

**Social Integration following a stroke:  
Understanding meaning and process in  
older people**

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## ii. Abstract

This study focused on understanding the meaning and process of social integration in older people who had experienced a stroke. Straussian grounded theory guided the study design. Older people living in their own homes in three counties in southern England were included in the sample. A total of 30 people were purposively selected and semi-structured interviews were conducted with older people (mean age 76) between four and eight years after their stroke. The substantive theory *from indecision to volition* was generated and conceptualised as the core category and comprised of four related categories: *Gaps in identity, internal conflict, negotiating and exploring and renegotiating and reconciling*.

It was found that people did not feel they had managed to attain social integration; instead they described a more restricted but evolving social world and a process within the context of a personal journey to establish meaningful relationships. After people's strokes an empty social space unfolded from the loss of social groups. Within this space, feelings of fear emerged and people experienced increasing self-consciousness and an erosion of self-confidence. The journey described was encompassed within a complex framework shrouded in effort and hard work that required many people to make a conscious decision to act in order to forge new relationships outside of their homes and families. This study identified variation in the process with people describing differing social progression. Those people that were able to make progress needed to access and utilise resources, but only at the right time for them, which for some took many years. Only a few people had returned to previous social groups. The majority slowly built new friendships and a new social world began to emerge; one that was often fraught with setbacks or pauses. Targeted and effective interventions that support people's individual social needs have been suggested. These and opportunities for further research will continue to build a greater understanding, enabling people to move from uncertainty and indecision to an active volitional choice in order to form new and personally meaningful social worlds.

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#### **v. Author's Declaration**

I have nothing to declare.



## Chapter 1. Introduction

*“Human beings are social creatures. We are social not just in the trivial sense that we like company, and not just in the obvious sense that we each depend on others. We are social in a more elemental way: simply to exist as a normal human being requires interaction with other people.”*

(Gawande 2009)

### 1.1 Background and Context

This thesis presents a grounded theory study, which aims to understand the meaning and process of social integration in older people following a stroke. This chapter will introduce the reader to the research by presenting the background and context of being an older person in the United Kingdom; the importance of social integration; the impact of experiencing a stroke and my own personal background in stroke rehabilitation. Finally, an overview of the structure of the thesis will be given.

#### 1.1.1 *The ageing population*

The population of the United Kingdom is ageing and there are now more pensioners than there are children under 16 (Office for National Statistics 2011a). Currently, there are 10.8 million people aged 65 or over living in the UK with over 1.4 million people aged 85 or over (Office for National Statistics 2013). Looking ahead, the number of people aged 65 or over is projected to rise by nearly 50% in the next 20 years to over 16 million. In addition, the number of people over 85 in the UK is predicted to double in the next 20 years and nearly treble in the next 30 years (Office for National Statistics 2011b). The welfare of older people in this ageing society is of paramount importance and whilst many older people live a long, healthy and satisfying life, with age comes a greater risk of ill health. Over two thirds of people aged 85 and over have a disability or limiting long-standing illness and nearly a

quarter of people over 65 report that their quality of life has got worse over the last year (Department for Work and Pensions 2009; Age Concern and Help the Aged 2009). Heart and circulatory diseases are the largest causes of mortality in adults over 65 (Office for National Statistics 2009). An ageing population brings not only the risk of rising ill health but also a more hidden epidemic of social isolation and loneliness amongst older people (Age UK 2010), which will now be considered.

### *1.1.2 Loneliness and social isolation in older people*

The terms loneliness and social isolation are often used interchangeably, but are distinct concepts. People can be socially isolated without feeling lonely, or feel lonely amongst others (Victor and Bowling 2012). Loneliness is most widely defined as a subjective negative feeling that can encompass emotional loneliness; the absence of a significant other, and social loneliness; the absence of a social network (Victor and Bowling 2012). In contrast, social isolation tends to be defined as an objective state referring to the number of social contacts or interactions. The relationship between social isolation and loneliness is a complex one, and is likely to change over a person's life course. (Age UK 2010).

There are a number of population groups vulnerable to social isolation and loneliness, (e.g. young care leavers, refugees and those with mental health problems). Older people have specific vulnerabilities owing to loss of friends and family, loss of mobility or loss of income (Age UK 2010). Indeed, as middle aged and older adults move through the life course, they experience critical transitions that can make them vulnerable to threats of social integration (Victor and Bowling 2012). Five key transitions have been identified for older people; dispersion of children and other relatives, retirement, death of close friends, family members becoming isolated and declining health. The impact of any of these transitions challenges people's abilities to participate and experience integration within their communities and thus increases their risk of social isolation (Pillemer 2000). It has been found that 17% of older people have less than weekly contact with family, friends

and neighbours and 11% have less than monthly contact (Victor and Bowling 2012). There is also evidence that both the quantity and quality of social relationships in industrialised societies are decreasing and related to reduced intergenerational living, greater social mobility, later marriage, dual-career families, an increase in the number of people living alone, and more age-related long term illness (McPherson and Smith-Lovin 2006; Holt-Lunstad et al. 2010). Despite significant increases in technology and globalisation which would be presumed to foster social connections, instead people are becoming more socially isolated (McPherson and Smith-Lovin 2006; Holt-Lunstad et al. 2010).

These findings help to highlight the challenges that ageing can bring and the importance that older people are supported in being able to live meaningful lives. Whilst social isolation has been characterised as an objective lack of social relations and fulfilling roles, at the other end of the continuum lies social integration which can be described as the entire set of an individual's connection to others in his or her environment (Pillemer et al. 2000). People being involved and feeling integrated within their communities is important for all of society and will be considered in the next section.

### *1.1.3 The importance of social integration*

The positive impact of social integration on people's health and well-being has been established over the last three decades. By the late 1970s, several investigators had begun to examine the influence of social networks, social support, and aspects of community engagement on a number of health outcomes. In a seminal study, after following nearly 7,000 adults in Alameda County, California, over a nine year period, Berkman and Syme (1979) found that people with fewer social and community ties were significantly more likely to have died. The mortality rate for the men with the fewest ties was 2.3 times that for the men with the most ties, whilst the mortality rate for the women with the fewest ties was 2.8 times than for the women with the most ties. The effect of social ties on mortality was independent of such factors as, the health of the participants at the beginning of the study, socioeconomic status,

smoking, drinking, obesity, and level of physical activity. In a follow-up to the original Alameda study (Berkman and Syme 1979), Seeman and colleagues (1987) reported that over a 17 year period, subjects with stronger social networks and community ties were significantly less likely to die. The types of social ties with the greatest effect on mortality differed by age. For adults aged 60 years and younger, marital status had the greatest association with the risk of dying, with people who weren't married at greater risk. For those over 60 years of age, the most meaningful relationships for health and well-being were those with close friends and relatives. A more recent meta-analytic review of data of over 300,000 individuals, followed for a mean of 7.5 years, supported the previous findings and indicated that people who reported satisfactory social relationships were twice as likely to survive compared to those with poor or insufficient social relationships (Holt-Lunstad et al. 2010). The size of this effect was found to be comparable with stopping smoking and it exceeded many other well-known risk factors for mortality (e.g., obesity and physical inactivity) (Holt-Lunstad et al. 2010).

Evidence has also established that people who are socially integrated are more likely to survive myocardial infarction (Berkman 1995; Seeman 1996); are less likely to report being depressed (Cohen and Wills 1985); are less susceptible to infectious illnesses (Cohen et al. 2003); and are protected against dementia (Fratiglioni et al. 2004). A recent prospective cohort study by Boden-Albala and colleagues (2005) found that social isolation following a first stroke was significantly associated with increased risk of a recurrent stroke or even death. They defined social isolation as knowing fewer than three people well enough to visit in their own home (Boden-Albala et al. 2005).

It is argued that social integration fosters people's well-being and improved health outcomes, as described, in two main ways. Firstly, it is suggested that it provides people with cultural norms and shared values that give a sense of meaning, belonging, self-worth and stability (Thoits 1983). Secondly, it promotes feelings of responsibility for others that enhance motivation to take care of oneself in order to fulfil these responsibilities (Cohen et al. 2000).

Most health professionals take risk factors such as smoking, diet, and exercise seriously; but there is equally a compelling case for social relationship factors to be added to that list (Holt-Lunstad et al. 2010). Whilst the benefit of social integration is not exclusive to older people, it is known that as people age they are at greater risk of social isolation often due to chronic ill health; the most common cause of complex disability being stroke. The impact of experiencing a stroke will now be highlighted.

#### *1.1.4 The impact of stroke*

Stroke is a sudden and devastating illness. Stroke incidence in England is approximately 25% higher in men than women, with an incidence of 178 men per 100,000 and 138 women per 100,000 (Townsend et al. 2012). To put this number into context that is more than one stroke every five minutes (Townsend et al. 2012). The incidence of stroke increases sharply with age and over 75% of all strokes occur in people 65 and older (Scarborough et al. 2009). The incidence of stroke in the UK has reduced by approximately 20% in the last 20 years due to improved primary prevention (Townsend et al. 2012). The prevalence of stroke in England is 2.4% of all men and 2.2% of all women. This means that there are over a million people living with the effects of a stroke in the UK (Townsend et al. 2012). One in five strokes are fatal and in 2010, stroke was the fourth largest cause of death in the UK after cancer, heart disease and respiratory disease (Townsend et al. 2012). There are two main types of strokes; ischaemic strokes account for 85% of strokes and haemorrhagic strokes for the remaining 15% (Intercollegiate Stroke Working Party 2011).

Stroke is the largest cause of complex disability in adults (Adamson et al. 2004) and more than half of all people with stroke are left reliant on others for support in carrying out everyday activities (Intercollegiate Stroke Working Party 2011). Stroke causes a larger range of disabilities than any other long term condition (Adamson et al. 2004). For those people who survive a stroke at six months, approximately 42% will be independent; 22% have mild disability; 14% have moderate disability; 10% have severe disability and 12%

will have very severe disability (The Stroke Association 2012; Intercollegiate Stroke Working Party 2011).

#### 1.1.5 *The organisation of stroke services*

Just after the inception of this research study, the UK government released a ten year National Stroke Strategy in 2007, which recognised that the aim for people living with a stroke would be

*“..to achieve a good quality of life and maximise independence, well-being and choices”.*

(Department of Health 2007, p.34).

The strategy was supported with an initial investment programme and most of this money was focused on improving the delivery of acute stroke care: direct admission to dedicated stroke units; a national awareness campaign; and improved management of hyper-acute stroke including rapid thrombolysis, which helps to breakdown clots in ischaemic strokes, for those who meet defined criteria. This has led to a significant improvement in the identification of stroke and the acute management of stroke during the last seven years (The Stroke Association 2012).

In 2010/11, 1% of all National Health Service (NHS) inpatient episodes in England were due to a stroke (Townsend et al. 2012). People looked after in a dedicated stroke unit with organised services are more likely to survive, have fewer complications, return to their own homes and regain independence faster than people admitted to a general medical ward (National Audit Office 2005). In addition community based specialist rehabilitation such as Early Supported Discharge can provide improved and potentially more cost effective outcomes for people with moderate disabilities (National Audit Office 2010; The Stroke Association 2012). Due to the improved co-ordination of acute services, the mean length of stay in NHS hospitals for people who have experienced a stroke has decreased significantly from 32 days in 2000, to 20 days in 2010 (Intercollegiate Stroke Working Party 2011) although only 36% of hospitals have specialist supported discharge schemes (National Audit Office 2010). Although there

has been an improvement in the acute management of stroke, with three years of the ten year national strategy remaining, it is recognised that there needs to be an increased focus on the longer term rehabilitation and support that people may need following stroke (The Stroke Association 2012). The National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party 2012) have recently recommended that healthcare commissioners should commission a system that provides routine follow-up of people six months post discharge and thereafter annually after a stroke. In addition to many other recommendations, they have also highlighted the importance of integrated working between health and social services and other agencies such as charities. This recommendation aims to ensure that people receive the practical and emotional support that they may need, and that people can access suitable social opportunities outside their homes if they wish. Both this guideline and new UK rehabilitation guidelines reinforce the fact that the long term support of people after a stroke needs to be personalised. It is highlighted that everyone should have their individual feelings and wishes acknowledged and the opportunity to participate equally in the process of goal setting. Furthermore these goals should be meaningful, relevant and tailored towards individual needs (Intercollegiate Stroke Working Party 2012; National Institute for Clinical Excellence 2013).

Despite improvements in mortality and morbidity, people also need access to effective rehabilitation services (Intercollegiate Stroke Working Party 2012). Stroke rehabilitation is described as a multidimensional process, which is designed to

*“facilitate restoration of, or adaptation to, the loss of physiological or psychological function when reversal of the underlying pathological process is incomplete”*

(National institute for Clinical Excellence 2013, p. 14).

Furthermore, rehabilitation aims to enhance functional activities and participation in society and thus improve quality of life (National institute for Clinical Excellence 2013). At some point after the onset of stroke no further changes can reasonably be expected at the impairment level, however many

changes can still be made in terms of social integration into an individual's family, social and community life (Intercollegiate Stroke Working Party 2012; National Institute of Clinical Excellence 2013). Despite national strategies and guidelines, some people continue to experience limited access to rehabilitation services after their stroke. Additionally rehabilitation services that are available for people often continue to focus on the restoration of physical impairment and not maximising people's psychological or social outcomes (The Stroke Association 2012).

#### *1.1.6 The longer term impact of stroke*

Stroke is a sudden event, affecting all facets of a person's life; physically, psychologically and socially. As previously mentioned, at least 20% of people who have a stroke die within the first month, whilst over a third are left with a long term disability. The longer term effects can include aphasia, physical disability, loss of cognitive skills, depression and other mental health problems. All of these can leave people and their families ill-prepared to deal with the complex range of disabilities and the uncertain future which it brings (The Stroke Association 2012).

Five years after a stroke, a third of people are likely to remain severely or moderately disabled (Intercollegiate Stroke Working Party 2012). Loss of confidence is a common problem after a stroke which compounded with reduced mobility, problems using public transport and driving can make getting out of the house a challenge for many (Barnsley et al. 2012). Whilst there are many visible consequences after a stroke, there are also many hidden dysfunctions caused by stroke including increased fatigue (Crosby et al. 2012), concentration and memory difficulties, irritability, emotional instability, impaired stress tolerance, sound and light sensitivity, reading and writing problems and cognitive difficulties (Gunnel et al. 2004; Pallesen 2014). Depression is common after a stroke. Lincoln and colleagues (2013) found that depression and anxiety in people has been found to increase over time, with 33% of people experiencing depression and 29% experiencing anxiety five years after their stroke. People with stroke related emotional problems



have also been found to report higher unmet needs, between one to five years after their stroke, than people without (McKevitt et al. 2011).

Many people want to return to the varied roles they had before their stroke and play an active part in their own lives as well as their communities, but often there appears to be a gap between the life a person aspires to after a stroke and the reality of living with their condition (Healthcare Commission 2006). Qualitative researchers working with people after a stroke have highlighted that any strategies for support will need to look beyond improving discreet physical functioning, and take into account the social and personal context of disability if they are to be effective (Palmer and Glass 2003; McKevitt et al. 2004; Kubina et al. 2013; Pringle et al. 2013). Following a stroke, resuming old or forming new social ties is of crucial importance to people. There is a risk for people to become socially isolated after a stroke (Reed et al. 2010; Northcott and Hilari 2011), due to range of reasons; loss of shared activities, poor mobility, lack of energy, the reported unhelpful responses of others, barriers in the environment, aphasia, and changing social desires (Davidson et al. 2008; Northcott and Hilari 2011). Social support is also important for people after a stroke and can present in different forms; practical, emotional, and educational support and can be delivered by people's families, friends or groups (Ch'ng et al. 2008; Pringle et al. 2013). Family members most commonly provide help in accessing resources on behalf of the person after their stroke and strong family bonds can also bring people an important sense of belonging (Erikson et al. 2010; Wood et al. 2010). Whilst some relationships with family can become close after a stroke, for others, relationships may be more complex and the family can sometimes be seen as preventing people from doing things for themselves. The changes in the balance and reciprocity of the relationship can cause distress for some people (Northcott and Hilari 2011; Pallesen 2014). Loss of friendships outside of the family is also common after a stroke with people describing difficulties in maintaining relationships (Northcott and Hilari 2011; Kubina et al. 2013). Some people, after their strokes also find benefit in joining groups and more specifically for some, stroke groups or clubs where they can meet with other

people with similar experiences (Murray and Harrison 2004; Ch'ng et al. 2008).

People's unique social environments (which can be made up of their families, neighbourhoods, other social groups and community networks) have been found to impact on their psychological well-being through their ability to be internalised as part of their own social identity (Haslam et al. 2008). If these social environments are able to provide people with a positive sense of social identity (i.e. sense of belonging, meaning and purpose) then they will tend to have positive psychological consequences, and people will also have a feeling of social integration (Haslam et al. 2008; Wood et al. 2010). Two years or more after a stroke, people described how their changed roles and relationships were of more concern than physical functioning (Kirkevold 2002; Pallesen 2014) highlighting the importance of this issue.

## **1.2 The researcher – personal motivation**

I have a clinical background and qualified as a physiotherapist in 1998. I worked in direct clinical care for a decade, specialising in working with older people in community settings, including those who had experienced a stroke. I then moved into a clinical management role, initially as a therapy manager and then as a general manager for older people. In 2001, I was awarded a bursary to travel to Canada to gain direct insight into their models of community rehabilitation and support for older people. Following this visit, I collaborated with colleagues from health and social care, the voluntary sector and academia and we were successful in receiving a grant from the National Lottery to carry out a mixed methodology evaluation of a community exercise and tailored education programme for people following a stroke. I worked as the programme manager co-ordinating the research study at the University of Bath. The study comprised of a randomised controlled trial (RCT), an economic evaluation and a qualitative study (Harrington et al. 2010; Reed et al. 2010). My main role was leading the RCT, and I was also able to attend some of the exercise and education groups. It was through these groups that I became even more interested in the stories of people many years after a

stroke and the difficulties people had experienced in socialising after their strokes. One of the measurement tools that we used as part of the RCT was the Subjective Index of Physical and Social Outcome (SIPSO) (Trigg and Wood 2000). The SIPSO was developed to measure physical and social reintegration following a stroke. In parallel, a qualitative study was carried out that highlighted the issue of social isolation for older people after their stroke and that the scheme for many people had been their first opportunity to get out and about into their communities and socialise outside of their homes (Reed et al. 2010).

Despite having a background as a physiotherapist and an initial interest in physical function, I was becoming increasingly interested in the social context of ill health and the impact that experiencing a stroke had on people, in particular older people. It was this interest that motivated the topic for this study. When the RCT ended I moved back into working within the NHS and I am now employed by NHS England, where I have oversight for regional clinical strategy; whilst I continue to work part time as a researcher.

### **1.3 Rationale and Purpose of the study**

This study was a culmination of personal interests, including many years working with older people within the NHS and experience in co-ordinating an RCT with older people after a stroke. This research is concerned with a medical condition -stroke, with older people who have experienced a stroke and their individual experiences following their stroke. However, it is not directly concerned with the medical aspects of stroke, but instead the effect of experiencing a stroke on people's lives. Social integration is an important concept within both research but also rehabilitation practice, having grown out of a deliberate move away from a medical model to a more holistic bio- psychosocial model of healthcare (World Health Organisation 2001). Social integration could be viewed as the ultimate outcome of rehabilitation by supporting older people's activities, participation and subsequent quality of life after a stroke. Some initial work has been carried out in this area and is discussed in the next chapter. However, what is less well known is the

process of attaining social integration from the subjective understanding of people many years after their stroke.

The aim of this study was to gain a greater understanding from older people of the meaning and process of social integration following a stroke. Specific objectives were to gain an understanding of:

- Whether people felt they had successfully integrated following their stroke.
- How they had (or had not) integrated and what factors had helped or prevented the process of integration.
- What factors could have improved their, and perhaps other people's, experiences of integration.

## **1.4 Structure of the thesis**

This thesis is organised into eight chapters, the remaining seven are as follows:

### **2. Initial literature review.**

This chapter opens by discussing the use of literature in grounded theory studies. It then provides the initial literature review to the study that was carried out in 2007, prior to any data collection.

### **3. Methodology.**

This chapter gives consideration to the selection of the paradigm of inquiry and methodology which will underpin the method used to consider the research aim and objectives. It provides a description of the chosen methodology of Straussian grounded theory.

### **4. Method.**

This chapter outlines the design of the study. It justifies and describes the recruitment and data collection strategies and gives detail of the process of data analysis. Furthermore, it presents the ethical considerations involved in this research and offers a reflexive account of the process of data generation and analysis.

**5. Findings: Introduction.**

This chapter introduces the people within the study and then introduces the core category by the use of an integrative storyline. The substantive theory *from indecision to volition* is presented by use of a metaphor and visual model.

**6. Findings.**

This chapter describes in detail the main findings within each of the four major categories and enhances these by the use of current literature.

**7. Discussion.**

This chapter highlights and elaborates on the five key findings from this study and compares and contrasts these with current literature, highlighting how this study has created new knowledge. The limitations of the study are then considered.

**8. Conclusion.**

This chapter concludes by reflecting on the study aim and objectives. It discusses the use of the new substantive theory and how it informs clinical and research implications.

## Chapter 2. Initial literature review

### 2.1. The use of literature in a Grounded Theory study

Grounded theorists do not agree about when and to what depth the literature should be reviewed and consulted. As Bryant and Charmaz (2007, p.19) commented:

*“Ever since the publication of The Discovery of Grounded Theory, concerns have arisen regarding how students and researchers should approach and use the existing literature relevant to their research topic”*

Whilst an examination of the literature prior to data collection is characteristic of most research methodologies, it was Glaser and Strauss (1967) who reasoned against this and which led to Grounded Theory being set apart from other qualitative methodologies. Glaser (1998, p.67), although at times recognising the practical difficulties of strict adherence, has remained resolute in his position:

*“Grounded theory’s very strong dicta are a) do not do a literature review in the substantive area and related areas where the research is to be done, and b) when the grounded theory is nearly completed during the sorting and writing up, then the literature search in the substantive area can be accomplished and woven into the theory as more data for constant comparison.”*

Glaser is supported in his view by other researchers (Mills et al. 2006; Holton 2007). The fear for these traditionalists is that any review may lead to elements of contaminating or inhibiting the researcher’s analysis of codes and concepts emergent from the data (Glaser 1992; Mills et al. 2006). Stern (2007) agrees with the stance but recognises that with the requirements of ethics committees, research funding applications and other university procedures, it becomes practically impossible to postpone a literature review to the later stages of the research. Meanwhile, Lempert (2007) highlights the need for deviation from the traditional stance in that with no background knowledge there is a risk that what may seem a completely unique and new

concept, may be quite simply an ignorance of knowledge and understanding in the topic area being researched.

Whilst Glaser (1992; 1998) has continued to counsel against any initial depth of review, Strauss and Corbin moved away from this stance (1998). They suggested a provisional exploration of relevant concepts was helpful in providing a background and focus for the research. They recommended that focused reading was needed to stimulate theoretical sensitivity and to help the generation of hypotheses, but they warned against complete immersion in the literature as it may colour the researcher (Strauss 1987; Strauss and Corbin 1998; Corbin and Strauss 2008). Contemporary grounded theorists (Cutcliffe 2000; Morse 2001; Schrieber 2001) agree with Corbin and Strauss that a preliminary review of the literature is sensible. However, Morse (2001, p.9) suggested that whilst the literature should not be ignored it should be “*bracketed*” and used for comparison with emerging categories. Her concern was that without any context, new researchers can find themselves “*rapidly mired in data*”.

Cutcliffe (2000) recommends an initial review but only general reading before the study to assist in conceptual clarity. In addition Cutcliffe (2000) recognises that a researcher is being unrealistic if they propose to undertake a study without some level of prior knowledge or idea, as no-one is an “*empty vessel... with no history or background*” but that acknowledging this is a crucial part of the process (Cutcliffe 2000, p.1480). Urquhart (2007) supports this by highlighting that as long as researchers are self-aware then they should be able to “*appreciate other theories without imposing them on the data*” (Urquhart 2007, p.351). One important approach that researchers practice to counteract this early engagement with the literature is that of reflexivity which Robson (2002, p.22) has defined:

*“An awareness of the ways in which the researcher as an individual with a particular social identity and background has an impact on the research process.”*

The practice of reflexivity is not a new concept in the qualitative research field and is based on the principle that as the researcher influences data generation and interpretation then the need for reflexivity is an important and crucial part of the entire research process (Heath and Cowley 2004). This will be discussed further in next chapter.

For this study and following discussion with my supervisors, I carried out an overarching but brief initial scope of the literature (sections 2.3-2.6), to give me enough understanding of the topic area but not to allow myself to become too engrossed and potentially contaminated or influenced.

## **2.2. Ongoing use of the literature**

Although there remains some contention to the amount of pre-consultation of the literature, there is less division over the on-going review of the literature throughout the study. Corbin and Strauss (2008, p.37) described seven key functions for the utilisation of literature:

- A source for making comparisons
- Enhancing sensitivity
- Providing a cache of descriptive data with very little interpretation
- Providing questions for initial observations and interviews
- Stimulating questions during the analysis
- Suggesting areas for theoretical sampling
- Confirming findings and reversely illustrating where the literature is challenging, simplistic or only partially explanatory of a phenomenon.

In this study, once I had started data collection and constant comparative analysis, I then started to review and consult the current literature to help guide my enquiry and utilise the literature as listed above. This new search brought the literature up to date and filled in the timeline since the initial review. It also broadened the search in line with the findings that were being discovered. As the core category emerged and the substantive theory was developed, a further search to compare and contrast other theories and



frameworks was carried out. This literature is presented within the findings and discussion chapters.

## **2.3. Social Integration and Stroke**

### *2.3.1 Introduction and searching strategy*

My initial literature review up to 2007 is considered here. A search of electronic databases was initially employed. The period of time searched was 1987-2007 but earlier seminal works were also included. The first search used the combinations of the following key words: *Stroke, older people, ageing or elderly or geriatrics, social (re)integration, reintegration, community (re)integration, integration, and disability*. Truncations such as *disab\** were also used. The databases accessed were CINAHL, Medline, PsychInfo, Science Direct, SocIndex, and Health source, Nursing / Academic Edition. Sociological abstracts, webofscience, and ZETOC. Searching was also extended to checking references from retrieved studies. As will be discussed later in this chapter a further search was subsequently carried out to expand on some areas of the literature identified.

The impact of experiencing a stroke, including a brief summary of the longer term psychosocial effects, and the significance of social integration have been presented in chapter one and will not be repeated here. In this section I will initially discuss the literature in relation to social (community) integration and stroke and then in the following sections I will summarise additional literature identified in relation to (social) participation and stroke, and integration and brain injury. Finally, terminology will be considered.

Up to 2007 there was very little written in relation to social integration and stroke; and only nine studies were found that directly related to social or community integration following a stroke (Bélanger et al. 1988; Santus et al. 1990; Trigg and Wood 1999; 2000; 2003; Barry and Douglas 2000; Bhogal et al. 2003; Hoffmann et al. 2003; Egbert et al. 2006). Six papers reported on empirical studies, one concerned a systematic literature review, and two further papers presented the validation of the Subjective Index of Physical

and Social Outcome (SIPSO). The original SIPSO paper in the series of three (Trigg and Wood 1999) will be considered here and the SIPSO measure will also be discussed but these other two papers will not be covered further as they only consider the validation of the outcome measure. The systematic review (Bhogal et al. 2003) will be considered initially and then the six empirical studies will be discussed in relation to terminology and definitions used; participant characteristics; time since stroke; the use of standardised measures; and an overview of findings.

### 2.3.2 *Systematic review: Bhogal et al. (2003).*

Bhogal and colleagues (2003) carried out a systematic review of stroke literature between 1970 and 2002 to highlight the issues facing people and their families following a stroke upon reintegration into the community. They reviewed a broad range of studies in relation to six areas: social support, caregiver burden and depression, family interactions, family education intervention, social and leisure activities after a stroke, and leisure therapy. Thirty six studies were identified from six different countries, the majority using quantitative designs such as randomised controlled trials, cohort or case controlled studies. Only five of the 36 studies identified utilised qualitative methods. The authors did not define community reintegration after stroke and did not specify why they had specifically searched in relation to the six areas outlined above. The studies included in the review utilised a vast range of outcome measures and most of these individual studies did not include any specific measures in relation to community reintegration.

Two findings from this review most relevant to the current study will be mentioned here; social support and social and leisure activities. Firstly, Bhogal and colleagues found that there was moderate evidence that increased social support as an intervention improved outcome after a stroke (Bhogal et al. 2003). Only four quantitative studies were identified in relation to social support (Glass and Maddox 1992; Friedland and McColl 1992; Glass et al. 1993; Knapp and Hewison 1998). Within these four studies a range of measures were used which made comparison difficult. The Barthel index

(Granger 1979) was the most common measure identified and was defined as the main outcome in three of the studies. Two studies additionally used direct measures of social support; The Social Support Inventory (Timmerman et al. 2000) and The Inventory of Socially Supportive Behaviours (Barrera et al. 1981). Bhogal and colleagues reported that these studies showed that moderate amounts of instrumental support and high amounts of emotional support, appeared to be most beneficial with a range of improved outcomes linked to functional, general wellbeing, anxiety and depression, support and interaction. The nature of social support, as mentioned in chapter one, is broad and complex and can be provided by family, friends, professionals and also in many different group settings. These identified studies specifically looked at interventions in group settings within the first six months after stroke and mostly focused on people's functional improvements and so may not have fully captured this breadth of social support in the intervention or the potentially changing needs of people who have experienced a stroke after the initial six month period.

Secondly, Bhogal and colleagues (2003) identified seven individual studies in relation to social and leisure activities (Lawrence and Christie 1979; Labi et al. 1980; Belcher et al. 1982; Feibel and Springer 1982; Putterill et al. 1984; Davidson and Young 1985; Niemi et al. 1988). These individual studies were wide ranging. Three used qualitative interviews and the other four used quantitative questionnaires. Time since stroke ranged from days to over three years, the number of participants from 29 to 262. The review highlighted that people commonly experienced deterioration in social and leisure activities after a stroke and this deterioration appeared to be greatest in women, the young, and those who were better educated. Other than this overall reduction in social activities, the studies yielded only individual findings as they were non-generalisable due to the range of study aims and differing methodological approaches. Individual findings of note included that people found their physical disability in itself less important than the response of others to their disability (Lawrence and Christie 1979). People who had a spouse or a caregiver who lived with them and attended to their needs, were not as

inclined to engage in frequent socialisation as those that did not (Lawrence and Christie 1979). Labi and colleagues (1980) found in their study that even when people regained their physical independence they did not return to their previous social lives, but no further detail was given as to why this occurred. Davidson and Young (1985) found that people considered joining new social activities outside of their homes too risky and consequently people tended to stay within their homes, for many people in their study this increased their risk of isolation and loneliness. One study also identified that depression was strongly linked to loss of activity (Feibel and Springer 1982). These individual study findings gave some interesting insight into the issues people faced after stroke. However the review also highlighted the range of outcomes used, even with similar study aims, and the subsequent difficulties in drawing comparisons in relation to social (or community) integration after a stroke. The six empirical studies identified will now be discussed; an overview of these papers can be seen in **Table 1**.

