the Barker and Brauer (2005) study had similar experiences and felt that doctors did not appreciate how important it was to regain some use of the arm and hand. Doctors are well positioned, often on commissioning panels, to influence stroke services and if they were more aware of the impact of upper limb dysfunction on peoples' lives, as this study has shown, then they could be facilitators of improved longer term services that would address recovery of the upper limb.

There was an interesting transition at twelve months post-stroke in that all participants were now very much concerned about their upper limb and, in some cases, more so than their lower limb. It was the desire to resume some valued activities and roles and the limits that their upper limb dysfunction was bringing. Even Harry, who had been happy to

ignore his arm previously was now seeing how it could help him to feed himself independently. Twelve months might be perceived as a long time after stroke to be just beginning to resume activities and roles and recognising the importance of the upper limb, but Eliertsen et al (2010) describe the women in their study only beginning to pick up the threads of their lives in the second year after stroke. Kirkevold (2002) found that it was only at six months post stroke that the shift towards trying to resume valued activities began in the people in their study. It could be then that this process of trying to get with their lives was occurring for the participants in this study between six and 12 months and so at the 12 month post-stroke interview it became very obvious that this was happening.

There seemed to be little change in competence in self-care, valued activities and fulfilling life roles since the six month interviews and this could be due to the lack of therapy. It is not surprising in the light of little change in peoples' lives that low self-esteem and issues with self-image and identity were still prevalent in some. Where there was some resumption of activities because of adaptation, this seemed to help psychological adjustment. As in the case of Colin, who was driving again in a car adapted to his hand functioning. He was able to resume the role of driver as a husband. Where people still needed help with self-care then adjustment was harder.

It seems that it was at this 12 months post stroke point that participants were recognising that their recovery was not matching the hope and expectations they had in the early days after their stroke. The comments from some about their expectations for spontaneous recovery and regaining normal life on discharge home were very revealing and perhaps reflect the lack of information and advice that was not available, or they had not been able to absorb in the early stages. Where improvements in function of the arm were still occurring, as in the experience of Colin, even though at a slow rate, then hope for more recovery was still alive, and again this was evidence of the continuing re-negotiation of expectation for recovery. This resonates with the experiences of people in other research on the upper limb. Barker and Brauer (2005) identified a theme in their research of

'keeping the door open' to more recovery and participants in Doyle et al (2014) considered it important to keep hope alive and to continue to work hard even when recovery had slowed down. This shows how hope is an important factor in maintaining motivation to regain more recovery.

Having access to information and advice about the upper limb could be an important factor in enabling people to have realistic hopes at this point after stroke and to maintain motivation to work for more recovery where appropriate. Unfortunately, though, for these participants there was no one to turn to for this advice as therapy had stopped and, there was no interest in the upper limb from GPs or hospital consultants. There was the desire to keep trying for recovery but, participants were in the dark as to how they could progress their recovery forward. Peoples et al (2011) points out how important it is for people with stroke to receive some encouragement about their progress and to have their worries acknowledged and listened to. It seems that the lack of services was not meeting this need in the participants in this study.

At 18 months post-stroke the focus on the upper limb was very established in all participants, as it seemed that many had not been able to resume all of their valued activities. This was particularly so for several of the women who were not able to do the domestic tasks important to them and their identity. Interestingly, Harry was seeing some of the household responsibilities he could resume and now do from a wheelchair, such as taxing the car and house insurance, if he had more function in his hands to write and use a computer keyboard more easily. His desire to relieve his wife of some of those things could be a desire to resume some of his role as a husband and to restore some of his self-esteem. He was still describing himself as a *'useless old bugger sitting in a chair'* although he did seem more reconciled to having help with self-care. Harry's experience shows how important it is for rehabilitation to attend to both the upper and lower limbs. If attempts to restore mobility are not successful and the upper limb has been neglected

then this can consign people to a very limited life in a wheelchair, with little opportunity for resuming valued activities or finding new meaningful ones to replace them.

Colin's experience on the cruise where the waiters routinely offered to cut up diner's food because of the number of disabled people present shows how important finding context is for people. Clearly Colin did not feel conspicuous as he was not alone in his difficulty using cutlery. Indeed, the waiters' actions seeming to be part of their normal duties helped to normalise Colin's upper limb dysfunction and this changed his attitude in general to accepting help. It eliminated any discomfort with his disability that is often present in people with stroke in public settings (Dowswell et al 2000, Murray and Harrison 2004). Similarly, Bob appeared to be able to normalise his upper limb dysfunction by comparing himself to his father who had been a paraplegic, and he appeared to have no issues with self-esteem as a consequence. There was evidence of some people feeling more positive and accepting of their limitations, as with Lily who explained she was '*still the same person but just slower*', but for those who still needed help with self-care then self-esteem remained at a low point. Losing that competency and privacy that the upper limbs bring to the very personal tasks, such as toileting and bathing, seemed to be a very hard issue for participants to adjust to psychologically, and corresponds with findings in Clarke (2003), who found much lower levels of well-being in people who required assistance in self-care. The passing of time had not made it any easier for people to accept and indicates, as in the literature on stroke in general, how vulnerable and worthless people can feel (Pound et al 1998, Secret and Thomas 1999, Burton 2000, Salter et al 2008). It could also mean, as in Eilertsen et al's study (2010), that participants were just beginning that process of rebuilding their lives in this second year after their stroke and adjusting to upper limb dysfunction was proving to be a difficult barrier to overcome.

As in some of the literature on stroke, many participants still held on to hope for more recovery, but the passage of time was moderating this further in some (Wiles et al (2002).

There was less optimism for a full recovery but still a sense of keeping hope alive for some recovery. Their negotiation with themselves appeared to be ongoing, but there was a re-alignment, to some extent, of their expectations with the reality of the function they now had in their arm and hand. As with participants in Doyle et al (2014), there was a restructuring how participants saw their arm in the future, and hope that perhaps there may be some function, if not all. Ellis-Hill et al (2000) refers to this as a negotiated settlement, where there is an acceptance of the person they now are in the present and will be in the future. Dowsell et al (2000) refer to this as stroke survivors arriving at a truce with themselves, as they come to terms with a more realistic picture of the future.

There were two participants who had achieved some very good hand function but had differing perspectives. Lily had diminished sensation but had decided it would not improve further, whereas Gordon was holding out for a full recovery. Doyle et al (2014) found that their participants were unsure of how to help improve sensation as this was a neglected aspect of rehabilitation, and so Lily may not have felt there was anything further she could do to improve it. Gordon however, had been devising his own exercises and activities to improve strength and dexterity throughout the eighteen months of the study and was continuing to do so despite the lack of information and therapy. His attitude was similar to those people with stroke in Mangset et al (2008) who had a strong belief that more exercise would improve their recovery and as in Bays (2001) and Ch'ng et al (2008) it would keep hope alive, which is important in achieving goals and regaining lost activities.

This section has shown that after stroke individuals' will have changing priorities with regard to the recovery of their upper limb, often seeing walking as more important. However as they make the transition from hospital to home they begin to see the importance of their upper limb in managing their self-care and resuming meaningful activities and life roles. Hope for a full recovery is very strong initially but this begins to fade as time passes and recovery slows down. Information and advice about upper limb recovery is scarce and, therefore participants were unprepared for this slowing of

recovery. Unfortunately, as will be seen in the next section, therapy services are short-lived and therefore people lack support as they try to recover.

5.4 Delivery of Therapy for the Upper limb after Stroke

The findings of the study indicate that with regard to the upper limb after stroke there are issues with the priority that the upper limb is given in therapy, and this therefore influences the type of interventions used. Also it seems that the timing and duration of therapy are inadequate. It did seem from participants' experiences that their prioritisation of the lower limb over the upper limb, at two months post-stroke, matched those of the therapists.

Despite there being a degree of satisfaction in participants, at two months post-stroke, about the amount of therapy they received as in-patients, it seemed that interventions had been more focused on the lower limb. Several participants reported that their arm and hand were not touched at all by therapists during their stay in hospital, as mobility was the priority for therapists. It was interesting to see that, although participants admitted to their priority being the lower limb, they still expected some therapy to be directed towards their upper limb. Colin and Gordon's experience of the priority being on walking to facilitate a speedier discharge from hospital is similar to that in Doyle et al (2014) where their participants recalled little attention being paid to their upper limbs. Similarly, studies by Connell et al (2014) and White et al (2009) report physiotherapists being focused on the lower limb and mobility at the expense of the upper limb. This may well be due to pressures on therapists to prioritise mobility in order to reduce length of hospital stay on stroke units, to address financial constraints in the health service. Furthermore, length of stay is an outcome recorded by the Stroke Sentinel National Audit (RCP 2014), where a shorter length of stay on an acute stroke unit is regarded as a positive outcome.

However, if follow-on services providing rehabilitation in the community are inadequate then it is possible that the upper limb may continue to be neglected, and this did seem to be the case for those participants who were living at home at two months post-stroke.

The infrequency of therapy in the community and the limited attention being paid to the upper limb at such an early stage after stroke do not meet current guidelines and standards. Quality marker 10 of the National Stroke Strategy (2007) states that early rehabilitation is effective and can prevent longer term disability, and so should be provided, wherever the patient might be. Similarly, both the National Clinical Guidelines for Stroke 4th edition (ISWP 2012) and the NICE Quality Standard for Stroke (2010) recommend a minimum of 45 minutes per day of each therapy for 5 days per week. It has been recognised for some time that stimulation and movement of the arm after stroke will facilitate brain re-organisation, and potentially maintain the representation of the arm on the motor and sensory cortex (Johansson 2000) and the National Clinical Guidelines for Stroke (ISWP 2012) recommend that treatment for the upper limb should be incorporated into early rehabilitation. It would seem that some participants in this study were missing out on a crucially important window of opportunity for recovery in their upper limb. Neglecting the arm at this stage could potentially reduce the effectiveness of any later therapy to the arm and hand. Although people with stroke might see walking as more important at this early stage, therapists could be educating them about the need for therapy in relation to the longer term outcomes for their arm and hand, in addition to ensuring that therapy is available. Unfortunately, the experience of these participants is not unique. The recent Post-acute Stroke Commissioning Audit (RCP 2015) found that there is a widespread variation nationally in the rehabilitation services provided in the post-stroke period with many areas failing to provide comprehensive care.

It is unfortunate that the duration of therapy after discharge from hospital was poor. At the six months point after stroke, when participants were becoming concerned about their upper limb, therapy was not available to them, and there was dissatisfaction from many with this. The limited therapy that had been available from leaving hospital to the six month interview was disappointing to participants. The six week duration of therapy that some had received after discharge from hospital is consistent with the time-scales

typically allocated to intermediate care for the elderly (Department of Health 2001) and not in line with the guidelines and standards on stroke (ISWP 2012, NICE 2010). They recommend that therapy should continue for as long as people are benefitting from it, rather than stopping at an arbitrary point in time that seems driven by the needs of the service rather than the stroke survivors. The participants' experiences confirm what the SSNAP audit results (RCP 2015) found, that there is insufficient commissioning of post-acute stroke services nationally, and stroke survivors are let down by this. Unfortunately, the literature shows that the experiences of the participants is not unique and has not improved over time. Several studies have reported people with stroke feeling abandoned or disregarded by the healthcare system after returning home from hospital, as services either reduced or ceased altogether (for example: Sabari et al 2000, Martin et al 2002, Cott et al 2007, Cameron et al 2008, Ch'ng et al 2008, Mangset et al 2008).

It would seem that the focus on the lower limb by the therapists at two months post-stroke continued in the six months post-stroke period, for those who had received some therapy. The comment reported from a physiotherapist – *'what would you rather have – your hand or your walking'*, implies that the physiotherapists are having to make decisions about priorities that are determined by the time available to spend with patients, rather than on whether there is potential for more recovery. Meg had stated at six months post-stroke that she wanted to be able to walk to the shops, and while this may have been directing the focus of therapy, it seems that it was at the expense of time spent on her arm and hand. From the findings this was the case for others where, either the upper limb was ignored or there was fleeting attention to it, with no opportunity for it to be followed up, as in the case of Gordon who had followed the prescribed exercises on a written hand-out given to him during the one fleeting visit he had from a physiotherapist. His upper limb had improved but he did not know how to progress further in his recovery. Again the participants' experiences resonated with the literature where the short term nature of therapy after stroke is reported (Sabari et al 2000, Wiles et al 2002, Cott et al 2007, White

et al 2009). The importance of regaining some upper limb function that the participants were now seeing at six months post-stroke was either not recognised, or not prioritised, because of limited resources, and therefore the potential for more recovery was lost. This was also the case for people in studies by Barker and Brauer (2005) and Barker et al (2007) and so it could be argued from the findings in this study that little has changed in stroke care in recent years, again supporting the findings of the SSNAP Post-acute Stroke Commissioning Audit (RCP 2015).

It is interesting that, although therapists' priorities were on improving mobility, they did not appear to recognise that the upper limb has a role in walking and balance, as explained in the first chapter. Many stroke survivors never achieve full recovery in the lower limb and therefore some recovery in the upper limb could supplement this. Even partial recovery of the upper limb with some movement and strength in the arm could restore its use as a counterbalance in walking, for righting reactions to maintain balance, a support to lean through and a stabilising tool in bilateral hand activities, thus releasing the unaffected arm and hand for more complex and dexterous tasks. As the study by Jeka and Lackner (1994) found, even light contact from the hand on a static object can reduce the effect of postural sway. Having some of this function in the arm could improve stroke survivors' access to more challenging environments outdoors in the community, to negotiate through crowded areas, cross roads and negotiate steps and kerbs. If this is lacking then, as could be seen by Eve's experiences, a person with stroke could become house-bound. Eve's fear of falling was very real as she described what might happen to her if she walked outdoors or rode on a bus. She knew her left arm was of no use in assisting her balance, or in helping her to get up from the floor after a fall. The fear of falling is common in people after stroke and, indeed, actual falls are more common, and often then lead stroke survivors to limit their activities (Williams and Murray 2013), so interventions that address upper limb dysfunction could be an important consideration in reducing falls.

The practice of referring people with stroke on to local gyms after discharge from therapy, which was the experience of several of the participants, while improving mobility and general fitness, will not necessarily address upper limb dysfunction. The lack of a physiotherapist at the gym to prescribe appropriate exercises was enough to dissuade participants attending. The gym did not provide the equipment and therapy needed to retrain the specific movements and function in the arm and hand to enable a return to some meaningful activities for participants. Therefore, this referral of patients to gyms, falls below the national stroke guidelines and standards as the type of therapy available was inadequate in terms of the upper limb. The National Clinical Guidelines for Stroke (2012) and the NICE guideline for Long Term Rehabilitation after Stroke (2013) recommend that people with upper limb dysfunction should be given every opportunity to practice activities for the upper limb, within their capacity, and to engage in repetitive task specific training, but from the experiences of the participants the local gym did not provide opportunity for any of this with regard to the upper limb. Tasks should be meaningful to the person and for Bob the meaning in his life was centred on his activity and role as a musician, and therefore his upper limb was of great importance to him. Participants in the study by Burton (2000) were dissatisfied with therapy when it took place in contexts that were not relevant to their everyday lives, and certainly the gym was not a meaningful place for Bob as a musician. It is not just in specific stroke guidelines that the participants' experiences fall short, but also in regard to the wider aims of recent health care reforms. The concept of patient centred care is at the heart of the recent NHS reforms in the Health and Social Care Act (2012) and the NICE guideline on Patient Experiences in Adult NHS Services (2012). The lack of therapy for the upper limb could mean that patients are not being given the opportunity to express their wishes and goals for their arm and hand after stroke, and so they are not being acknowledged let alone addressed.

It is unfortunate that for most participants there was no contact with or access to therapy at 12 months post-stroke to help them with regaining any upper limb recovery or return to

valued activities and roles. There was a common perception of having been abandoned by therapy services. Even where therapy continued to be available, for one participant (Harry) at 12 months it was still addressing the upper limb dysfunction, despite this having become more of a priority to this participant. It was clear from his comment of *'feeling left out in the cold'* that his opinion and desire to be able to feed with less dependence was not listened to, and mobility was seen as the priority by the professionals. As this study has shown, Harry was struggling with his self-esteem because of his level of dependency, and so it is not surprising that his upper limb was important to him. This shows how important it is for therapists to be truly patient centred and not to assume that mobility is important to everyone. Low self-esteem is associated with poorer rehabilitation outcomes and if Harry felt his aims were not being addressed then it is possible his engagement in therapy would be limited. As a participant in Barker and Brauer (2005) observed, there is much one can do from a wheelchair provided one has two functioning upper limbs, and Harry may well have been able to do more meaningful and valued activities that were sedentary if his upper limb had improved.

Unfortunately, as the situation with access to therapy had not changed at 18 months post-stroke, participants had no help with the process of adapting and adjusting, or indeed of continuing with any recovery. The experience of Eve having Botulinum Toxin injections to relieve spasticity in her arm without then having access to physiotherapy, or occupational therapy, shows how disjointed and limited services were, and not in line with current guidelines for best practice. The National Clinical Guidelines for Stroke (ISWP 2012) recommend that Botulinum Toxin should only be administered in the context of a multi-disciplinary team, who can then provide rehabilitation and/or maintenance strategies to capitalise on the effect the toxin will have on the muscles. For Eve, the timing of the injection did not coincide with a review by a physiotherapist, who considered there was little prospect for further improvement as the spasticity was preventing any useful movement in her arm, and so the injection was of little value to Eve.

It is not surprising, as participants reflected back on their experiences of therapy, that there was dissatisfaction. As the hoped for recovery had not materialised by this point there was a feeling that therapists should have concentrated more effort on their upper limb from much earlier after the stroke and for longer. Barker and Brauer (2005) found the same thoughts in their participants who questioned whether more recovery might have occurred in their upper limbs if more had been done in the early stage after stroke. For those participants who had received some therapy for their arm, they looked back and thought it should have been a more hands-on approach to facilitate and guide movement in the early stages. This reflects current debate about approaches to therapy and although research has found little difference in long term outcomes between the two main approaches of a 'hands-on' approach, which uses facilitation, and the 'hands-off' approach, which emphasises strengthening exercises, repetition and practice of tasks, some would argue that where people have very little movement to begin with then facilitation is necessary and beneficial to prime the motor system (Shumway-Cook and Woollacott 2007). Of course a 'hands-on' approach can be resource intensive and in the case of these participants, where therapy services were so limited, then a 'hands-off' approach may have been the only option for the therapists. It is important to note here Jenny's experience of interpreting the disinterest of the therapists in her arm as meaning that they expected spontaneous recovery of her arm and hand to occur, and so she paid little attention to it while waiting for this recovery to come about. It is sad that, when Jenny did realise her mistake, therapy was not available and neither was any information for her or any of the other participants to guide them in their recovery and expectations. Mangset et al (2008) comment, that there needs to be a professional presence available to stroke survivors in order for meaningful and accurate information to be conveyed to them.

The findings in this study bring to light that the recommendation in the National Clinical Guidelines on Stroke, 4th edition, (Intercollegiate Stroke Working Party 2012), and the NICE (2013) Guideline on Stroke Rehabilitation, that therapy should continue until no

further recovery is apparent, is not being implemented in practice with regard to the upper limb after stroke. Therefore, therapy after stroke is not addressing the issues of the altered life and the disrupted self that can occur when two-handedness is lost.

Furthermore, by prioritising mobility only, therapy practice is not patient-centred, as the activities and roles that are important and meaningful to stroke survivors are not being considered or used as goals to direct therapy. For stroke survivors to have any hope of regaining or rebuilding a meaningful and purposeful life, and a positive and coherent sense of self then interventions to address upper limb dysfunction must be an essential part of rehabilitation after stroke.

5.5 Opportunities for Self-management of the Upper Limb

Peoples et al (2011) explain that there can be a difference in people with stroke with regard to their willingness to take an active role in their rehabilitation as some will prefer to be passive and see it as the health professionals' role to make decisions and drive forward their recovery. However, in this study, all of the participants recognised they had an important role to play if they were to achieve some recovery in their upper limb. There appeared to be two things that participants saw as primarily their responsibility: keeping positive and motivated, and complying with advice and prescribed exercises or activities. This is something that is common in some of the stroke literature where Jones et al (2008) and Olofsson et al (2005) both report people having this attitude. Some of the participants in the study seemed to use self-talk in that they were telling themselves how to feel and act, as with Colin, who explained how he kept telling himself to '*stop moaning and get on with it*'. This was a strategy that Cox et al (1998) found in some of their respondents, who used self-talk to motivate themselves to comply with exercise and activity. It perhaps shows that there was a struggle for some participants psychologically, as Barker and Brauer (2005) also identified in their study, where some respondents struggled to maintain a positive attitude and motivation for more recovery. It is challenging to live with the frustration of limitations in activities while at the same time maintaining motivation and

striving for more recovery. The need for acknowledgement and support for this struggle is something Peoples et al (2011) say should be available, and Doyle et al (2014) note how this mental effort to stay positive is draining on fatigue levels after stroke. This is where support from therapists is needed so that opportunities to capitalise on stroke survivors' enthusiasm and willingness for exercise and activity to improve the upper limb is not lost.

The participants showed remarkable resilience in maintaining hope for more recovery and perseverance in finding their own ways of improving their arm and hand, as in Harry and Meg who had purchased specific equipment. It is sad, however, that when therapists were present they appeared to ignore this and not engage with the participant's efforts. It would seem that the participants were trying to exert some influence and control over the direction of their therapy, but their priorities were not being acknowledged. Olofsson et al (2005) reported how important it was to their participants for their priorities to be recognised, but it seems that their experiences are not uncommon. Jones et al (2008) found dissatisfaction in people who had experienced therapists taking full control over the direction and content of therapy and activities, as they thought it should be a joint effort between patient and therapist. It is important that therapists should be truly patient-centred and pay attention to the needs and hopes that individuals with stroke may have for their upper limb. Barker and Brauer (2005) and Doyle et al (2014) both agree that losing use of the arm is of great concern to stroke survivors and, as this study has shown, it can have a devastating effect on all areas of a person's life and their sense of self. For the participants in this study, the purchase of the equipment specifically for their arm could have been a strategy to signal to therapists their concern about their arm and desire for more treatment, as other measures to get their attention were unsuccessful. It is unfortunate that this too seems to have failed.

Gordon epitomised the opinions of many of the participants that exercise and activity was the key to more recovery in the upper limb, and he showed perseverance in the face of little therapy after discharge from hospital by devising his own exercises and activities.