Study Aim & Authors	Study Description	Participant Characteristics	Key Findings	Strengths and Weaknesses
<p>To understand the relative importance of after-effects, environment and socio-economic factors on the social integration of stroke victims.</p> <p>Bélanger et al. 1988.</p>	<p>Longitudinal evaluation following 129 people after discharge, living in Quebec province in Canada.</p> <p>People were followed for six months after discharge from hospital with three assessments.</p> <ol style="list-style-type: none"> <li>I. Assessment of functional autonomy at 7-10 days after admission</li> <li>II. Tests and interviews (personal perception of health situation, after-effects, factors relating to social environment and information of a socio-economic nature 10-15 days after discharge home</li> <li>III. Same measures as in the second stage plus environmental factors and integration variables six months after second stage.</li> </ol>	<p>Average age 66.8 years.</p> <p>Average hospital stay 43.6 days and then six month follow up period after discharge from stroke.</p> <p>72.9% returned to their own home.</p> <p>Number of men and women in the study not declared.</p>	<p>Individual functional autonomy increased whilst an inpatient and in the first six months home</p> <p>Decrease in the practice of many activities occurs six months after a stroke</p> <p>Social contacts are more frequent than for comparable populations as far as children and close family are concerned but less frequent with friends</p> <p>A quarter of people experienced issues with psychological well-being.</p>	<p>Modified Barthel index was the only standard outcome measure declared and so unclear what other questions were asked of people and therefore difficult to interpret the results.</p> <p>Further evaluation of findings was carried out against a comparable (non-stroke) population to show interesting finding in relation to social contacts.</p> <p>Difficult to ascertain the exact attrition rate during the six months of the study evaluation period.</p> <p>No split in gender was declared.</p>

**Table 1:** A summary of the identified empirical studies.

Study Aim & Authors	Study Description	Participant Characteristics	Key Findings	Strengths and Weaknesses
<p>To understand social and family Integration of hemiplegic elderly patients one year after stroke.</p> <p>Santus et al. 1990.</p>	<p>76 elderly hemiplegic patients living in Italy were interviewed, one year after their acute stroke.</p> <p>Assessment of:</p> <p>Cognitive impairment using the Mini-Mental State Examination.</p> <p>Functional autonomy using the Barthel Index.</p> <p>Mood disorders using the Hamilton Rating Depression Scale.</p> <p>Social integration using the Social Functioning Exam.</p>	<p>Mean age 68.4 years.</p> <p>Males 36 Females 40</p> <p>The people were all discharged from hospital during 1998. One year after a stroke was stated as the time of the interviews, but no further information was given and no range or mean time was found.</p> <p>People also included if living in residential and nursing homes.</p>	<p>12.1% had significant cognitive impairment</p> <p>53% were functionally self-sufficient</p> <p>35.5% showed depressive symptoms</p> <p>57.9% had problems with social and family integration</p> <p>Functioning self-sufficiency was significantly correlated with age</p> <p>Depression was significantly correlated with cognitive impairment, the level of functional autonomy attained and social and family integration.</p>	<p>Difficult to understand methodology in relation to time since stroke, and also how and where the interviews were carried out.</p> <p>Demographic characteristics collected were very comprehensive which allowed further exploration.</p> <p>Although the study abstract states that 120 people were interviewed, from the remaining paper it appears only 76 (63%) were actually interviewed.</p> <p>No definition of integration was given and limited detail on social and family integration was presented.</p>

**Table 1 (cont.):** A summary of the identified empirical studies.

Study Aim & Authors	Study Description	Participant Characteristics	Key Findings	Strengths and Weaknesses
<p>The development of the social index of physical and social outcome to measure social reintegration after a stroke.</p> <p>Trigg and Wood 1999.</p>	<p>Qualitative study using in-depth interviews with 30 people at least six months after a stroke. People all living in the South West of England.</p> <p>Interviews were based around three main aspects: environment, activities and social interaction.</p>	<p>Purposefully selected sample with range of disabilities and types of stroke and age.</p> <p>Mean age 65.4 (range 40-82).</p> <p>Males 17 Females 13</p> <p>No further details on time since stroke apart from <math>\geq 6/12</math></p>	<p>People reported a change, usually for the worst in their levels of integration after a stroke. Decrease in both the quantity and quality of activities especially those in regard to leisure and also those occurring outside of the home.</p> <p>Social interaction was reduced as well in terms of frequency and quality</p>	<p>Study sampling process led to the inclusion of a wide range of people being included.</p> <p>No detail of time after stroke other than at least six months was provided.</p> <p>Definition of social integration was used and interview schedule was adopted in relation to the three components of this definition but one component (environment) was subsequently dropped from the development of the measure.</p> <p>In-depth interviews which led to small sample size but only included people living in one discrete geographical area.</p>

**Table 1 (cont.):** A summary of the identified empirical studies.

Study Aim & Authors	Study Description	Participant Characteristics	Key Findings	Strengths and Weaknesses
<p>To understand the social integration of individuals with aphasia</p> <p>Barry and Douglas 2000</p>	<p>Four male participants living in Melbourne, Australia, who were aphasic as a result of a single left hemisphere stroke, were interviewed with their significant other.</p> <p>The Interview Schedule of Social Interaction (ISSI) was used to measure the perception of social support.</p> <p>Several aphasia-related variables and contextual factors were also assessed using a standardised language assessment and a range of questionnaires.</p>	<p>Four men with aphasia living in the community.</p> <p>Time since stroke ranged between 7 to 25 months from text (9-25 months stated in the abstract)</p> <p>The age of the four men ranged from 29 to 65 years.</p>	<p>Several factors were identified that potentially shaped the networks of the four participants. These factors fell into two broad categories: aphasia-related and contextual factors. Aphasia-related factors included severity of aphasia, time post onset, and inherent disease characteristics. Contextual factors included degree of distress exhibited by the recipient, age at onset, life cycle stage, quality and type of relationship, social network characteristics, and family constellation.</p>	<p>A detailed study with a comprehensive use of measures to ensure both subjective and objective components of social integration were included within the limitations of people's communication problems.</p> <p>A small sample size of only four men with a broad range of age and time since stroke. But this was a pilot study and therefore the results were able to be presented as a rich descriptive analysis due to the small numbers.</p> <p>No definition of social integration was given</p> <p>This was the only study that highlighted the dynamic process of social integration and therefore the potential difficulties in capturing information.</p>

**Table 1 (cont.):** A summary of the identified empirical studies.



Study Aim & Authors	Study Description	Participant Characteristics	Key Findings	Strengths and Weaknesses
<p>Understanding of three main outcomes after a stroke: Basic and instrumental activities of daily living, community reintegration and generic health status</p> <p>Hoffman et al. 2003.</p>	<p>51 people with an initial stroke admitted to an acute hospital in Queensland, Australia, and subsequently discharged to the community were studied</p> <p>Data were obtained by chart review.</p> <p>Follow-up status was determined by telephone interview using:</p> <p>The Modified Barthel Index The Assessment of Living Skills and Resources, The Reintegration to Normal Living Index, The Short-Form Health Survey (SF-36).</p>	<p>51 people</p> <p>Mean 18 months' time since discharge; range 5-36 months</p> <p>Mean age 69. (range 44-90)</p> <p>58.8% (30) men 41.2% (21) women</p> <p>Only people discharged back to independent community living.</p>	<p>At follow up telephone interview:</p> <p>57% of participants were independent in basic ADL 84% had a low risk of experiencing instrumental ADL difficulties, and most people had few concerns with community reintegration.</p> <p>SF-36 physical functioning and vitality scores were lower than normative values.</p> <p>Poorer discharge basic ADL status was associated with poorer instrumental ADL and community reintegration status, and older participants had poorer instrumental ADL, community reintegration and physical functioning.</p>	<p>Of all people eligible only 59% consented to participate. Study was limited to people from one hospital, with their first stroke and those returning to live in the community. These factors limit the generalisability of findings and potentially explain the high levels of ADL and community reintegration found in this study. No age matched control group</p> <p>No specific definition of community integration was used. The range in length of time of follow up was large (5-36 months) and this may have impacted upon the results.</p> <p>Some of the assessment tools may have lacked the sensitivity to accurately measure the capabilities of people after stroke, particularly as in this study many people were functioning at a high level.</p>

**Table 1 (cont.):** A summary of the identified empirical studies.

Study Aim & Authors	Study Description	Participant characteristics	Key Findings	Strengths and Weaknesses
<p>To understand the role of social support in the family and community integration of right-hemisphere stroke survivors</p> <p>Egbert et al. 2006</p>	<p>Qualitative grounded theory study. Single open ended interviews were carried out with 12 people living in the community with a right-hemisphere stroke and their family caregivers living in Ohio, USA.</p> <p>Thirteen interviews carried out in total as one person had two significant care-givers.</p> <p>Definition of community integration given</p>	<p>Mean age of people following stroke 60.7 years.</p> <p>2 females 10 males.</p> <p>Living independently in the community.</p> <p>Time since stroke not given other than saying people were recruited through community stroke groups.</p>	<p>Seven main challenges were identified that hindered community integration: physical, cognitive-perceptual, emotional, relationship, employment, financial, and challenges to activities of daily living and three type of resources were required; formal external, informal external, internal</p>	<p>In-depth study with small number of people and their caregivers' but detailed analysis described to allow audit trail for others. Right-hemisphere strokes selected to give specific insight into specific issues.</p> <p>No time since stroke given.</p> <p>Limited number of females and so potential gender bias.</p> <p>People were recruited from established stroke support groups and therefore may be more able to access the resources needed to integrate into their communities than those who are more isolated.</p> <p>As interviews were also carried out with people's caregivers, people may have been anxious about voicing any concerns or criticisms.</p>

**Table 1 (cont.):** A summary of the identified empirical studies

### 2.3.3 Empirical evidence: Terminology and Definitions

The six empirical studies with people following a stroke were carried out in Italy, England, America, Canada and Australia. Terminology was varied with two studies exploring social integration (Bélanger et al. 1988; Barry and Douglas 2000); and single studies exploring, community reintegration (Hoffman et al. 2003); social reintegration (Trigg and Wood 1999); community integration (Egbert et al. 2006); and social and family integration (Santus et al. 1990). Only three of the empirical studies defined integration within the context of their study (Bélanger et al. 1988; Trigg and Wood 1999; Egbert et al. 2006). Bélanger and colleagues (1988) and Trigg and Wood (1999) both used the same definition based on the normalisation approach (Wolfensberger 1972).

*“..to live in the most natural environment possible, to interact with a wide variety of people, and to take part in the usual activities of our society”*

Egbert and colleagues (2006) in their study, defined community integration using a definition from Dijkers (1999) who carried out his research predominantly with people following spinal cord injury, but developed this conceptual definition through identifying an ideal type of community integration:

*“Re-establishing to the degree possible, previously existing roles and relationships, creating substitute new ones, and assisting people in making these changes.”*

(Dijkers 1999)

Dijkers' (1999) definition brings in the component of social support and also more specifically talks about people returning to old roles and relationships or forging new ones. This definition is more specific to individual people and therefore makes it potentially more helpful for rehabilitation purposes. Unlike the social integration definition used by Bélanger and colleagues (1988), it does not directly incorporate the broader physical environment or the rights of equal access to society indeterminate of people's individual disabilities. The range of definitions identified, combined with the often interchangeable nature

of terms; integration and reintegration; social and community, makes it important for researchers to be clear which definition they are using. It was therefore surprising that three of the studies identified did not attempt to define social (community) (re)integration. This will be discussed further in section 2.3.11.

#### *2.3.4 Empirical Evidence: Participants*

As can be seen in **Table 1**, the number of people involved in the identified studies ranged from 4 to 129. The range in numbers of people related to the individual studies methodologies. The study with four people was a pilot study which aimed to describe the social integration of four men with aphasia but also to identify specific factors that potentially shaped the social integration of the men and their families (Barry and Douglas 2000). Structured interviews were carried out and a rich descriptive analysis was presented due to this small number. The pilot study was also able to explore and critique the study design, including the use of measuring tools for people with aphasia and suggest changes for future research. The largest study involved 129 people in a six month longitudinal case series study carried out by Bélanger and colleagues (1988). Although 129 was the initial number of people at the first assessment, the number of people remaining at six months, and the subsequent attrition rate, was not declared in the write up of this study.

The mean age of the people in each study, ranged from 47 to 69 years. One of the studies, aimed to look specifically at the experiences of older people after a stroke (Santus et al. 1990). Although the mean age in this study was 68, some people were in their 50's at the time of their interview and the study did not report the age required for inclusion. One study purposively sampled, amongst other variables, for a broad range of ages (Trigg and Wood 1999). The others studies did not restrict recruitment to a defined age range, but included a wider and thus more representative sample of the general stroke population. One study attempted to provide some matched controls in order to explore the effects of people with 'normal' ageing with those of stroke. Minimal detail on this comparison group was given apart from these controls

came from the same region of Canada (Quebec) and were recruited from three studies conducted with 'normal' old people (Bélanger et al. 1988).

One paper specifically chose to study people with right-hemisphere stroke, providing specific insight into the unique cognitive-communicative impairments that can occur with people following this type of stroke (Egbert et al. 2006). One paper, as mentioned, only studied people with aphasia so providing insight into social integration in people with ongoing communication issues following their stroke. They also considered study design and methodological approach for future studies with this population group (Barry and Douglas 2000). One study purposively sampled people with different types and effects of stroke as part of the development of a new measure of social reintegration following a stroke (Trigg and Wood 1999). This sampling approach ensured that people experiencing a broad range of stroke sequelae were included and hence would increase the new measure's external validity, without reducing its responsiveness and reproducibility. Only 30 people were interviewed, and from only one geographical area in south west England. This relatively small initial number was partially mitigated against in the later testing phase, although the extended testing continued to be with people living in the same small geographical area in England, thus potentially reducing transferability and validity (Trigg and Wood 1999, 2000, 2003). The remaining studies all recruited people who had been discharged from hospital back to their own homes in the community and so also described a range of residual morbidities.

### *2.3.5 Empirical evidence: Time since stroke*

Following my experience as part of a previous research study with people after a stroke, I perceived time after a stroke to be a potentially important factor in relation to studying social integration. Both the findings from the RCT (Harrington et al. 2010) and the qualitative interviews in this previous study (Reed et al. 2010), highlighted that even many years after a stroke, people continued to feel lonely and were at significant risk of social isolation. The six empirical studies identified all showed a range of time since stroke from

seven to 36 months. One study gave no detail at all of the time that people were interviewed since their stroke (Egbert et al. 2006) and two only gave vague details (Santus et al. 1980; Trigg and Wood 1999). Trigg and Wood (1999) purposively sampled 30 people as part of the initial development of a new social integration measure but did not choose to sample people in relation to time since stroke. They only said that people were interviewed at least six months since their stroke, giving no further information. Only one study discussed the time since stroke as an important factor in relation to their findings and the dynamic nature of social integration (Barry and Douglas 2000). This lack of detail of time since stroke, particularly in the two qualitative studies, was surprising as the time since stroke could therefore be an important component in relation to people's integration following their stroke. Furthermore, the information would also enable readers to judge relevance or transferability of the findings.

### *2.3.6 Empirical evidence: Measures of social (community) integration*

Four of the empirical studies used standard measuring instruments to assess social (community) integration. One series of papers developed a new measure for social reintegration; The Subjective Index of Physical and Social Outcome (Trigg and Wood 1999; 2000; 2003). The other measures used were: the Social Functioning Examination (Robinson et al. 1985); the Interview Schedule of Social Interaction (Henderson et al. 1980); and the Reintegration to Normal Living Index (Wood-Dauphinee et al. 1988). An overview of these four measures can be found in **Table 2**.

Measure	Author	Development	Content	Comments
The Reintegration to Normal Living Index (RNLI)	Wood-Dauphinee et al.1988	<p>Developed via reviews of the literature and expert panels.</p> <p>Once developed, tested with different groups of people including people with stroke.</p>	<p>Consists of 11 declarative statements. Each of these statements are rated by the respondent on a visual analogue scale with the two anchor statements:</p> <p>“Does not describe my situation” (minimal reintegration) and</p> <p>“Fully describes my situation” (maximum reintegration).</p> <p>Individual item scores are combined to provide a total score.</p> <p>Two subscales have been identified within the RNLI; Daily Functioning and Perceptions of Self. These are calculated by combining the responses to the first eight statements and the final three statements respectively.</p>	<p>This measure is strongly linked to health related quality of life and addresses family and productive roles and leisure activities.</p> <p>It has not been specifically tested in older people following a stroke or people many years after stroke but it does include subjective perceptions (final three statements) particularly in relation to self-confidence.</p>

**Table 2:** A summary of measures used in the identified empirical studies

Measure	Author	Development	Content	Comments
The Social Functioning Exam (SFE)	Robinson et al. 1985	<p>Developed conceptually and then tested with 103 people living with a stroke.</p> <p>Limited further detail on the development identified.</p>	<p>28 item measure.</p> <p>Carried out as a semi-structured interview.</p> <p>Each item is rated on a three point scale and added up into a total score.</p> <p>The measure was specifically developed to quantify patient satisfaction with their social functioning both before and following their stroke.</p> <p>No detail was identified on how it could be used before and after.</p>	<p>The measure has been specifically used in the assessment of post-stroke mood disorders and has shown a correlation between the severity of depression and the degree of dysfunction in social functioning at six months after a person's stroke (Starr et al. 1983).</p> <p>This measure has not been as frequently used in the literature as other measures and does not appear to measure the breadth of social integration that some studies have proposed.</p>

**Table 2 (cont.):** A summary of measures used in the identified empirical studies



Measure	Author	Development	Content	Comments
The Interview Schedule of Social Interaction (ISSI)	Henderson et al.1980.	<p>Conceptually developed and tested with a large sample of the general population.</p> <p>Initially designed as a survey method to measure social factors associated with the development of neurotic illness.</p> <p>Developed and tested with Australian population.</p>	<p>Structured interview schedule that assesses two dimensions of social support, availability and adequacy, for two relationship categories; close attachment and social integration.</p> <p>These are broken down further into four scales:</p> <p>Availability of Attachment Adequacy of Attachment Availability of Social Integration Adequacy of Social Integration</p> <p>Interviewees respond to each item using a categorical response system scored dichotomously.</p>	<p>Developed to measure feelings or perceptions of attachment as opposed to the nature of support.</p> <p>It is long and takes 45 minutes to administrate. Needs to be carried out face to face.</p> <p>Has mostly been used in the mental health field with people experiencing 'neuroses'.</p> <p>Was not developed specifically with people following a stroke or those experiencing aphasia but has been developed with Australian population.</p> <p>Used in this context with people with moderate to severe aphasia for the first time and its structured nature made it useful.</p>

**Table 2 (cont.):** A summary of measures used in the identified empirical studies

Measure	Author	Development	Content	Comments
The Subjective Index of Physical and Social Outcome (SIPSO)	Trigg & Wood 1999; 2000; 2003	<p>Developed from in-depth interviews with 30 people following a stroke in the South West of England.</p> <p>Subsequently tested with a larger sample group but all from the same geographical area.</p>	<p>Ten item index designed to assess the long-term physical and social situation of people after a stroke.</p> <p>It contains questions referring to quantitative indices of ability but also some more qualitative aspects of integration such as satisfaction, boredom and self-image</p>	<p>Quick and easy to administer.</p> <p>The initial qualitative interview schedules were developed in relation to the three main aspects of a person's life (environment, activities and social interaction) based on the definition from Bélanger's study as discussed previously (Bélanger et al1988).</p> <p>During the later stages of test development the test items relating to environmental change were omitted as they failed to fulfil the required psychometric criteria.</p> <p>Only developed with people six months after a stroke, although limited information regarding time since stroke.</p> <p>Only developed and tested in one discrete geographical area in England.</p>

**Table 2 (cont.):** A summary of measures used in the identified empirical studies

In addition to these four identified measures, Bélanger and colleagues (1988), who were looking at social integration, utilised the modified Barthel Index (Granger 1979) as their main outcome measure. They also stated that they

*“examined factors relating to the social environment and information of a socio-economic nature and environmental factors and integration variables”.*

However, they did not give any further detail (Bélanger et al.1988, p.254).The modified Barthel Index is a popular measuring instrument in relation to people’s level of dependence in carrying out activities of daily living. However, it does not purport to measure people’s social activities or integration and so will not be considered here in any further detail.

As can be seen in **Table 2**, only one of the measures (SIPSO) was initially developed with people following a stroke. The other measures were all conceptually developed by researchers but were subsequently tested with different groups of people. All measures, apart from the ISSI where no evidence could be identified, had been tested with people following a stroke. The SIPSO was initially developed by carrying out interviews with 30 people following a stroke in one geographical areas in south west England (Trigg and Wood 1999). The initial qualitative interview schedules were developed in relation to the three main aspects of a person’s life (environment, activities and social interaction) and these were based on the definition from Bélanger’s study as discussed previously (Bélanger et al. 1988). During the later stages of test development, the test items relating to environmental change were omitted as they failed to fulfil the required psychometric criteria; hence the measure was re-defined in relation to physical and social outcomes alone. Environmental factors were shown to be of lesser impact in the context of this study (Trigg and Wood 1999).

Three of the measures identified contained a mixture of both objective and subjective questions (SIPSO, RNLI, SFE).The RNLI has been tested and utilised quite extensively, particularly in North America. It is most often used with people after stroke, but often within the first six months or year after a stroke; no studies were identified, prior to 2007, with it being used on people

many years after a stroke. Limited information was identified on the SFE. The tool was developed to quantify people's social functioning after a stroke but has nearly exclusively been used in the assessment of post-stroke mood disorders and has displayed a correlation between the severity of depression and the degree of dysfunction in social functioning six months after a stroke (Starr et al. 1983). This narrows its potential scope and limits its ability to capture other areas of social function after a stroke. Unlike the other three measures, the ISSI only measured people's individual perceptions or feelings of attachment as opposed to the nature of support, thus capturing only subjective perceptions. The ISSI was used in the study by Barry and Douglas (2000) and they recognised this issue and so added *The Number of Social Network Contacts Index* (NSNCI) (Moos et al. 1988), which collected information regarding the frequency of contact with friends and relatives in order to complement and add more context to the ISSI and their findings. This added both subjective and objective richness. As mentioned the ISSI was not specifically developed for people with stroke, nor for people with aphasia. Its highly structured format lent itself well to nature of the study but more importantly the ISSI had been developed and tested in Australia and so the cultural relevance of the questions would be most appropriate to fellow Australians as in the study by Barry and Douglas (2000).

In summary, each of the four measures were developed from different conceptual frameworks and definitions of social (community) integration and so the questions developed were varied and all measured different aspects. These measures are only four of many that have been developed and by their very nature the measurement tools all placed emphasis on outcomes of social (community) integration rather than assessing the process by which people achieved this, which is a core component of the current study. Only one of the measures identified was developed directly with people who were living with a stroke. Until there is further agreement and understanding of a definition of social (community) integration that is meaningful to people who have experienced a stroke, then there will continue to be a plethora of outcome measures. These measures will continue to display a range of content,

offering both strengths and weaknesses and differing outcomes and the cohorts of people being studied are likely to continue to influence the results of studies as much as the measures themselves.

### 2.3.7 *Empirical evidence: critique*

The six empirical studies yielded a range of findings which were difficult to compare and contrast due to their different aims and approaches but key findings will be discussed below.

The main finding that many studies highlighted was that people experienced reduced social contact outside of their homes after their stroke, and this reduction in activities outside of their home often resulted in increased contact with close family (Bhogal et al. 2003; Bélanger et al. 1998; Trigg and Wood 1999; Egbert 2006). Bélanger and colleagues (1998, p.257) compared their findings from people following a stroke with a comparable population of '*normal old people*' also living in Quebec province. They found that, at six months after discharge, people with stroke had an increase in social contact as far as close relatives were concerned but less frequent contact with friends. Barry and Douglas (2000) carried out structured interviews with four men with aphasia. Interestingly, for each of the four men there was minimal perceived change in the availability and adequacy of close attachment relationships within their social networks and all four men perceived that the quality of their relationships with their very closest attachments had been improved by the experience of stroke (Barry and Douglas 2000). This was surprising considering the level of communication impairment in the men. The authors suggest that the findings could be related to the relatively short time since their stroke and could therefore change and worsen over time; highlighting the dynamic nature of social integration and participation. Trigg and Wood (1999) and Egbert (2006) carried out qualitative interviews with people and showed how social interactions within the extended aspects of their social networks appeared to be most vulnerable to change. Trigg and Wood (1999) found that all people experienced a reduction in activities outside of the home but it was the quality of activities and social interactions

that were found to be as important as the actual frequency. This was an important finding and highlighted the importance of the subjective nature of social integration.

In contrast to many of the other studies, Hoffmann and colleagues (2003) found that most people in their study reported a good standard of community reintegration and people only expressed challenges in two specific areas: the greatest difficulty was with taking trips out of town but the ability to fill one's day with necessary or important activities was also of some concern. This finding needs to be considered within the context of the sample. In Hoffmann and colleagues study (2003) only 59% of eligible people consented, it is therefore possible that the population was not representative and this could have led to a degree of sampling bias and those included people could have been more functionally able and active.

Three of the studies highlighted that the reduction in activities identified was only partially explained by the physical effects of stroke (Bélanger et al. 1998; Santus 1990; Egbert 2006). Santus and colleagues (1990) measured mood in the people in his study and found a third of people had symptoms of depression and this was significantly correlated to levels of social integration. Over half of the people (58%) in their study (Santus et al. 1990) were identified as having problems with social integration a year after their stroke but no detail was given as to what these problems were.

The qualitative study from North America (Egbert et al. 2006) involved in-depth interviews with 12 people after a right-hemisphere stroke and their care-givers. They chose to focus on people with right-hemisphere stroke due to the unique cognitive-communicative impairments that can occur. The purpose of the study was to promote a better understanding of the challenges to community integration and to identify strategies to help negotiate the constraints. Egbert and colleagues (2006) identified seven main challenges for people after stroke; physical, cognitive-perceptual, emotional, relationship, employment, financial, and challenges to activities of daily living. In addition, and similar to Bélanger (1998) and Santus (1990), Egbert and colleagues

(2006) found that the degree of community integration was less dependent on the level of disability but found it was more linked to a function of the ability of the person to utilise internal resources (which included motivation, a positive attitude, and patience) in the mobilisation of needed external resources (including social support from family and friends, formal resources and assistive devices). Furthermore, Egbert and colleagues (2006) found that several of the people highlighted the importance of having a sense of belonging and acceptance. This linked to the findings by Trigg and Wood (1999) in that it was the quality rather than the quantity of relationships that were of key importance to people. The study by Egbert and colleagues (2006) was the only study to explicitly discuss the role of the external environment and the interplay between the person and society in integration following a stroke. Instead, most of the other studies primarily focused on stroke as an event and how the subsequent bodily impairments that resulted from the stroke influenced social (community) integration, thus placing the focus on the individual's deficits and not on the wider environment.

### 2.3.8 *Summary*

Only a small number of studies were identified in relation to social (community) integration and stroke. These studies helped to build a picture of the challenges of social integration faced by people after a stroke; there was only a limited insider perspective with only two studies using qualitative interview methods. Additionally, none of the studies identified looked specifically at the issues facing older people, or the actual process of integration for people following a stroke. I subsequently looked more broadly at the literature and specifically at stroke papers in relation to the term participation, in order to identify if any of the particular aspects in relation to my proposed study had been covered elsewhere.

## **2.4. (Social) participation and stroke**

Nine papers were identified in relation to participation and social participation after a stroke (Cardol et al. 2002; D'Alisa et al. 2005; Amarshi 2006;

Desrosiers et al. 2005, Desrosiers et al. 2006; Hammel et al. 2006; Cott et al. 2007; Rochette et al. 2007; Hartman-Maeir et al. 2007). Similar to the previous identified studies in relation to social (community) integration, most of these papers (six) were quantitative studies, two used qualitative design and one was a theoretical paper.

In the quantitative papers, researchers found that people experienced reduced social roles after their stroke (Cardol et al. 2002; Rochette et al. 2007), activity limitations and participation restrictions (D'Alisa 2005; Desrosiers et al. 2005; Rochette et al. 2007; Hartman-Maeir et al. 2007) and associated longstanding dissatisfaction with life (Desrosiers et al. 2006; Hartman-Maeir et al. 2007). Functional scores and emotional status were also found to be independent predictors of participation restriction among people in the longer term after a stroke (D'Alisa 2005; Desrosiers et al. 2006). Many of the studies identified were focused on the individuals' deficits caused by their stroke in relation to participation and not on the broader role of the environment (Cardol et al. 2002; D'Alisa 2005; Hartman-Maeir et al. 2007; Rochette et al. 2007). One quantitative study did discuss the need for more consideration and measurement of environmental factors that could prevent social participation (Desrosiers et al. 2006).

Two qualitative studies were identified in the literature (Amarshi et al. 2006; Hammel et al. 2006). Hammel and colleagues (2006) conducted participatory action research, examining the communities that people wanted to participate in and identifying the barriers to full participation. The first phase of this research was an intensive qualitative study conducted over time and across contexts with 20 people living in Chicago, USA. Surprisingly, no details of the twenty people's ages or time since their strokes were provided which limits its potential transferability. Hammel and colleagues (2006) highlighted the important relationship between people and the environment and argued that community participation is more than a static measurement of 'activity in context'. They suggested it is instead a 'doing in context' and that being a respected and valued member of the community, was therefore more than just a physical or cognitive independent performance but an active and



interdependent relationship between the person and the environment (Hammel et al. 2006, p.55). The study also found that people focused on access to participation opportunities, having control over decision making and negotiating a variety of supports. Hammel and colleagues (2006) found that they did this by actively strategising how to adapt the environment (social, physical, cognitive, sensory) in order to promote and sustain meaningful participation in light of limitations. This was the first study identified that focused specifically on the interplay between the person and their environment and not predominantly on the individual's deficits after a stroke in relation to integration or participation. The study also highlighted the dynamic nature of participation, as previously found in the Barry and Douglas (2000) paper previously, reinforcing the complexity of measuring such a multidimensional and fluid construct.

Amarshi and colleagues (2006) carried out the other qualitative study that was identified, looking at social and leisure participation with older people between one and nine years after their stroke (mean 4.4 years), with a mean age of 72 and who were living in Greater Toronto, Canada. They explored experiences as people transitioned and aged in their own homes. Using the concept put forward by Hammel and colleagues (2006) they also found that participation involved more than a performance in context by pointing to issues of meaningful inclusion and social engagement and to participation as a dynamic process rather than a static event. Similar to Hammel and colleagues (2006) they also considered the impact of environmental and societal barriers on participation (Amarshi et al. 2006). This study added new understanding to the meaning of social and leisure participation and activities outside of the home. The people in this study were all retired and living in their own homes many years after their stroke and so the findings were most pertinent to the current study aims. One main limitation identified was that Amarshi and colleagues (2006) recruited people from two active stroke support groups in Greater Toronto and so as a result they are likely to have greater and broader support networks than other people after a stroke.

These two qualitative studies added richer information in relation to the important and dynamic relationship between people and their environments in supporting participation and social integration. They also emphasised the need to ground research in relation to social integration and participation in the first hand perspectives and experiences of people. Amarshi and colleagues (2006) also conducted their research many years after people's strokes which added a new dimension to the initial literature review highlighting how even four years after a stroke, participation was experienced as a dynamic process. Neither of the two qualitative studies looked at how people actually increased participation after their strokes.

Cott and colleagues (2007), in a theoretical paper discussing models of transition after stroke, argued how the main tenet of rehabilitation remained focused on people's functional recoveries rather than on a return to meaningful roles and activities. They also highlighted how little attention is paid to the transition of people, the role of the environment, the nature of the community, the importance of meaning and choice when thinking about life situations, and change in abilities over the life course. These aspects highlighted themes from other reviewed studies and resonated with some of the findings highlighted by both Hammel and colleagues (2006) and Amarshi and colleagues (2006). This additional review of the literature in relation to participation and stroke allowed for an increased understanding with the two qualitative studies adding an insider perspective. No studies were identified prior to 2007 that considered the process of participation. Therefore, a further review of the literature in relation to social (community) integration and brain injury (traumatic and acquired) was carried out to see if it had been covered in this area.