This belief in the effectiveness of exercise in general for stroke is present in the literature. Stroke survivors in Mangset et al (2008) had a strong belief that more exercise would improve their recovery, as did participants in Bays (2001) and Ch'ng et al (2008). Participants in Barker and Bauer (2005) saw exercise as the means to physical recovery in the upper limb. Gordon's experience in devising his own exercises was not unique, as in Doyle et al (2014 p997) where one person expressed they were '*writing the book as they went along*' because there was no guidance. It was clear from participants in the study that they wanted specific guidance about exercises and activities that were tailored to the upper limb, but there was no access to this type therapy. There was frustration in those who had followed initial advice given early after stroke but were then unsure how to move forward. Although the amount of movement in the upper limb varied between participants, with some having only minimal gross movement of the arm, they all felt there were some exercises they could carry out alone. This is different to Barker and Brauer (2005) where some people felt they did not have enough movement to work with. Certainly it could be argued that it is easier to prescribe exercises for the lower limb than the upper limb. A person does not need much movement in the foot, for example, to be able to stand, whereas some grip in the hand is necessary to make exercise for the upper limb more functional (Pomeroy et al 2011). Nevertheless, Feys et al (1998) would argue that some exercise and activity for the arm itself could improve the ability to use it for support or balance, areas in which both Eve and Meg recognised they had deficiencies. Furthermore, recovery in the upper limb can be from proximal to distal, as well as distal to proximal (Hunter et al 2008), and if the arm is weak and restricted in movement when the hand is recovering, then it cannot place and stabilise the hand where it needs to be for activity. Therefore, there could be potential in some people with stroke to participate in an exercise regime, that they could carry out on their own, directed at improving the reaching and placing of the arm in readiness for more recovery in the hand, and also in the role and function of the arm in walking and balance.

It is interesting that participants were realistic about the finite resources in health care and there was a clear message from them that they did not expect therapy to be continuous, but wanted access back into services for regular review and advice on progressing recovery further in the upper limb. These views of the participants are nothing new as they were evident in the literature as far back as 2000 when a stroke survivor in Sabari et al (2000) suggested that therapy should be available every two to three months for guidance and progression in exercises and activity. Olofsson et al (2005) too found that people wanted some means of keeping in contact with health professionals for advice and encouragement. Participants in Barker et al (2007) and White et al (2009) wanted intermittent access to rehabilitation to provide them with the knowledge and skills to drive their own recovery forward and achieve new goals. Gordon, in this study, even described a more cost effective way of providing therapy through group sessions. He saw that stroke survivors in this setting could be a means of support and encouragement to each other, something recognised by the members of a stroke support group in Barker and Brauer (2005). Harry clearly saw that people with stroke were their own best asset and resource for recovery in the long term but, if there was no recognition of this, and no guidance then services were 'wasting assets' and the untapped potential left people more disabled than they might have been.

Self-management programmes for stroke are becoming more prevalent as a means of engaging people with stroke in taking more responsibility for their condition and a more active role in maintaining good health. A recent systematic review by Warner et al (2015) found that there is growing evidence that self-management after stroke can lead to improved functional ability and social participation. Self-management is defined as an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (Barlow et al 2002). It would seem that the participants in this study would have been ideal candidates to participate in a self-management programme that recognised the

importance of the upper limb to people after stroke. Many participants seemed to have the belief that they could be active agents in their care, and had the desire to drive their recovery forward and manage their condition. These are factors identified as being crucial to self-efficacy, which is thought can be developed further through self-management programmes and deemed necessary for people to successfully manage their stroke (Jones 2009). Self-efficacy is a 'person's belief about their capability to produce designated levels of performance that exercise influence and control over their life' (Jones and Riazi 2011 p798).

The common strategies in most self-management programmes are: setting goals that are meaningful to the stroke survivors; follow up by health professionals; individualised approaches with structured information and access to professional support (Warner et al 2015). It is interesting that these strategies align with the desire for support, advice and information that participants in this study were asking for. The participants were realistic in their expectations of available therapy resources, but they could see that these scarce resources could be better utilised by providing service users with intermittent access to support and guidance for exercise and activity programmes. The positive attitude of the participants in this study to be active partners with therapists in managing their recovery may be typical of stroke survivors and, therefore, therapists should be looking for opportunities to support and foster this through self-management programmes. In the longer term, self-management programmes may be a more efficient way of supporting stroke survivors to regain more recovery in their upper limb, to provide a service that is patient led, rather than therapy led, and will enable people with stroke to set their own goals that are meaningful to them. Of course recovery in the upper limb may not occur, or be very limited, in some stroke survivors, and this is where self-management, and access to advice and support, could assist in adaptation and adjustment to upper limb dysfunction through compensatory strategies when recovery is no longer feasible. A self-management programme that included activities and advice for the upper limb would also

help to address the issues identified earlier in this chapter about the altered life and the disrupted sense of self. Empowering stroke survivors to take control through self-management might improve their self-esteem and self-image, and enable them to negotiate a new view of how they could be in the future.

5.6 Chapter Summary

This chapter has discussed the interpretation of the findings that were identified in this study. It has identified some important, new knowledge about the effect that upper limb dysfunction can have on stroke survivors. It has added to what is already known about the effect of stroke in general, and shown that losing two-handedness is a very significant issue for stroke survivors. It can alter and disrupt many areas of life, bringing loss and change, and has the potential to greatly affect the sense of self. This chapter has also identified the transitions, changing priorities and hope for recovery of the upper limb in stroke survivors. It has highlighted the current limitations in therapy for the upper limb, but has identified the desire in people with stroke to be active agents in their recovery and to work with therapy services. Alternative models of service delivery, not necessarily providing continuous therapy, but intermittent access to advice and information about activities and exercise for the upper limb, such as self-management programmes, could be a way forward.

Chapter 6: Conclusions

6.1 Introduction

This chapter will draw final conclusions and consider the implications from this longitudinal, exploratory study of stroke survivors' experiences of upper limb dysfunction. It will also consider the limitations of the thesis and suggest further post-doctoral research that could build on the findings in the thesis.

6.2 Final Conclusions from the Study

The findings from the study have shown that upper limb dysfunction after stroke can permeate through into many areas of a person's life, as seen by two of the main themes that were identified in the data; The Altered Life and the Disrupted Self. The study indicates how vital it is for a person to have two hands that can work together cooperatively in completing tasks that are valued and meaningful to them. In other words, it is vital for a person to be two-handed, rather than one-handed, as many participants in this study found themselves after their stroke. Upper limb dysfunction meant the loss of two-handedness for participants in the study and this had altered how they were able to live their lives. The findings bring to the fore how vital both upper limbs are for people to live a full life after stroke, and it is clear that upper limb dysfunction can significantly change most areas of a person's life bringing dependence in self-care, loss of purpose and meaning, because of inability to participate in tasks and activities that are valued and meaningful to them.

It can also result in changes in important life roles and relationships. The findings add to the existing literature on stroke as a whole. A disrupted or interrupted life is a common phenomenon reported in research, but this study shows that a dysfunctional arm and hand could be a significant factor in this, and just as important as lower limb dysfunction. Being able to walk is important for accessing the home and wider community, but walking alone was not sufficient for the participants in this study to be independent in self-care or

to return to all of their valued activities and life roles. Furthermore, this study has brought to light that the loss of two-handedness can have consequences in self-image. Because of difficulties in activities of feeding and dressing a person can feel they no longer conform to the accepted social norms, and therefore, withdraw from social interaction. Similarly, this can occur when there is embarrassment with the cosmetic appearance of the arm and hand, or alternatively individuals will strive to conceal this. Losing the ability to participate in tasks, activities and roles that are meaningful to the individual, and are part of the fabric of their life, can mean losing pleasure and purpose in life, and instead bring frustration loss and sadness. This again adds to the literature on stroke as a whole, where loss and changes to the self are reported, but what is new knowledge from this study is that two-handedness can be integral to the tasks and activities that make up a person's life and, when the upper limb is affected after stroke, and they can no longer carry them out, the consequence can be loss, low self-esteem and a disrupted self-image and identity. Upper limb dysfunction can break the threads of a predictable life, bringing disruption and discontinuity, as the person they have become in the present is so different to before their stroke and to the person they thought they would be in the future.

The third main theme in the study; Experiences of Recovery, indicates that there are transitions in stroke survivors' priorities and hopes for recovery of the upper limb. Priorities change over time from initially being focused on the lower limb, gradually to the upper limb. The desire to walk is a strong drive in stroke survivors; however, in the transition from hospital to returning home, where they are faced with trying to return to their pre-stroke life or to rebuild a new life then the upper limb becomes as much of a priority as improving walking, if not more so. Hope for recovery in the upper limb is a strong feature in people after stroke, even in the face of little available therapy, and this hope can persist even when recovery is slowing down or is minimal. Stroke survivors gradually re-negotiate with themselves their expectations for recovery. Adapting and adjusting to upper limb dysfunction after stroke is easier for a person if they have a valued

and meaningful activity that they wish to return to. This can be a driving factor in adapting but may not be at the expense of maintaining hope for some recovery. Adaptation and adjustment is more challenging for those who remain dependent in self-care because of their upper limb dysfunction.

There is a real desire and willingness in people after stroke to be active partners with therapists to promote more recovery in the upper limb. Unfortunately, this is not matched by therapy services. Often the duration of therapy services is short-lived and not available at the times when stroke survivors are becoming more concerned with their upper limb. The priorities of therapists are on lower limb recovery and mobility, and this then influences the type of interventions in therapy, both in the acute in-patient phase and in the community. There is little information and advice available to stroke survivors about the expectations and predictions for recovery in the upper limb, and this can lead to individuals filling that void with their own assumptions and therefore, having inaccurate information. The consequences of upper limb dysfunction for people with stroke seem to be little understood by therapists, and therefore the arm and hand often ignored. This study has shown that people with stroke can recognise that their upper limb dysfunction has an effect on their balance and walking, and this can limit their ability to participate in meaningful activities and life roles. However, as there is little therapy for the upper limb then this aspect of mobility may have little opportunity for improvement.

6.3 Implications from the Study

The purpose of this study was to explore peoples' experiences and perceptions of upper limb dysfunction after stroke, and the findings have show that there is much to learn from listening to, and paying attention to people's experiences. It is hoped that this will bring to the attention of therapists how vital it is to attend to the upper limb in rehabilitation. It can be, and should be, as important as the lower limb. Recovery of mobility is important for people to access their homes and community but it should not be the end point of rehabilitation. Indeed this study has shown that the upper limb plays an important role in

balance and walking and therefore any recovery in it will enhance mobility. Furthermore, achieving some upper limb recovery, or adapting successfully to it, could be a significant factor in enabling a person to regain valued and meaningful activities and life roles, or establish new ones, thus improving self-esteem, self-image and identity. This in turn can enable stroke survivors to envision a future meaningful life, all of which adds to a coherent sense of self, and should be important issues to consider in rehabilitation after stroke. This study and the experiences of the participants have a message for therapy services. There is a need for services in the community to remain available to people for longer so they can be supported with advice and information as they strive for more recovery in their arm and hand, or to adapt to their impairments if recovery becomes unattainable in the longer term. Participants were clear that this does not mean services should be continuous, but rather structured in such a way that regular review and access to services should be available to them. Therapists should recognise that stroke survivors want to be active agents in their recovery of the upper limb, and want advice and information on exercise and activities they can implement so that they can self-manage their upper limb. It is recognised that developing such services could be challenging financially, but ignoring the upper limb could leave people more dependent on care services, which then uses up vital resources, and individuals become less productive in their families and communities. Viable models of services that capitalise on people's desire to take responsibility for their recovery, such as self-management programmes, should be explored as a potential cost-effective way of keeping access to services open to people with stroke and upper limb dysfunction.