## **2.5. Social (community) Integration and brain injury**

A final brief review was carried out in the literature in relation to traumatic and acquired brain injuries other than stroke. This literature yielded more studies than the stroke literature but the majority of these studies used quantitative methods. I was particularly interested in seeing if there was any development

of knowledge from the insider perspective. Only two related qualitative studies were identified that offered such perspectives, in relation to community integration after a brain injury (McColl et al. 1998; Karlovitz & McColl 1999). Both of these studies were carried out in Ontario, Canada.

McColl and colleagues (1998) carried out a large qualitative study with 18 adults after traumatic brain injury over a period of a year, with each person being interviewed eight times. Their ages ranged between 19 to 58 with a mean age of 30.5 years. The interviews took place between 1 to 45 years (11.5 years mean) after their injury but these people had only in the previous year been repatriated from the USA back to Ontario in Canada and into supported living within the community. Hence all the interviews occurred within each person's first year of living in their new communities.

The study found nine distinct indicators of community integration:

- |                               |   |
|-------------------------------|---|
| <b>Conformity:</b>            | Knowing what is required to fit in and being comfortable in fulfilling those criteria.                        |
| <b>Acceptance:</b>            | Perceptions that individuals are allowed to be themselves in the community in which they seek to participate. |
| <b>Orientation:</b>           | Knowing one's way around in a community.  |
| <b>Close relationships:</b>   | Having significant others such as a spouse or a parent in the community.                                      |
| <b>Diffuse relationships:</b> | Having relationships that are not necessarily characterised by closeness, reciprocity, mutuality or intimacy. |

<b>Productivity:</b>	Being involved in structured, productive activities, such as education, employment preparation and volunteer work.
<b>Leisure:</b>	Participation in opportunities offered in the community in free time.
<b>Independence:</b>	Exercising self-determination in terms of one's own abilities.
<b>Living situations:</b>	The actual living arrangements in which individuals could be autonomous and reside outside of institutions.

These themes gave a rich insider view which McColl and colleagues (1998) then organised into four components: general factors of integration, social support, occupation and independent living. From this study a definition of community integration was proposed. Community integration was recognised as a multi-dimensional construct and comprising of three key areas: relationships with others, independence in one's living situation and activities to fill one's times (McColl et al.1998). This study gave a broad understanding of community integration from people living in the community and also included the role of the wider environment and not just that of the individual. The study also explicitly highlighted the importance of having a wide range of relationships with others both close or diffuse, bringing in the importance of both quantity but also quality of relationships. Although the study was longitudinal and people were interviewed eight times in a year, it focused on gaining an insider's view and definition of community integration and not on the actual process of how people managed or did not manage to integrate. In addition, this research was mostly carried out with younger people following traumatic brain injury so not all of the concepts would necessarily be relevant with older people after a stroke.

Karlovitz and McColl (1999) used McColl's framework in a subsequent study. Eleven people between four to six months after brain injury and living in residential rehabilitation programmes were interviewed to understand how they were coping with community integration. This study found seven stresses associated with community integration and these were similar to those of McColl and colleagues (1998). The stresses were: orientation, transportation, living situation, loss of independence, relationships, loneliness and routine, and problems with work. The people interviewed were still in residential programmes and so these findings will be particularly linked to their situation and potentially less applicable to people living in their own homes and so was less helpful to the current study.

The study by McColl and colleagues (1998) offered a really useful framework of nine indicators of community integration to consider and many of which complemented and added some richness to the findings in the stroke literature. However both of these qualitative studies identified were carried out with much younger people who had experienced traumatic brain injuries and so not all the findings would necessarily be transferable to older people after a stroke. No studies identified looked specifically at the actual process that a person may experience after a stroke (or brain injury) in attaining social (community) integration.

Having provided an overview of the literature, the range of terms and definitions identified will now be discussed and then a summary of the findings from the initial literature review will be given.

## **2.6. Definitions and terminology**

Within the literature reviewed, two issues arose. Firstly, a clear definition of social integration was often not given and secondly, differing terminology was often used. Berkman and colleagues (2000) highlighted this by commenting that when researchers were writing about the important impact of social relationships on health, many terms were found to be used both loosely and interchangeably. Such terms identified were social networks, social support,

social ties and social integration. In this initial literature review I also found that in addition to social integration, the term community integration was regularly used and that integration was often changed to reintegration.

The lack of a standard definition of social integration is most likely to be due to conceptual origins arising from many different theoretical frameworks and contexts. All studies that defined social or community (re)integration did agree that they could be seen as multidimensional constructs. No definitive difference between community and social integration could be found, although in some studies social integration was described as a subsection of community integration (Dijkers 1999; McCabe et al. 2007) whilst in others there was less distinction (Egbert et al. 2006; Winkler et al. 2006). One main difference found in the literature between social and community integration, was that whilst the opposite end of the continuum for social integration has been defined as social isolation (Pillemer 2000; Boden-Albala 2005) for community (re)integration, this has been defined as institutionalisation (Dijkers 1999).

Additionally, in the identified literature the term reintegration and integration were often used interchangeably, but the interpretation of reintegration could imply different meanings. Dijkers (1999) argued that for people experiencing a head injury or sudden illness, this occurred to people who were previously healthy, active and integrated into social life. Following their illness and once people had returned to living in the community after inpatient rehabilitation, Dijkers (1999) suggested that community reintegration was the main aim. This involved re-establishing to the degree possible, previously existing roles and relationships, creating substitute new ones and assisting with this life transition. People who were previously integrated into society prior to their illness would therefore be considered to be reintegrating. Although Dijkers (1999) included creating substitute new roles and relationships into the definition of reintegration, there is a risk that this term could potentially be interpreted in the context of people only returning or reintegrating into old roles and relationships and not developing new ones. No other papers reviewed offered a definition of why they had used integration or reintegration.

To add further complexity, since the inception of the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation (WHO) (2001), the concept of participation has also become an interest in rehabilitation. Conceptually, participation is defined as *“involvement in a life situation”* (WHO 2002, p.10). In the ICF (WHO 2001) participation is described together with the concept of activity, which is defined as *“the execution of a task or an action by an individual”* (WHO 2002, p10). A person’s activity and participation are subsequently proposed to be the result of dynamic interactions between health conditions and contextual factors, including both personal and environmental factors (WHO 2001).

Whilst there is some obvious overlap between participation and social integration, there were two reasons why social integration was the preferred term to use in this study in 2007. Firstly, there had been criticism that the definition of participation as offered in the ICF (WHO 2001) did not explicitly include subjective experience or satisfaction and instead placed a greater emphasis on capacity and performance; therefore participation became more of an objective condition (Wade and Halligan 2003). For this current study, I was particularly interested in this subjective experience. Secondly, the role of the environment is a separate component in the ICF and although it does emphasise the interaction between the environment and functioning, actual indicators of environmental factors determining the quality of participation are not included. In contrast, the definitions and meanings of social (community) integration that were identified in this initial literature review, did add more emphasis in relation to people’s choices to engage fully in society and included the concept of a dual role between the individual and society working in partnership (van de Ven et al. 2005). This current study will use the term social integration whilst recognising the overlap with other terms (community integration and participation) but will be asking people living with a stroke what matters to them from their own personal experiences.

## **2.7. Summary**

This initial literature review has added to the findings in the first chapter and highlighted the importance of social integration in improving health and well-being following a stroke. It has shown that there is no consensus around the definition of social integration. The experience of a stroke, as highlighted from the studies reviewed, can have a lasting impact. People often lose social groups and networks outside of the home and this can lead to a reduction in participation and a loss of social integration. There remains a lack of detailed understanding in the research field into the meaning of integration from the insider perspective and the actual process of moving towards or reaching successful integration, particularly in older people, many years following a stroke. The aim of this current study is to develop a greater understanding of both the meaning and process of social integration in older people at least three years after a stroke and the methodology and method used to achieve this will be described in the following chapters.



## Chapter 3. Methodology

### 3.1. Introduction

This chapter will aim to explain the rationale for choosing Straussian grounded theory to guide the study design for my research (Strauss and Corbin 1990; Strauss and Corbin 1998; Corbin and Strauss 2008). It will start by examining philosophical assumptions about what constitutes knowledge and then examine the strategy of inquiry. The following chapter will give a detailed account of the method of data generation and analysis.

### 3.2. Philosophical approach

Researchers subscribe to different views of the world, often referred to as paradigms, which support different philosophical stances. These views are underpinned by three major dimensions; ontology, epistemology and methodology. The researcher's choice of paradigm or paradigms of inquiry will influence their work since their world view and accompanying philosophical assumptions will guide how they think and behave throughout the research process (Guba and Lincoln 2005).

Ontology relates to the nature of reality (Hudson and Ozanne 1988), asking what things, if any, have existence or whether reality is *"the product of one's mind"* (Burrell and Morgan 1979, p.1). The researcher's view of reality is the cornerstone to all other assumptions and what is assumed here predicates their other assumptions. Epistemology is the relationship between the researcher and the reality (Carson et al. 2001). It concerns the study of the nature of knowledge, that is; *"How is it possible, if it is, for us to gain knowledge of the world?"* (Hughes and Sharrock 1997, p.5). Rosenau (1992, p.109) describes it as *"the nature, validity, and limits of inquiry"*. A person's views about what constitutes reality are thought to determine those of the nature of knowledge and, brought together, these determine the methodological principle. The three concepts of ontology, epistemology and

methodology are related in that epistemology is defined by ontology, and methodology is influenced by both ontology and epistemology (Guba and Lincoln 1998).

In this research I took a particular view of reality and a specific ontological position, which influenced my methodology and the methods used. I took an interpretivist view (Carson et al. 2001), which meant that I assumed that research is guided by a relativist ontological perspective. This contends that there is no one external reality or truth, but rather multiple realities (Burr 2003). These multiple interpretations are individual, situated and may change over time and according to context (Guba and Lincoln 1998). Thus, empirical observations will not produce the same perspectives or interpretations and local realities can only be approximated within their dialectical processes. So, for example, in speaking with people in an interview, the narratives produced are created in the moment and are not necessarily reflecting a fixed internal cognitive state (Willig 2001).

A subjectivist epistemology guided my study (Pidgeon and Henwood 1997). Knowledge that emerged as a consequence of the research inquiry was based upon the transparent relationship between myself and the people that I interviewed and was co-produced. However, this relationship was not value free and it was not possible (or necessarily preferable) to strip the relationship of any bias. The knowledge produced was therefore valid for the purposes of this inquiry, and will not be exactly replicable (Schwandt 2000).

Epistemological and ontological assumptions identify the kinds of knowledge that research can produce and the extent to which that knowledge reflects the reality or truth of the phenomenon under study and, therefore, what claims can be made. These assumptions assist in specifying the methodology adopted and the research's particular contribution (Parahoo 2006). The decision of which methodology was chosen for this study will be discussed later in this chapter but first the interpretivist approach chosen will be considered.

### 3.3. Interpretivism

The interpretivist approach that was used in this study stems from the constructivist paradigm and emerged in the 19<sup>th</sup> century as a reaction to the positivist quest for objectivity, and theory and hypothesis testing (Holloway and Wheeler 2009). As positivism appears historically to have been the benchmark against which other views have been compared and critiqued (Benoliel 1996); this paradigm of inquiry will be used here to provide contrast.

Using an interpretivist approach, researchers believe that reality is relative and multiple. In line with this perspective there can be more than one reality and subsequently more than a single organised way of accessing such realities. Lincoln and Guba (1985) explain that these multiple interpretations are complex to understand as they depend on many other systems for meanings and the knowledge generated from interpretivism is discerned through socially constructed and subjective interpretations (Hudson and Ozanne 1988; Carson et al. 2001). In contrast to this, the positivist ontology presents a single, external and objective reality to any research question, which remains independent of the researcher's belief (Carson et al. 2001; Hudson and Ozanne 1988). Positivist researchers take a controlled and structured perspective to conducting research by determining an area of research and building research questions and hypotheses that are then tested (Carson et al. 2001).

Interpretivist research understanding is created from "*value-laden socially constructed interpretations*" (Carson et al. 2001, p.6) and therefore researchers apply more individual and fluid research frameworks than in positivist paradigms. This research approach will therefore need to be more open, be able to give understanding to meanings in human interaction, and have the ability to make sense of what is comprehended as multiple realities (Carson et al. 2001). Positivists attempt to remain disconnected from the research participants they are studying by actively creating space between themselves and the participant. They work to remain emotionally neutral by making clear distinctions between reason and feeling (Carson et al. 2001).

Furthermore, positivists assert that it is important to differentiate between fact and value judgement: They constantly strive for objectivity and use consistently rational and logical approaches to research (Hudson and Ozanne 1988; Carson et al. 2001).

Interpretivists enter the research field with some preliminary insight about the research topic but want to understand the perspectives of their participants, not test out their own ideas (Carson et al. 2001). In order to do this it is recognised that during the data generation stages, the researcher and the people they are researching are interdependent and mutually interact with each other, and co-produce a collective account of perceived reality. The researcher remains fresh to new ideas throughout the research process and allows them develop (Lincoln and Guba 1985). The use of such an emergent approach is also consistent with the interpretivist stance of a person's ability to adapt and that no-one can gain an advanced understanding of time and context bound social realities (Hudson and Ozanne 1988). In contrast, in the positivist approach, statistical and mathematical techniques are core to the research methods embraced and researchers stick to detailed and structured research techniques to reveal single and objective realities (Brannen 1992).

The goal of interpretivist research is to understand and interpret human behaviour rather than to generalise and discover causes and effects (Carson et al. 2001). The interpretivist researcher needs to understand reasons, meanings and other subjective experiences which are time and context bound (Hudson and Ozanne 1988). The goal of positivist researchers is to make time and context free generalisations which they consider possible because human actions can be understood as a result of genuine causes which precede people's behaviours (Hudson and Ozanne 1988; Carson et al. 2001). Positivist scholars believe in the power of replication research. Interpretivist researchers are seeking to carry out studies which uncover inside perspectives or meanings of social phenomena from its study participants. From a methodological perspective the interpretivist researcher prefers to work with qualitative data which provides rich descriptions of social constructs. Alternatively, the positivist researcher uses quantitative methods

to focus on facts that are gathered through direct observation and experience, and are measured empirically (Carson et al. 2001).

In summary, researchers will find that these philosophical assumptions are consequential to each other, that is, their view of ontology affects their epistemological persuasion which, in turn, affects their view of human nature. Having discussed my ontological and epistemological assumptions I will now turn to methodological considerations.

### **3.4. Methodological considerations**

Research methodology and research method are distinctive concepts.

Analogically, a methodology is a domain or a map, while a method refers to a set of steps to travel between two places on the map (Jonker and Pennink 2010). A methodology refers to a model to conduct a research enquiry within the context of a particular paradigm; in this case an interpretivist paradigm.

The methodology comprises the underlying set of beliefs that guide a researcher to choose one set of research methods over another. I chose a qualitative approach because I was interested in understanding the social behaviour of people who had experienced a stroke, by exploring accounts of their social life and gaining an *“insider’s view”* (Avis 2005, p.4). This could not be achieved by using a quantitative approach, which would utilise forms with pre-determined questions and categories. It was my research question that drove this decision as I wanted to give precedence to obtaining an insider’s view of social integration from older people who had experienced a stroke.

I subsequently needed to choose the methodological approach for my qualitative research study. Many qualitative approaches share common elements and are based on a similar stance to research. However, the choice of my approach depended most importantly on my research aim and objectives but was also influenced by my skills, epistemological stance and even my personality as highlighted by Holloway (2005). There is a considerable overlap in terms of procedures and techniques in different qualitative methodological approaches. Holloway and Todres (2005) describe the overlap of epistemological, aesthetic, ethical and procedural concerns as

being able to encourage a fairly generic view of qualitative research, in which similarities are considered more important than differences and that flexibility becomes an important value. The alternative view to this perceived value of flexibility is the concern that this can lead to inconsistency and a lack of coherence. This has been described as method slurring (Baker et al.1992) and therefore risks diluting the integrity of the approach. Holloway and Todres, (2005) argue that it is possible to “*transcend this tension*” (p.102) and shift the emphasis away from method for method’s sake by encouraging the researcher to be more thoughtful, reflective and transparent, and therefore able to represent diversity in approach and practice whilst acting as a “*faithful mediator between communities in their quest for understanding*” (p.102).

I considered three different qualitative approaches to help me answer the research question for my study; Phenomenology, Ethnography and Grounded Theory.

The term phenomenology is popular and widely embraced, but its meaning has become confusing. Patton (2002) described how the term can refer to a research paradigm, an interpretive theory, a philosophy, an analytical perspective, a major qualitative research tradition or a research method framework. In spite of the differences, all of these approaches share the focus of phenomenology, which is to describe human experiences and the meaning they give to these experiences (Creswell 2012). Phenomenologists are interested in how people put together the phenomena they experience in such a way as to make sense of the world and develop a worldview (Patton 2002). The phenomenologist aims to describe this in so much detail that the reader can feel what it is like and gain insight into the lived experience. This approach would have allowed me to give a rich description of the lived experience of people who had experienced a stroke. However, I wanted to explore the processes people were going through rather than describe their experience in detail.

An ethnographic approach to qualitative research has developed from the field of anthropology, where the researcher studies the structure and function

of a group of people (Creswell 2012). The aim of ethnographic studies is to give a holistic picture of the social group studied, attempting to describe aspects of the cultural and social system of that particular group. In healthcare, ethnography has been used in topics related to health beliefs and practices, allowing these issues to be viewed in the context in which they occur and therefore helping broaden the understanding of behaviours (Savage 2006). I could have observed people going about their lives and seeing how social integration was incorporated by people through interviews, but I felt that for me this approach would have been too obtrusive and also would not necessarily give me an in-depth understanding of how people defined social integration for themselves.

I decided to use a grounded theory approach. Grounded theory is a qualitative research approach that was originally developed by Glaser and Strauss in the 1960s (Glaser and Strauss 1967). The self-defined purpose of grounded theory is to develop theory about phenomena of interest. However, this is not just abstract theorising; the theory needs to be actually grounded or rooted in data, hence the term (Glaser and Strauss 1967). Grounded theory is recommended when studying social problems and in the case of this study, understanding situations such as living with a long term condition where people may need to adapt (Schreiber 2001; Corbin and Strauss 2008). Holloway and Todres (2005) expand on this and add that grounded theory is most suited to studying the process of human action and interaction. Furthermore, grounded theory, unlike other qualitative research approaches, facilitates a shift from reporting simply descriptions of what is occurring, to an understanding of the actual process by which it is occurring (Corbin and Strauss 2008; Cooney 2010). The aim of grounded theory is not only to describe the area of research well but also to advance theoretical conceptualisations of findings. The researcher starts with individual cases (chosen purposely or theoretically), and then generates and analyses data concurrently whilst enabling findings and conceptualisations to develop and also cross-fertilise (Schreiber 2001; Cooney 2010). One data generation episode (usually an interview, as in this study) adds to previous ones and the

conceptualisations that have emerged (Strauss and Corbin 1998; Corbin and Strauss 2008). The process is ongoing until saturation is reached.

Importantly, Corbin and Strauss (2008) highlight how conceptualisations are steered by theoretical sensitivity which is underpinned by the individual researcher's unique skills and experiences (Corbin and Strauss 2008).

For this study, I was specifically interested in trying to understand the process and meaning of social integration from older people who had experienced a stroke. By using a grounded theory approach, I would be able to develop a substantive theory, (in this case substantive, meaning one that is close to real world situations), which would increase understanding of people's experiences of integration following a stroke.

### **3.5. Grounded Theory**

#### *3.5.1 Philosophical underpinning to grounded theory methodology*

The philosophical assumptions underpinning grounded theory are derived from symbolic interactionism (Cutcliffe 2000; Holloway and Todres 2003; Heath & Cowley 2004; Bluff 2005; Carpenter 2006). Symbolic interactionism focuses on how meaning is derived in social situations and the symbols used to convey these meanings. Mead (1934) produced the philosophical underpinnings of symbolic interactionism in 'Mind, Self and Society' (Mead 1972) whereas Blumer (1969) is credited with the term itself and its application as practical sociological research. Symbolic interactionism is founded on three premises:

- Human beings act towards people, objects or things on the basis of the meaning that things have for them.
- Meaning is derived from, or arises out of, social interaction
- Meanings are modified through an interpretive process (Blumer 1969).

The core principles underwriting the process of symbolic interactionism are meaning, language and thought (Charon 2006). Meaning is socially



constructed and language is the source of meaning. Meaning, therefore, occurs out of social interaction and is not inherent in objects. Knowing depends upon the symbols applied or the naming of objects and language. Meaning is negotiated through language and its symbols whilst thought subsequently modifies each individual's interpretation of those symbols. Thought or thinking is an inner conversation where the self exists as 'I' and as spontaneous and subjective, and 'me', as objective and a reflection of how others see you (Mead 1972). Self is therefore an ongoing adaptation. People effectively act (or behave) as they do because of the way in which they interpret meaning and situations in situated interactions. In symbolic interactionism the overt and covert thought or meaning in (environmental) processes and interactions (with others) is dynamic and ongoing (Mead 1972).

Symbolic interactionism has relevance for the area of social integration in this study on several counts. Firstly, the study of meaning, thought and language in a dynamic interplay is considered important given the social nature of this study and its situatedness. Secondly, the role of the researcher is also given due concern with Blumer (1969) suggesting that scientific study needs to '*lift the veil*' (p.39) of the phenomenon under study by getting close to the area and by digging deep into it through careful study (Blumer 1969). The researcher's role in the research, therefore, is legitimised and made transparent. Finally, the notion of 'thought' and 'self' recognises the need to address the self, like the researcher role, as an integral entity in this co-produced enterprise (Mead 1934; Blumer 1969).

In summary, Blumer (1969) highlighted that when individuals interact with each other, they do not merely respond directly to the actions of another person as behaviourists had presupposed. Instead, they interpret these actions, ascribing meaning to these behaviours, which in turn shapes their response. Consistent with this perspective, grounded theorists often study how social interactions shape meaning and how individuals conceptualise or define themselves. That is, researchers are interested in how people being

studied define the context and situation and also how they are defined (Bluff 2005).

Since its development, grounded theory has evolved and diversified and the differing approaches often cause confusion for novice researchers on deciding which approach to choose. Whilst grounded theory continues to share a single ontology the diversification has mostly been within its methodological approach (Heath and Cowley 2004). At the heart of grounded theory is the belief that knowledge and understanding may be enhanced by generating new theories rather than analysing data within existing ones (Heath and Cowley 2004; Cooney 2010). However, there have emerged philosophical differences between Glaser and Strauss in the process of theory generation. It is likely that Glaser and Strauss' differing academic backgrounds and understanding shaped their differing perspectives on grounded theory, which emerged specifically when they started writing as individuals (Heath and Cowley 2004). This will be now be explored further.

### 3.5.2 *Background to Grounded Theory*

The grounded theory method has grown over the years from the seminal work of Barney Glaser and Anselm Strauss (1967). These two American sociologists come from different research backgrounds and their collaborative work blends rudimentary practices in sociology (Glaser and Strauss 1967; Glaser 1978; Strauss 1987; Glaser 1992; Glaser 1998; Strauss and Corbin 1998).

Anselm Strauss trained in symbolic interaction at the University of Chicago's school of qualitative research, where he was influenced by the pragmatist philosophical tradition (Glaser 1998; Strauss and Corbin 1998, Charmaz 2000). Barney Glaser was trained at Columbia University in quantitative methodology, qualitative mathematics and theory construction, particularly in theoretical coding (Glaser 1998). It was the combination of these two distinct backgrounds of Strauss and Glaser, whilst collaborating during the early 1960s, which produced the constant comparative method which was later named grounded theory (Glaser and Strauss 1967).

Much debate has occurred over the last few decades on what are the core constituents of grounded theory. Urquhart (2007) emphasised two key tenets as fundamental building blocks of grounded theory: (a) the researcher has to set aside theoretical ideas; and, (b) the concepts are developed through constant comparison. The first tenet, that the researcher has to set aside theoretical ideas, indicates that avoiding preconceptions is of prime importance in carrying out grounded theory. However, Charmaz (2000) has highlighted that it is not possible and instead these preconceptions must be noted and reflected on, throughout the entire research process. This requirement for both continuous reflective practice and reflexivity is an important part of the method. With grounded theory, if the researcher holds some ingrained convictions then these can be encapsulated as text and then analysed with all other texts (Glaser and Strauss 1967; Glaser 1978). The data analysis, will then contradict, validate, or extend the relevance of the theory to the substantive area being considered. Most important here is that these beliefs must be exposed and utilised and not hidden or ignored.

The second tenet that Urquhart (2007) proposed was that without the constant comparison approach, grounded theory cannot emerge. Since its first inception, the constant comparative method has been a main concept in the evolution and appreciation of grounded theory (Glaser 2001). Glaser and Strauss (1967, p.113) described the constant comparative method as facilitating

*“the generation of complex theories of process, sequence, and change pertaining to organisations, positions, and social interaction that correspond closely to the data since the constant comparison forces the analyst to consider much diversity in the data”*

This diversity they described is attained by comparison between incidents and properties of a category and in a circular and consistent manner (Glaser and Strauss 1967). Over time the constant comparative method has been used to produce either conceptualisations or rich descriptive accounts and it is this conceptualisation versus description debate that has emerged as one of the

key differences between the Glaserian and Straussian approaches to grounded theory and will now be considered (Heath and Cowley 2004).

### 3.5.3 *Glaserian and Straussian approaches*

Methods will develop and evolve and their key advocates will often differ in their explanation and understanding of the best way for these to mature and develop. This has been the case with grounded theory. The publication of *'Basics of qualitative research: grounded theory procedures and techniques'* by Strauss and Corbin (1990) and the subsequent condemnatory reply from Glaser (1992) heralded the materialisation of a division in grounded theory resulting in the 'Straussian' and 'Glaserian' models (Stern 1994).

A main difference between these two models has been their perspectives and approaches to data analysis. Glaser has been viewed as remaining closer and more steadfast to the classic grounded theory model, whilst Strauss (with Corbin) is considered to have moved away and reformulated the original version (Glaser 1992; Annells 1997; Heath and Crowley 2004). Interestingly data analysis is only very broadly described in the initial book (Glaser and Strauss 1967). Two subsequent books published by Strauss (with Corbin) attempted to make clear the actual steps involved in data analysis (Strauss and Corbin 1990; 1998). Corbin (with Strauss) published the 3<sup>rd</sup> edition, 'The Basics of Qualitative Research' in 2008; two years after Strauss had died. In this book she acknowledges that her thinking of grounded theory had evolved and modernised, and that her aim was not to recreate Strauss's approach to analysis but instead to bring together all the good in previous editions with some new aspects of contemporary thinking.

Strauss's more explicit description of data analysis has been criticised. Melia (1996) felt it was far too over formulaic. Glaser (1992; 2002) was severely critical and accused Strauss of not being true to the original method and that Strauss had moved away from emergence of data and promoting "*forced, full, conceptual description*" (Glaser 1992, p.5). Strauss and Corbin (1998), in the second edition of their book, adjusted their initial approach and emphasised that it had never been their intention to promote inflexibility and structure but

to offer researchers guidelines for data analysis. This second edition was far less prescriptive than the first, and the third edition (Corbin and Strauss 2008) has continued along this line and yet most criticisms seem to always refer back to the first edition.

One of the main areas of divergence between Strauss and Glaser has been in relation to the debate of whether verification is an outcome of grounded theory process (Charmaz 2000; Heath and Cowley 2004; Holloway and Wheeler 2009). Strauss (1987) indicated that induction, deduction, and verification all took place whilst Glaser (1992) maintained that grounded theory is inductive only. This difference of opinion seemed to be partly due to a matter of interpretation and may simply be implicit in the process. In 1967 (p.28) Glaser and Strauss together wrote,

*“.....generation of theory through comparative analysis both subsumes and assumes verification and accurate description, but only to the extent that the latter are in the services of generation.”*

Glaser (1978; 1992) remains faithful to this tenet and views induction as the key process, with the researcher moving from the data to empirical generalisation and then on to theory (Bulmer 1969). Glaser (1992) also describes how the data are analysed and coded, and memo's used to record ideas and potential insights as they develop. The creativity used in memo writing is a crucial process if a theory is to be attained but that the data are allowed to speak for themselves (Glaser 1992; Heath and Cowley 2004).

In contrast, Strauss and Corbin (1990) highlighted the significance of both deduction and verification but also considered that the place of induction was overemphasised (Byrant and Charmaz, 2007). In the two later additions of their books, Strauss and Corbin (1998 and Corbin and Strauss 2008) only refer to deduction superseded by validation and elaboration and no longer mention verification. This was highlighted by Byrant and Charmaz (2007) who claimed a shift to abductive reasoning. Abductive reasoning has been defined by Byrant and Charmaz (2007, p.603) as:

*“A type of reasoning that begins by examining data and after scrutiny of these data entertains all possible explanation for the observed data and then forms a hypothesis to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data”*

Within this definition Byrant and Charmaz (2007) proposed that Straussian grounded theory was more aligned to contemporary constructivist thinking.

Byrant and Charmaz (2007) highlighted a few other key differences between Straussian and Glaserian approaches. Firstly, Strauss places emphasis on the need to look beyond the data to the wider context for possible explanations whilst Glaser believes the theory emerges from the data. Also, whilst Glaser outlines two types of coding processes; substantive and theoretical, Strauss (with Corbin) describe three distinct types; open, axial and selective. Finally, Strauss and Corbin also added to the process the conditional matrix or paradigm (Strauss & Corbin 1990) renamed the consequential matrix (Strauss & Corbin 1998). This matrix, they claim, helps to determine the questions that will be asked of participants and directs the theoretical sampling (Strauss & Corbin 1990; 1998). Due to the evolution of grounded theory method and the emergent differences in approach it is important for all researchers to be explicit as to which approach they use (Stern 1994) and the approach chosen for this study will now be discussed.

#### *3.5.4 Approach for this study*

The differing perspectives outlined above, made the selection of a grounded theory approach for my study a difficult decision. In addition to choosing a Glaserian approach or a Straussian approach, I could also have chosen a combination of these approaches; move towards a more evolving approach, such as constructivist grounded theory (Charmaz 2000) or even revert to the original or classical approach (Glaser and Strauss 1967). Most importantly, there is no right approach and each has both advocates and critics. I decided to choose between the Glaserian or Straussian approach as this would be my first time utilising grounded theory and I wanted to gain some understanding initially from using one of these two main approaches. Whilst it was clear that

there was no correct framework, I was also aware of my concern over which choice to make, feeling out of my depth with the amount of information and breadth of arguments. I therefore considered four key issues to choose between a Glaserian or Straussian approach to grounded theory: The use by others in the same field of research; their potential to generate theory; their congruence with current thinking and my own thinking; and their general user friendliness.

- I looked at the literature within the rehabilitation field and found that it was mostly within the nursing literature where a significant amount of study utilising grounded theory was identified. I did not find any preferred approach, instead, followers of both schools many with their own preferences and stances. I found this interesting but as a novice nothing particularly resonated.
- The quality of the output of the Straussian approach has been highlighted as a potential issue with studies often failing to generate a theory (Artinian 1998). Glaser (1992) is clear that failure to produce a theory is simply at odds to the intent of original grounded theory. Nonetheless from my reading, Strauss with Corbin (1998) and Corbin with Strauss (2008), offered a broader utilisation of grounded theory and recognised that not all studies intended to build theory, and acknowledged that sometimes researchers may choose to use the framework and process of grounded theory to produce rich and purposeful descriptions. This approach offered by Strauss felt personally more comfortable and less pressured.
- I also felt that the Straussian approach was more aligned with contemporary thinking and my own personal stance. Although contested by some, the Straussian approach has reflected a shift towards postmodernism and a relativist perspective (Annells 1997; Byrant and Charmaz 2007). Annells (1997) also advocated that Straussian grounded theory had shifted to the constructivist paradigm, which reflected my own stance as discussed earlier in this chapter.

- Finally, whilst Strauss has been criticised for excessive rigidity, for me there was a certain resonance in having the opportunity to use a more systematic approach in carrying out grounded theory research set out in his work with Corbin (1998; 2008).

In considering these four areas, I decided to use the Straussian approach to grounded theory and so whenever the term grounded theory is used in this thesis, then it will refer to the grounded theory work carried out by Strauss and Corbin (Corbin and Strauss 2008; Strauss and Corbin 1998).

### **3.6. Implementing grounded theory**

This section describes some of the key characteristics of Straussian grounded theory. The following elements all need to be considered when planning a study: Theory development; theoretical sampling and sample size; data analysis; the literature as a source of data; theoretical memo's and field notes; methods of data generation; maintaining rigour and validity; theoretical sensitivity; reflexivity and overall ethical issues. To avoid inappropriate repetition and in an attempt to improve flow, I have only covered the first three topics in this section. Literature, as a source of data, is covered in my initial literature in chapter two and the other areas are considered in the following method chapter.

#### *3.6.1 Theory development in Straussian grounded theory*

The goal of grounded theory research is the discovery of theory that emerges from and is grounded in the data (Glaser and Strauss 1967; Strauss and Corbin 1998; Heath and Cowley 2004; Bluff 2005; Carpenter 2006; Corbin and Strauss 2008). It is this emphasis on theory development that is the key distinguishing feature of grounded theory (Carpenter 2006).



Strauss defines theory as:

*“.....A set of well developed categories (e.g. themes, concepts) that are systematically interrelated through statements of relationship to form a theoretical framework that explains some relevant social, psychological, educational, nursing, or other phenomenon. The statements of relationships explain who, what, when, where, why, how and with what consequences an event occurs.”*

(Strauss and Corbin 1998, p.22).

A grounded theory is expressed in the form of a core category, its related categories and their properties. Strauss and Corbin (1998) emphasise that the key difference between theory and description is its power to explain and predict and therefore providing “*guides to action*” (p.25).

Two types of theories can be developed using grounded theory: substantive or formal theory (Glaser and Strauss 1967; Strauss and Corbin 1998; Corbin and Strauss 2008). Formal theories are more general than substantive theories and examine wide areas of interest (for example socialisation and stigma) and the theories apply across groups (Carpenter 2006; Holloway and Wheeler 2009). Substantive theories focus on specific social processes or a particular context and consequently are more limited. Substantive theory is the most common type of theory derived from grounded theory and was the aim of this study as data collection is from one substantive area; older people who have experienced a stroke.

### 3.6.2 *Theoretical sampling*

The purpose of theoretical sampling is to co-produce data with people, places and events that will maximise opportunities to develop concepts, uncover variation and identify relationships between concepts (Corbin and Strauss 2008). The process can be described as simultaneously collecting, coding and analysing data to generate theory. The main concern here is the representativeness of ‘concepts’ rather than people or events (Corbin and Strauss 2008). Data collection is therefore controlled by the emerging theory.

A theoretical sample evolves as the study progresses. However, some initial sampling decisions do need to occur and are taken on the grounds of what is logical and practical (Cutcliffe 2000). Purposeful sampling was used initially, this technique is a type of non-probability sampling where the researcher consciously selects particular subjects (in this case older people after a stroke) for a study to ensure that the people will have certain pertinent characteristics (Patton 2002). In this study, people were initially chosen simply in relation to meeting the study inclusion criteria. In grounded theory studies, once data generation has begun then purposeful sampling is superseded by theoretical sampling (Corbin and Strauss 2008). Theoretical sampling being simply a process whereby data analysis directs the decision for further data collection. In Straussian grounded theory, the focus of sampling changes according to the type of coding (open, axial or selective) in progress. Strauss and Corbin (1998) identify three forms of theoretical sampling; open sampling, relational and variational sampling, and discriminate sampling.

Open sampling aims to keep data gathering open, thus allowing discovery. Strauss and Corbin (1998) provide some examples of open sampling approaches:

1. Purposeful selection of persons, sites or events.
2. Systematic or convenience sampling, for example, sampling in order of a list of names. This form of sampling assumes that differences in data will emerge naturally because of natural variation in the situation.
3. Sampling events that occur unexpectedly in the field.
4. Sampling by returning to the data to reanalyse these in light of emerging theoretically relevant concepts.

Relational and variational sampling focuses on collecting data that enable the researcher to identify significant variations (Strauss and Corbin 1998). Comparison between incidents produces questions that guide subsequent data collection. The researcher then purposefully chooses sites or persons that have the greatest potential of maximising or minimising differences.

Interview or observation questions are also adjusted in response to emerging concepts (Strauss and Corbin 1998).

Discriminate sampling focuses on selecting sites or people that maximise opportunities for comparative analysis. This may mean returning to old sites or people, or going to new sites or people to achieve saturation. Sampling at this stage is said to help fill in the categories and flesh out relationships (Strauss and Corbin 1998; Schreiber 2001).

The sampling strategy utilised in this study is discussed in the next chapter.

### 3.6.3 *Sample size*

Neither the sample nor the sample size can be predetermined. In grounded theory, theoretical sampling continues until saturation is achieved (Schreiber 2001; Carpenter 2006; Morse 2007; Stern 2007; Corbin and Strauss 2008). Morse defined saturation as data adequacy and that saturation is attained by collecting data until no new concepts emerge (Morse 2007). Charmaz argued that new data will fit into the categories already devised and that the categories are well developed in terms of their properties and dimensions (Charmaz 2000).

Ritchie et al. (2003, p.84) outlined seven factors that might affect the potential size of a sample:

- Heterogeneity of the population
- Number of selection criteria
- Extent to which 'nesting' of criteria is needed
- Groups of special interest that require intensive study
- Multiple samples within one study
- Types of data collection and method used
- Budget and resources available

To these, Morse (2007) added: Scope of the study; nature of the topic; quality of the data; study design and use of 'shadowed data'. She described this as

the information that people give the researcher on types, characteristics and dimensions of others in addition to themselves.

Compared to large survey studies, a small sample is normal in a grounded theory study. The focus is on adequacy and depth of the data and not on the number of people included. However, amongst researchers there is a difference in opinion on how small. Morse (2001) recommends that the sample size in a grounded theory study should be approximately 30-50, whilst Stern (2007) estimates 20 to 30 interviews or similar hours of observation. It has been reported that diversity is difficult to achieve with samples of 20 or less (Morse 2001) but there is also a fine line between enough and excess which can result in conceptual blindness where the researcher is at risk of having so much data that they struggle to analyse (Morse 2001).

Saturation is also more than a matter of no new categories and themes emerging (Charmaz 2006). It also denotes a development of categories in terms of their properties and dimensions, including variation, and possible relationships to other concepts. This provides a depth and ability to explain. It is only when the researcher has explored each theme in some depth, identifying its various properties and dimensions that the researcher can say that a level of saturation has been achieved (Charmaz 2000). In reality, a researcher could go on collecting data forever by adding new properties and dimensions to categories. They will need to be clear that the concept is sufficiently well developed for the purposes of the research study in question and what has not been covered will be one of the limitations of the study. Alternatively, studies can be concluded too soon (Stern 2007). Researchers equally need to be aware, and able to discern between, saturation of categories and their own saturation with the data collection process, which could be lack of time, money and energy (Corbin and Strauss 2008). Charmaz (2006) suggested that a small study with "*modest claims*" (p.114) might achieve saturation faster than a study that is proposing to describe a process that covers many disciplines. For example, in this current study, I have explored the understanding of social integration specifically with older

people who had experienced a stroke and not how all people integrated following an illness; 30 people took part in this current study.

There remains ongoing discourse over the understanding of saturation. Morse (2001) felt that researchers often claimed to have attained saturation but were often unable to prove it. This was also suggested by Bowen (2008) who suggested that saturation is most often stated in qualitative research papers but without any open and clear explanation of what it meant or how it was actually achieved. Strauss and Corbin (1998) suggested that saturation was a matter of degree and that the longer researchers study and analyse their data, there will always be the possibility for “the new to emerge” (1998, p.136). Instead, they concluded that saturation should be more focused on reaching a point where it becomes “*counter-productive*” and that “*the new*” that is uncovered does not add anything further to the overall theory or framework (Strauss and Corbin 1998, p.136).

### **3.7. Summary**

This chapter has provided a rationale for the selection of Straussian grounded theory to guide this study. Grounded theory is suited to studying social processes and interactions which are intrinsic to this study. This chapter also introduced three of the key characteristics of Straussian grounded theory; theory development; theoretical sampling and sample size. The remaining key characteristics will be discussed in the next chapter.

## Chapter 4. Method

### 4.1. Introduction

This chapter provides a description of the design of my research study. The selection of participants, ethical issues, approach to data generation and analysis and how rigour was demonstrated, are described. The chapter aims to provide sufficient detail to permit readers to judge for themselves the suitability of the research design for addressing the research question and the overall quality of the study (Patton 2002). It also aims to meet the criterion of providing an audit trail.

### 4.2. Study Context

The aim of this study was to gain a greater understanding from older people of the meaning and process of social integration following a stroke. Specific objectives were to gain an understanding of:

- Whether people felt they had successfully integrated following their stroke.
- How they had (or had not) integrated and what factors had helped or prevented the process of integration.
- What factors could have improved their and perhaps other people's experience of integration.

Corbin and Strauss' (2008) version of grounded theory guided the study design. Grounded theory supports the generation of emergent theory when little is known about the topic in question, and so this study aimed to develop a substantive theory. There were two distinct phases of the study. Phase one involved 14 interviews and an emerging model and in phase two a further 16 interviews were carried out until saturation of the core concepts was reached and a final model developed (**Figure 2**, chapter five). I will present the processes involved in both phases together to avoid repetition.

## 4.3. Sample

### 4.3.1. *Selecting study participants*

For the initial phase, I interviewed 14 people who had experienced a stroke. Participants had previously been recruited as part of a randomised controlled trial, led by the University of Bath (Harrington et al. 2010). The implications of recruiting from this trial are discussed below and also in chapter seven. I used this approach as it enabled me to access a potentially large number of people, who had already agreed to further contact for research purposes. In addition, the research question had been shaped to some extent through contact with some of these people during the trial as discussed in chapter one. The previous trial had examined the provision of community schemes offering eight weeks of twice weekly, exercise, education and goal setting in an informal group setting for people at least six months following their stroke, held across two counties in South West England. After the intervention period and once data collection had finished, participants in the control arm of the trial were then offered the opportunity to attend the community schemes. The schemes ran over a two and a half year time-frame with the final scheme finishing in 2005. As part of the trial, people had also given consent to be approached for taking part in other studies.

People in the trial had been recruited through local stroke clubs, multidisciplinary community stroke clinics, General Practice stroke registers and community advertising via posters. It is possible that, due to the nature of the intervention and the recruitment, extremely disabled and socially isolated people may not have come forward. However, when the baseline characteristics of the 244 people who took part in the previous trial were examined, they had a wide range of disabilities, cognitive and functional characteristics, including people who appeared to be very active within their communities and people who were reporting high levels of social isolation (Harrington et al. 2010; Reed et al. 2010).

The following inclusion criteria were already determined by the randomised controlled trial at the University of Bath and therefore concurred with this study:

- People living in the community following their stroke including supported housing and residential accommodation.
- People who are able to take part in a simple interview on their own or with a friend/carer present. Communication problems after stroke did not preclude any selection, and a friend or carer was asked to be present to support.

In addition, this current study also adopted the following additional inclusion criteria:

- People with a Mini Mental State Examination (MMSE) score above 24 (Folstein 1975). These scores had already been collected as part of the previous trial and were used to add confidence that people were fully able to undertake the interview, which would involve discussions of complex and abstract ideas.
- People of any gender but aged 65 and over as I was particularly interested in the challenge of integration for the older person who had also experienced a stroke.
- People at least three years after their initial stroke. This was important as the aim of the study was to understand more about the actual process of integration for a person following a stroke and I wanted to talk to people who had lived for a period with their stroke, who were not in the initial couple of years after their stroke and would therefore be able to give more perspective. In addition, having this timescale also meant that the experience of the eight week course they attended as part of the randomised controlled trial would not be uppermost in their minds.



Exclusion criteria already adopted for the randomised controlled trial and subsequently for this current study were:

- People living in nursing homes: This criterion had already been set as part of the trial and so was continued for this study. I wanted to explore an understanding of the meaning and process of integration in the everyday world and the factors and processes that allowed perceived successful integration. Although understanding this from the perspective of people who lived in a nursing home was recognised as an important area to consider, it was felt that these people may have different experiences following their strokes, and so not including them for this study was appropriate.

No other additional exclusion criteria were set for this study.

In phase two, I interviewed a further 16 people. They were all recruited from the East Kent stroke group. This group is a registered charity that has a large database, which includes people who are discharged from three large stroke units in Kent. The charity works in partnership with the three local hospitals and on discharge all people are given a detailed stroke information pack provided by the charity but are also subsequently sent bi-monthly newsletters via email or post. The charity also offers the opportunity for people to attend regular social events and meetings, but many people just choose to receive the newsletter and this means their membership is not exclusive to people who attend the social groups. It was due to this inclusive approach that I approached the chairperson of East Kent Strokes. The large number of people would also allow me to carry out theoretical sampling in phase two, which will be discussed in the next section. The same inclusion and exclusion criteria were utilised as for phase one, except for the mini mental state examination test (Folstein 1975) as this had not been collected for people who were part of phase two. Nobody in phase one had been excluded in relation to this and therefore it was not felt a necessary criterion for the second phase.

#### *4.3.2. Research governance and ethical approval*

Research governance approval was gained from each of the local Primary Care Trusts for phase one. As I was recruiting via a community setting for phase two, NHS research governance approval was not required. As the participants were a vulnerable group and I would be going into their homes, police clearance via a CRB check was obtained. Ethical approval for phase one had already been obtained for the randomised controlled trial from Bath Local Research Ethics Committee. Additional ethics approval was gained from the committee for this qualitative study. This included permission to re-access the database in order to gain details needed to inform the sampling of the stroke survivors (Appendix A-1). In phase two ethical approval was obtained from the Brighton Local Research Ethics Committee (Appendix A-3). Particular ethical considerations for this study are discussed in section 4.4.4

#### *4.3.3. Maintaining anonymity and confidentiality*

A number of measures were adopted to ensure participants' anonymity and confidentiality. Only one database with the participants' names was kept and this was secure and password protected. All digital recordings were destroyed as soon as they had been transcribed. Transcriptions all used pseudonyms so they could not be traced back and are also held in a secure password protected file. The same pseudonyms are used in this thesis and will be used in any conference presentations and future publications.

#### *4.3.4. Risk Assessment*

A risk assessment was completed looking at the safety of both myself and the participant. I adhered to the University of Southampton lone working policy (where I was studying initially) for visiting people in their own home for phase one and a similar policy from the University of Bournemouth for phase two, adopting the same approach. A third party was made aware of each visit and it was agreed that I would call after each interview. If after a specified time I had not called and was unable to be contacted on my mobile phone, then a sealed envelope with the details of the visit including the person's phone

number would be opened and further action could be taken as needed (Appendix A-5).

#### 4.3.5. *Gaining access to the setting*

In phase one, I had already been working as part of the trial in the setting and had established a network of contacts, which included the coordinator for the original study at the University of Bath. Ethical approval to approach people to see if they were interested in future research had been obtained as part of the original research programme. During management of this programme, I had visited many of the intervention and control group's sessions. However, I had not had any individual contact with the people or their families or carers. For the second phase, the interviews in East Kent were established through East Kent Strokes. I made contact through the Chair of the charity who was known to one of my supervisors.

#### 4.3.6. *Gaining access to the participants*

**Phase one:** The trial database was used to identify people that met the eligibility criteria for this study. This database was updated if the project team were informed of any deaths. On completion of the trial, all people were sent a newsletter which included asking people to let the University know if they did not wish any further contact. The database was updated with this information. Just over 100 participants on the database were suitable to be approached. However, some of these had incurred no contact with the project team for over two years and so I decided not to approach these people. This reduced the number to 59 people to be approached. These people were contacted by letter (Appendix B-1). A total of 57 letters were posted; the full addresses of two people were not available. I made the decision to not send any follow up letters as these people were older and many were potentially vulnerable, and I did not wish them in any way to feel coerced or uncomfortable. The letter was sent from the original trial research co-ordinator, who had led all the initial recruitment. The letter contained full written information of this new study (Appendix B-1). It offered all people an opportunity to ring the co-ordinator or myself for further information.

From the 57 letters sent out, 16 people confirmed they were happy to take part. Two people responded that they did not want to take part and one person's daughter informed me that her mother had recently passed away. Out of the 16 responses, I was able to interview 14 people; two of the people's health deteriorated prior to the interview and they did not make any further contact.

**Phase two:** The Chairperson of East Kent Strokes sent letters and information out to people who were identified as meeting the inclusion and exclusion criteria for this study and in line with the sampling framework that was developed after phase one (Appendix B-2). This is described in the next section. He also placed an advert into the charity's quarterly newsletter. From 20 letters there were 14 responses, which led to 13 interviews. A further three responses came directly from the newsletter and all led to interviews. One person was unable to be interviewed due to the sudden ill health of his wife. All the people who responded met the eligibility criteria.

During the initial telephone call, people from both phases of this study were offered the opportunity for the meeting to occur in a venue of their own choosing. All participants invited me to visit them in their own home. This telephone call was followed up with a letter or email confirming the interview appointment and also gave details of how to contact me if they needed to cancel with a reminder to ensure that my identification as the researcher was checked before allowing me into their house. On meeting the potential participants and before any interview began, I reviewed all information already given and, discussed and answered any further questions. If the participants were in agreement to proceed with the interview, they were asked to sign two identical consent forms (Appendix B-3 & B-4) allowing for the interview and recording to take place. One copy of these forms was left with the person and the other one was filed with the study record.

#### *4.3.7. Sampling*

The use of theoretical sampling in grounded theory studies has already been discussed in the previous chapter (section 3.6.2). In this study open sampling

was initially employed in order to keep the data open. I wanted to purposively select people who would be able to share the knowledge and experience of their stroke and allow the collection of information rich data. The response rate from the initial 57 letters in phase one was only 28%. Consequently, the ability to use theoretical sampling techniques as data generation and analysis progressed, was limited and so a more pragmatic approach was adopted. This was not a major concern as this was the first phase of a two part study and more theoretical sampling would be able to occur, if required, in phase two.

In phase two, I utilised theoretical sampling. Initially, I employed variational sampling techniques, as I specifically focused on increasing the number of women to give more balance to the study; in phase one only three of the 14 people interviewed were women. This was potentially important as initial analysis had identified differences that could have been gender specific. As the analysis progressed, I tried to employ discriminate sampling techniques. I was interested in conducting interviews with people who were perceived by others as managing well socially after their stroke and those that were doing less well. This was less successful and will be discussed further in the data analysis section (4.5).

#### **4.4. Data Generation**

##### *4.4.1. Interview structure*

For this study qualitative interviews were the method utilised. Burgess describes qualitative interviews as a “*conversation with a purpose*” (1984, p.102). Interviews are often seen as the easy option for the novice qualitative researcher (Taylor 2005) and Taylor (2005, p.53) highlights how they give

*“a window on which participants think and how they report their feelings and actions”.*

However, she (Taylor 2005, p.53) also reminds us that they do not capture actual behaviours and actions, instead they

*“investigate perceptions of a phenomenon but might not explore the reality of the phenomenon itself”*

Interviews may be unstructured, semi- structured or structured (Taylor 2005). The degree of structure and participant control characterises the type of the interview. Pontin (2000) likened structured interviews to questionnaires administered face to face and hence they are rarely used in qualitative studies. In contrast, unstructured interviews are carried out with little or no organisation allowing the participant maximum control (Corbin and Morse 2003). Semi- structured interviews fall between the two. A set of questions are worked out in advance but there is flexibility in the phrasing and order of the questions (Holloway and Wheeler 2009). This was the type of interview I carried out. I made judgements about what was appropriate to ask in the context of the conversation, including whether to omit or add questions, and allowed flexibility in the order and the direction. The key strength of using semi-structured interviews was that they kept both myself and the people I was interviewing on track whilst also allowing us both some degree of freedom of expression (Holloway and Fullbrook 2001).

There is some debate between the uses of unstructured or semi-structured interviews in grounded theory but in reality most grounded theory interviews become semi-structured because, as key issues emerge, there is a need to focus on these to facilitate development of the theory. Furthermore, issues that lack relevance are not pursued (Bluff 2005).

#### *4.4.2. Approach to interview*

I ensured the experience for the participants would be as pleasant as possible, recognising that some of the questions and the topic matter could cause upset. I used the key strategies identified by Robinson (2000) for supporting older people during an interview. These included: tuning into stories, steering the conversation, providing a frame of reference to aid recall, conveying empathy and being sociable. Robinson (2000) also recognised that

some older people needed to be reassured that what they had to say was important and helpful; I allowed sufficient time, balancing this with recognising that the interview may be an exhausting experience. Although I had many years of professional experience working as a community physiotherapist visiting older people in their own homes, I explored the literature and sought guidance from fellow researchers and my supervisors for advice on conducting interviews.

#### 4.4.3. *Interview procedure*

Prior to the interview and before I went through any paperwork, I endeavoured to spend some time getting to know the person or people that I had met. Each meeting was different and I used my own experience and background in judging how to approach the interview. I was aware that I was in people's own homes and I knew that if they were relaxed in my company then they would be more able to talk freely.

The information that had been sent to the people in advance of the interview, introduced me as a researcher but also as a physiotherapist with a professional background. I was aware from the literature that the way the people responded to questions was likely to be influenced by their perceptions of the role and status of the interviewer (Richards and Emslie 2000). However, this was not just about my professional status but also potentially my class, age and gender. Letting the people know about my background as a physiotherapist, risked them perceiving me as an expert and being more sensitive about responding with the answer that they thought I might expect. It also risked them feeling less able to talk about bad experiences of physiotherapy. On the other hand, it gave them some reassurance that I had experience and some form of understanding of their experience of a stroke. Some of the people in the current study did talk to me about issues they had encountered in rehabilitation and physiotherapy after their stroke which gave me reassurance that they felt comfortable to do so.

I was an integral part of the research process and made sure that I continued to examine and reflect on my role and how I co-produced data with the people

that I was able to interview. I also ensured that both the people interviewed and their partners present were able to ask me as many questions as they wanted. I deliberately allowed adequate time before and after the interview for further conversation and did not want people to think I was ever pressed for time. In addition, I looked at all times for clues of tiredness and checked in with people to ascertain how they were feeling when it felt appropriate. Interviews lasted between 40 and 100 minutes and the time was very much guided by the people I interviewed.

Written permission for digital recording of the interview was obtained and all but three people were happy for this to occur. This recording ensured that a verbatim written account of the participants' comments could be created, reducing the potential for interviewer error and enhancing validity (Patton 2002). One of the people I met, decided on the day, that she did not want to be recorded but was very happy for the interview to go ahead and for me to make notes as we spoke. One man was unwell on the day that I visited him, I offered to return but he insisted that we went ahead. However, due to his illness, I decided not to record the interview but instead helped him make a cup of tea and stayed with him until his daughter arrived as had been planned. He was keen to talk to me about his life after his stroke and I made detailed field notes once he was safe with his daughter and I was back in my car. Although I have been unable to use any direct quotes for these two interviews, the data from my field notes has still been part of my analysis. I made a decision not to record one further woman; as soon as I arrived she became extremely emotional and it was difficult to understand her. I sat with her and listened to her and she was able to calm down. She told me that she was extremely depressed and had been all her life, since a teenager. She had a lot of support from her neighbours, her family, and the local health service. One of her neighbours was taking her to the supermarket as I was leaving.

Once the interviews had come to a natural end, I turned off the recorder and as I felt appropriate, I continued to talk with the people. As appropriate, we discussed their plans for the day or week ahead or about any event coming



up, but also I made sure that I continued to affirm their contribution to the study. I was sensitive that the interview may have been emotional for some of the people and so did not want to rush away. I thanked people for their time and allowing them to visit me in their homes. I was also aware that the interview process should not feel to the participant like a hit and run event (Cutcliffe and Ramcharan 2002) but equally it would be unethical to raise false expectations or pose as a friend (Corbin and Morse 2003). All the people had a contact number for me and my email address on the documentation; I did not advertise for them to keep in touch but I reassured them that if there was an issue after I had left, I would be easy to contact by themselves or their family or friends. One man emailed me following our meeting with some further thoughts, and to thank me for letting him talk about his life after his stroke. With his permission, the information in this email was used as part of the analysis.

#### *4.4.4. Ethical considerations during data generation*

Dilemmas can often arise during data generation, in this case during interviews. Holloway and Wheeler (2009) believe it is possible to anticipate these to some extent and so I considered, in advance, possible issues that could arise in relation to the study and discussed these with my supervisors. It is however impossible to predict all potential scenarios and ethical issues that may occur.

One main concern was the possibility that the interviews may cause distress to the people that I met (Corbin and Morse 2003). However, there is little published evidence that supported the fact that people can become harmed or distressed by taking part in qualitative interviews. An alternative view is that people can find unstructured interviews validating and an opportunity to freely voice their feelings and tell their own stories (Cassell and Symon 1994; Corbin and Morse 2003). Nevertheless, it was important for me to consider the impact of the interview on people I was meeting and how I would handle the distress if it occurred. Smith (1992) believed the researcher has an ethical responsibility to handle distressing material with sensitivity and judgement,

and recommended listening and acknowledging but not continual probing that may produce further pain. Corbin and Strauss (2003) also made a distinction between what could be termed normal upset and deliberate probing causing distress. Corbin and Morse (2003) recommend stopping the interview should the person become distressed and resuming when they have regained composure. How best to respond is of course a matter of judgement. Over half of the people that I interviewed showed some emotion during their interview. This ranged from a slight quiver of their voice to tears. On a few occasions and without cutting across the person, I offered for the interview and recording to stop temporarily. This was declined but I ensured that my questioning did not cause further distress, whilst allowing the person to express their feelings. One woman was deeply distressed when I arrived at her house, I subsequently was informed by her neighbour, who visited whilst I was there, that sadly, this was her normal state of mind. As discussed previously, I assessed the entirety of the situation and I made the decision not to record the interview and instead sat with her and listened. Although I was clear that I was present in the capacity of a researcher and not as a clinician, on this occasion I did ascertain that her family and General Practitioner were aware of the situation and that the woman was being supported as it would have been against my duty of care and morally reprehensible for me to leave her.

#### *4.4.5. Development of the interview guides.*

An initial interview guide was developed (Appendix C-1), comprising of open ended questions which would give people the freedom to voice their opinions and describe their experiences about social integration in their own way. Topics included questions in relation to their life before their stroke and the subsequent changes since their stroke, specifically the impact on their social life. The aim was to use the guide flexibly to enable more of a conversation to occur and to enable the interviewee to feel as relaxed as possible (Taylor 2005). Over time the interview guide gave way to an exploration of emerging concepts as adhering rigidly to initial questions would have hindered discovery.

This initial interview guide was pre-piloted with a research colleague who had recent experience of interviewing older people who had experienced a stroke, and so she used this experience to assimilate the role in order to help test the questions. Immediate changes were made as the questions were found to be far too formal and not easy to answer. I had asked directly about social integration which was not a term that many of people use in day to day language and so these more formal questions were adapted to more user friendly terminology. I used words like getting out and about, social groups, social world, relationships and taking part in things both inside and outside of the home. A second interview guide was then developed (Appendix C-1) and this was piloted with one of the people from phase one. My supervisors listened to this interview and advised on any changes needed to improve the quality of future interview techniques. Particular advice was given on extending and improving the use of both follow up and probing questions. Due to the initial pilot interview being carried out with a colleague and the subsequent change to the interview guide, this first interview was successful in gaining some useful insights and has been included in the analysis.

Earlier interviews were more fluid and allowed people to tell their stories. They covered a wide range of discussion about people's social lives after their strokes and their own thoughts and experiences. However, as is the norm in grounded theory, later interviews, although still flowing, became more focused. Consequently, people interviewed later in the study were asked different questions than those interviewed earlier because the questions asked were shaped by the emerging concepts and on-going analysis (Schreiber 2001). For example, I became interested in how people described the specific issues around realising that they needed to start getting out and about again and how they tackled these issues. I therefore started asking more specific questions about this area. Interviews in phase two also utilised more comparative questions; for example, "*other people have told me that they had to really think hard about deciding to start getting out and about again, is that how it felt for you?*" I tried hard to adapt my use of language and vocabulary for the person I was talking with to make them feel at ease. As I

neared saturation of the major categories and the core concept, I focused my final few interviews on teasing out and testing the emerging theory (Appendix C-2).

I listened back to all of my interviews to help immerse myself in the data and also as a critique and reflection of my interview style. Initially, my inexperience as a novice qualitative researcher often meant that I sometimes did not seize the opportunity to probe and explore important remarks made by the people. Instead, I inadvertently closed the topic down and moved onto a new question. When listening back to the interviews, I also reflected on my own struggle with allowing silences, and how I was concerned that the person was looking to me to ask another question and not that they may be thinking. I worked hard to ensure more space in future interviews, thus potentially allowing a greater depth of response. Over time, my interview style and technique improved and this is an area of expertise that will continue to develop over time.

#### 4.4.6. *Field notes*

Field notes are the written account of the researcher's thoughts and observations and are used to enhance data collection (Bluff 2005). Description and the researcher's perceptions are also important areas to be recorded. Burgess (1984) summarised field notes as a combination of the researcher's personal reflections as well as detailed descriptions that help the remembrance of events in the setting. Field notes covering my immediate reflections on each of the interviews were written in my car straight after the interview and then reviewed the morning after. I included in these field notes my immediate thoughts about the interview and any other observations that would not have necessarily been picked up on the recording, and areas of the discussion that I wanted to reflect on. An example of one of my notes is included in Appendix D-2; this was one of my earlier interviews. These notes were incredibly important to me as my study has been protracted and I found re-reading these in collaboration with the transcripts enormously invaluable. In my later interviews, I noticed at times, that my field notes also contained

some information that was also pertinent to my memos, with particular areas encouraging further analysis or interrogation of the data. My use of memos will be discussed in the next section.

#### 4.4.7. *Transcribing*

Although the literature on transcription provides general agreement on the interpretive and constructed nature of transcripts (Baker 1997), transcription often continues to be overlooked by qualitative researchers (Kvale 1996; Bird 2005). Davidson (2009) highlighted, in her review of the transcription literature, that the relationship between theoretical assumptions of a study and transcript development are frequently left implicit or ignored. Lepadat and Lindsay (1999) notably asserted that when researchers do not explain the theoretical perspectives that inform transcript development or address choices made in transcription, they assume a default position whereby they appear to take transcripts as transparent, thus inadvertently presenting a positivist position on transcription by omission.

For this study, having discussed possible transcription notations with my supervisors, I initially worked with a professional transcriber who was linked to the University of Southampton, to carry out the transcribing of the interviews. I had discussed this with fellow researchers and had been advised, from an efficiency of time perspective, that this approach would be helpful and sensible. The transcriber had many years of experience and we agreed together that she would transcribe verbatim all words and maintain confidentiality of the recordings and transcriptions by using password protected NHS mail, adhering to strict information governance protocols. But I soon realised that the outsourcing of the transcribing separated me from process and that transcribing was not simply an arduous chore but an integral and important part of the analysis. I decided to try and transcribe myself, I received training from the transcriber and although I was slow and it took me many hours longer than the professional, it was this process of transcription in itself that often yielded important insights. In total I transcribed 20 of the 27 recorded interviews. I found this invaluable and part of the beginning of

making sense of the co-produced data. A page of transcription can be seen in Appendix E-1.