6.4 Limitations of the Study

As with any research there are some limitations to this study, specifically regarding the sample and the data analysis. Firstly, the participants were all recruited from one stroke rehabilitation unit and so the findings, in particular regarding therapy and services, are unique to that location. Therefore, the transferability to other similar settings could be in

doubt; however the SSNAP audit results (2015) found that there are insufficient community services for stroke nationally, and so the findings could have some relevance to other locations in England. It was noted in the methodology chapter that there was an imbalance in the number of males and females in the study, which was due to external factors at the time of recruitment, and the availability of participants that met the inclusion criteria. Also the nature of the research means that people with dysphasia or cognitive problems are not represented in the findings. This also resulted in more people with left sided hemiplegia, and consequently less people with their dominant hand affected, because dysphasia is more common in people with right-sided hemiplegia, due to the location of the areas associated with speech in the cerebral cortex. All of these factors could mean that the findings are less transferable to the wider stroke population (Hansen 2006). However, there is sufficient description of the participants in this study for others to decide whether the findings are transferable to their patients and situations. There are limitations in the data analysis processes that could call into question the credibility and dependability of the research findings. Not all of the transcripts were analysed by a second researcher and so the dependability of the findings could be questioned (Tong et al 2007). The second researcher analysed only a sample of the transcripts from each of the four data collection points and so relevant data, or data that contradicts the themes, could have been omitted. However discussions around decisions made at each stage of analysis were discussed with the supervisory team. Participant checking was limited to a summary of the overall findings being reviewed by the participants. A full checking of the transcripts of all four of their interviews was considered to be too demanding for the participants. This could mean that the findings are not a true reflection of the interview conversations (Finlay 2011).

The credibility and dependability of the findings could have been enhanced through triangulation and by using focus groups as another method of data collection, but this was

not considered practical or feasible because of the long recruitment period and, therefore, participants being at different stages in their recovery.

6.5 Considerations for Further Research

There are several ways in which the research in this study could be built upon. A limitation of the study, as mentioned in the previous section, is that only one centre was used for recruitment. A multi-centre study to capture the experiences and perceptions of a wider population of people with stroke could be developed as this could mean the findings would be more transferable to the wider population of stroke. In addition, participants could be followed up over a longer period than the 18 months of this study to explore the longer term effects of upper limb dysfunction. As Wolfe et al (2008) and Fraas (2011) suggest; the experiences and views of people with stroke are vital in guiding the development and structure of holistic services that address the whole person and not just the impairment.

Another way forward could be to develop a study that could explore the experiences of therapists working in stroke rehabilitation and their perspectives on upper limb recovery after stroke. The issues that were raised regarding therapy and therapy services in this study by the service users do warrant further investigation into the views of therapists and service providers, and the factors that are driving the current provision post-stroke. The participants in this study made suggestions about improving services and this could be built upon. There could be research that explores and evaluates longer term services for the upper limb that offer opportunities for regular review of recovery, and re-entry into services when deemed necessary. Self-management programmes that include exercises and activities for the upper limb, and group interventions could be developed and evaluated.

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Appendix 1 Focus Group Information and Consent Forms

RESEARCH CONSENT FORM

- ◆ Name of Researchers: Judy Purton, Nikki Perry, Gemma Thompson

- ◆ Title of study: Consulting stroke survivors with upper limb dysfunction to identify topics of relevance and importance to them for the development of a narrative interview schedule for future research

Please read and complete this form carefully. If you are willing to participate in this study, ring the appropriate responses and sign and date the declaration at the end. If you do not understand anything and would like more information, please ask.

- ◆ I have had the research satisfactorily explained to me in verbal and written form by the researcher.

YES / NO

- ◆ I understand that the research will involve participating in a focus group discussion or an interview, lasting approximately 45 minutes, conducted by two students and a lecturer from the Faculty of Health and Life Sciences, York St John University. The focus group and interview will be recorded and later transcribed.

YES / NO

- ◆ I understand that I may withdraw from this study at any time without having to give an explanation. This will not affect my future attendance at the drop-in group in any way.

YES/ NO

- ◆ I understand that all information about me will be treated in strict confidence and that I will not be named in any written work arising from this study.

YES / NO

- I understand that any audiotape material of me will be used solely for research purposes and will be held for a minimum of 5 years after completion of the project and following this will be destroyed.

YES / NO

- ◆ I understand that you will be discussing the progress of your research with others in the Faculty of Health and Life Sciences at York St John University

YES / NO

I freely give my consent to participate in this research study and have been given a copy of this form for my own information.

Signature:

Date:

Information for Participants

The aim of this project is to consult with the members of the drop-in group about the development of a research study into stroke survivors' experiences and perceptions of upper limb dysfunction during the first 18 months after stroke. The researchers want to gain the opinions of the members about topics related to the arm and hand that should be included in interviews with stroke survivors, and also, to identify the key times during recovery after a stroke when interviews should take place. The research is being conducted by a senior lecturer and two third year students from the Faculty of Health and Life Sciences, York St John University.

A focus group or interview will be held with group members to discuss the issues around problems with the arm and hand after stroke. It will last approximately 45 minutes, and will be tape recorded. The information gathered will be used by the senior lecturer and the students to develop an interview schedule for use in the research study and will also be written up as a dissertation by the students.

Any group member who agrees to participate in the study may withdraw at any time without having to give an explanation and this will not affect their future attendance at the drop-in group in any way. All information about group members will be treated in strict confidence and no participants will be named in any written work arising from this study. Any audiotape material will be used solely for research purposes and will be held for a minimum of 5 years after completion of the project and following this will be destroyed.

Appendix 2: Quotations from Focus Group Data

Category	Theme	Quotation
Self-care	Mobility	<p><i>'When I was in hospital the physios started getting us out of bed the banisters down the side of the wall' (referring to horizontal grab rails along the wall) ... they took me for walk one day down end of corridor and coming back the banister was on the left hand side (affected side) and I threw a wobbly but that hand grabbed it just like that.'</i></p> <p><i>'One thing I did notice when I started walking, erm the tendency ... was the arm that had been affected you hold out....away from your body Whether it was a question of balance or what But erm you didn't swing it like you would normally or hold it down.'</i></p>
	Toileting	<i>'It's the sense of e-masculineness,that you're in bed, you want to go to the toiletyou have to get somebody to take you.....'</i>
	Feeding	<p><i>'Well initially your hand and arm so you can eat.... In fact when you first started eating on your own er in the hospital erm you were pushing food all over your plate and off your plate, and they gave me a little like a er, not a pusher, something you could push against.'</i>(plate guard)</p> <p><i>' What I find is I get hold of a fork correctly... but it tends to twist it round as I'm going to eat and instead of stabbing it I find my fork is upside down and I have to concentrate hard to make sure I get it right.'</i></p>
Valued Activities	Driving	<i>'Biggest thing I've found is we can't manage to drive anymore ... I was never a car driver I was a motorcyclist...'</i>
	Leisure	<i>'Can't play cricket. I used to swim, they recommend it. I do swim'</i>
Therapy	Amount	<p><i>(therapy) That starts from the minute you wake up after your stroke because ... you're paralysed and you want to get going.'</i></p> <p><i>'There is a lot of pressure by the erm physiotherapist and in particular the occupational therapist to use your hands to get going ...'</i></p> <p><i>'You are awake from 7 o'clock 6 o'clock in the morning you've got up to 7 o'clock 8 o'clock at night and you have half an hour it's not enough.'</i></p> <p><i>' somebody came out to the house and assessed me. She said "oh we can't do any more for you" and at that time I walked with a crutch ... I was bent double wan't I'</i></p> <p><i>' to do exercises in the home first of all and then gradually build up outside walking... 'mainly for mobility rather than to do with your hand and fingers.'</i></p>
	Information	<p><i>'I went out and bought an exercise cycle to get this left hip going but I found I couldn't do it very well so after a while I gave it up.....I think it'll end up donated to charity.'</i></p> <p><i>'Well what can they tell us? You know I mean the hospital have made it quite clear there is nothing else they can do. They've gone as far as they can it's up to, you know, individuals with help obviously.'</i></p>

Recovery	Motivation	<p><i>'They tell you to do it individually but carrying them on at home and you do for a while but then you get bored with them all whatever.'</i></p> <p><i>'Those exercises you think oh I won't do them today. I'll sit down and do them tomorrow or I'll sit down and read a book or something'</i></p> <p><i>'but if you are going to a class where other people go you've got the discipline to do it and that's what you need really otherwise you don't do it.'</i></p> <p><i>'If I don't exercise one day I start from scratch the next, you go back a bit.'</i></p> <p><i>'You know you've got to use it or lose it.'</i></p>
	Attitude	<p><i>'I think you've got to get over depression before you can get on with your life. I find erm I got bit depressed afterwards and they gave me Some sort of tablets for it but didn't work..... so I got rid of them and er worked on it myself. But one thing that arrived was the er the first grandchild so that was good for me'</i></p> <p><i>'It's the things that work for you and you don't think of working you just get up and do things. But I was a bit slow at first – oh god I've gotta go into town, gotta do this, but it's not that anymore.'</i></p> <p><i>'It's a challenge but you overcome the challenges and then it's a benefit.'</i></p> <p><i>'Its coming up 3 years in April and you sort of never thought of it much after a couple of years you know.....I was sat in the chair at home ... and I was doing something and I suddenly went over like that and I did it with this hand (gestures with affected hand) and I didn't know I'd done it. I look at it as a positive as a bit of a good omen actually..... but I think I've not finished improving, that's what I like to think anyway.'</i></p>
	Priority of arm or leg	<p><i>'My leg, my leg Well I couldn't get around if I couldn't balance on me leg. This (raises his left hand) I could concentrate on later. It wasn't too bad at least I could pick things up.'</i></p> <p><i>'With me it became more important when you couldn't eat.'</i></p> <p><i>'Well initially your hand and arm so you can eat and do your bodily functions and things. That's the initial thing but secondly it's get up on your feet and moving and mobility so you can get a little more independence that's the critical thing.'</i></p> <p><i>'Mobility is probably the most important thing to all of us.'</i></p> <p><i>'Because if I can do it (walking) here they'll let me go home.'</i></p>

Appendix 3: Notes from a Consultation with a Hand Therapy Expert

This colleague is a senior lecturer in Occupational Therapy in the Faculty of Health and Life Sciences, York St John University. She is a member of the College of Occupational Therapists Specialist Section in Rheumatology and on the Education Committee of the British Association of Hand Therapy.

The following aspects were recognised as being significant in people with pathologies or injuries that affect the hand.

Role of the hand in communication

We use the hand to supplement our verbal communication to express ourselves to other people - often indicating the feeling and emotion behind the words used. In people with dysphasia then an inability to use the hand is a double whammy – they have lost both verbal and non-verbal communication.

The hand is used in meeting and greeting people – handshake, hug. A firm handshake may be essential in a work role. If you cannot put out a hand to greet someone then the other person might withdraw, or the person with the hand problem might withdraw from social occasions where a handshake is the norm.

Inability to hug properly – person can feel emotional distance from loved ones, cannot express feelings.

Adorning the Hand

Wearing rings, watches, bracelets, nail varnish etc is part of cultural norm for some people to bring attention to the hand. Rings can be symbols of status – married, engaged etc. It is part of their expression of their personality and identity. Being unable to do this or not wanting to do it because of deformity etc can affect body image, sense of identity. Some people might want to hide their hand so will wear longer sleeves to cover it.

Physical ability to maintain self-image

Limited hand function – being unable to fasten buttons, zips etc means often therapists suggest alternative types of clothing, but clothes are symbols and expressions of self-image. Similarly being unable to style hair may lead to a change to a more manageable hairstyle, but may not truly represent who a person is. Same thing can apply to wearing jewellery, applying make-up, putting in contact lenses etc.