The transcription of interviews and analysis occurred simultaneously. All names were changed to a pseudonym and the only transgression from verbatim transcribing was to assure people's confidentiality. For example, one person mentioned her actual address during the interview and so on the transcription this was changed by removing the road name and number. Transcriptions also included any non-verbal or background sounds (laughter or coughs) which were typed in parentheses. Non-verbal utterances, such as hm, um, yeah were also transcribed and long pauses or silences were noted. The transcriptions included line numbers to support analysis.

In addition to ensuring confidentiality of the transcriptions, issues of quality and trustworthiness are also crucial and again often overlooked (Lapadat & Lindsay 1999). To assure the quality of the seven transcriptions carried out by the transcriber, I carried out spot checks against the original recordings and found no differences and I asked a colleague to do the same with those that I had transcribed. I also listened to each of the recordings and then immediately afterwards read the transcription through in its entirety to personally help with the transition from audio to written word and also ensured the flow and feel of the interview had made the transition. For the interviews that I personally transcribed, I fully immersed myself and allowed myself to question the data as part of the transcription, often writing comments in parallel.

## **4.5. Data Analysis**

### *4.5.1. Coding*

Analysis is the act of giving meaning to data. Corbin and Strauss (2008) describe analysis as a process that involves taking data apart, conceptualising it and developing those concepts in terms of their properties and dimensions in order to determine what the parts tell us about the whole.

Constant comparative analysis was performed concurrently with data generation. In grounded theory, coding refers to the process by which concepts within the data are firstly identified and then named (Corbin and Strauss 2008). The coding process started the transformation of raw data into theory. In this study, due to complexities of data generation and the fact that I was only able to research on a part time basis, interviews were carried out in blocks of two or three and then were followed by more detailed analysis. Consequently, data co-production was sometimes ahead of analysis. Having a slightly larger data set to analyse allowed me to explore concepts across interviews. In addition there was also a longer break between phases one and two of data collection. During this time, I was able to spend more time on my analysis, develop an initial visual model to help describe my initial findings, and develop the concepts that I wanted to explore further in preparation for phase two.

In the beginning of a grounded theory study the analysis tends to be more microscopic and detailed, and yet the later type of analysis tends to be more general in order to fully develop and validate interpretations. Corbin and Strauss (1998) use concepts which form the basis of analysis and are the foundation of the theory building. Theorising is the act of constructing an explanatory scheme from data that systematically integrates concepts, their properties and dimensions through statements of relationship. Grounded theory identifies four stages of analysis and these were followed in this study:

- Codes** Anchors, that allow the key points of the data to be gathered.
- Concepts** Collections of codes of similar content that allow the data to be grouped.
- Categories** Broad groups of similar concepts that are used to generate a theory.
- Theory** A collection of explanations that explain the subject of research.

Strauss and Corbin (1998) identify three forms of coding: open, axial and selective. In practice however, these are never as distinct as the way that

they are described here, due to the cyclical nature of the analysis (Strauss and Corbin 1998).

**Open coding** (Strauss and Corbin 1998) or Level 1 coding (Hutchinson and Skodol Wilson 2001) starts by naming and giving meaning to the data. The analysis of my data began with a sentence by sentence examination of the initial interview transcripts alongside the accompanying field notes. Next, the data were coded into discreet ideas, incidents, events or acts and given a name to represent them. These names or codes were written in the right hand margin. Initially, the sources of these codes were based only on terms used by the people that I had interviewed (in vivo codes). I then started the process of continuously asking questions of the data and comparing the codes for similarities and differences (Strauss and Corbin 1998, p.102). I compared the data that emerged from the first interview with those of the second and then I compared and contrasted these data with new data as they emerged, highlighting similar codes and then concepts. I constantly returned to earlier interviews as new codes and concepts emerged from later ones to compare and contrast. Concepts emerged from the grouping of similar names or codes that shared common characteristics or related meaning. Concepts are more abstract codes and so their names sometimes came from the researcher. However, in this study they also came directly from an in vivo code. Appendix F-1 shows an example of some initial coding and concepts and also shows how these later helped to form one of the major categories “negotiating and exploring”. This is an illustrative example as this process happened over a long period of time and utilised far more data to bring richness and depth to the categories. It gives an example of how codes, concepts and categories were identified including the use of in vivo codes with some more abstract naming.

I continuously moved between the data and the interpretations, and between transcripts; this helped me to become more sensitive to the emerging findings (Strauss and Corbin 1998). I continued to ask basic questions; who, where, when, what, why and how at each stage. I tried to move away from simply asking what is going on in a descriptive sense but to how this compared



dimensionally along the relevant properties with the others already identified. I found this initially challenging and found myself purely describing; I think in part I was so focused on keeping the voice of the people that I had interviewed that I became quite constrained. I was also fixated on being true to the Straussian process and as this was my first time of carrying out qualitative research, I undertook a great deal of reading of methodological texts and became overwhelmed. To rectify this, I concentrated only on the transcripts and field notes and slowly built up confidence to move ahead.

Over time, the groups of concepts formed provisional categories. Strauss and Corbin (1998) describe categories as groups of concepts that are derived from data and stand for phenomena. They explained that phenomena are important analytical ideas that emerge from the data and answer the question “what is going on here” and hence categorising is the processes of grouping concepts together which pertain to the same phenomena. They then described a new phase of coding, axial coding.

**Axial coding** is the act of relating concepts and developing categories and linking categories to their subcategories (Corbin and Strauss 2008). The aim of axial coding is to relate categories conceptually at the level of their properties and dimensions. Strauss and Corbin (1998, p.117) described

*“properties as the general or specific characteristics or attributes of a category. Dimensions represent the dimensions of a category along a continuum or range”.*

An example of one of my emerging categories was ‘*exploring*’. This had emerged from people talking to me about meeting with new people or groups, often after many years. This was contextualised by many people in a tentative and provisional way as if it was totally new ground that was needed to be covered, and therefore the term *exploring* was chosen. In addition, people spoke about how they were able to start getting out and about and joining new groups, how they made this personal decision and negotiated their way. As this was discussed as part of the process of ‘dipping their toe in the water’ and exploring new ground, a major category ‘negotiating and exploring’

subsequently emerged from these concepts and linked to its properties. Checking and testing was carried out with new people being interviewed.

During this cyclical phase of coding and analysis, a paradigm model was employed to support my analysis and will be discussed in the following section. I also explored and tested the dimensions of responses. As an example, I was keen to understand the emerging concept of '*dipping a toe in the water*' and its dimensions and variation between people I had interviewed. Variation was shown between people who had not at the time of interview initiated any social change outside of their home following their stroke, to people who described some progression to getting out and about. This helped me to formulate new questions in subsequent interviews, and also helped identify people that I would like to interview. Hence, new people were asked questions that had been generated from the data and also from working hypotheses or propositions that could be validated in subsequent data collection; highlighting the unique inductive and deductive process in grounded theory.

As part of the ongoing analysis in phase two, I employed theoretical sampling, using a discriminant sampling technique, as I wished to talk with people who others perceived had integrated well following their stroke. This would enable further understanding of the dimensions and properties of the emerging categories and an understanding of how people had managed to integrate. I asked the Chair of East Kent Strokes to identify people who he thought were socially integrated. We discussed the types of criteria this may include: For example, people who were active in their communities, or people who were members of groups other or in addition to stroke groups. On meeting, these people were unable to recognise themselves as being 'socially well integrated' although they were still able to generate rich data to analyse.

**Selective coding** is the third phase of coding described and is focused on integrating and refining categories (Strauss and Corbin 1998). The goal was to integrate categories into a larger theoretical scheme. This phase involved identifying the core category around which all the other categories were

integrated (LaRossa 2005; Corbin and Strauss 2008). This core category is pivotal and has the greatest explanatory relevance. It should explain the majority of the variation in the data.

For this study, the core category was identified as *'from indecision to volition'* and is underpinned by four major categories due to the broad scope of the study. The process of refining and integrating the categories took many months. Many of the categories were changed as they did not 'feel' right and initially I could not find the right words. The emerging core category and major categories were tested and refined in the final interviews.

#### 4.5.2. *Reaching Theoretical Saturation*

The criterion for judging when to cease sampling is theoretical saturation. The concept of theoretical saturation in grounded theory has been initially discussed in the previous chapter (section 3.6.3). Strauss and Corbin (1998) defined saturation as the point in category development at which no new properties, dimensions, or relationships emerge during analysis. The concern is with representativeness of concepts and how concepts vary dimensionally (Strauss & Corbin 1998). Thus, saturation is a function of theoretical completeness (Baker et al. 1992). Strauss and Corbin (1998) set out three criteria for guiding the decision that theoretical saturation had been reached:

- No new relevant data has emerged regarding a category.
- Categories are well developed in terms of their properties and dimensions demonstrating variation.
- Relationships among categories are well established and validated.

The area of this study was broad and each person brought a unique story and understanding, with significant variation in personal experiences of social integration. Over time, I began to recognise how the categories were becoming richer and better developed and the important relationships between categories had been tested and validated in the final interviews. At this stage I decided that after 30 interviews, I had attained saturation for the purposes of this study.

#### 4.5.3. Supporting tools

Strauss and Corbin (1998) offer the researcher some additional tools and techniques to help develop the core category and organise the emerging connections, these are: the paradigm model; using and reviewing of memos; diagramming and writing the storyline.

**The paradigm model** is a guide to aid researchers to think systematically about the data and to identify relations between and among categories and their subcategories (Kendall 1999; LaRossa 2005). The coding paradigm focuses on three aspects of the phenomenon:

- Conditions, which answers the why, when, how come, and where the phenomenon occurs.
- Actions/interactions of the people in response to what is happening in the situations (answers, by whom and how).
- Consequences of the action taken or inaction (answers what happens as a result of those actions/interactions).

The focus of analysis became one of purposefully looking at action/interaction and noting sequences and changes, and how these evolved in response to changes in conditions. As I was new to grounded theory I decided to use the paradigm model to help guide my data analysis which allowed me to focus on both structure (conditional context of phenomenon) and process (sequences of action/interaction over time); this was crucial to my research and development of a theory. By using this model I identified that I had spent a lot of time understanding why people who had experienced a stroke acted and interacted but less about how, and thus I had a greater understanding of the structure and less understanding on the process of social integration. I began to ask more questions such as: *“How had people managed to take action?”*; *“How had they built their confidence?”* and *“How did they try again after suffering a knock back?”* The paradigm model therefore helped me to understand and relook at my data, stimulated my thinking and helped to guide further data collection. An adapted visual model is shown in Appendix G-1.

**Using and reviewing memos** helped me to define my core category. Memos are the written records of abstract thinking about the data (Strauss and Corbin 1998; Schreiber 2001; Lempert 2007; Corbin and Strauss 2008). They are a record of the data analysis (Strauss 1987) and therefore include questions that are generated from the data; they also give direction for future data collection. I started writing memos as soon as I started my very first round of analysis and continued all the way through. Due to the length of time of my data collection, I found reviewing the memos really helpful. Their key functions were to 'ground' the research and to maintain my awareness by helping to maintain 'analytical distance' because memos "*...force the researcher to work with concepts rather than with raw data*" (Strauss and Corbin 1998, p.220). Strauss and Corbin (1998) describe four types of memos:

- i. Code notes. Memos containing the actual products of the three types of coding
- ii. Theoretical notes. Memos that sensitise and summarise and contain an analyst's thoughts and ideas about theoretical sampling and other issues.
- iii. Operational notes. Memos containing procedural directions and reminders.
- iv. Summary notes, or other variations of the other notes.

In practice, I found that I used a combination of these and didn't always differentiate between the four types, although my earlier memos were more descriptive and later ones more analytical. Examples of two memos taken from my logbook are shown in Appendix D-1.

**Diagramming** was another useful technique that I used. They were able to supplement the memos and visually represent the relationship between concepts and categories, and then between my major categories and core category. I used mind maps to help pull ideas and emerging categories whilst carrying out analysis. I then attempted to draw my model as my theory emerged. An initial visual model was developed at the end of phase one (**Figure 1** below). This model went through further iterations during phase two

(Appendix H-1). The final visual model (**Figure 2**) is presented in the next chapter (section 5.5).

**Writing the storyline** was a useful tool in helping me pull everything together into a comprehensive narrative. As Corbin points out, it helps the researcher, who is immersed in their data, to stand back and ask “*what seems to be going on here?*” (Corbin and Strauss 2008). It took me a few attempts to write the story and I needed to keep returning to the data. Pulling it together into a comprehensive story helped to fully integrate my categories and also highlighted the core category. I then attempted to move from description into conceptualisation and developed the narrative as a more integrative story using the major categories and subcategories as the foundation for theoretical structure to tell the story, framed by the core category “*from indecision to volition*”. This storyline memo is the basis of the next chapter and helps to give the reader a narrative introduction to the more detailed findings chapter which then follows.

**Refining the theory.** All of the tools mentioned played their part in helping to refine and integrate the theory. The writing of the storyline helped to improve its clarity, whilst constantly returning to the data to help develop greater understanding of structure and process. I also found that re-reading the memos helped to check for internal consistency. As mentioned previously, the final people that I interviewed were also asked to review the findings and these interviews helped to refine and validate the emergent theory.

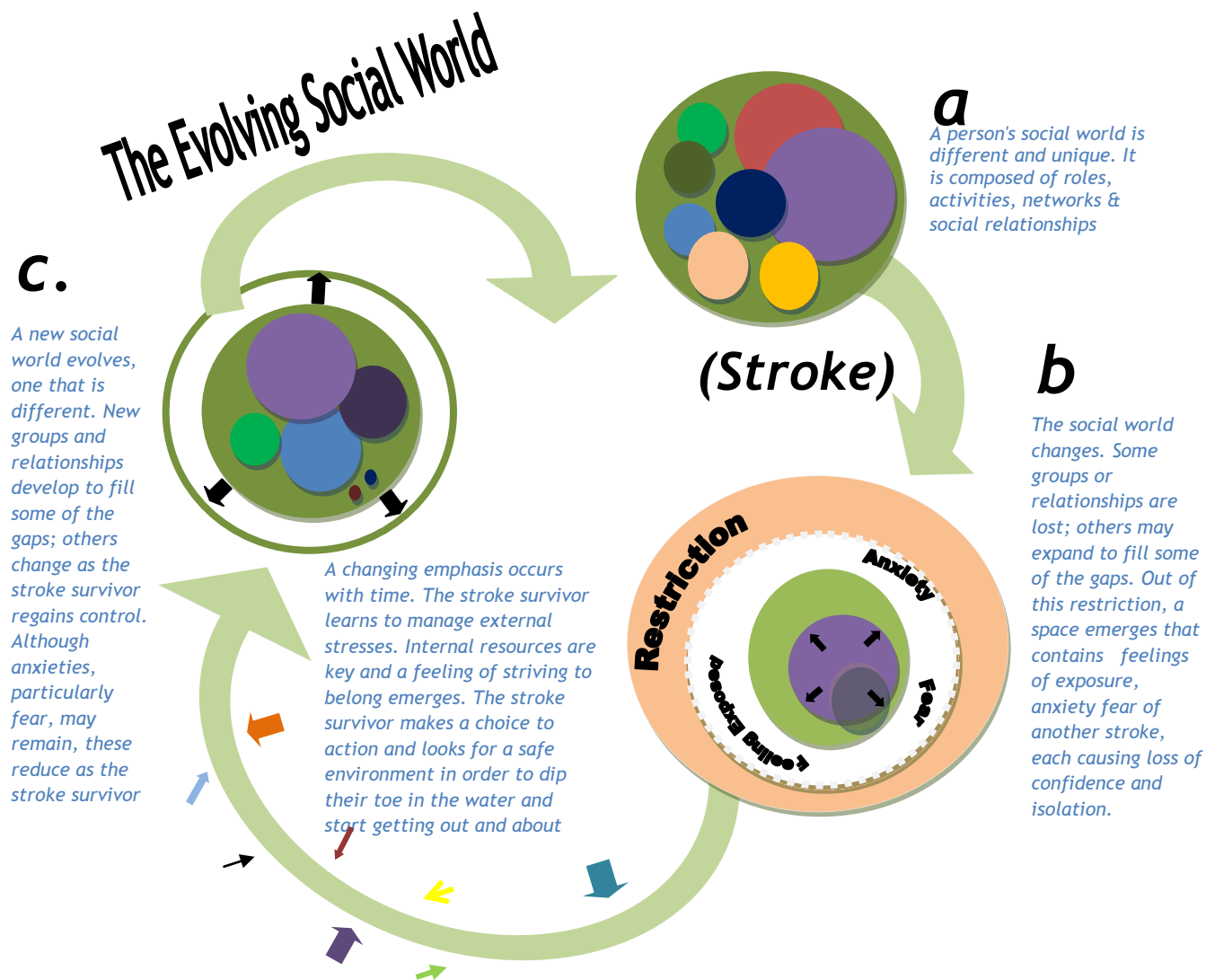


Figure 1. An initial visual model developed at the end of phase one

#### 4.5.4. Summary

The analytical approach as described by Corbin and Strauss (2008) and Strauss and Corbin (1998) is often explained in a step by step way, which is helpful. However, breaking the process into its component parts can risk it feeling rigid and stilted. The process must be dynamic otherwise the intuition or 'magic' as May (1991) describes it, can easily be lost. As described, I found myself at times getting lost in the process and eventually allowed my intuition to lead. The importance of intuition in identifying the central category is acknowledged by grounded theorists (May 1991; Schreiber 2001). It was important, therefore, that I remained as consistently open as I could to the process and I tried hard not to be overly constrained by the analytical frameworks and schemes offered by Strauss and Corbin (1998).

#### 4.6. Quality of research

Corbin and Strauss (2008, p.302) describe quality, as applied to qualitative research, as something that should resonate with readers' and people's life experiences.

*“ it is research that is interesting, clear, logical and makes the reader think and want to read more.....It is research that blends conceptualization with sufficient descriptive detail to allow the reader to reach his or her own conclusions about the data and to judge the credibility of the researcher's data and analysis”*

Qualitative researchers contest and reject the positivist concepts of reliability, validity and generalisability based on the inherently different epistemological and ontological foundations (Carter and Little 2007). They argue that reliability, defined in quantitative research as the consistency of the means of data collection, is largely irrelevant in the case of qualitative research as it does not seek to be consistent, and that situations can never be exactly replicated. The term validity refers to the degree to which research truly measures what it was meant to measure. If quantitative research seeks the absolute truth then patently validity is required (Parahoo 2006). Conversely, qualitative research does not lay claim to 'truth', but rather claims there are



multiple realities and meanings and as Sandelowski (1995, p.86) maintains, if *“reality is multiple then repeatability is not essential”*. Hence, from this perspective, validity or truth cannot be grounded in an objective reality. Finally, in relation to generalisability, qualitative researchers do not look to extrapolate findings from a specified sample of participants to the wider population. Instead, they look to show how findings may have meaning or relevance if applied to other contexts or situations (Parahoo 2006).

Although qualitative research does not ‘fit’ with the criteria used to measure rigour in a quantitative study, it is absolutely clear that the integrity of the research process and the quality of the end product needs to require evaluation criteria of a different order (Finlay 2002). Using explicit criteria offers both the researcher and the reader many opportunities to be able to evaluate the overall quality of the research. Although there is general consensus amongst qualitative researchers about the importance of critically evaluating research through the application of certain criteria, variance occurs when it comes to actually choosing criteria (Willig 2001).

#### *4.6.1. Conceptualisation of rigour and relevance in grounded theory*

Glaser and Strauss (1967) emphasised two main criteria for judging the adequacy of an emerging grounded theory; that it fits the situation and that it works. In their discussion on applying grounded theory, Strauss and Corbin (1998) added that the theory should be understandable and allow the user partial control over the structure and process of daily situations as they change over time. Corbin and Strauss (2008) discussed these further and offered eight general conditions for consideration when carrying out high quality research; ten more specific criteria for judging the quality of research using their method and they offered 13 additional criteria for evaluating the credibility of the theory constructed. In addition, Strauss and Corbin (1998) were clear that product criteria (criteria that evaluate the adequacy of the theory) and process criteria (criteria that evaluate the adequacy of how the grounded theory techniques were implemented) are both important and interrelated.

I will now self-evaluate my study against the ten criteria for evaluating the quality of Straussian Grounded Theory from Corbin and Strauss (2008) but will also partially draw on other frameworks as required. I will finally discuss the role of reflexivity within this section.

**i. Fit**

Do the findings resonate or fit with the experience of both the professionals for whom the research is intended and the people that were interviewed (Corbin and Strauss 2008)? In the last four interviews I shared the emerging narrative and categories with the people I interviewed and tested ideas with them to help expand the concepts and also to see if the findings felt right for them. I recognised that not every detail would apply; however they could all see themselves as part of the story and different findings resonated with different people.

**ii. Applicability:**

Corbin and Strauss (2008) describe this as usefulness of findings; whether they add new insight and explanations? Can they be used for actually changing practice and add to the knowledge base of a profession? This current study has examined an important area that is finally being acknowledged within health policy and practice within the United Kingdom (Intercollegiate Stroke Working Party 2012). It brings some new insight and endeavours to identify areas for further research and examination.

Lincoln and Guba (1985) discuss the issue of applicability of the findings within other contexts or times or with other participants and label this transferability. They contend that advancing hypotheses, together with a thick description of the time and context in which they were found to hold, allows others to make decisions regarding transferability. A description of the people who were interviewed is provided in the next chapter. Because the goal of this study was theory-building, the term explanatory power is used rather than generalisability. Explanatory power means the ability to explain what might happen in given situations (Strauss & Corbin 1998). This research was conducted with older people living with a stroke in two different geographical

parts of the south of England and findings are based on their experiences. The theory is narrower in scope and abstraction than formal theories, thereby limiting its applicability (Corbin & Strauss 2008). A substantive theory does not have the explanatory power of a larger formal theory because it does not include broad propositions (Strauss & Corbin 1998). However, the real merit of a substantive theory lies in its ability to speak specifically for the populations from which it was derived (Strauss & Corbin 1998). The theory *from indecision to volition* derived from gaining a greater understanding of the meaning and process of integration in older people after a stroke is therefore more context-specific. However, I hope to give readers enough information to make judgement of whether this theory is relevant and applicable in another context.

### **iii. Concepts:**

These are important for developing common understandings and language. Corbin and Strauss (2008) explain that what is important is not how the findings are presented but that they have substance; something greater than a mass of un-interpreted data. I tried to develop this substance by returning constantly to the data and asking continual questions to bring richness and depth to the findings.

### **iv. Contextualisation of concepts:**

Findings need to have context. Without context, the reader cannot fully understand

*“...why events occurred, why certain meanings and not others are ascribed to events, or why experiences were one way and not another.”*

(Corbin and Strauss 2008, p.306).

The data was co-produced and both myself and the people I met brought context from our backgrounds and previous life experiences. I practiced a reflexive approach throughout, which is discussed in the next section. Contextualising was also an important part of constant comparative analysis in which questions were constantly asked of the data and concepts were also

situated within the stroke literature, which brought additional context. The next chapter will introduce the people that I met and interviewed.

**v. Logic:**

Corbin and Strauss (2008) ask, is there a logical flow of ideas? Do the findings make sense or are there gaps that can cause confusion? Are methodological decisions made clear so that the reader can judge their appropriateness for gathering data and doing analysis? Ensuring an audit trail is also a necessity. Auditability involves the researcher maintaining a record of raw data, sources of data, sampling decisions and analytical procedures. This audit trail makes it possible for others to understand the research journey and the logic and systematic approach used. The use of memos and recording of decisions helped me to keep an audit and this chapter, with support from the appendices, espouses to give the reader enough information in order for them to judge the quality of my methodological process.

**vi. Depth:**

While concepts provide a common language for discussion and give organisational structure to the findings, it is the descriptive details that add the richness and variation and lift the findings out of the realm of the ordinary. Corbin and Strauss (2008), considered how depth of substance could lift and make the difference between thin uninteresting findings and findings that have the potential to make a difference to policy and practice. I worked hard to bring depth to my findings returning constantly to the data and trying to integrate my findings into contributions of interest and worth.

**vii. Variation:**

Has variation been built into the findings? Corbin and Strauss (2008) ask are there examples of cases that do not fit the pattern or that show differences along certain dimensions or properties? By including variation the researcher is demonstrating the complexity of human life. Variation was an important component in this study as people described their unique and personally meaningful social worlds.

**viii. Creativity:**

Are the findings presented in a creative and innovative manner? Does the research say something new or put old ideas together in a new ways? Procedures must be used consistently, creatively and flexibly rather than in a dogmatic fashion (Corbin and Strauss 2008). The writing of qualitative research is deeply important. It needs to more than engage a reader's intellect; it should also speak to their emotions (Holloway 2005). This is the first time I have written up qualitative research and have found this challenging. I wanted to present the findings so that the reader could hear the voice of the people in this study and feel their stories. Finding a balance in length, the appropriate use of the accompanying literature, the use of quotes and describing in depth the emergent theory all needed to be tackled. During the development of the theory, I began to think of the process of social integration in terms of a journey on an underground train system which I found helped to paint a visual picture and I have included this metaphor as part of the findings in the next chapter.

**ix. Evidence of memos:**

Corbin and Strauss (2008) ranked the use of memos as amongst the most necessary of all procedures. They should also grow in depth and abstraction as the study and analysis progresses. I have discussed memos earlier in this chapter but throughout this study, I have kept written memos in a university log book. The ability to return to memos written in phase one whilst analysing data from phase two was invaluable. An example of a written memo from this study is in Appendix D-1.

**x. Sensitivity:**

Corbin and Strauss (2008) asked three pertinent questions: Did the researcher demonstrate sensitivity to both the participants and to the data? How did the researcher put aside bias and honestly seek to find contradictions in the data to their own assumptions and therefore were the questions driving the data collection arrived at through analysis? Data collection and analysis have, from a traditional quantitative approach, called

for objectivity, but in qualitative work it is recognised that this is not possible. Researchers bring to the table their own particular research paradigms (Guba and Lincoln 1998) and these include perspectives, training, knowledge, and biases; these aspects of self then become woven into the research process. Therefore, if objectivity is not possible, sensitivity needs to be utilised. Theoretical sensitivity is demonstrated by the researcher's ability to conceptualise, visualise, understand, organise, make abstract connections and separate out what is not pertinent (Glaser 2004; Corbin and Strauss 2008). To achieve this, it is important that the researcher constantly challenges her preconceptions about the data (Schreiber 2001). Strauss and Corbin (1998, p.46) describe the theoretically sensitive researcher as being able to "see beneath the obvious to discover the new". In effect they are able to try out different explanations for what is happening in the data and remain open to a range of theoretical possibilities (Schreiber 2001; Holloway and Wheeler 2009). This is in contrast to premature closure in favour of a pet theory (Schreiber 2001). Corbin and Strauss (2008) list various sources of theoretical sensitivity: the literature, professional experience and personal experience, these last two will be discussed in the next section on reflexivity. The literature can be helpful in providing background information that sensitises the researcher to what is happening in the data, but it is important that the researcher discriminates between sensitising concepts, which can help focus data collection, and the use of concepts to impose an existing framework on the data (Schreiber 2001; Corbin and Strauss 2008). In the initial literature review, I was able to explore broad concepts of social integration after a stroke to enable the development of sensitivity. However, as analysis got underway I referred back to the literature in relation to concepts that emerged from the data.

#### 4.6.2. *Reflexivity*

Reflexivity is often used for ensuring transparency as part of the validation process in qualitative research, but it also has a far broader role. Reflexivity is the researcher's scrutiny of their research experience, decisions, and interpretations in ways that bring the researcher into the process and allow

readers to assess how and to what extent their interests, positions, and assumptions influenced the research (Bryant and Charmaz 2007).

Holloway (2005, p.279) defines reflexivity as:

*“The interaction of the researcher with the research and the participants as well as the reciprocity between the researcher and the process of inquiry”*

She also believed it important that the researchers' role should be clarified, their assumptions and background uncovered and that they are themselves:

*“..Participants in the inquiry with their own identities and personal stance; they do not merely retell the experience, feelings and behaviours of those whom they study”*

Reflexivity in research is not a single or universal entity but a process, an active, ongoing process that saturates every stage of the research. My personal research interests and the research questions I posed, reveal something about who I am. Additionally my choice of research design, methodology, and the theoretical framework that informed the current study are governed by my values. Also, my interpretations and analyses, and how I choose to present my findings, are all constitutive of reflexive research (Guilemin and Gillam 2004). Reflexivity in research is thus a process of critical reflection both on the kind of knowledge produced from research and how that knowledge is generated (Guilemin and Gillam 2004).

Reflexivity needs to include self-awareness, critical evaluation, and self-consciousness of the researcher's role. There is also a need for the recognition of power between the participants and the researcher. In addition, it must involve being self-aware and self-critical about the ethical procedures and issues in the research (Guilemin and Gillam 2004). It is also important to not perceive the researcher's effect as always negative. Finlay (2002, p.532) states that

*“through the use of reflexivity, subjectivity in the research can be transformed from a problem to an opportunity”.*

During the entire process of this study I have strived to practise reflexivity. This has involved continuously reflecting upon my own position in relation to the research, and the impact that I may have had. I have already discussed my background and motivation for this study in chapter one, and in this chapter I have endeavoured to give an open and reflexive account of the study methods.

Working with people after a stroke as a physiotherapist, a research manager during a randomised controlled trial, as a commissioner and now in a role developing health service clinical strategy at a regional level, is open to scrutiny. All these roles have given me valuable insight into how services work and people access care, and this potentially enables me at times to understand more quickly what is seen and heard. Conversely, this experience may block recognition of things that may feel more routine or obvious to me. Strauss and Corbin (1998, p.47) advised the researcher to compare what *“one thinks one sees to what one sees at the property or dimensional level”* and therefore preventing me inadvertently imposing my own experience on the data.

I reflected upon and considered my own role at all stages of the research. For example, the accounts that people gave were influenced by the questions that I asked and the interpretations I made during the analysis were part of the co-production of data and findings. As I had a background in physiotherapy but also within clinical management, I also approached the research topic from a particular angle. This was a conscious decision; I wanted my research to be something that could not only be of interest in academic forum, but also be of interest and potentially useful for health professionals and patients. In addition to this conscious decision, I believe that my training as a health professional and the many years spent working in commissioning of health services will have influenced the way I perceived the people I met. I found myself feeling deeply troubled when people told me stories of poor care from health professionals or difficulties with navigating the stroke system as a whole. In my clinical leadership role, I wanted to contact the local commissioners to find out more about their commissioned stroke pathways and why there were



gaps. I had to remind myself of the role I was employing, but the overwhelming urge to fix things, not only at a service level but also at an individual level, was ever present. I was conscious throughout the research process of the potential practical applications of my research. I believe that these influences had generally a positive impact on my research, as I could sympathise with both academic and clinical aspects of the research.

I attempted to manage my personal influence on the findings by reflecting and documenting my own feelings after each interview and before undertaking analysis. Doing this helped me to move beyond my own presumptions and subsequently closer to the actual experiences of the people that I met. I also wrote memos outlining my own personal beliefs and potential biases and pet theories to help challenge me into allowing theory rather than experience to emerge and this was supported by regular discussions at supervision meetings. Furthermore, I used ongoing discussions with my supervisors and the testing of potential categories and the emerging model with new people being interviewed to add additional balance. The concepts that emerged from the data were influenced by my own life experiences, both in relation to stroke and my professional experience as a physiotherapist but equally in other more personal aspects; I saw many facets of myself within people's stories. Just as the people I interviewed may have been changed by the interview process and prompted to think about certain features of their own lives, I have also changed. Over the last seven years and during the course of this study I have been developing as a researcher, and also as a person, through listening and learning from other people's stories and reflecting on my own.