Relationships

Sexual relationships – partners may be frightened to touch the person's hand. Person might feel clumsy because of lack of hand function, lack of sensation. The importance of physical touch in close relationships

Holding hands, linking arms can be an outward symbol to others of the importance and closeness of a relationship.

Observing a partner fulfilling tasks and roles the person previously carried out can be a daily reminder of their lack of ability and function, and can change the balance of relationships.

Inability to handle money while making purchases in shops etc – dependent on partner.

Parent/child, grandparent/child relationship – physically handling a baby, toddler, child.

Objectifying the hand

Some people will refer to their hand as 'the hand' not 'my hand'.

They will 'hand over' their hand to the therapist as if it is separate from the rest of their body.

Patients with Complex Regional Hand syndrome often perceive their hand as larger than it actually is.

Challenges for therapists

We emphasis personal care, but leisure pursuits, work roles, status and providing for the family are more important to some people.

Appendix 4: Initial Interview Guide

Can you tell me about the ways in which the difficulties in your arm and hand, since the stroke, have affected you?

(A general question to ensure I begin with their perspective not mine)

Physical Appearance

Can you tell me about how you feel about the appearance of your arm and hand since the stroke?

In what ways has it affected how you feel about yourself when meeting people?

(prompts: family, friends, acquaintances, colleagues, strangers)

Can you tell me about any changes you have had to make, or think you will have to make, in the type of clothing or jewellery you can now manage to put on (fastenings etc), or the way you style your hair or use make-up etc?'

'How has this affected you and what does this mean for you?'

Personal care

Can you tell me about any help you need with personal care because of the problem with your arm and hand? (prompts: washing, dressing, toileting, feeding)

How does this make you feel about yourself when having help in these personal areas?'

Communication

Can you tell me about any effect the restriction in your arm and hand has had on you when meeting and communicating with people around you?

(prompts: new people, familiar people)

Activities

Can you tell me about any activities that are important to you that you are now restricted in doing, or you are worried that you may not be able to do when you get home, because of the difficulties in your arm and hand?

(prompts: home, work, leisure, hobbies, community)

What does this mean for you and how will it affect your life? How are you feeling about it?

Roles

Can you tell me about any changes this has brought or might bring to the roles that you have in different areas of your life?

(prompts: spouse or partner, parent, grandparent, sibling, friend, carer, employment, community, leisure).

How would you describe yourself in that/those roles previously and what will the changes mean for you and how does it make you feel?

Control

Can you tell me about how these limitations and changes we have talked about have affected your ability to feel in control of your life since your stroke?

(prompts: making decisions, finance, living arrangements, leisure, work)

Recovery

Can you tell me about any areas of your recovery from stroke that are more of a priority for you than your arm and hand at the moment?

Is there anything that gives you hope for further recovery in your arm and hand?

What are your goals and hopes in terms of recovery in your arm and hand? How long do you think recovery might take?

Therapy

How do you feel about the attention given to your arm and hand by the therapists you have seen or are still seeing?

What have the therapists told you about the recovery in your arm and hand?

When do you think is the best time to begin therapy for the arm and hand and what activities for the arm and hand should therapists focus on?

Advice & Information

What advice or information have you been given about your arm and hand that has been helpful to you?

What advice or information should be available and when is the best time to provide this?

Appendix 5: Information and Consent Forms



K E E L E
U N I V E R S I T Y

Participant Information Sheet

Study Title: A longitudinal exploration of stroke survivors' experiences and perceptions of the impact of upper limb dysfunction

Aims of the Research

The aims of this research are to explore: stroke survivors' experiences of problems with movement and activity in their arm and hand after stroke; whether stroke survivors' perceptions of the effect that their arm and hand problems have on their everyday lives change over time; and what long term goals are important to stroke survivors with regard to their arm and hand.

Invitation

You are being invited to consider taking part in the research study entitled "A longitudinal exploration of stroke survivors' experiences and perceptions of the impact of upper limb dysfunction". This project is being undertaken by Judy Purton (Chief investigator), Dr Sue Hunter and Professor Julius Sim as part of a research degree at Keele University, Staffordshire.

Before you decide whether or not you wish to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information carefully and discuss it with friends and relatives if you wish. If there is anything that is unclear or if you would like more information please contact Judy Purton (chief investigator) whose contact details are on page 3.

Thank you for taking the time to read this information sheet.

Why have I been chosen?

You have been chosen because you have recently had a stroke and now have problems with movement and function of your arm and hand. Altogether, there will be approximately 16 stroke survivors taking part in this study.

Do I have to take part?

You are free to decide whether you wish to take part or not. If you do decide to take part you will be asked to sign two consent forms, one is for you to keep and the other is for our records. You are free to withdraw from this study at any time and without giving reasons. If you choose not to take part, or if you take part but choose to withdraw from the study at a later date, your ongoing and future health care or rehabilitation will not be affected in any way.

What will happen if I take part?

A researcher will conduct a series of four interviews with you over an 18 month period of time. Before each interview the researcher will make an appointment with you at a time convenient to you for the interview to take place. Each interview will last approximately one hour. Your GP and hospital consultant will be informed of your participation in the study. However, no information you provide during the course of the interviews will be discussed with them.

If I take part, what do I have to do?

A member of the research team will come to see you up to four times over the next 18 months, either in hospital or at home, and ask you to talk about what it is like to have difficulties with your arm and hand following your stroke.

What are the benefits (if any) of taking part?

Sharing your experiences (anonymously) with the wider stroke community could enable a greater understanding of what it is like to live with problems of movement in the arm and hand after stroke. This could inform service providers about the needs of patients and therefore improve services.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher who will do her best to answer your questions. You should contact Judy Purton on 01904 876345

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Nicola Leighton who is the University's contact for complaints regarding research at the following address:-

Nicola Leighton
Research Governance Officer
Research & Enterprise Services
Dorothy Hodgkin Building
Keele University
ST5 5BG

How will information about me be used?

The interview will be recorded using a digital voice recorder and the content of the recording will then be transcribed word for word. The researcher will read the transcription in detail and depth many times to identify the important issues in order to address the aims of the research. The findings will be included in a PhD thesis and may also be used subsequently for publication in professional journals. Some direct quotations from your actual words during the interview may be used in the thesis and any publications. The information may be retained for future studies but further ethical approval would be sought for this. In order to maintain your privacy and the confidentiality of any information you give, your name will not be included in any written or published material. No information that you provide will be discussed with anyone other than the research team.

If for any reason during the study you are unable to consent and take part in one of the later interviews then data already obtained in previous interviews with you may still be used in the study.

Who will have access to information about me?

Only the research team will have access to the recordings and transcriptions.

- The recordings and transcriptions will be stored at the principal researcher's place of work, York St John University, and will be kept in a locked cupboard in a locked room. They will also be stored digitally on a password protected computer.
- Your real name will not be used on any transcription to maintain anonymity
- After the study has ended data from the research will be stored electronically, in accordance with the policies and procedures of the Research Institute for Life Course Studies, Keele University, for up to 10 years and then securely disposed of. All data will be anonymous and stored on password protected computers.

Who is funding and organising the research?

The research is organised by the Research Institute for Life Course Studies at Keele University and is being undertaken as part of a PhD programme of study.

Contact for further information

Judy Purton
Head of Programme BHSc Physiotherapy
Faculty of Health and Life Sciences
York St John University
Lord Mayors Walk
YO31 7EX

01904 876345
j.purton@yorksja.ac.uk

Patient pseudonym for this study:

CONSENT FORM

Title of Project: A longitudinal exploration of stroke survivors' experiences and perceptions of the impact of upper limb dysfunction.

Name of Chief Investigator: Judy Purton

Please initial the box

1. I confirm that I have read and understand the information sheet dated(version 2) for the above study. I have had the opportunity to consider the information, ask questions and I 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, without my medical or legal rights being affected.
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Keele University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I agree to my GP being informed of my participation in the study.
5. I agree to take part in the above study.

Name of person taking part

Date

Signature

Name of Researcher

Date

Signature

CONSENT FORM

(for use of quotes)

Title of Project: A longitudinal exploration of stroke survivors' experiences and perceptions of the impact of upper limb dysfunction.

Name of Chief Investigator: Judy Purton

Please initial the box

- 1 I am happy for any quotes to be used
- 2 I don't want any quotes to be used
- 3 I want to see any proposed quotes before making a decision

Name of Participant:

Signature:

Date:

Appendix 6: Letter to Participant's GP



K E E L E
U N I V E R S I T Y

(insert recipient's name)
(insert date)

Dear Dr

Re: *(insert participants name)*

I am a PhD student in the Research Institute for Life Course Studies at Keele University and also Head of Programme for the BHSc Physiotherapy course at York St John University, and I am writing to inform you that the person named above has given their consent to participate in a research study I am undertaking. The aim of the research is to explore stroke survivors' experiences of upper limb dysfunction during the first 18 months after stroke. There is little current research on the experiences of stroke survivors specifically with regard to upper limb dysfunction. Stroke can affect the social roles and valued activities of survivors but it is not clear how much impairments of the arm and hand contribute to these.

The participant will be taking part in a series of four in-depth, semi-structured interviews at two months, six months, 12 months and 18 months after stroke. This will enable them to express the meaning and significance they ascribe to their experiences and perceptions of a dysfunctional arm and hand over time. Each interview will last approximately one hour and be audio-recorded for later transcription. In view of the potential for deteriorating health or mortality within stroke survivors in general, I would like to ask your permission for me to contact you to ensure that the patient's medical condition has not deteriorated in the time between interviews and so prevent me from making any untimely or insensitive contact with the participant or their family members when arranging the interviews.

The study has been approved by Keele University Independent Peer Review Committee and is being submitted for NHS ethical and R&D approval. The data collection should commence in October 2010. Should you have any further questions regarding this research please do not hesitate to contact me or my academic supervisor at Keele University: Dr Sue Hunter (s.m.hunter@shar.keele.ac.uk).

Yours faithfully

Judy Purton MSc, MCSP
Head of Programme, BHSc Physiotherapy
Faculty of Health and Life Sciences
York St John University, Lord Mayors Walk
York, YO31 &EX
j.purton@yorksja.ac.uk
01904 876345

Appendix 7: Tables of Themes and Charts

Colin (2): Table of Themes

<i>Theme</i>	<i>Quote/key words</i>	<i>Page/line number.</i>
Altered life	Everything stops, everything you used to do stops... because you've got no grip	1/16-26
	It just stops your life ... you lose your balance ... you can't put your handout	2/39-66
	Everything stops and you've got to rely on your family	9/234
	Doing normal things... gardening, sport	7/173
	We used to go out everyday... can't drive, go to garden centres, or run around, just go off for enjoyment	8/228 – 9/231
	Changes everything, whole way of life, it's difficult, very difficult	32/963
	Don't get your freedom back when you come home	26/766
	Very frustrated, 100% frustration , I can't just do stuff	6/163, 11/306
	Everything stops and you've got to rely on family – others have to drive, I'm putting on people – I used to do it all myself	9/234-251
	Imagine, lost arm, day spent with arm strapped and can't use it (said with aggression)	6/16733/999
Self-care	No grip – so someone has to wash you	1/24
	Can't dress yourself	4/95,
	You can't fasten buttons, can't put your socks on, help from wife	4/105 - 117
	Can wash and shave but with great difficulty	4/126-128
	Wife helps me but I won't let other people help me	8/204-208
	You can't pick up a fork	26/756
Meaningful activities	Domestic tasks, we used to help each other out (wife)	1/22, 6/150-155
	Gardening	1/20, 7/178
	Bowls – national competitions –balance not good enough due to arm	7/182, 19/557-576
	DIY, decorating	17/509-516, 29/853-861
	You can't drive	1/18, 6/159
	We used to go out everyday (in car), shopping, garden centres, just for enjoyment, can't do it now, have to rely on family	8/228-9/234
	If I could drive it wouldn't be half as bad	11/315
Life Role	Driver- wife doesn't drive, now can't go out for enjoyment	8/228
	Other people have to come and drive and take my wife to shops – loss of role	9/241
	Head of family- I would just say what we're going to do – could make decision and just set off – that's gone, now have to wait for family	10/277-286
	If I want to go to coast now have to wait until they want to go – they just tell me	12/329
	Helper is now the helped	29/849

	Grandfather, role reversal	27/789-802
Self esteem	See I won't let other people help me – only the wife	8/206
	You feel useless	8/216
	You have to ask people – get me this , get me that You feel inadequate	8/218, 10/268 15/522
	Before the stroke I wouldn't have been begging	9/255-266
Recovery	Will take a long time, slow (arm), too long, 2-3 year or 18 months	3/78, 13/363-386
	If I could grip ...	6/145, 13/389
	They tell me arm will come back	12/357
	Usage,exercise will help – physio informed me	14/400-405
	My part to do exercises, do as I'm told, take advice on board	16/455-458, 17/484
	Small improvements give hope	17/488-501
Therapy	Private physio (daughter-in-law) does hands on	14/407, 21/608- 620, 24/708724
	Physios come every week (NHS) but don't do anything, just talk to me, no hands on, advice, exercises	14/414-429, 23/672-693, 25/727
	Hospital physios quite good, but no attention to arm, did a lot on my hands, they just get you out of there	21/625-652

Alan (6): Table of Themes

Theme	Quote/Key Words	Page/line no.
Self-care	I have them in once a day, get me dressed, washed	1/20
	Have a good laugh with them – trying to make light of situation	2/55
	Can't have a bath on me own... or a shower	3/66-68
	I used to have to rely on ... to wipe me backside	3/73
	Unable to wear 'decent' 'normal' trousers – can't manage fastenings toileting, looser jogging bottoms	8/217-222
	Extra large cardigans, because of arm movement and getting arm in	10/269
	Putting on a coat – thumb, fingers get stuck	35/954
Life Roles	He was the driver in the relationship	5/129-6/165
	Unable to drive so limiting his social activities	9/227-210/50
	Unable to drive so cutting him off from friends and family	14/376
	Grandfather	15/396, 38/1027-1037
	Partner now a carer – changed relationship	21/545- 566
	Fear of abandonment by partner – 'what she doing with a bloke like that?'	25/652, 20/534
	Can't take partner out	25/673
	Its changed the way we are	38/1032
	Used to be no 1 in relationship but now no 2	21/565
Meaningful Activities	Cooking – using OT work station	3/79-4/97
	Can't drive, has to use bus, vibration makes him pee	6/144
	Decorating, DIY	7/168-179
	Bingo caller – linked to driving problems	22/588- 23/607, 24/627
	Walking dogs	25/675
	Cutting grass, gardening	24/629
	Shopping	30/814
Identity	I can't stand up to urinate – male identity	12/310
	Can't urinate as a man	12/310-314
	Driving, masculine role, adapted car threatens masculine identity	5/119-6/163, 13/351- 14/374, 22/591- 23/622, 27/710-720
	Lazy man's way of driving	13/353,14/374
Self-esteem Downgraded	I feel hopeless	7/184-188
	Can't put my hand in pocket like everyone else	11/292-297
	I feel scruffy sometimes – linked to clothes	10/254-271
	Feel dirty, not dressed properly	9/222
	I feel scruffy, used to being dressed smart - I'd put a tie on	10/254
	Wearing sock on hand in cold weather – can't get gloves on - embarrassed	10/272-288

	Embarrassed – sock on hand instead of glove, can't put hand in pocket	11/295
	Embarrassed – sitting to pee	12/303-310
	Lazy (referring to driving with adaptations)	13/353
	Complex - inferior	20/534-541
	Guilty – preventing partner from doing things	21/560
	I was number 1 now I'm number 2	21/565
	Was a first class person now I'm second class, it downgrades you	25/660- 668
	I feel lazy	31/822
Altered Life	Fed up at not being as before, frustration	24/634-648
	Everything takes longer to do (inc personal care)	35/942-953
	Unable to drive – it's murder, lost independence	5/135-6/163
	Can't drive, has to use bus, vibration makes him want to pee	6/144
	Not contributing to chores	25/668
	Accessing house – locks had to be changed	28/754
	Not in control now	31/828-834
	Less choice/ spontaneity about when to do things	36/978-999
	I feel lost	21/551-555, 37/999-1003
Recovery	Work station, OT	4/94, 16/408
	OT assessment for driving	4/100,13/343
Information	Hope for arm recovery dashed by info from other stroke survivor	12/326- 338
	Just has to wait for arm to improve	31/835-843
	Dr's opinion about recovery is important	32/865-888
	Dr gave encouragement about leg only	33/88
Therapy	Lack of physiotherapy/more physio	16/412-441, 17/455-472, 22/577-582, 26/693-700, 27/721-735
Priorities	Leg more a priority than arm	19/497,20/522, 27/707-709

Eve (12): Table of Themes

Theme	Quote/key words	Page/line number
Self-care	Help with dressing, shower, meals - homecare	2/61
	Toileting – cleaning after bowels opened	6/170
	Neighbour selects clothes – cannot get upstairs to see what she has got	25/771
	Little choice in what to wear, cannot get upstairs to wardrobe to choose clothes	26/789
	Hair – carers put it in ponytail for her	10/294
	Clothes, manipulating buttons, resignation about lack of choice, comfort more important than appearance	10/292-325
Altered Life	Dependent on others , can't choose what to do because no-one here to help me	22/680
	Life is non-existent – sitting in chair watching TV all day	22/672, 25/761
	Not in control of standard of housework - annoyed	10/285
	No control or choice – have to wait for carers or husband to come and do things for me or with me	22/684
	Fear of falling on stairs so lives downstairs, sleeps in chair	13/382-397
	Wouldn't wish this on my worst enemy – life has changed	27/850
Social isolation	Don't go out anywhere	2/40-45
	Friends don't visit, she can't get out to town centre, resigned herself to watching TV all time	15/444-460, 22/672, 25/761
Meaningful Activities	Not returned to swimming, cannot swim with one arm, could not get out of pool with one arm	13/411-440
	Not returned to dancing	13/411-440
Life Roles	Grandmother – changed role, affected activities they can do together (some tearful distress expressed)	6/188-231
	Can't hold granddaughters hand - spasticity	6/180-
	Can't babysit granddaughter – can't get upstairs	15/466
	New grandchild expected, won't be able to hold properly, look after	15/488
	Not 'trusted' to look after granddaughter now because of disability	23/716
	Terrified she will hurt granddaughter – spasticity in hand, fear of hurting new grandchild in same way	7/195, 16/478
	Housework – husband does it but she no longer has control over standard	8/245-286
	More angry than she used to be, gets angry quickly with herself and her husband, husband doesn't understand why she can't do more	26/813-847
Balance	Stick in good hand prevents doing tasks	5/156
	Aware that arm cannot help with balance - bus, functional tasks, stairs	5/150-162
	Involuntary spasm affects balance during functional tasks	26/827, 17/516
	If arm improved then she would go up stairs, go outdoors, go on bus	13/395-405
Self esteem	Embarrassed having to help with cleaning herself after using toilet	6/170

	useless	6/178, 22/690, 28/862
	Useless – now granddaughter is helping her	7/227
	Hopeless and helpless	23/694
	Embarrassed to be seen in nightie in middle of day if anybody called	10/308
Recovery	Arm is worse, increased spasticity, no control over it	1/21-32, 6/184, 24/732
Priorities	Arm recovery is key to her being more independent, personal care, granddaughter, getting outdoors	5/129-143, 23/697
	Arm is her priority for recovery	21/645, 661
	Would like to hope arm will have recovered by next interview, but not hopeful	19/597
	Optimism about arm recovery from previous stroke ?TIA	17/537
	Expectations on coming home – worse than she thought, really slow recovery – thought she would be doing more by now	17/520-530
	Should be specialist services available to help with arm recovery	30/923
Information	Fear that arm won't improve	3/79
	Needs advice re how to progress exercises	19/587
	No information from hospital consultant, no opportunity to ask questions 'oh everything is fine' says doctor, no discussion re arm, abandoned by services – not bothered about you	18/553-571, 30/913
	Should have opportunity to get more information from consultant, advice for arm	19/579-591
	No point of contact to discuss her arm	24/748
	I'm putting effort in – nobody wants to sit in a chair for rest of their life	
Therapy	Therapy has stopped – 3 months ago, left in limbo	3/86-101, 11/339
	Physio has stopped so arm will not improve	4/122
	Doing exercises given by physio earlier but no improvement, does not know what to do now	12/358
	Previous therapy was focused on leg and getting upstairs	12/377
	Home care manager trying to re-instate it	4/102-116
	Annoyed at lack of physio – should be continuing until arm is better, wants more physio	11/329-342, 19/587-614
	Lack of therapy is reason for lack of recovery, should have regular physio, she cannot do it on her own	20/602-640

Meg (18): Table of Themes

Theme	Quote/key words	Page/line number
Self-care	Carers 2x day, dressing, washing, bathing 2 x week	19/385, 415-429, 50/1013
	Feeding – husband cuts up food, I have a go but I get frustrated	28/557
	When eating out choosing food that is easier to feed herself, sometimes has food cut up for her when eating out	28/566-582
	When you get an itch you can't scratch it	3/59
	Fed up with me clothes, always dragging down (referring to her arm), wears scarf to camouflage arm	17/339
	Can't do me hair, can comb it but not put in rollers or back comb it and spray it, hairdresser once a week but can't look after it each day	17/346-369
	Wearing pull up trousers – don't like it	22/440
	Like me nails doing, grandson painted them for her	51/1034
	Make-up doesn't seem to go on properly – using one hand	52/1043
Self -image	Always been tidy with myself	17/345
	Always been a smart person, like clothes to fit properly, to match – get really fed up with it	23/456
Self-esteem	Food comes out of her mouth when eating - I'm embarrassed, embarrassed when having food cut up when eating out but doesn't stop her going out	28/564, 29/581
Role	The washer – husband puts it all in together, but I don't say anything, because he's doing his best	25/492
	Husband gets things all over the cooker, want to do it myself, don't want to upset him, he's sometimes bad tempered	37/741
Activities	Husband brings in washing and forgets, leaves it, she's tried to do ironing but can't because of hand	38/766
	I want to go in kitchen , balance a problem, to be more stable, arm has an impact, I try to do it, want to do it myself	4/63, 16/323-337, 37/737
	I get so mad because I think I'll put it in the washer but I still can't	25/503
	Really frustrated she can't cook, husband making a mess, I like to be independent	38/759
Altered Life	Relying husband now to drive her – like to go on my own, I just wish, oh, don't like to keep asking him	24/475-485
	Just feel like jumping up and getting in car, now husband has to take me to dentist, doctor, hospital.	24/469,
Recovery	I've improved a lot, can open hand and bend fingers	1/12, 8/145
	Wants more improvement in arm, wants to walk a bit better	8/154
	Recovered more than she expected	8/160
	Hope for more recovery even at her age	12/227
Priorities	Wants to drive again, walk to shops, get on a bus	34/677-691
	To use arm to steady card/paper while she writes	35/701
	To wash things out – I was good at wringing them out	35/711
	Hand arm and leg recovery equally important, hopeful for	39/787

	more recovery	
	To walk and carry things, to put kettle on, get out cutlery	41/823
Responsibility	Her effort is important, sometimes feel like giving up, I get depressed but I don't get too down	45/904-916
	Family have kept her motivated	49/997
	Important that family recognise she is trying hard	32/636-653
Therapy	Saw advert for class in paper – for her balance	4/72-90
	Referred herself back to physio, previously they worked on walking, getting in/out car, now she wants to be able use steps	5/94-118
	Negative feedback from PT 'that was crap'- made her more motivated	9/166
	Later realised PT's prediction 'we thought you wouldn't walk again' – motivated her	9/179
	She wants more physio to be able to lift up foot and step up	7/123
	Important to her that PTs knew she was trying hard – she thought her age might be reason for PT to stop, re-assured her it was not	10/197-226
	Hoping PT will work on her arm – at ex class could not hold theraband	36/717
	Wants more PT – saw Andrew Marr on TV – most important thing is PT, paying for private PT, she would consider private PT	41/834-869
	PT – had a lot it's done me good, but would like more	43/872
Balance	Unaffected arm sore with pressing down on tripod, cannot keep affected hand on frame	2/39-53
	Cannot let go of tripod to put washing in	25/504
	Can let go to switch bathroom light on and flush toilet	26/510
	Can't walk and carry things – had to put phone in her top to carry it back to her chair	26/524