#### **4.7. Summary**

This chapter has described how the study design was implemented. Ethical considerations have also been considered. A reflexive account has been given to allow the reader to consider the quality and suitability of the study. The 30 people who were interviewed as part of this study will be introduced in chapter five.

## Chapter 5. Findings: introduction

### 5.1. Findings: Introduction

The following two chapters present the study findings. This chapter introduces the people who co-produced the data, recounts the integrative storyline of the core category and then presents the substantive theory *from indecision to volition*, with the help of a visual model and a metaphor. The storyline integrates the major categories and subcategories as a foundation for the theoretical structure (Corbin and Strauss 2008). The narrative does not include any direct quotes or examples but instead introduces the theory by the use of an overarching storyline and with the subsequent visual model, helps to provide a comprehensive overview to the next chapter.

At the beginning of this study I discussed with my supervisors the nomenclature that I would use when talking and writing about the people who took part in the study. The term *participant* had always felt cold and distant and in the previous research that I had been involved with, the research team had used the term *stroke survivor* (Harrington et al. 2010; Reed et al. 2010). I initially proposed that this would be the term I would use, albeit with a conscious niggles. I didn't need to call the people I met and interviewed *stroke survivors* as they were *Mrs Smith or Sally*; whichever name they asked me to call them. Since I have started writing up my findings I have felt uncomfortable each time I have typed *stroke survivor*. Instead, throughout this account I have used people's pseudonym names when talking about individuals and yet when I am talking generally I have simply called these people, *people*. They are people who have experienced a stroke but as you will now hear in the following chapters, some of these people have struggled to feel like 'normal' people and so, in a small, insignificant way, I hope I will honour them, for being the normal and often resilient people that I saw them to be.

## 5.2. Introducing the people in the study

Thirty people were interviewed for this current study. **Table 3** shows the names, ages and time since their stroke for those interviewed. All names used are pseudonyms, but wherever possible I have kept to similar names that represent era and background. There were 17 men and 13 women. Everyone was interviewed in their own home and interviews occurred in two phases, in different parts of Southern England.

The ages of the people at the time of the interview ranged from 68 to 88 years, with a mean age of 76. The time since stroke is rounded to the nearest year and ranged between four to eight years. Thirteen people lived alone; whilst the others lived with their spouses. One man was estranged from his wife but for financial reasons they continued to live in the same house and told me they carried out separate lives. Eight spouses were present for the interviews. Three men continued to experience aphasia, but were able to communicate directly with me, although for two, their wives sometimes helped them to find words or clarify points they had made. One woman had moderate dementia and her husband needed to help her to remember aspects of her experience. One person used a wheelchair both in and outside of his flat, whilst three others used a wheelchair when outside of their homes. Walking aids (either sticks, or walking frames) were used by a further 19 people. All people reported on-going problems with their walking and this was immediately recognisable for 12 people. Five people had obvious and significant on-going problems with their hemiplegic arm.

All people had lived in England for many years and spoke English as their first language. Sixteen people owned their own homes, these ranged from flats to detached houses. One woman lived in an annexe attached to her daughter's house but with a separate entrance and her own kitchen. The other 13 people lived in rented accommodation, some privately rented and some through local authorities.

Name (pseudonym)	Age at interview	Time since stroke (nearest year)	Interview comments
Patricia	77	4 years	Lived alone
Mike	72	7 years	Lived alone
Elsie	88	5 years	Lived alone
Tom	70	4 years	Married. Wife present
David	68	4 years	Married. Wife at work
Reg	75	5 years	Lived alone
Peter	69	4 years	Lived alone
Jean	78	5 years	Married. Husband present
Stephen	70	7 years	Married. Wife was out
Jim	72	8 years	Married. Wife was out
John	87	7 years	Married. Wife present
Roy	80	6 years	Estranged from wife
Fred	76	6 years	Married. Wife present
Bernard	82	6 years	Married. Wife present
June	78	7 years	Lived alone
Richard	68	6 years	Lived with partner. Partner out
Susan	68	7 years	Lived alone
Jane	72	5 years	Married. Husband present
Stella	71	6 years	Lived alone
Mary	73	unsure	Lived alone. Interview not recorded
Dorothy	78	5 years	Lived alone
Alice	80	4 years	Married. Husband present
Raymond	78	8 years	Married. Wife out
Joe	73	5 years	Married. Wife present
Carol	77	7 years	Lived alone
Frank	79	unsure	Lived alone. Interview not recorded
Marilyn	70	4 years	Married. Husband present
Evelyn	77	5 years	Lived alone. Interview not recorded
William	78	5 years	Married. Wife out
Charles	83	7 years	Married. Wife out

**Table 3:** *The details of the people interviewed for the current study*

Three people lived in purpose-built accommodation specifically designed for older people needing support from a residential carer; one of these flats was within the same complex as a residential home. All but four people reported generally good health prior to experiencing their stroke. One man had chronic renal disease; one man had experienced a heart attack many years previously, which he reported he had recovered from completely; one woman had type two diabetes diagnosed a year prior to her stroke; and one woman reported numerous health issues including long-standing depression. This woman was one of the three people whose interviews were not recorded digitally as discussed in the previous chapter.

### 5.3. Introducing the researcher

When reading the analysis it is important that my own contribution to the co-production of the people's stories is taken into account. The people I interviewed were talking to a white, middle class woman aged between 43 and 46 at the time of the interviews. I introduced myself as a researcher interested in people who had experienced a stroke but in the supporting information that had been sent to people prior to the interview, it mentioned my clinical background as a physiotherapist. As discussed previously (section 4.4.3), some of the people asked me questions about my role and my background, which I answered openly and honestly. If appropriate I made it clear that I no longer worked as a clinical physiotherapist and also had no direct influence over their local rehabilitation services.

### 5.4. The Integrative Storyline

People found the meaning and process of social integration to be fluid and highly personal. For many, the process was underpinned by relentless effort and hard work and people needed to make a conscious decision in order to begin to develop a new social world. This was conceptualised as ***from indecision to volition*** and was identified as the core category. Four related major categories were identified: ***gaps in identity, internal conflict, negotiating and exploring and renegotiating and reconciling***. The

framework of the major categories and subcategories is shown in **Table 4**. The four major categories will be discussed in full in the next chapter.

The model described is dynamic and multidimensional. Time since people's stroke provided a linear trajectory to the narrative but at any point the journey could progress or regress; ebb and flow or remain static or pause and not move forward for periods of time. The journey described was never ending. The model will not apply to all people after a stroke and only directly applies to older people from three counties in southern England.

Prior to experiencing a stroke, the day to day social world of a person will change and adapt according to many factors. It was recognised that, due to the complexities, co- relationships and dependences of factors both within and out of people's control, there was always a constant flux. The person's social world prior to their stroke was unique to them; made up of differing roles, relationships, groups and networks. For many people, their family or their occupation took up the largest space or time. Many networks or groups overlapped, with family and friends often appearing in more than one group. Some people did not have many social groups or networks and chose to spend time on their own whilst others, who appeared to get their energy from others, had multiple social groups.

The stroke happened suddenly and had an immediate and often dramatic effect on people's social worlds. Overnight, many roles or groups were lost or reduced. Their previous social world had shrunk and after the initial shock of their stroke, people became aware of the sudden space left by the loss of some of their previous networks and relationships. Most people described an initial focus fixed on physical recovery with a belief that once they were physically recovered then everything else would simply return to normal. Although this was potentially a good initial coping strategy, it often caused further shrinkage of previously important social networks and relationships. This empty social space within their restricted social world confronted people and for many, this space became filled with feelings of fear; fear of another stroke, fear of falling and fear of their own mortality. This fear led to people

feeling frozen and vulnerable and caused many of the people to withdraw and lose confidence. For over half of the people in this study a downward spiral leading to introspection and further social isolation was created. People also experienced heightened feelings of loss; loss of role, loss of independence, loss of control, feelings of uncertainty and **gaps in identity** of self, causing further erosion and loss of self-confidence. For a significant time (sometimes years and not months) after their stroke, people described a continuing sense of unreality and disconnection. A genuine fragility and vulnerability exuded from people's stories. As the reality of their situations slowly began to take hold, so too did the feelings of aloneness, shock, anxiety and low mood, amplified by uncertainty of self. A lot of the time, people's families mobilised to help fill the empty social space, left by the loss or restriction of other friendship groups or networks. Although people were grateful, some experienced feelings of being a burden. They also found an imbalance of roles and a lack of reciprocity in these relationships hard to accept, particularly in relation to family support.

Many people described feelings of not quite being there and feeling blank, and a self-consciousness that they had never previously experienced prior to their stroke. These feelings often prevented any initial action to increase social interactions and therefore heightened people's feelings of loneliness. Over time, some of the people described the awareness of an inner voice or **internal conflict**. People felt that they needed to act; to try and start getting out and about and yet, because it was going to be such hard work, doing nothing was quite often the easier option. A growing awareness of a need to belong and be part of something more was a key driver for many in finally making the conscious decision to act. This required a lot of energy and was a complex task in which people needed to be able to utilise important internal resources and mobilise appropriate external resources in finally making the action. This was a conscious decision which required focus and effort, to dip their toe in the water and begin the process of getting out and about. The need to belong was felt as something more than a need for mere affiliation and frequent contacts with others. Some people described a need for

something more than their families could offer; a need to forge reciprocal relationships outside of their homes.

People continued to struggle with internal conflict and imbalance in their lives. This struggle for many was to become part of the process for change in which they moved to **negotiate** a new identity and began to **explore** a new social world that was meaningful for them but was within their own capabilities. Awareness emerged that, to change, people would have to do it themselves. Although their family and friends could help, it was up to them to move forward. Some people talked about a prevailing lethargy and for some a low mood or depression, and for these people they resigned to their new life. For the majority of people their unique social worlds were able to slowly expand allowing less time for feeling lonely and reducing the fear that had expanded into the space. The on-going ability to mobilise and synchronise both internal and external resources was key to progression. Important internal resources identified included motivation, resilience, patience and a positive outlook. External resources identified mainly focused on the help of family and friends, stroke groups and occasionally more formal community support. For many people the attendance at stroke groups was a core component of this exploring or “dipping a toe in the water”. The use of social comparison was important and helped many by downward comparison. People used stroke groups as a place to gain knowledge, build new safe relationships and improve self-confidence. Some people used the groups more as a stepping stone to building other new relationships or networks with perceived “normal” people. Outside of stroke groups there seemed to be limited other opportunities to test the water.

Asking for help and swallowing pride was seen as an important step. For many this took a long time to work out; it needed the person to recognise that accepting help from others was a positive approach as opposed to feeling they were failing. By showing some vulnerability and asking for help, a framework of interdependency was developed that allowed people to regain control and move forward. Timing was important and people needed to muster the energy and all the resources needed. Some people temporarily



resigned or paused but were able to take further action as timing allowed. This process could take many years during which periods of inactivity could then be followed by times of action and moving forward. Slowly people regained some control over their own social world often gaining confidence to try something new. The majority of people forged a new social world and only a few people returned to old friendship groups. This was seen as a time of negotiating and **renegotiating** to continue to explore the gaps in their own identities. Sometimes, in winter or with further illness, shrinkage of people's new social worlds occurred again and the hard work that was needed to maintain their social world or to expand it was all consuming.

The degree of social integration seemed less dependent on people's levels of disability and more of a function of their ability to optimise resources, and consciously manage the process. External environmental factors and societal acceptance were found to be not as important as had been originally proposed in the initial literature review. People had realised that their daily life was an ongoing process of change which could so easily drain all their energy. Whilst some people felt only able to resign themselves to the situation, for others, they coped with this continuous process by devising a daily project of living. This involved developing an emphasis on other possibilities and slowly formulating a new more positive self-image.

After many years, nearly all the people were living a life which was more centred around their home with a more restricted social world but some people had managed to negotiate and explore new opportunities. Their journey was continuing; it needed daily effort and hard work, but they had regained some control and were looking forward. Very few people spoke of acceptance. There was no ending, but as they continued on their unique journeys and developed their new social worlds the people were able to reflect and understand their stories and for some a form of **reconciliation** was able to occur.

<p style="text-align: center;"><b>From Indecision to Volition</b>                      Social integration following a stroke : understanding meaning and process from older people</p>			
<p style="text-align: center;"><b>Major Categories &amp; Subcategories</b></p>			
Gaps in identity	Internal Conflict	Negotiating & Exploring	Renegotiating & Reconciling
<p><b>Suddenness of stroke</b>                      Confusion and bewilderment                      Emotive                      Irrevocable change / uncertainty</p>	<p><b>Empty Social Space</b>                      Impact of the space                      Fear                      Energy draining downward spiral                      Ongoing erosion of confidence                      Vulnerability &amp; Empty feelings</p>	<p><b>Needing to belong</b>                      On-going struggle into process for change                      Heightened awareness of need to act                      Conscious and negotiated decision to act                      Effort and focus</p>	<p><b>The on-going journey</b>                      Regaining and maintaining control and exploring new opportunities                      Planning                      On-going utilisation of internal resources                      Life experience and positive outlook</p>
<p><b>Loss of self-confidence</b>                      Independence                      Changes in roles                      Loss of self                      Loss of control                      Erosion and existential changes                      Worthlessness and emptiness                      Isolation                      Cognitive changes                      Initial focus on physical impairment</p>	<p><b>Role of the family</b>                      Discontinuity &amp; Estrangement from old life and from body                      Increased practical support/buffer for social space                      Imbalance vs. reciprocity vs. burden vs. motivators and resource</p>	<p><b>Dipping a toe in the water</b>                      Testing and safe havens                      Mustering, mobilising and utilising resources                      Personal characteristics – life experience prior to a stroke.                      Motivation                      Social comparison/Social Positioning                      Seeking knowledge to move forward                      Feeling Normal/Being with normal people                      Reconnecting with old groups</p>	<p><b>Hard work and Setbacks</b>                      Further illness and challenges of ageing/ winter                      Relentless effort &amp; resilience vs. falling back                      Good days/bad days                      Regaining some control                      Increasing and sustaining self-confidence                      Planning &amp; setting realistic goals vs. Health professional approach</p>
<p><b>Shrinkage of social world</b>                      Unique social worlds                      Increase in social (empty) space                      Loss of esteem &amp; increased self-consciousness</p>	<p><b>Inner voice</b>                      Increasing self-awareness                      Effort and hard work                      Internal struggle                      Striving to construct continuity                      Blank indifference                      Depression &amp; lethargy                      Uncertainty/conflict/indecision                      Resignation vs. need to change</p>	<p><b>Asking for help</b>                      Swallowing pride &amp; accepting help                      Interdependence                      Exposing vulnerability &amp; taking back control</p>	<p><b>A new evolving social world</b>                      New world / ever changing world                      Integration v reintegration                      Reflection                      Finding meaning                      Pervasive hard work                      Acceptance or reconciliation</p>

Trajectory

**Table 4.** Framework of the major categories and subcategories

## 5.5. From indecision to volition: a substantive theory

Throughout this current study, people described their experience of developing a new social world after their stroke in relation to a journey. A model and metaphor have evolved imagining the idea of travelling on an underground train system. This metaphor aims to paint a picture to help add colour to the detailed findings presented in the next chapter. The visual model is shown in **Figure 2** and represents the substantive theory *from indecision to volition*.

I imagined a person encountering the London underground train system for the very first time. They are standing in an unfamiliar station looking at the large topological map on the wall. They have never seen a map like this, and it feels utterly bewildering. After a long time staring at the map, whilst busy commuters rush around them, they finally find the 'you are here' arrow on the map. This gives them an anchor. They keep looking at the map to find their initial destination but it just doesn't make sense, there are so many colours and names and lines and they feel totally overwhelmed to even consider how they can navigate such a confusing system.

Finally, they locate their destination on the other side of the map. There seems to be many different options for how to get there which will involve moving across the different coloured lines and they can't decide which way to go; it feels such an enormous task. They seek help about how to make the journey. Staff members mean well and try to explain but they can't fully grasp what they are saying. After a long time considering, they muster the courage and make a decision to give it a go. They make their way tentatively down the escalator and into the unknown. The person boards the first train that arrives, not realising it is the wrong one and going in the opposite direction until it is too late. They get off at the next station, navigate to another platform and try again. Slowly they begin to make progress towards their chosen destination. The tube train they are on suddenly stops and someone tells them that this is the end of the line and they need to get off and get on another train. They wait in the station until eventually another train arrives. After many attempts and

dead ends, they finally reach their chosen destination and surface above ground and look around with a sense of achievement.

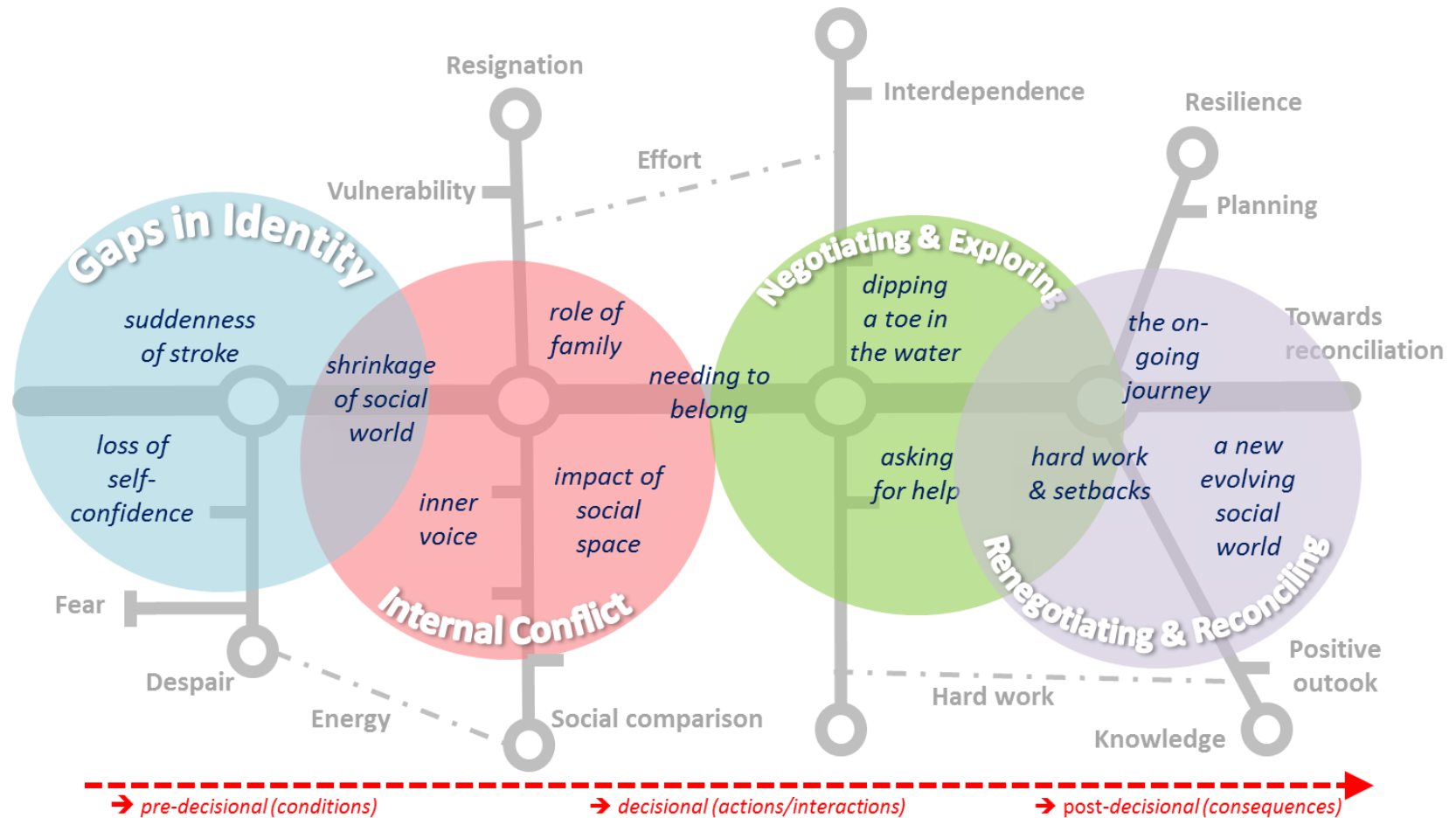
After this initial journey the person continues to need to use the underground system every day. Over time they feel less fearful as they learn how to navigate the system. They begin to recognise other people taking a similar journey, often using the same carriage. Whilst on some days the journey goes as planned, on others they are confronted by new issues; escalators are out of order; lines are closed for maintenance; carriages have broken down; drivers are on strike. On these days they have to work out new routes in order to get to where they need to go. Every day requires planning and effort to get to the station and navigate the underground system. Sometimes they are simply unable to get to where they need to go and they give up and get off the train.

This metaphorical experience of someone travelling on the underground system helps to paint a picture of the complexity of the journey that people in this study described in order to develop a new social world following their stroke.

## **5.6. Summary**

This chapter has presented the people who took part in the current study and given an initial overview of the findings. The integrated storyline has introduced the reader to the theoretical framework and a visual model and metaphor has also been presented. The next chapter will now describe in detail the findings within each of the four major categories and will hear the voice of the people interviewed.

## From Indecision to Volition



**Figure 2.** A representative model for the substantive theory “from indecision to volition”.

## Chapter 6. Findings: Major categories

### 6.1. Introduction

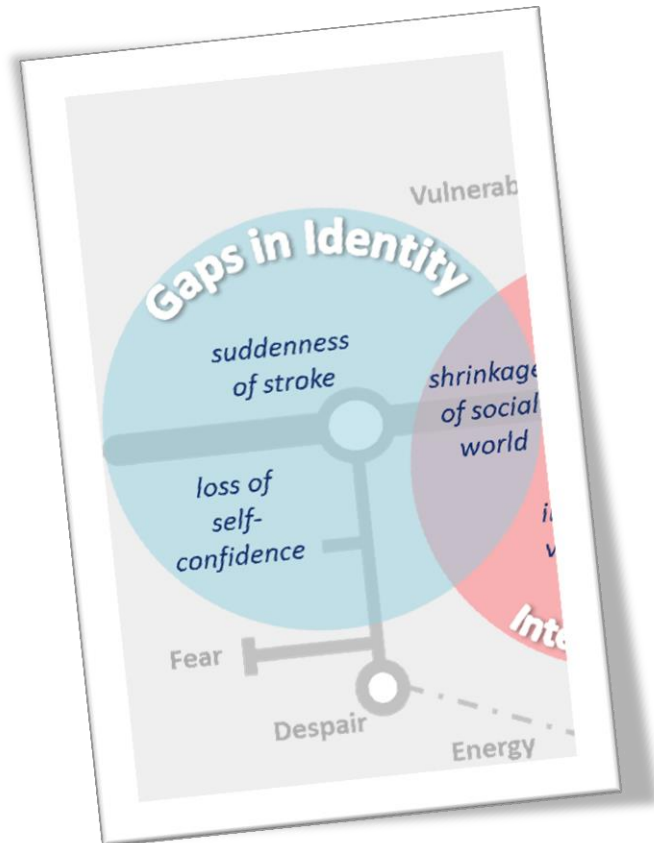
Within this grounded theory four major categories comprising the core category, *from indecision to volition*, were conceptualised. These four were: *Gaps in Identity; Internal Conflict; Negotiating and Exploring* and *Renegotiating and Reconciling*. These categories are highly interrelated and intertwined and although they follow a certain trajectory of experiences after a stroke, the model as described in the previous chapter shows that this is not always a linear process and people's experience ebbs and flows. In addition, some of the subcategories were linked to more than one major category but to avoid duplication they will only be discussed once. The findings are also presented in relation to current literature which brings the initial literature review up to date.

Throughout this chapter, I have utilised direct quotes from people who were interviewed, the line number from the transcript is shown after the quote and the name used is a pseudonym. The presentation of each major category is commenced on a new page.

## 6.2. Gaps in identity

*"I've lost the business of being very independent and I was extremely independent".*

Patricia, 137



The first major category, *gaps in identity* is made up of three sub-categories; suddenness of stroke, loss of self-confidence and shrinkage of social world.

### 6.2.1 Suddenness of stroke

A stroke is different to other chronic illnesses in that it happens suddenly, and often with minimal warning. For the people interviewed this sudden impact meant that neither they, nor their families and close friends were prepared. A period of shock and numbness ensued. This initial period, which included the time in hospital, was described by the people as almost surreal and one of confusion and bewilderment. The world that they knew, that was reliable and had a certain rhythm to it, both good and bad, was suddenly and irrevocably

changed. Some people talked in terms of their life coming to an end; a fundamental change and disruption in their life course. Initially, for most people, they were simply focused on surviving each day and it was only as months and the years passed did they reflect on the enormity of what had happened. Roy and Jim described how it had felt for them.

*“The problem when you first hit a stroke is it doesn’t matter if you know anything about a stroke or not as when it happens to you, you lose um not consciousness, but you are not aware of anything else around you, are not aware of what has happened to you but you just worry about what the future is going to hold, not death, just what the future is going to hold.”*

Roy, 104

*“It just hits you. Stroke is a good word for it because that’s what it does. It does strike you back. You feel that perhaps the person that you are has come to an end and your life has come to an end to a certain extent at that point. And that you know you don’t know how you’re going to cope really. It’s a matter of acceptance and coping and at the time you just can’t, you just can’t see what it is. You’re frightened because you don’t know what’s going to happen next, or whether it’s going to happen again.”*

Jim, 81

Even after so many years, many of the people became emotional talking about this initial period after their stroke. It was obviously emotive recounting this time, but when offered the option not to talk about it, they were very clear they wanted to tell their story, and let me bear witness. Tom’s stroke happened four years previously.

*“I was totally bewildered to be honest with you. I just didn’t know what to do. It seemed to take my life for me, without my dear wife I don’t know what I would have done. I felt terribly useless which was hard to get to grips with. I got very emotional, which even now talking about it I get.”*

Tom, 95

With the value of hindsight and reflection, people were able to discuss their initial experiences within the context of many years having passed. Rather than talking about the initial month or months after the stroke, the majority of people talked about their entire first year being fraught. The suddenness and lack of ability to prepare were key issues.



Many studies with people who have experienced a stroke have also reported the initial period as one of emotional chaos and crisis (Becker 1993; Pilkington 1999; Burton 2000; Eilertsen et al. 2010). Pallesen (2014, p.232), talked about stroke entailing a “*violent rupture*” to a life that the person had taken for granted and expected to run its course according to an expected pattern. Kirkevold (2002) carried out a longitudinal study of nine people who had experienced a stroke and interviewed them between five and ten times in the first year following their stroke. She found that in interviews initially after their stroke, people did not construe it as an immediate crisis. Over the period of a year however, people’s initial optimism had mostly diminished and they described their experience differently (Kirkevold 2002). The time the person is interviewed after their stroke may well alter their perception of the experience but the severity of the stroke may also be a factor; the people in her study had experienced mild or moderate strokes. Kirkevold (2002) also noted that during initial interviews in the weeks after the stroke, people recounted the event without any evident emotion. This was contrasted against later interviews close to a year after the stroke, when several people expressed sadness when reflecting on the event. In this current study, over half of the people interviewed showed emotion when recounting this initial phase, despite it being between four and eight years later.

The findings from the current study also support Charmaz (2000) who focused on the issue of uncertainty, as a defining feature of chronic illness. She found that bewilderment began with the diagnosis of a chronic illness and the subsequent loss of what was previously a taken-for-granted continuity of life. The diagnosis of chronic illness produced crises which she described as throwing people out of ordinary life and where:

*“order becomes disorder, the controllable becomes uncontrollable, the understandable becomes unfathomable”*

(Charmaz 2000, p.280).

### 6.2.2 Loss of self-confidence

Experiences of loss were described by all and were multifaceted: Loss of independence, loss of previous roles, and a loss of choice and control in people's day to day activities, all led to an erosion and significant loss of self-confidence in people's own abilities and a lost concept of themselves as a 'normal' person. This was a common thread running through all their stories.

*"Everything stops doesn't it? I mean your everyday life stops. The confidence, oh the confidence. .... It's just feeling like you are not important any more, you are not there anymore, and lack of confidence is huge."*

William, 93

*"Utter total lack of confidence, you wouldn't trust yourself not even to answer the phone, you are not there anymore, the physical recovery has progressed better than the psychological recovery; no one supported me in that at all."*

Stephen, 121

Stephen and William both felt they no longer existed, that they were now insignificant. Raymond and Joe both described how losing their traditional male roles around the home had deeply affected them and their self-regard.

*"I learnt about the male psyche, men get confidence from doing things, fixing, I couldn't do any of that I came home and I didn't want to go out of the front door, I just wanted to sit in my chair and I still struggle to go out, before I used to be a party boy."*

Raymond, 231

*"This lack of confidence is just so important to males but perhaps everyone, I know talking to other male stroke survivors that it was important to them. I feel so guilty as my wife is doing the man size work around the house and it doesn't make me feel good at all. I don't like myself very much."*

Joe, 83

Equally, the women also described how they lost their practical roles around the house and the impact of these and the need to rely on their husbands or loved ones.

*“The frustration. It is frustrating. Because you want to do things and it is ooooooh, you know, even housework, you are doing stuff and you think, well I don’t do an awful job, you know, but I can’t do a lot as I say, oooo, I have a wonderful husband, he does it for me and with me not seeing very well, I just can’t cook.”*

Jean, 134

Murray and Harrison (2004), in interviews with ten people, two years following a stroke, identified that loss of confidence and psychological issues in relation to the physically disabling aspects of their stroke were significant factors in reduction in activities. Importantly, and in line with the findings in this current study, they also found that these factors went beyond the person’s mental and physical abilities to engage and triggered a profound sense of loss of self.

Cognitive changes were also experienced and described by many of the people in the current study. Some of the changes were apparent to others but many were described as more subtle and ambiguous. The early confusion of stroke was experienced as things not making sense and the people felt overwhelmed and lost, but some ongoing hidden issues remained for many years. People described emotional difficulties with thinking, memory, attention, concentration, organising, and planning. Other studies have also found the impact of cognitive changes and in particular those hidden difficulties experienced by people following a stroke. Particular issues highlighted in the literature were being short tempered, easily overwhelmed, lacking in concentration or memory and being easily tired (Northcott and Hilari 2011; Green and King 2007; Murray and Harrison 2004).

The stroke had initially changed the people in the current study physically, but was also changing them on an existential level. Managing the changes was all consuming and shrouded with upset, guilt, emotional pain and a growing awareness of the enormity of the situation. The physical impact of the people’s stroke was their initial main focus, often reinforced by their families and the health professionals approach. They clung on to the belief that if they just got better physically then everything would be fine.

*“I have underestimated the amount of mental side of it the psychological side recovery needed, I ignored that initially and that is as or more damaging than the physical recovery and I focused on the physical recovery and thought once I was better then everything would return to normal.”*

William, 113

This may have been a good initial coping strategy for the people and their families, but waiting until they were physically better often caused further shrinkage of previously important social networks and relationships. People would hold off returning to any groups or meeting up with friends until they were physically better and as the timescales increased, some groups were lost and friendships estranged. For many people, this was a stage that they needed to go through. Mike, seven years after his stroke was able to reflect back on the initial stage and on the emotions that he and other people were likely to feel.

*“They are still in shock and more concerned and anxious about what the future will hold I think they all think it will just naturally get better, it just won’t.”*

Mike, 524

For those people who lost significant roles, they had to deal with the emotional impact of this loss. Patricia, who was a retired health care professional, had been a carer to a disabled friend for 25 years. Elizabeth had lived with Pat for all this time.