Six month Post-stroke Theme: Managing self-care

Participant	Experiences				Perceptions	Meanings
	Toileting	Washing/Bathing/grooming	Dressing	Feeding		
P1		<p>Takes an hour to wash herself 3/78, needs help in shower 8/277</p> <p>Can't style her hair with hot brush, burnt her hand, was part of her routine 4/117</p>	<p>Fastening clothing – had to make changes to clothes she wears 3/99, can't get to wardrobe to choose clothes 4/133</p>	<p>Daughter gets tablets out of containers so she doesn't know what she is taking 3/87</p> <p>Living with daughter now – can make a cup of coffee that's my limit 2/39</p>	<p>Been in that house 50 years 10/326</p> <p>Dependence, can't be on my own 5/159,</p> <p>'Look at the state of my hair ' 4/117 it's awful really bad 4/127,</p>	<p>Dependence, not normal, no choice 4/129</p> <p>Feels awful, like to be independent, 4/117</p> <p><u>Altered Life</u></p> <p>Would never let anybody see me with hair like this 16/530 <u>Self-esteem</u></p>
P2		<p>Can't wash & style hair 3/130, help with bathing 5/206</p>	<p>Help with dressing – try myself, too slow 2/89, can't do buttons 3/113</p>	<p>Can't use knife and fork 1/44</p>	<p>Daughter cuts up food 2/64,</p> <p>Dependence</p> <p>Used to doing it myself 2/76 Slow 2/89</p> <p>Don't seem to go right, don't like my hair 3/149,</p>	<p>Useless, you ought to do it for yourself 2/71</p> <p>always looks a mess 4/156,</p> <p>you feel really useless 5/220</p> <p><u>Self-esteem</u></p>
P3	<p>Partner helps with cleaning</p>	<p>Carers wash me 1/20, jokes with carers</p>			<p>Can't have a bath on my own 3/66, carers decide when I have a bath 36/982</p> <p>Embarrassed 12/303</p>	<p>Dependence , privacy, choice, spontaneity – have to plan ahead , feel lost 37/991</p> <p><u>Altered life</u></p> <p>Trying to make light of</p>

	3/73 Can't stand to urinate 12/314		Wearing loose fitting trouser and T shirts 9/222 Wearing sock on hand to keep warm – can't get gloves on 10/272 Carers dress him in morning 36/960, hand gets stuck in sleeve of coat 35/954		Used to wear decent, normal trousers 8/217 Used to being dressed smart, tie, decent trousers 10/258 Embarrassed, everybody else showing their two hands, putting hands in pockets 11/293 Sometimes embarrassed , sometimes not 36/965	difficult situation <u>Identity</u> as a man Feel dirty 9/222 Feel scruffy 10/254 <u>Self-image</u> <u>Self-esteem</u> Different <u>Self-image</u>
P5				Carrying hot drinks from kitchen 21/636	Concentrating hard 21/635	<u>effort</u>
P6	Have to wait for carers to clean her after toilet 27/847	Carers shower her 2/57 Cannot style hair 5/161 No make-up since			Embarrassed but necessary 27/857 Embarrassing , but put it to back of your mind and get on with it 3/89 I'd rather have the shower and not think about what they're doin 3/94 Hair annoys me, can't cope with it 5/150	<u>Self-esteem</u> Powerless, you have to put up with it don't you 3/78, have to live with it or don't live with it, I choose to live with it 28/872 <u>Altered life</u> depressed

		stroke 5/143 Arm feels like an alien not part of me 8/238	Can't fasten a button so everything has to go over my head 4/110		Not normal clothes 4/115	Comfortable like this – might be too restricting 4/119 comfort over appearance, depressed 6/179 self-image
P8	Carer morning to empty commode 2/51	Shower with one hand	Can't button anything, pull things over my head 2/57 fastens bra then pulls over head 3/78		I get by 2/61 not affected by clothes she wears	
P9	Realised how slow she is in public toilet compared to other women 15/491	Can't do my hair as well – drop things more than I used to 11/367	Takes longer to get dressed – fastening buttons, zips 10/315 Tights difficult to pull up 12/398		Wearing different clothes, Try to buy things without buttons 10/322 Annoying 12/372 Other woman had come and gone and she was still fiddling with clothes - thought it was funny 15/491	Slow, but too old to worry about things like that (appearance) 11/343 self-image I was a very quick person, very active, always doing things 16/508 self-image
P10	Wife washing back and under arm in bath 12/412		Can bring cup up to mouth 1/9, can't use knife 1/21 Can make drink but not carry it from kitchen 10/352 Wife helps with sock,		It's a bit embarrassing 12/422 Could use clip on tie	Father was paraplegic – he was not ashamed of it, comparing himself with father 22/817 Annoyed by stroke trying my best to make things work 23/840 Adapting & adjusting Self-image

			shoe, calliper, knee brace 11/376, Can't tie a tie 11/394		11/394	
P12	Carers 4 x day, can't get me clothes down myself 6/160	Don't put any make-up on, can't do it right 9/272 Can't do hair myself, can't wash and blow dry it 8/242	Carers dressing her 5/156 Don't wear the same clothes, just these pull ups and tops, easy to get on and off, used to have things to match nice 9/267	Just use a fork, have to have it all cut up 21/659, put a pinnie on but still make a mess 23/700	Tired of them coming in/out of house, but they are helping me 16/484 Clothes never look right, lop-sided with this arm 9/268 Can't tidy myself up, it's all changed with this (arm) 9/272 Annoying 8/247 Embarrassed 23/698	You try to do it ...just feel hopeless 16/500 Can't reach for things – sick of asking for help 11328 <u>Altered Life</u> <u>Self-image</u> Feel as though I've aged 10/303 <u>Self-image</u> <u>Self-esteem</u>
P14			Tight trousers, tight jumpers, buttons, getting short round body with one arm 11/327 has altered what he wears, wearing more t shirts, normally wears a tie 12/360	Can't just pick your fork up	Not dressed up 13/369 Look untidy 14/408 always liked to get dressed up, look smarter 15/431 <u>self-image</u> Not embarrassed 18/521	If it weren't for wife I wouldn't be coping 20/598 I'm dependent on wife now - annoys me 33/966 <u>Life roles</u>

				17/507 wife cuts up meat 18/519		
P15	Can't push himself up out of bath, partner helps 1/21		Can't tie shoelaces 3/73 Small tight button-holes 16/489	Can't grip knife 3/70	Don't like other people doing jobs for me 19/554	I've always done em, I'll always keep doinem .. when my arm gets better 19/556 <u>Altered Life</u>
P16	Hoisted to toilet by carers	Carers wash and dress him, I help a little but not much, shaves with electric razor 3/64		Can't cut up food 21/673	Very annoying really 4/95 You feel a bit of an idiot 24/756 <u>self-esteem</u>	If everybody does everything for you you've got nothing left 24/759 <u>altered life-loss</u>

18 Month Post-stroke Theme: Meaningful Activities

Participant	Experience s				Perceptions	Meanings
	Domestic /household tasks	Driving/ Cycling	Working	Leisure		
P2	I want to do cleaning, can only wash pots in a morning 3/89			Competitions – book keeps slipping 8/255	Frustrating 3/97 I just feel lazy cos I never used to sit all day like I do now 9/287	I always used to be doing things all day 4/100 <u>Altered Life</u>
P3	<p>Can cook for partner and father-in law – using ‘work station’ 16/477 Can’t decorate – someone else came in to do it 16/493 Can’t put up Xmas decorations 20/612 Friend came in to do some DIY, put up pictures, clock 20/620, move furniture 21/645</p>	<p>Failed driving assessment – using knob on wheel 1/8 needs some lessons 9/273 Will drive adapted car 8/241</p>		<p>Can’t walk dogs – can’t steer scooter and hold lead 19/596</p>	<p>Not proper way of driving but I’ve gotta do it 8/241 Cost for lessons and adapted car 10/296 Over the moon when I got behind the wheel, I’m back behind the wheel again 8/251</p> <p>He says my cooking is perfect 16/481</p> <p>I had to sit in kitchen out the way and let them get on with it – terrible 16/500</p> <p>Can’t go out with partner to walk dogs together</p> <p>Feel guilty, lost independence 20/636 always done it meself, always been get up and go 21/641</p>	<p>Feel like 2nd class citizen – can’t drive, can’t do things I did before 15/456 getting used to how things are but not normal because I can’t drive yet 7/194 <u>Identity, Downgraded</u></p> <p>Have a bit more independence 17/511 Can contribute</p> <p><u>Meaningful, role</u></p> <p>Changed me as a person 21/643 <u>Disrupted Self</u></p>

P5	<p>Can't lift anything heavy – out of oven – groceries, don't do any cooking – ready meals 2/34</p> <p>Cleaner 2x week – heavy cleaning, carries things up and down stairs – holding on to hand rail and carrying at same time is not easy 5/127</p> <p>Couldn't hold cloth to sew or mend – used to turn up trousers for me and for friend 14/405</p>			<p>Use my arm a lot while sitting down – TV remote, laptop, holding book 9/255</p>	<p>Used to love cooking 2/52</p> <p>Family think I sit here far too long 11/322</p> <p>That's why it has recovered more than leg, arm and hand are stronger 9/272</p>	<p>I'm the sort of person who can adapt – I've just had to accept I can't do things as I did 11/337</p> <p>Still independent – when in hospital all I wanted to was get home and do things for myself 15/449 <u>Adjusting</u></p>
P6	<p>Can't do anything, hoover or dust, mop floor, hang up washing 6/270</p> <p>Would love to cook for myself 6/261</p>			<p>Friend has taken her out once or twice only 9/433</p> <p>Can't even walk down the road in case I fall 16/766</p>	<p>Feel useless – depending on other people all the time 21/1006</p> <p>I'll never sit down again once I get out of this chair properly 6/261</p>	<p>Fed up of sitting in this chair all the time 1/6 <u>Altered life</u></p> <p>Isolated, can't choose when to go out <u>Altered life, choice loss</u></p>
P8	<p>Using adapted tools in kitchen, butter bread etc 3/67</p> <p>Can hang out washing 3/65</p> <p>Can't lift things out of oven 12/346</p>				<p>Hand has slowed me down 3/62, difficult to do with left (unaffected, non-dominant) hand. 3/75 tricky but I accept it now 3/84</p> <p>Use microwave, slow cooker, halogen cooker</p>	<p>I get by, using left hand, you find easy ways round things 2/56 <u>adapting</u></p>