*“It changed it enormously because I couldn’t manage Elizabeth’s care really, that was basically was what, I had to start getting carers in which felt, made me feel unkind, but I couldn’t do anything about it, and then of course she fell and broke her hip, and because of the stroke I wasn’t able to have her at home, she had to go into a nursing home which was the death of her.”*

Patricia, 57

All the people interviewed had experienced changes and loss in roles from the time before their stroke. There were obvious role changes, such as those linked with work or caring like Patricia, but there were also more subtle role changes, those that underpinned their identity; such as the role that many had in their marriage but also within the wider family (partner, parent, grandparent). They were now the ones being looked after and not looking after others; the balance

in the family had been disrupted. A change in status from giver to receiver was hard for many and will be discussed later.

The impact of stroke on people has repeatedly been described as “*loss*” in the qualitative literature. McKeivitt and colleagues (2004) in their systematic review of the qualitative literature of living with a stroke summarised the feelings of loss in terms of three areas: Loss of activities, abilities, personal characteristics and independence; emotional and social loss and a loss or change in the individual’s own identity. All of these losses were grounded within the context of reduced functional ability. In line with this current study, Secrest and Thomas (1999) who carried out interviews with 14 people with a median time of two years after their stroke, suggested that the world of a person who had a stroke was “*grounded in loss and effort*” (p242). Similarly, Pilkington (1999) also found restrictions and losses of taken for granted freedoms, abilities and ways of relating. She also proposed a theme entitled “*suffering emerges amid unaccustomed restrictions and losses*” p342. Pilkington’s study (1999) was carried out with people only in the initial few months after their stroke. Pringle and colleagues (2013) carried out interviews with 12 patient carer dyads after initial discharge home. They summed up the range of losses (ability, future plans, and losses within a relationship) as a grief that they described as a “*living loss*” (p.1996) as opposed to a loss associated with death, and one that affected the entire family.

Unlike these last two studies (Pilkington 1999; Pringle et al. 2013), people in this current study were talking about their feelings and experiences of loss, many years after their initial stroke and described how these feelings continued over a far longer period than just the initial few months. After the initial phase after their stroke, the experience and range of losses all culminated in a loss of self-confidence that stayed with most of the people for many years, and for many continued to be present.

### 6.2.3 *Shrinkage of social world*

In parallel to changes in family roles, loss of previously established social groups and networks led to shrinkage of the people's own social worlds. For each of the people interviewed they described their own unique social world; made up of differing roles, relationships, friendship and community groups and networks. The time a person may have spent alone prior to their stroke varied but for most, this time was chosen. Although each social world was unique, it was most common that the people's family or for those still working, their job took up the largest space in their social world prior to experiencing a stroke. Some of their established social networks or groups would overlap; for example, Jean's family all attended the same church.

Although the youngest person was 61 at the time of their stroke, seven of the people interviewed had still been working in some form of paid (most often part time) employment at the time of their stroke, the majority working past the age of 65. Many more people described important non paid roles as carers, or carrying out other community work; one man was working in a senior voluntary role with the National Trust. For all of those people who were working, their job was also their main social network and took up most of their time. The stroke meant that overnight they all lost their jobs: Reg ran his own shop; Tom was a labourer who not only lost his job but also his house which was tied to the job. David was an IT consultant, Stephen worked as a part time book keeper and Jim as a part time porter. Susan worked part time as a financial advisor and Dorothy was a local artist who was reliant on income from selling her paintings and ceramics. Those people who were retired before their stroke had filled the space in their social worlds left from leaving their job with hobbies and interests. Elsie played bingo almost every day in the centre of town and would meet friends for shopping and tea. Patricia owned and rode a horse and cared for a disabled friend. Fred and his wife played bowls and danced. Over half of the people had close family networks and a lot of their time was spent with them. All this activity and filling of their own social space prior to their stroke was not in their conscious awareness; it was simply life as they knew it.

The reason why people in the current study lost their social groups and networks varied and was not as straight forward as might initially seem. Physical restrictions were coupled with loss of self-confidence, an increasing self-consciousness, and anxiety of becoming a burden. People described how they subsequently withdrew from their previous friendship groups due to these feelings; initially thinking that they would return once they were better. This finding is supported by Murray and Harrison (2004), who found that the people in their study tended to undergo a process of social withdrawal from their friends. The identities of the people they interviewed, their friends and social activities before and after their stroke now appeared quite incompatible and were often abandoned. In addition, Murray and Harrison (2004) found that these friends were not considered to be able to cope with what had happened, and the people who had experienced a stroke did not want to embarrass them. They found that often old relationships did not fit and resulted in either a search for new friends or people remaining social isolated (Murray and Harrison 2004).

Raymond described the complexity of this social shrinkage and the conflict of emotions that will be discussed in the next section.

*"I miss work and miss the friends, I do go out to the pub once a month, but I feel it is just such hard work. I don't feel the urge, I feel like my social chip has been removed, a bit like a sim card from the phone. It doesn't make me sad as I don't let myself think about it."*

Raymond, 421

Patricia had been a keen horse rider prior to her stroke and this had taken up a large amount of her time.

*"You see because I had a horse and I knew all the horsey group, I had my own group. I used to go up and look after my horse and meet all my friends up there. Once I had to give up riding and my poor horse had to go to heaven anyway, that was one of the things I did lose, and then where do you go then?"*

Patricia, 265

Mike used to go to a social club to drink and play cards, his doctor advised him to stop drinking alcohol after his stroke, to which he agreed. But he found that

his friends were no longer so keen to see him and therefore he lost his only social activity.

*"I used to go to the club three times a week and we used to play cards, dominoes and that. It was same five every week, every time especially on a Monday nights when it is quiet and that, we used to play cards for something to do. And we used to have a drink; enjoyed it too. I can't drink now, they stopped me drinking. They told me not to drink anything. Well, uh, it was strange because a lot of them didn't want to know and they knew you were bad but they didn't want to know you."*

Mike, 56

Erosion of confidence meant that William completely withdrew from previous activities and didn't even try to walk his dog even for shorter distances.

*"Um, there's so much I can't do. I mean I used to be a great walker in early days. I used to walk miles and miles and miles. Then I had a couple of dogs when I first came here and I used to walk at least 5-6 miles a day, but of course I can't do that anymore. So um, yes I lose, I lost confidence, and I still have no confidence, but I don't try and do these things anymore, cos I know I can't and I don't want to try. So I won't do them."*

William, 307

Elsie's anxiety about becoming a burden to others and her anxiety about not being able to keep up prevented her from ever returning to play bingo.

*"I used to go to town every afternoon, I used to go up and play bingo, but I don't get up to bingo because I can use my hands, but they seem to be slow, do you know what I mean? I missed it at first, 'cos when they said to me come to bingo hour, I said no, no I said I'm not quick enough now. Cos I've never tried, but I wouldn't like to try, I wouldn't like to think I've got to say to the person next to me, what was that number, I wouldn't like that."*

Elsie, 59

For many of the people interviewed, the stroke had affected their self-esteem and they had become significantly self-conscious. Although some people talked about this being in the initial year after their stroke for others, many years after their stroke, they still felt self-conscious. The effect of this further eroded their confidence and caused further restrictions in their social worlds and a subsequent increase in the empty social space.



*“Um I feel sometimes, I feel very self-conscious about the way I walk and the fact I can’t wear nice shoes and I have got old granny slippers on, things like that.”*

Stella, 176

Susan also withdrew from friends.

*“Yes it was very hard I got very, quite withdraw and ur I didn’t want to be with people who were extremely active you know the friends although, you know, I used to see them a lot the friends I had so couldn’t hang round with them, I didn’t want them to see me and I got very lonely.”*

Susan, 97

Elsie, who used a wheelchair outside of her house, initially even struggled with her own family seeing her.

*“I didn’t want people to see me like I was, do you know what I mean, even afterwards when I was alright, but when I come home, when my grandchildren come round, I didn’t want them to see me like this…… I didn’t like seeing strangers being nosy and saying “oh I didn’t know you were in a wheelchair, what’s wrong with you?”*

Elsie, 44

These feelings made getting out and interacting with people even harder.

People’s new bodily appearances had become central to their social identity.

Patricia also recognised how she had become increasingly self-conscious about meeting new people. She questioned whether this had been due to her stroke or would have happened anyway due to her simply getting older.

*“Well, I think generally I did lose my confidence, ‘cos I’m quite a gregarious sort of person, I found it very difficult when I was meeting new people to sort of find a level to talk about because I felt a bit self-conscious, I don’t necessarily know whether that was the stroke, or just because I was older.”*

Patricia, 88

This loss of confidence in their appearance did appear to be a more common theme in the women interviewed but a few of the men also described feelings of self-consciousness.

*“Why’s that bloke staggering about mid-afternoon, you know. It’s that kind of thing that makes you a little bit self-conscious.”*

David, 171

*“I don’t know how other people react but I would think they are similar to me when you have first had a stroke and people say don’t be too conscious of it but you have got to develop as quickly as possible the attitude that ‘bugger it’. I am like how I am and if I take a bit longer across the road people are going to wait I can’t do anything about it’, I think initially you are really conscious of how you look and also being a bit of a nuisance uh and I think the sooner you can get over that the better. I am not quite over it now [ six years later] but um yeah.”*

Richard, 404

Other studies have also found that people who experienced a stroke expressed discomfort with their current selves in terms of both physical ability but also appearance (Becker 1993; Burton 2000; Ellis-Hill et al. 2000). Subsequently, people become more withdrawn in order to avoid becoming a burden to family and friends but also coupled with anxiety of facing the world. The person’s body has reported to be experienced as alien, as a broken tool, leaving the individual with feelings of helplessness and loss of control (Burton 2000; Cott et al. 2007). It appeared that altered self-identity and image could continue for many years after a stroke.

Three of the people interviewed in this current study were still experiencing minor speech problems. Two studies carried out with people who have aphasia, have shown the additional effect of loss of communication can have on people following a stroke. The two most common sequelae being loss of self – confidence (Pearl et al. 2011) and difficulty in sustaining friendships (Northcott and Hilari 2011). Jim talked about his own self-consciousness particularly in relation to his speech.

*“You’re self-conscious too at first you see, about people seeing you the way you are, or whether your communications are working. You might be self-conscious about your voice. I still am strangely enough.... And I’m conscious of trying to get my points across to them, because I struggle sometimes. And I’m saying, I hope you can understand me. I am quite self-conscious even these days about my communication.”*

Jim, 165

For a significant time (years and not months) after their stroke, most people in the current study described a continuing sense of unreality and disconnection. A fragility and vulnerability exuded from people’s stories. As the reality of their situations slowly began to take hold, so too did feelings of aloneness, shock and

anxiety amplified by uncertainty and gaps in identity of themselves. These people who had experienced a stroke now saw themselves as different people. Long held assumptions about themselves and their social worlds were shattered. Their assumed futures no longer made sense to them in terms of the lives they had lived and thus were lost to them. They compared themselves to others and simply didn't feel normal; their perception and understanding of themselves now had gaps in it, gaps that they couldn't initially fill and the future was uncertain.

The ways in which a stroke affects people's sense of identity is a common theme in the literature (Sarre et al. 2013). Kouwenhoven and colleagues (2011, p.9) talked about;

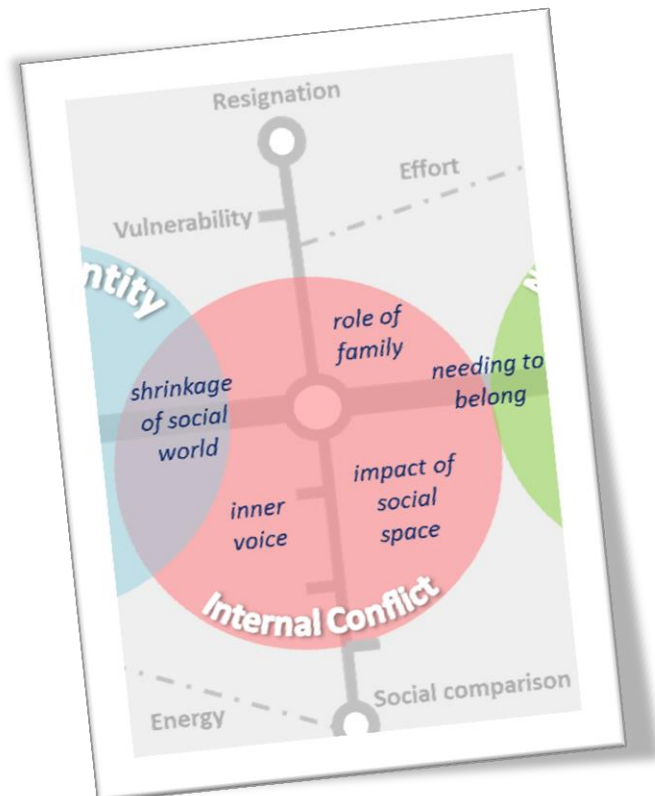
*“a distinct relationship between the experience of the lived body ....the ability of the “doing” and the concept of self.... The experience of the “being”.*

It is particularly in the first year that the body could be described as unreliable (Ellis-Hill et al. 2000), unpleasant or embarrassing (Eilertsen et al. 2010). Identity is a relational and ongoing process that is fluid and not fixed. Watson (2008) considered the fact that 'identity work' is therefore likely to be taking place for a participant even during the context of an interview. This may be more likely to occur in the early transformation phase where realisations are first occurring (Kaufman 1998). This current study took place a minimum of four years after people's strokes and described people's changes in identity following stroke as gaps in identity. Whilst most of the people experienced significant changes and an unexpected disruption to their self- identity they also maintained some links to their pre-stroke self. This finding is supported by Ellis-Hill and colleagues (2008) and Kitzmuller and colleagues (2012) who also found that people felt a gap between themselves and their bodies leading to what Thornberg and colleagues (2014, p.4) described as a *“feeling of being homeless in the world.”*

### 6.3. Internal Conflict

*"I lost control, I found it difficult. Before I wrote poetry but afterwards I couldn't. I feel now like a fruit husk, I have lost my fruit, I feel like I am not wholly alive."*

*Dorothy, 111*



The second major category, *internal conflict* is composed of three subcategories; impact of empty social space, role of the family and inner voice.

#### 6.3.1 *Impact of empty social space*

People described how they had lost many of their friendship groups and other social networks: bingo, bridge, horse-riding, bell-ringing, dog walking or pub crawls. They had also lost roles within their families; housework or DIY, cooking the Sunday roast for the extended family and more subtle supporting roles, all of which caused an increase in social space. This empty space confronted them and for many this space became filled with an energy draining fear, which in

turn caused people to withdraw and thus further erode their self-confidence. A downward spiral leading to introspection and for many people significant social isolation was created. Although the fear described was greatest in the initial year after their stroke, some people continued to describe feelings of fear many years after their stroke, it often re-emerging during times of less social activity.

People talked in retrospect about these feelings of fear; fear of another stroke, fear of failure and fear of the future as Reg, Marilyn and Jean described.

*“Well, I have two big problems. Two big worries in my life, that I have another stroke or I fall over and everybody’s that’s had a stroke lives in constant fear of these .....Well every time you get a twinge or an ache you always worry or something goes wrong and especially when you have a fall. You see, I’m now getting unsteady on my feet, which is why I’m in a wheelchair most of the time, and it’s easier to, yes, so I fall over now quite often. Um you know, it used to be once a year, but now it’s quite regular so I have to be very careful. And you always worry that if you fall over you might damage yourself or have another stroke.”*

Reg, 912

*“Well, fear of the future. Because you’ve plans and you just worry you’re not going to be able to have them. And it’s the continuation you know of your life you know. You feel as if it’s a cut-off point and that you’re not going to be allowed to do things that you know you’ve probably planned to do.”*

Marilyn, 126

*“I found it very difficult because I was nervous. I mean I had this sort of awful feeling, suppose I have another stroke..... You felt very isolated.”*

Mike, 98

The consequence of the empty social space and the energy draining fear that took hold within the space caused a huge challenge on people’s internal resources; taking control, making choices and managing stress. This challenge for many led to an even greater vulnerability and exhaustion and particularly in the initial phases, more difficulty in regaining any sense of control over their lives. Stephen talked about coping strategies for handling his fear but also how no-one had told him that it would ease.

*“I had major fear, major fear of losing my mind, it does get better, but initially it is such a fear I wish someone had told me that you can get over it, and you have to work hard on it, distract your mind and retrain it, I pick up a book that touches me and make myself read it and think about it”*

Stephen, 61

No explicit links to the increase in social space and the fear that became part of this space has been identified in the literature although Pringle and colleagues (2013) found that people in their study described looking to a mortal future in which death had to be faced, whether this was explicit or implicitly referred to. They also found that people were more aware of their age and felt more vulnerable and needed to seek reassurance that another stroke wasn't going to happen.

Some people in this current study also described that after time, a feeling of being empty also emerged from the space. This emptiness was linked to feelings of worthlessness; lack of trust in who they were, what they could do, or not recognising themselves anymore which further consolidated the downward spiral of erosion of confidence, withdrawing further, and becoming and feeling increasingly isolated and lonely, and thus reinforcing feelings of emptiness. Moving out of this space would take an enormous amount of hard work.

*“...And when you start to lose your confidence that is a marathon to try and get over. You felt very isolated. It was very much an isolation of, you know, this has happened to me and I don't know what is happening. You are isolated.”*

June, 117

### 6.3.2 Role of the family

As time passed, a discontinuity from the people's previous life and an estrangement from their pre-stroke social world caused, as previously described, an enforced social space and gaps in the people's own identities. People described a gradual realisation that life was never going to be the same. Their families, where able, often stepped in to fill the space left by other groups or networks but often the imbalance of new roles and a feeling of lack of

reciprocity not only continued to erode people's self-confidence but caused upset and an increasing awareness of difference.

The balancing and stabilising effect of relationships after experiencing a stroke are important. Pilkington (1999) described how relationships supported, comforted, and consoled individuals and that loving supportive relationships brought them comfort and encouragement. Having connections with others helped bridge the schism in the discontinuity of people's lives after stroke. Many studies have found the importance of reciprocity in relationships, particularly within the family, whilst finding that disconnection from relationships enhanced the discontinuity of self and was particularly painful (Salter et al. 2008; Haslam et al. 2008; Kubina et al. 2013).

In the current study, for those people who had relatives living close by, their family attempted to fill the empty space from which other friendships had fallen away. With the benefit of hindsight people recognised the importance of this support but equally struggled with the changed role and the perceived imbalance within the relationships. Although the breadth of the relationship had often increased and more time was filled by family interactions, the depth of the relationship was often lacking and this in itself brought, for some people, a frustration or unhappiness. The family role often became more task orientated, including carrying out practical support that the people required but negated the depth of social needs which caused many to feel inadequate as their range of social and psychological needs were not being met. Dorothy expressed this succinctly.

*"I am fortunate to have a family and I rely too much on my daughters, I get frustrated, as they aren't always reliable and they do practical things, and not social things."*

Dorothy, 26

Pallesen (2014) also found in her interviews with 15 people five years after their stroke, how reciprocity in close relationships had been disrupted for almost all of those interviewed and negatively affected the self-perception of the people she interviewed. Ten of the people interviewed were greatly dependent on help from their partner, family or from private or public support arrangements. She found

autonomy was a central theme that affected self-perception and also the moods both of the person with a stroke and of those in their immediate circle.

Over 20 people in this current study filled a large amount of their empty social space by spending more time with their families, but six people lived alone and had neither a partner nor close family living nearby and the remaining people, although living with their spouse, had no other immediate family with which they had contact. The experience of those with limited or no close family contact felt especially hard and they recognised the additional challenges that this had brought them.

*“...And I do feel sometimes, I sort of put it from my mind, [not having a family] saying don't be so silly, you're lucky to be able to do the things you can do. And don't worry about it, although sometimes I get a bit fed up..... all my friends they've all got families and they are very involved with their families and they've got husbands, and rightly so. And therefore I haven't got anybody who's like me, on their own.”*

Patricia, 308

The people who received family support were grateful but for half of them this thankfulness was sometimes tinged with concern about feeling a burden. Often they did not feel that they were able to give anything in return and the feelings of mutual benefit had diminished within these relationships. Many people held on desperately for strands of continuity in their roles as parents or grandparents but this was hard work. For these people the expansion of the empty space by family members didn't feel the same. They described feelings of not being fully satisfied as they experienced difficulties in redefining their own contributions to family life.

Kubina and colleagues (2013) also found in a recent study of six people, who were interviewed five times during the first two years after their stroke, that reciprocity and not feeling a burden were important dimensions of social connection. They defined reciprocity as a sharing of mutual interest and concern and this closely aligned with doing one's share and not being a burden. They found that doing things for others was associated with *“motivation to continue to do self-identifying activities despite challenges”* and a sense of satisfaction (Kubina et al. 2013, p.239).



For a couple of people in the current study their relationship with their spouse had suffered irreparably. Roy had become estranged from his wife due to the impact of his illness on the both of them, but they could not afford to live separately and so continued to live in the same house and rarely spoke. Roy talked in the third person.

*“I think a bigger problem in terms of relationships is marriage and partnerships and the fact that the person who hasn’t had a stroke is now married to someone they didn’t marry a different person altogether that is a big problem that”*

Roy, 339

In contrast, other people described that in addition to acting as an initial buffer by filling the sudden social space, their family also acted as their main support and motivator to enable change and transformation, as described by Bernard.

*“The family wouldn’t let me get depressed – the grandsons wouldn’t. We have a strong family, our son lives along the road and his wife and they have three boys, but it’s my son and his family who are the most pushy, like they wouldn’t let me get depressed.”*

Bernard, 226

The family acted for many as a key external resource bringing immediate support and comfort after their illness and starting the process of building confidence and motivation. Some people recognised that the family could also become overly protective.

*“Some relatives want to do everything for them, and the victim must be encouraged all the time and if you keep encouraging them eventually they get the hang of it, but the relatives need telling as well. I saw that with some of the stroke victims at the hospital.”*

Charles, 534

Jim, who helped out at his local stroke club, highlighted the motivational role that family could take.

*“It can only be the nearest and dearest that really help. For most stroke survivors you can’t get through to them initially the seriousness of motivating themselves to get going and get out. The nearest and dearest will be the ones to encourage and get them going.”*

Jim, 217

Eight people described an increase in personal value of their family and how family members had filled most of the social space. Instead of reconnecting or making new friendship groups over time their family had remained their only on-going source of social interaction in the years since their stroke. For a further 12 people the support from the family in this study, gave them the confidence to access new social networks, in beginning to strive to belong.

For Elsie, four of her five children lived within a 15 mile radius and, following her stroke, they arranged for her to move into a warden supported flat and instigated a rota for her care.

*“Me children come, me children come every night to me. They won’t let me cook. They cook me dinner every night. And um, I go to coffee mornings, they’re all down in the lounge, and I come back and now and then I go for a walk done the corridor with my trolley, and every weekend one of the children helps me and they take me out in a wheelchair, they won’t let me walk [laughs], I do walk when I’m in their house because I’m going to the toilet when I want to, I don’t ask them to take me to the toilet, so I always take myself.”*

Elsie, 161

During the first couple of years, for the people in this study that were able to access family support, most of their roles were crystallised within a carer/receiver framework. Whilst they were appreciative, many continued to strive to develop new, additional contacts and potential friendships that would be more equal and reciprocal. Jane described the importance of doing things for other people and how that could help with self-worth.

*“You have to stay busy, there are people so much worse than I am – do something constructive and do something to help someone else. I am alive.”*

Jane, 413

In this current study, support from the family was multidimensional and for many a crucial component of improving social connection. Particular resources that the family brought were practical support, emotional support, knowledge and advice and these were hugely appreciated by most people. This increased role of the family was often seen as an interim arrangement and not a long term

solution. The impact of the new relationship was often complex and brought mixed emotions to people after their stroke.

### 6.3.3 *Inner voice*

Some of the people talked about the emerging presence of an inner voice or for others an increasing self-awareness. The option of doing nothing and simply rolling over and giving in to the stroke felt like it was the easiest route to take; the alternative felt such hard work and required a lot of effort and commitment. Close family and friends could help, but the struggle was an internal one and the people became aware that only they could make the change. Many of the people continued to feel an indifference to making any change and at times dull or blank feelings or a low mood consumed them. They felt that it was too great a hurdle to get over.

*“I used to feel clever and have a spark of creativity and I just don’t feel that anymore. It just hasn’t come back I have become far more intolerant and foul mouthed, Like I was not alive and I had to accept, it was like a blank feeling, a blank indifference.”*

Dorothy, 368

Four of the people interviewed were able to construct some continuity by framing the stroke as part of normal ageing and one person by using their religious beliefs. Charles didn’t focus on the disability that happened after a stroke; instead he linked it to getting old and was able to renegotiate his new world with what appeared far less conflict.

*“I never thought about a stroke. I just got on and did what I can and tried to improve but I never consciously thought of my stroke, I am just getting older and I need to do what I can”*

Charles, 242

Several researchers have theorised about the role of illness in the construction of self (Bury 1982; Charmaz 1983; Bury 1991; Williams 2000). Charmaz (1983) highlighted how illness disrupts individuals’ abilities to continue constructing identities as they did prior to their illness. Bury (1982) hypothesised that this is because the material and symbolic resources used in pre-illness self-construction are no longer relevant for the post-illness situation. Hinojosa and

colleagues (2008) challenged these views. They carried out 122 interviews with men living in the USA, a month after discharge following a stroke. They proposed, from their findings, that people could construct continuity of self by drawing on personally accessible discursive resources not affected by the onset of illness. This has also been found by other researchers. (Pound et al.1998; Williams 2000). Hinojosa and colleagues (2008) argued that two discursive resources, expectations for ageing and religious beliefs, were actively employed in some people's narratives of continuity following their stroke. Rather than simply being adaptive resources that minimised the disruptive impact of illness, they proposed that these represented pre-existing explanatory frameworks that made continuity of self discursively possible (Hinojosa et al. 2008). The study by Hinojosa and colleagues (2008) was carried out only a month after people's strokes and so caution should be applied. The findings in the current study showed the first year to be one of constant flux, which included people describing constantly changing feelings in relation to their stroke. The explanatory frameworks that people will have used a month after stroke are likely to vary to those at a year or more later.

The people in this current study had to manage their internal conflict amongst on-going physical limitations. They realised that just focusing on the physical elements was simply not the answer. Many people had limited external support to help them and they had to rely heavily on internal resources and previous life experiences. Frustration was ever present. These experiences are not unique to people with a stroke, in many other studies involving people living with acquired disability or long term conditions, similar experiences are described. (Kleinman 1998; Charmaz 2000; Paterson 2001). Paterson (2001) found that living with a chronic illness was an ongoing and continually shifting process between illness and wellness and that both had specific functions in the person's world. This model, similar to the experiences of a stroke in this current study, described a continuous process that never truly stabilised (Paterson 2001).

Tom talked about his frustration and struggle.

*“There are times when I am so frustrated, I can’t do what I want to do and I can’t push myself, it’s so frustrating. I have to pace myself all the time and it is so annoying. I can’t push myself that bit more, I don’t want to pace myself, it’s infuriating, I am struggling to teach myself patience, I feel that the mind is where it is at.”*

Tom, 291

Nearly half of the people interviewed described this gradual realisation and self-awareness that things weren’t going to suddenly improve and that most importantly it was going to be up to them to make any change. This constituted a major shift in understanding.

*“You have just lost part of yourself that you depended on and needed and you just have to find a way around it. You could sit at home and feel sorry for yourself but what is the point, you have to get up and go do something.”*

David, 313

Underpinning the ability to make change and how people reacted and responded to their stroke were direct linkages to previous life experiences and the resources that were available to them. Some of the people talked about prior histories of low mood or depression and others talked about how hard it felt to make changes, particularly without support from loved ones or professionals.

*“I was so lucky I had my daughters, without them I would not be here, I have felt that I didn’t want to live but I wouldn’t commit suicide, I don’t want to be like this, I consistently had to think myself out of it, I know that if I let things go that would be the end.”*

Dorothy, 140

*“I have always had times of being depressed the stroke has made it all the time now, and my life is over.”*

Susan, 212

Richard talked about his experience of seeing other people who had experienced a stroke and he linked their responses to their character.

*“Some people are so defeated by the whole stroke experience that they don’t do anything well.....I say it must be temperamental disposition; I don’t know what to call it but I guess it’s the best thing you know it’s like your nature nurture debate. I am a great believer in nurture but I can’t deny that there are differences there before you start nurturing which will to some extent influence how far you get with it in terms of rehabilitation following a stroke there’s something there which will affect how effective or otherwise you are.”*

Richard, 351

The importance of growing insight and awareness was crucial, but it was hard work to tackle the emerging conflict. Stephen described how at times the dumbed down feelings would engulf him.

*“I struggle with the feeling of being so dumbed down, that dumbed down feeling and you could just sit down and let life happen, it is a conflict all the time one side of you just let it be and the other side come on you have to pull yourself out, it is such a conflict all the time and you can get so furious.”*

Stephen, 276

Richard also discussed his own inner voice.

*“I have a constant internal conflict; it is um the easier option is to give up to this inner voice. I have a feeling there is me and someone else inside me and he tells me I can give way to him and he is always there smiling and he is like god inside me and I can put a CD on and cheer myself up.”*

Richard, 382

William explained how he had to tackle this on a daily basis.

*“I have an inner voice. I still even now, I still very often like lying in a warm bed on a cold morning and I have these thoughts ‘you don’t need to get up, what’s the point I may as well stay here for another hour’ but you know if you do the following day it will be another hour and another hour but you know that once you have made the effort it will be okay.”*

William, 401

Dorothy also recognised the risk of giving in.

*“Get out of bed, I get out of bed early as I am simply too afraid to lie there”*

Dorothy, 170

A pervasive fatigue or lethargy shrouded many of the people and the effort to emerge from out of it and tackle the conflict became of upmost concern and one

of an on-going source of much distress. The effort required at times felt simply overwhelming.

*“I can’t bring myself to be bothered and it is such a hurdle and I know if I force myself I can surmount it but it so so easy to let it win and a real temptation and yet I can’t as it is so negative and I am tempted by negative things and it makes me feel such shame and it is the shame that drives me to do something about it and makes me get out.”*

William, 420

*“The biggest problem after a stroke is motivation, you get lethargy very easily, it is very easy to become very lethargic. I see people who have been quite capable in normal life but I can see through their mind thinking why should I bother I can’t work anymore, I am not going to do it but you have to think differently.”*

Stephen, 389

*“After a while it becomes too late, I don’t think it is depression, it is lethargy. It is very easy to say I don’t need to do this, should I bother and it is easier to stay sitting. I don’t need to do this, I don’t have to do it, I can’t do anything about it. They just give up.”*

Raymond, 291

Resignation was an important issue and within this study was found to have a range of potential connotations and could be interpreted as a passive or more active process. For some people the process of resignation felt more comfortable than others; they seemed at ease and didn’t feel the need to strive for any more social contact. Their families had often filled some of their social space, they were getting older and they resigned with a feeling of comfortable inevitability. For others a more uncomfortable resignation occurred where people described an enforced choice which occurred within the context of ongoing internal conflict. It is important to note that in the context of this study resignation was not necessarily a finality and could equate to a longer pause before people took a further step often months or years later.

Burton (2000) also talked about people feeling resigned to a more passive role after stroke. Pallesen (2014) added to this in her study in which she reported that people found it difficult to compensate for functions that had been lost, and that energy and strength were needed because the body continued to demand attention. This meant that it was hard to find the extra energy needed to

maintain former activities and to cope with new challenges. For this reason some of the people interviewed in her study chose to limit their activities and their involvement and resigned themselves by giving up or accepting a more passive way of living. Pallesen (2014) also described how an acceptance of being functionally aged could support the person's right to make a choice when they lacked the strength and energy to do more. She felt that this was a decision that many individuals had to make if they were able to have any sense of cohesion in their lives (Pallesen 2014).