	Have a cleaner, gardener 11/316 can hoe and plant with adapted tools 11/319			<p>Joined pensioners club – craft activities – needed help to make cards 2/37 Sit and watch a lot 4/97</p>	<p>12/348 Friends/family buy adapted tools as presents 11319 Living alone – if you don't learn how to do things , what do you do? 11/312 Came home from hospital and got back to my own way of living 15/455</p> <p>Would like to join in , feel my brain you know your hand wants to do it but it can't 4/100</p>	<p>Grin & bear it (emotional) 12/344 got used to it 15/448</p> <p>It pushed me I can assure you 16/497, <u>adapting</u></p> <p>Don't like it but just accepted it 4/109 <u>adjusting</u></p>
P9	Making beds- lifting mattress to tuck in	<p>Driven short distance – going to have lesson when weather improves 6/175 Friend giving her lift and fussing, helping her out of car 16/491</p>		<p>Sewing, threading needle 3/85 takes so long, won't be able to do the fine</p>	<p>You lose your independence 6/180 – have to see if husband's available and he has to wait outside class etc 7/195 Funny but I'm not particularly fit and wonder if I'll ever be – husband says well you're a year older but it wouldn't have affected me so much all at once like this 16/482</p> <p>It's a nuisance 21/646</p>	<p>Choice, control</p> <p><u>Altered life</u></p> <p><u>Self-image</u></p>

	<p>sheets – the weight 8/240</p> <p>Using gadget for opening tins & things 4/103</p> <p>Can't carry a lot of things – weight unbalances me 11/327</p>			<p>work 21/643</p> <p>Used to garden more than I do now – takes up so much time now to do housework now 20/615</p>	<p>Annoying I have to keep getting this thing out 4/101</p> <p>Takes me much longer 21/655 I get tired very quickly 22/677</p>	<p>I was a quick person find it quite strange that I'm so slow 22/666 <u>Self-image</u></p>
P10		<p>Driving – failed test – surrendered licence , using pedal with R foot was problem 3/82</p>		<p>Playing organ, bass recorder with one hand 5/136</p> <p>Adapted church organ to make rest for R foot 14/570</p>	<p>Thought test was a bit insulting 3/97 no information about why he failed, really annoyed 4/148</p> <p>Using taxis is expensive to get to his activities 11/438, nice that people do help – I'd like to do it myself – I am capable of driving,</p> <p>But cannot play organ in another church if asked to – previous to stroke may have done 14/575</p> <p>I want to choose when to retire from playing organ don't want my disability to choose for me 14/561</p>	<p>Loss of independence</p> <p>Limits activities</p> <p>choice, control,</p> <p><u>Altered life, loss</u></p> <p><u>Adapting</u></p> <p><u>Adapting</u></p>

	Wife does cooking, he can use microwave 17/701		Conducting & playing – recent trip to Japan 2/59 Travelled on his own, air line look after you 15/598 invited to conduct in Bingley 12/495,	Buying one-hand bass recorder 4/164	Re-wrote music to adapt for his one-handed bass recorder 9/340 Friend will drive and I treat him to lunch 12/495	<u>Adapting</u> nothing I used to do that I can't do, with difficulty and slower 15/625 <u>Self-image</u>
P12	I want to go in kitchen – still haven't got balance properly 4/63 To cook – hard to turn around, arm affects balance sometimes 17/337 Can't put clothes in washer or iron - balance , hand 25/504 Writing letters, cards – can't hold with affected hand 35/706	Just feel like jumping up and getting in car, could drive before stroke 24/471			I get so mad 25/503 Husband doing it - I want to do it myself 37/745 I'm really frustrated, I don't like it, I like to be independent 38/759 Now my husband takes me – dentist, doctor, hospital, I always liked to go on my own 24/475 Awkward 35/704	<u>Changed role</u> <u>Altered life, Loss of independence</u>
P14		Driving adapted car now 5/134			Don't like steering wheel ball – gets in the way 5/145	<u>Adapting, adjusting</u>

	Can't decorate, can't mow lawn or dig garden – lacks strength in arm 7/198			Returning to indoor bowling 18/567	Can get in car and go now 4/112 Frustrating 26/827 If it's not successful I've had a go 22/695 I'll need a wheelchair to walk from end to end – tire myself out 20/618	I'm in control of when we go – everything 26/814 <u>Altered life</u> <u>adapting</u>
P15	Cooking – can chop, peel, using spatula difficult, arm gets tired 6/156 Doing hoovering, cleaning , partner irons , dusts 7/182 Can't hammer a nail in – putting up pictures 2/44 Couldn't paint front of house 10/278		Missing working 7/197, no hobbies 8/212	Shopping – keeps all loose change in left pocket, debit card instead of handling money 8/231	You've got to push yourself 6/171 I have to give that to (partner) 2/59, like doing things for myself, 4/93 don't like asking people to do jobs 10/288 Makes you lazy 7/199 Easier than fiddling with money 9/270	<u>Responsibility, recovery, Motivation</u> You learn to put up with it 10/305 , don't like paying them 10/295 <u>adapting, adjusting</u> <u>loss</u> You'll notice I do everything with my left hand 8/235 <u>adapting</u>

		Not cycling yet, can't keep hand steady 16/471		<p>Don't shop alone 8/218 can't lift heavy bag use shopping trolley 8/222</p> <p>Crossword puzzles – practising writing with R hand 8/237</p> <p>Go out for a drink, someone has to carry drink for him 16/471</p>	<p>I can do, it just takes longer packing bag 8/219</p> <p>Getting better that way 9/252</p> <p>I'll get on bike when I get the courage 16/486</p>	<p><u>Adapting,</u> dependence</p> <p><u>Responsibility for recovery,</u></p>
P16	House insurance, car insurance, tax etc – can't type to do letters, use internet, can't write – it's a scrawl 5/132, 12/385				<p>Used to be able to touch type, now only one finger (non-dominant hand), takes forever, it's a nuisance 5/132, 12/385</p> <p>Feels useless 8/160</p> <p><u>Self-esteem</u></p>	<p>Everything's an effort, all jerky even with R hand (non-dominant), have to think, plan, not spontaneous, clumsy, knock things off, drop things 11/339, 12/375</p> <p>Everything's slowed down, body and thinking 10/295</p> <p><u>Altered life</u></p>

Appendix 8 Participants Summary

Participants address

Date

Re: Stroke survivors' experiences of upper limb dysfunction

Dear

I am writing to you about the above research study that you kindly participated in. The study is now finally complete and the findings have been analysed and written up. Included with this letter is a brief summary and overview of the findings for your information. Participants in the study all had different experiences; however from the analysis of all the interviews some common themes have emerged. If you would like to discuss the findings further then please indicate this by adding your name to the slip below and return it in the stamped addressed envelope provided. I will then contact you to arrange a convenient time to meet with you.

I would like to take this opportunity to thank you for your cooperation in the research study and your willingness to give up your time for the interviews and to talk freely about your experiences. The study is being written up as a doctoral thesis for submission to Keele University and there are plans to further disseminate the findings of the study in the hope of influencing the services provided to people with stroke and upper limb dysfunction.

Yours sincerely

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01904 876345

-
- I would like to discuss the findings further with the researcher

Name: _____

Summary of Findings for Participants

The results from this study could be considered wide ranging in terms of participants perceptions and experiences. The key findings are: Upper limb dysfunction resulted in loss of competence and capability in self-care, valued activities and fulfilling life roles. This in turn caused embarrassment, leaving some people feeling vulnerable and more like a child than an adult. The normal daily lives of people were disrupted by loss of valued activities and roles, and a lack of choice and change in many of the meaningful areas of people's lives. In addition this affected some people's self-concept through low self-esteem, and changes in self-image and identity.

Psychological adjustment and physical adaptation to upper limb dysfunction was possible in the 18 months period after stroke for some but not all. Having an overriding purpose in life, such as continuing to live alone or a significant valued activity, and the return of some function was an aid to this. However where significant help with self-care was required, valued activities not resumed and life roles changed, then it was more challenging.

Recovery of the upper limb was less of a priority than recovery of walking for some participants, who also perceived this to be the same for the health professionals caring for them early after stroke. The upper limb continued to be disregarded by health professionals but not by the participants, who came to see how vital it was in regaining a meaningful life and for their self-esteem, self-image and identity.

Therapy services after discharge from hospital were short-lived, inadequate and focused on mobility only and not on the upper limb. Participants were not prepared for this. They wanted more access to therapy for their arm and hand, and in particular physiotherapy, as they saw this as vital for more recovery.

Participants found there was a reluctance to discuss expectations of further recovery of the upper limb and insufficient time was given to them to ask questions while in hospital. After discharge home there was a lack of access to information

and advice from doctors and therapists about the rate of recovery after stroke and this caused confusion in what to hope for and expect in recovery of the upper limb.

Participants wanted to be active partners with therapists in their rehabilitation. They wanted exercise prescription and advice about activities that would foster more recovery. They did not expect therapy to be continuous in the longer term but rather to have regular review of their upper limb and access back into services.

In conclusion the findings indicate that having upper limb dysfunction after stroke is much more than just losing function. It can disrupt many aspects of a person's meaningful life and their self-concept. Furthermore these findings could indicate that health services, in particular therapy services, do not fully recognise this and are insufficient to meet the needs of people with stroke and upper limb dysfunction.

Appendix 9: GP Assessment of Cognition Test

Step 1: Patient Examination

Unless specified, each question should only be asked once

Name and Address for subsequent recall test

1. "I am going to give you a name and address. After I have said it, I want you to repeat it. Remember this name and address because I am going to ask you to tell it to me again in a few minutes: John Brown, 42 West Street, Kensington." (Allow a maximum of 4 attempts).

Time Orientation Correct Incorrect

2. What is the date? (exact only)

Clock Drawing – use blank page

3. Please mark in all the numbers to indicate the hours of a clock (correct spacing required)

4. Please mark in hands to show 10 minutes past eleven o'clock (11.10)

Information

5. Can you tell me something that happened in the news recently?

(Recently = in the last week. If a general answer is given,

eg "war", "lot of rain", ask for details. Only specific answer scores).

Recall

6. What was the name and address I asked you to remember

John Brown, 42 West (St), Kensington

(To get a total score, add the number of items answered correctly)

Total correct (score out of 9)

If patient scores 9, no significant cognitive impairment and further testing not necessary.

If patient scores 5-8, more information required. Proceed with Step 2, informant section.

If patient scores 0-4, cognitive impairment is indicated. Conduct standard investigations.

Informant Interview

Date: _____

Informant's name: _____

Informant's relationship to patient, i.e. informant is the patient's: _____

These six questions ask how the patient is compared to when s/he was well, say 5 – 10 years ago, Compared to a few years ago:

Yes No Don't Know N/A

- Does the patient have more trouble remembering things that have happened recently than s/he used to?
- Does he or she have more trouble recalling conversations a few days later?
- When speaking, does the patient have more difficulty in finding the right word or tend to use the wrong words more often?
- Is the patient less able to manage money and financial affairs (e.g. paying bills, budgeting)?
- Is the patient less able to manage his or her medication independently?
- Does the patient need more assistance with transport (either private or public)?

(If the patient has difficulties due only to physical problems, e.g bad leg, tick 'no')

(To get a total score, add the number of items answered 'no', 'don't know' or 'N/A')

Total score (out of 6)

If patient scores 0-3, cognitive impairment is indicated. Conduct standard investigations.

Appendix 10 Ethical Approvals