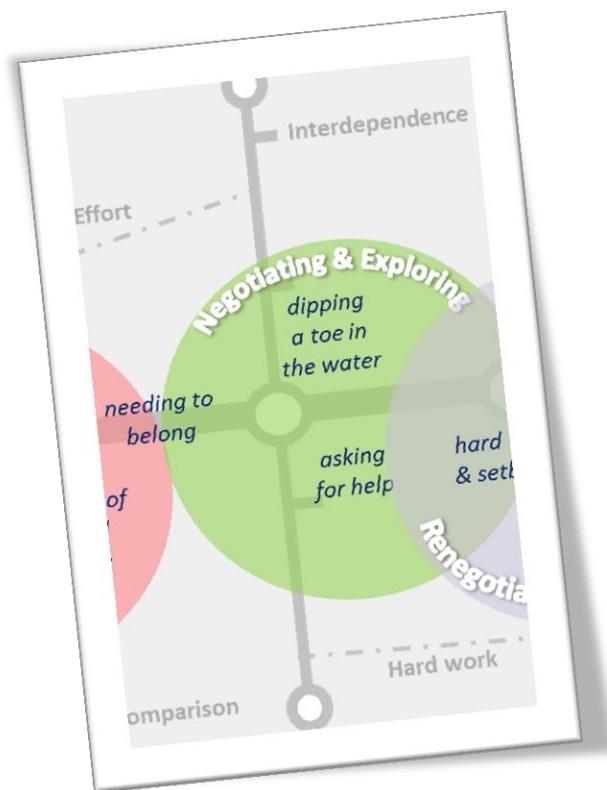
## 6.4. Negotiating and Exploring

*“You can’t just sit there and let life happen to you.”*

Charles, 71

*“Before the stroke you never thought of these things. You don’t equate integration with anything because we were part and parcel of anything that ever went on. I don’t think you ever stopped to think. Yeh, you know you have got to fight the isolation.”*

Jean, 301



The third major category, *negotiating and exploring*, is composed of three subcategories; needing to belong, ‘dipping a toe in the water’, and asking for help.

### 6.4.1 *Needing to belong*

People continued to struggle with conflict and imbalance in their lives. This struggle for many was to become part of the process for change in which they moved to negotiate a new identity and began to explore a new world outside of

their home. Awareness emerged that to change, the people would have to do it themselves. Although their family and friends could help, it was up to them to move forward. Many people talked about a prevailing lethargy and for some a low mood or depression. At this stage some people became resigned or temporarily resigned to life as it was; they chose to stay within a close family network or they didn't have access to the required resources at the time that they needed them to take the next step. This process could take many years and would ebb and flow.

*"There's no dream cures, you know. So I always thought, I, It's just unrealistic to think that one day you're going to wake up and be okay."*

Reg, 147

A key aspect of this phase was that the person's social space was now very much within conscious awareness. They described an internal conflict between wanting to get out and about and interact with people outside of their own homes against wanting to hide away and resign to what they had, and not to strive for more. A growing awareness of this conflict was described by many and significant effort was needed every day to challenge the negative feelings. Amongst this internal dissonance, some people described an emerging awareness of a desire or need to belong; to explore and make new connections or to try and reconnect with old networks or groups. All of this needed hard work, effort and courage to make the first move. The decision would need to be conscious and negotiated. People described it as a battle or something they had to and not always wanted to do, and was fraught with difficulties.

*"I always feel do I have to go to various functions or social events? I feel dopier, slower to fit things together and not quite there and I can't cope with lots of people talking and it makes me feel not quite there and I don't like going out, but I just have to do it."*

Joe, 398

*"If you are painfully aware of being apart from society, you may start to feel inadequate or bad about yourself which will obviously lead to sleep problems and all that kind of stuff, ...to a certain extent with me that is concealed or reduced because my wife looks after me a lot."*

Roy, 282

This growing awareness of a need to belong was a key driver to make change. The time it took varied between people. David described himself as very much a loner who, only recently, over four years since his stroke, had started thinking more about the need to get out and about a little more.

*“In my particular case because I am not particularly a sociable person. I’m pretty much a loner. ....So really I’m quite content in my own little sphere, which of course does help. The only trouble with that is that it can I think I mean, I’ve been thinking about it only lately actually, but I am a little bit concerned that I’m in a sense too comfortable, because now I mean I’ve got my own little world...And I’m thinking I don’t know, perhaps I ought to, to want to go out or do more and do more things...but I have been thinking about it though, just thinking possibly, possibly.”*

David, 225

Only one other identified stroke study has explicitly mentioned people making a conscious decision to act. Kessler and colleagues (2009) interviewed 12 people who described themselves as viewing life positively after a stroke. They were interviewed, on average, six years after their stroke but they were younger people than in this study, as the median age was 54. Kessler identified four major factors in adjusting after a stroke, one of which was named ‘choices to action’. This factor facilitated transformation of the meanings of work, family role, illness/health, identity, recovery, and living. People responded to their feelings of loss of control imposed by stroke by seeking control. Kessler described that this was achieved by making choices and taking action on these choices. When the result of such decision making was a success, people felt an increased competence. This, in turn, promoted ongoing decision-making and action. In Kessler’s (2009) study the focus for taking action was driven by the desire to seize back control. In contrast, in this current study regaining control was an outcome of the process, but the driver was an increasing awareness of a need to belong and to get out and meet with people outside of the home environment. People in this study also became increasingly aware that they could wait forever but they would need to muster the courage and channel the energy to act as it was never going to happen simply by chance.

*"I am not good at socialising and I still say now oh I will be able to start going out once my leg is better or once something else is better and I know that isn't the case"*

Mike 433

Patricia, who had lost her horse group and her role as a carer, also struggled to meet new people. She too had put a lot of thought into the situation and faced conflicts between recognising the need to go out and socialise and actually making the effort to do it.

*".....how do you find another group that has the same interests as you? It's certainly not easy, and you do have to think about it. And I didn't. I'd rather given up. I don't really care whether I belong to a group or not. I just, I do go out once a month with a group, two lots of different groups, for a dinner, once a month and I'm supposed to go to one tomorrow, and I can think up excuses because I don't really want to go. And I'm not going. I don't want to go because although they are all very nice, I find it all, you have to dress up and you think oh God, what am I going to wear, and how to get there and how to get home. So I find that, I don't find it easy and often don't bother because of it. But the other group, where I go out and I don't find them difficult at all. It's a smaller group and I chat away to them and it's fine. But, this one I'm supposed to be going tomorrow, they are a big society group, you know they're all yakking away about how much this cost and what, and I feel, oh for goodness sake."*

Patricia, 270

Jean was the only person who actively attended church and used this network as a great source of comfort and support. Others like June and Dorothy, recognised how difficult it was to break into new groups.

*"When your old friendship group breaks down, it's terribly difficult to go into another group, or into groups. If you don't belong to the Church, it's very difficult to do anything, and I don't belong to the Church and I'm not really interested in religion. And I'm not going to join the Church because I want to join a group."*

June, 133

*"And then again, it's difficult to make, to motivate myself to join again. And they can be very cliquey you know, all these groups can be very cliquey."*

Patricia, 240

Following a stroke, the initial focus for people in this current study, was on their physical body and loss at impairment level, whereas loss of social identity and

community roles and relationships was often neglected. The fundamental need to belong is not a new idea and must not be under appreciated; there are multiple links between this need and cognitive processes, emotional patterns, behavioural responses and health and well-being (Baumeister and Leary 1995).

Baumeister and Leary (1995) proposed a 'belongingness' hypothesis. They argued that human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships. To satisfy this drive they proposed two criteria; first, a need for frequent, affectively pleasant interactions with a few other people, and second, that these interactions must take place in the context of a temporally stable and enduring framework of affective concern for each other's welfare. Putting this into context, interactions with a constantly changing sequence of partners will be less satisfactory than repeated interactions with the same person(s). Relatedness without frequent contact will also be unsatisfactory and reciprocity is important in relationships as found in the current study.

Haslam and colleagues (2008) found that people who were members of many groups prior to their stroke fared better after their stroke than those who were members of fewer groups. This was simply due to the fact that with a larger number of pre-existing groups, the likelihood was that some would be preserved after stroke. They called this *social identity continuity* (Haslam et al. 2008). People in this current study were older and interviewed many years after their stroke. All people described a restriction of their social world outside of their homes and there were only a few examples of continuity in the first couple of years, although equally very few people described a social world prior to their stroke that had multiple group memberships.

Belonging is more than being a member, or affiliation, it also helps to understand how people can maintain or improve social identity. Haslam (2008) argued that the uncertainties of the person who had experienced a stroke could be best addressed by those who can provide the necessary reassurance regarding relationships and previously held roles. Similar to the current study, Egbert and colleagues (2006) described that as the support recipient became

more certain of his or her place within these vital new networks, the development of internal resources such as patience and a positive attitude were enhanced. The current study also found that people's self-confidence was improved and will be discussed further in the next section. Only one person in this current study was an active member of their local church and relied on this network. Stark and Bainbridge (1985) discovered that the need to belong was a far more compelling factor than the need to believe. That is, there seemed to be a far more heavy dependence on social ties than on ideological belief and the social support that the church could offer was therefore highly significant.

#### 6.4.2 *'Dipping a toe in the water'*

Just over half of the people interviewed described an awareness of the need to start to try and get out and about. The process as they described, happened sometimes two or three years after their stroke, a length of time that surprised the people themselves. David, as seen earlier, was still considering taking action, over four years after his stroke. A complex process of utilising and mustering people's internal resources, such as determination, motivation, effort and energy and then gathering information and knowledge from external resources, enabled the people to start planning and 'dipping their toe in the water.' Timing seemed crucial and needed to be led by the person, when they were ready, however many years after their stroke. Jane, who was interviewed with her husband present, explained how after two years she decided to start getting out and about.

*"It is the isolation, um. If I didn't make the big effort as, which I did, and I sat in here all day I wouldn't see anybody and it was getting like that and we decided to go didn't we? And then, eventually, as I say, it got that we were, you know, we were walking the dogs and it got me out more, you know."*

Jane, 695

Making the first move was far more difficult than many had ever imagined. Jane used walking in the park to start getting out and stopping to talk with other dog owners, as a means of testing out the new outside world. Jean attended her church as she felt comfortable there. Many people in this study were linked to a

local charity which ran community based stroke groups and so not surprisingly 18 people were attending or had attended these. But there seemed to be limited other opportunities available that allowed people to test out their decisions. Some people used their stroke groups as a place to gain knowledge and build new safe relationships; others more as a stepping stone for gaining confidence and then moving onto other new groups or networks. All those who attended stroke clubs or groups, recognised them as a means of improving their self-confidence and this happened predominantly by the use of comparing themselves with other people who had experienced a stroke.

Social comparison can play a role in the recovery for many people with chronic illnesses (Tobin and Weary 2008). Feelings of vulnerability and uncertainty after a stroke can influence an individual's ability to make objective self-evaluations. People may compare themselves with similar others to get a foothold for their self-perception. Support-groups fit the prototype environment for such social comparisons to occur. As in the current study, Tobin and Weary (2008) found that people reported using more positive social comparison strategies than focusing on the negative implications of social comparison. The mental strategy of downward comparison has also been found in the stroke literature (Pound 1998; Dowswell 2000; Bays 2001).

*“At the beginning, I found it really useful to be with others stroke survivors, just seeing the others worse off than me. I used it as a positive as I think most people do and, it is rather cruel but I compared my situation with a couple of men there who you know I was a lot better off.”*

Stephen, 322

*“In the back of your mind, you are thinking the person is worse or better than you and that tempers your feeling and you can't feel woe is me, you have to temper that with they are worse than me so yes you do do that when meeting stroke survivors.”*

David, 365

*“I suppose the real reason I would say it has to be a stroke group is because, it sounds a bit callous to say this, it is in actual fact mostly helpful to see people who are in a different situation, or a worse situation.”*

Jean, 404

Murray and Harrison (2004) in their study described how the experience of a stroke often left people with reconstituted personal and social identities in which their old relationships did not fit. This sometimes resulted in a search for new friends such as those found in stroke support groups, although other participants in this study remained socially excluded. Pringle and colleagues (2013) also found that people looked at others as a means of comparing and contrasting their own situation. By moving the focus from themselves to others, people seemed to be judging their own progress and often gaining inspiration and building confidence to carry on. Kessler (2009) in her study found that people sought control in their lives following stroke through seeking knowledge. This would help them understand what had happened to them, why it may have happened (risk factors) and what this meant in terms of possibilities for recovery and living their lives. Inherent in seeking and gaining knowledge was the aspect of reflection on the information obtained and its relevance to their reality. The importance of gaining knowledge was also found in this current study. Jim, who now helped out at his local stroke group, having found it so beneficial for himself, recognised the importance of peer support and direct sharing of learning and knowledge as compared to that offered from rehabilitation staff.

*“obviously I’m biased but I think it’s one of the best ideas because the professionals can only tell you what they’ve seen, not what they’ve experienced so much of what has been provided in the past and still is for a lot of patients it’s for what the government or the trusts think you ought to feel or ought to need, whereas we know the customers’ needs. They’re only just coming round to that, to the stage where they come and ask people who have had a stroke themselves”*

Jim, 399

Ellis-Hill and colleagues (2008) proposed a Life Thread Model and described that a significant part of the process of reconstructing activities and roles was how others in the person’s social context positioned them. It was these other people who helped to define what a person with this certain ability and in this certain social position was entitled to do (Harré & Langenhove 1999). Boxer and colleagues (2003) proposed that people actively define their identities by taking positions in relation to other people and in the social context. They take positions and assign positions to others as they negotiate power and parity.



They can subsequently accept the position that they take or are assigned or they can challenge it by rhetorically re-describing that position. In the current study, dipping a toe in the water by being with other people who had experienced a stroke was initially for many people a safer experience and social position.

In contrast to the positive effects of downward comparison, some people talked in terms of comparing being with other people who had experienced a stroke as opposed to being with 'normal' people, highlighting their own ongoing struggle with self-identity. Whilst some people described how attending a stroke group gave them a sense of *insiderness*, others described how they struggled to see themselves as a peer.

Mike saw himself as lucky to spend part of his life with perceived 'normal' people.

*"I think though more broadly I am lucky in that I have got a balance in the things I do. I have got other stroke survivors but I have also got quite a bit of my life which is not about them which is with normal people. I have got my family and my kids when I see them occasionally so it's a balance. If I was institutionalised with just stroke survivors I would go around the bend I think you know."*

Mike, 361

David also saw mixing with people who have experienced a stroke as a potential transition, to help build up confidence before beginning to mix with 'ordinary' people.

*".. I think you start off with that because it's like crutches in a sense. I suppose, you know, you mix with your own people and with your peers, now your peers anyway, and then you know, you meet people, you sum them up. You go to people, that's a nice person, God that person's thick, or whatever, 'cos there's still that, if they were thick before they're thick now, they might even be more thick, but you know what I mean. You see the person first, hopefully, and then you think well alright, they've been affected in this way. But you basically you're in a group where initially it's easy because they've all got a similar problem to you. You see them, then you get to see them as people and that hopefully may lead you to say, right okay, they're still people therefore I can mix with ordinary people."*

David, 786

Although Roy and his wife attended the local stroke group, he seemed more ambivalent about his attendance. Whilst he recognised what he gained from attending he found that being with perceived ‘normal’ people meant he didn’t have to face his own illness and he could be distracted. For those with partners the value of the club for the carers was of equal importance.

*“Sometimes I feel I don’t want to be there at the group, I’d rather be here with people who are normal, rather than people who are suffering like I am. It keeps my mind away from my problem. But we do go to Stroke Club. We get to learn all sorts of things about various bodies that are out there to help people who are in trouble. And we do get some very interesting speakers and activities too which the club itself is called the Active Stroke Group and active is a very prime word, primarily to make us become as active as possible. All things are related to that, round the club activities. In that way it’s very good. I actually don’t really need any, it hasn’t brought my leg back or my arm back by any means, but that’s what it is.”*

Roy, 164

As described, many of the people talked about being with ‘normal’ or ‘ordinary’ people. Pallesen (2014) in her study with people five years after their stroke didn’t find this. The people she interviewed in Denmark did not see themselves as being different from others but simply recognised they were going to have to take a different approach to their lives. In this current study, seven of the people interviewed had made an active decision not to join a stroke club, even as a temporary measure. This delineation between people who had experienced a stroke and ‘normal’ and ‘ordinary’ people continued to be a recurring divide.

*“No, not tempted to join a stroke club. Well, that seems to be not managing to come to terms with oneself. You could do some things, you can’t do some things and to join a stroke club appears to magnify the fact that you’ve had a stroke. And they seem to, well I don’t know I’ve never.. ..been to one, but they would seem to get around to talk about their strokes and things, which is not really very good for people I don’t think. It’s not very good for me anyway, because I don’t want to talk about my stroke. You know it’s as simple as that, I just want to get on with what I can do and that’s it.”*

Reg, 495

*“I didn’t get so involved with other stroke survivors as personally I don’t think that is a good thing. I think the more you can mix and socialise with non-affected people who accept you for what you are and take it automatically that you may be a bit slow with your walking for example I think it is better for you as you are treated as being fairly normal. Particularly if your brain is still working.”*

Charles, 411

Raymond only saw social integration as ‘real’ and ‘natural’ if it was with people who hadn’t experienced a stroke and that the use of social comparison as not helpful and possibly a regressive activity.

*“...For me if you mix too much with other stroke victims with other physical and psychological problems I think you risk becoming satisfied with your own lot and I am so much better than that man aren’t I a great person and in comparison to their life and if they are happy then I must be doubly happy and I don’t need do anything more about improving myself and you shouldn’t be thinking that way you should be thinking I am a normal person and you should integrate naturally.”*

Raymond, 380

These findings showed that for some people being with other people who had also experienced a stroke was paramount to their sense of belonging and subsequent well-being. However, of equal importance was that for others, these groups were not desired or advantageous, and hence one size did not fit all. The supporting literature highlighted how group memberships tended mostly to have positive implications for people’s well-being and play an important role in helping people adapt to the transitions they experience throughout life (Reicher and Haslam, 2006). An example of a positive transition could involve moving to a higher-status group (a more prestigious organisation or a more desirable neighbourhood) and the positive implication of this move for a person’s self-esteem could help counteract any adverse consequences of change itself (Reicher and Haslam 2006). A corollary of this is that negative life changes, such as experiencing a stroke, often involves loss of such memberships or movement into less attractive groups and this move can accentuate problems of uncertainty and challenge. In this context, people can display considerable resistance to new group memberships that are imposed upon them, especially if those group memberships are perceived to have lower status (Jetten et al. 2002). Such changes constitute major social identity threats (Haslam et al.

2008; Branscombe et al.1999), which may be critical to one's self-esteem and well-being. This helps to potentially understand some of the people's attitudes in the current study to the stroke groups.

Only three of the thirty people in the current study returned to previous social groups outside of their own homes, this important aspect will be discussed in section 6.5.3.

#### 6.4.3 *Asking for help*

A conscious decision had been made to act and people were beginning to explore and develop a new social world. Fear of failure was a concern and many people experienced knock backs, such as illness, that often took a time to get over. People had used their families, the church and sometimes stroke groups as a form of testing the water, to help build much needed confidence and regain some personal control. A form of internal negotiation became important to many, where trade-offs were made and goals set and then negotiated. People slowly and gradually learnt to manage expectations and to ask for and accept help from others. This was a crucial part of starting to build new social worlds but a balance was needed between managing energy, ability to do a task and the desire to do it well.

Asking for help was hard but people who felt they had at least partially integrated, described this as a significant step forward. An important factor was that in asking for the help, it put them back into the driver's seat by allowing them to take back some control. Developing a positive construct of interdependency was a significant challenge but a rewarding one for the people interviewed.

*"I think you have got to learn to, uh, swallow your pride a bit um not to the point where you give up all pride but for example um when I go on holiday and you get to the airport and you let them know you are disabled. I can remember Gatwick once they offered to give me a wheelchair I wouldn't have a wheelchair I would rather hurt badly because being in a wheelchair is a very negative experience but now um .....I am a little less proud in that sense and um in fact in the spring we went abroad for 3 or 4 days and we went to museum and I was very happy for Sally to push me around in a wheel chair nobody knew me there so it didn't matter and it was certainly more comfortable seeing the paintings there is a bit of swallowing of pride but yeah." (Richard)*

*"So what you were saying earlier about taking control you can still take control but actually you can do that in a way that you are letting go but you are in control of letting go?" (Rachel)*

*"Yeah it's not people taking you over it's you letting them think ...yeah they are ...it's a power thing I suppose which is interesting to know whether that's different from men and women because men traditionally in society have had more power haven't they than women?"*

Richard, 437

*"....You start to modify your pride yeah to cope with and I spose that would be a good thing to encourage people to do after a stroke not to be so proud to be more willing to accept help and not not to the point where people help you across the road even if you don't want to get across the road you know it has got to be done in moderation but its ok to accept the fact that people are going to open doors."*

Stephen, 347

*"You can still take control but actually you can do that in a way that you are letting go but you are in control of letting go of some of the things so you can still be in control and modify you know."*

William, 552

For Dorothy, she described how she had to accept help from a person that she didn't like but she used it as a means to an end, of helping her to get out.

*"Swallow your pride and accepting help, I find it so difficult, I have a volunteer driver pick me up for my lunch club, he is such a chauvinist and horrible man but I have to try so hard not to lose my rag as I need him to take me to the lunch club, so I can get out."*

Dorothy, 429

Accepting and showing feelings of vulnerability supported this process. Turning the feelings of vulnerability into a process for moving forward took time, and not everyone was able to do this, but it enabled an initially perceived weakness to

be translated into strength and an increase in control. In line with the current study, Pallesen (2014) also found that people talked about anxieties and feelings of vulnerability that led some into inactivity and resignation and spurred others on to act with dogged courage. She described one end of the spectrum that the feelings provoked resignation and at the other a stubborn insistence that their situation could be to some extent overcome or managed.

Asking for help and exposing vulnerability helped the people in this current study to regain some control which was a crucial component for moving forward. Many people described a continuing awareness that although others could advise and support, it was their own body, their own life and that they needed to be in charge. Wood and colleagues (2011), who carried out multiple interviews with ten people, supported these findings and found that creating balance between capacity, self-identity and personal expectations was the ultimate challenge of community reintegration. People who were able to come to terms with and adapt to their new capacity used strategies such as accepting help and taking one day at a time. However, Wood and colleagues' (2011) study was only carried out for the initial year after stroke, and although accepting help was recognised as a key component for integration, in this current study most people described this understanding and process happening far later than a year after their stroke.

## 6.5. Renegotiating and Reconciling

*“I think the hospital is too busy and focused on the physical recovery and all the tick boxes and Government standards and progress reports and the questions focus on particular things but never the emotional well-being and that is far more important.”*

William, 589



The final major category *renegotiating and reconciling* was composed of three subcategories: The ongoing journey; hard work and setbacks; and a new, evolving social world.

### 6.5.1 *The ongoing journey*

After many years nearly all the people were living a life more centred round their home with a more restricted social world. Some people had managed to negotiate and explore new opportunities; their journey was continuing but they had regained some control and were looking forward. The need to belong and get out and about was continuous; there was no end to this. It felt more than a need for mere affiliation with others but a need for an added dimension of quality and depth to relationships which many of the people were still striving to

attain. It remained hard work and one that needed constant, conscious attention. The risk of falling back or giving in was present at each juncture. Utilisation of all available tools and techniques was also required.

*“No I think I can honestly say I consciously made an effort to get on and to try and do things and to not sit about and mope or feel sorry for myself, I try never to feel sorry for myself because there are so many people a lot worse than me but sometimes it’s hard not to.”*

Susan, 148

People needed to develop an idea of themselves as a capable person. Failure to manage situations made them feel worthless and so they would not attempt them again or anything else for fear of ongoing failure.

*“I lost quite a lot of confidence, but now I, I still lack confidence in doing certain things, so I don’t try and do them anymore. It’s as simple as that.”*

William, 305

Problem solving strategies became important. For Reg, he needed to have something planned in advance to help him get out of bed in the morning, this planning was crucial for him.

*“Provided I’ve got something to do and go out the following morning, which I do, I know it sounds stupid, but I think to myself tomorrow I’ve got to go out and I’ve got to do something, you know. It might only be shopping, or it might only be going down the town, but I’ve got to do it. And if I get up and shower and clean up things and go out, I’m alright. But it’s when I think to myself oh, I’ve got a day off I’ll do nothing today, I’ll sit here for about an hour and a half, I’ll think Jesus Christ, I’m going bonkers here. So that’s it. So if I make my mind up to do something... so I always go to bed at night with generally what I’m going to do first thing in the morning.”*

Reg, 209

People continued to find the idea of tackling new tasks difficult but knew they needed to try. There were limited opportunities for trying out new things within their communities to help support them to build confidence and meet new people. In a recent study (Thornberg et al. 2014) highlighted how succeeding in doing something new could positively alter self-perception and improve confidence. Thornberg and colleagues (2014) carried out interviews with 17



people who took part in a community based rhythm and movement group between two and sixteen years after their stroke. They found that to participate in a new activity could be experienced as rewarding as it offered a feeling of having learned something new and having grown as a human being. Thornberg and colleagues (2014) found an actual change in people seemed to take place, which was described as a change in self-perception of “I can” instead of “I cannot”.

People in the current study, often spoke of personal characteristics or internal resources, which allowed them to cope with the daily challenges of managing after their stroke. Commonly mentioned characteristics were determination, a positive outlook, motivation, resilience and patience. Positive characteristics were mentioned by those people that had managed to make progress towards integration. In those people that had made less or slower progress and had experienced a greater struggle, there was a propensity for low mood or depression that all but one person reported had also been present prior to their stroke. Raymond talked about inner strength, taking control and planning.

*“Well I think, I say you’ve got to have the inner strength to do it, haven’t you. I think, that would be the kind of advice I’d give. Is, take advice, but sit down and plan your own way of doing things, and plan your own life, and think, I think to myself now, I’ve got to do so and so, now how am I going to do it. And I sort of try and work my way through it. Of course it doesn’t always work, but this is what I do. I plan things better than I used to. I used to just get on and do it but now I do try. And that’s what I would, advise I would be giving, is because of my own experiences. I would say nobody can do it for you, the only person that can do it is yourself, with a bit of help if necessary. Some people give in a bit don’t they, and don’t even try. And they’re so embarrassed about their not being able to manage, that that makes them hide away more than ever.”*

Raymond, 503

June, Charles and Jim all talked about what they saw as their own persistence and determination but also the effort required.

*“Sheer bloody mindedness to me and I worked very hard to get as good as I am today , you know I walk around the village and they say you know ‘oh you are wonderful for getting around’ and I say ‘well it is not my scene to sit back you know I could have easily sat back”*

June, 280

*‘Well, I am one of these people who is persistent in everything, or actually I’m bloody minded. I just get up; I have got to be doing. I’ve always been like that. It’s put me in trouble, who knows – well that’s what’s helped me. Being positive. I’m not going to let this beat me. I’m going to do something about it.*

Charles, 94

*“Determination, It definitely is, yes. The people that go to groups and join in the most are the ones who are the most determined. There are others that just go and they’ll sit back, you know, they sit and dream and have a cup of tea and when we get up to do some exercises or something they just sit where they want, and they’re quite happy with that. Because you know, I mean I don’t know what level of acceptance they’ve got, but they haven’t got the determination to push them through to the next stage if they want a next stage.”*

Jim, 358

William highlighted the converse effect of his own tenacity.

*“I am so stubborn and I am going to go through with it and that’s what is so annoying as my whole life is going the extra mile and now I simply can’t and I find it so difficult to accept.”*

William, 250

Life experience and outlook prior to the stroke shone through. Those people who described a positive outlook prior to their stroke and then the ability to access these resources and convert them into something meaningful, seemed to make more progress towards developing a new social world and differentiate them from others. This process required time, hard work and daily effort. It never ended. Richard, Raymond and Dorothy talked about their outlook and approaches.

*“I just tried to turn everything into a challenge which was always my approach all my life.”*

Dorothy, 289

*“I think I have always seen myself as a positive person yes and what’s the alternative? To be negative and miserable no I am not going to do that”*

Richard, 163

*“My wife says I am stubborn, I call it tenacity, it is to do with my background and I had a very humble beginning and I had to get on with things”.*

Raymond, 449

The importance of personal characteristics has also been reported widely in the stroke literature (Becker 1993; Dowswell 2000; Murray and Harrison 2004; Ch’ng et al. 2008; Carlsson 2009). Egbert and colleagues (2006) in her interviews with 12 people, who had experienced right hemisphere strokes, and their partners or carers, also mentioned all of these characteristics or internal resources as described above.

### 6.5.2 *Hard work and setbacks*

Life continued to be hard work and there were setbacks all the time. The people described being thrown unplanned punches of further illness or extreme winter weather against a continual backdrop of ageing to hamper their progress. When adverse events occurred, people’s social worlds often shrunk again and a focused effort was needed to recover and return. Poor weather affected people’s ability to get out and meet others, which could affect them, particularly in the winter.

*“Oh I don’t know, [If I can’t get out] I have a cup of tea, read a book, watch the television, I love my television or take the dog out that’s one of my biggest pleasures, if I couldn’t take her out then I would be really miserable if it’s a day like it was last year, remember what it was like last year? And I couldn’t get out I mean I was so sad.”*

June, 322

*“The cold and February is really really bad and I say I have got to do something about that and it is going to scare me slightly. I play chess and go out once a week to play, even my wife says “why do you go out its Monday evening and its cold” and I say “if I don’t I will just sit here and I will rot away”. You have to have social intercourse some way.”*

Bernard, 114

Charles and Jean talked about the necessary patience that was needed to keep moving forward. They both also talked about the importance of resilience. It was this resilience that also helped people manage with the setbacks as they occurred.

*“It is patience patience and patience....Very difficult but you have to go out to talk to someone. I do have a lot of resilience it may seem conceited. I came out with a wheelchair and I couldn’t talk and I can now drive”*

Charles, 371

*“Resilience is key, I never give up however badly I have been beaten and it helps me to get on with life.”*

Jean, 488

People had suffered many setbacks in the time since their stroke and of course had continued to age. The risk of becoming lethargic or depressed and giving up remained ever present. Managing the bad days became an important focus.

*“Yes you still can fall into a spiral occasionally, depression and the other type you have got to keep something you know something to do that you know I play lots of bridge now... the bridge is quite useful actually it does get your brain in gear.”*

Susan, 342

*“I have tried lots of things and even if I fail I will keep going, the garden has been one of them and I now manage to do the garden but initially I was unable to do it and it has now given me so much pleasure. The winter is difficult as you are restricted as I can’t go out in icy weather.”*

Joe, 208

*“You always have some off days with a stroke for no reason and there is no explanation and you must battle through it without forcing it. You just can’t give up. I need to get out every day you get in the habit and then you have to fight it less. I have different groups, cards, church, chess it is important to have different groups to get variety.”*

Charles, 591

Raymond talked about how small often imperceptible improvements kept him going.

*“I had to fight the demons, every few months just feeling microscopic like changes and it was these that kept me going and it was little changes that keep me going”*

Raymond, 532

For some people they continued to experience high levels of anxiety, even many years after the initial stroke. William explained how anxiety continued for five years since his stroke.

*“.....and I am more nervous about things and I worry about things that I never used to be, and I hate being like this , I am so much more nervy , I find some things worry me more than they used to.”*

William, 387

The strategy of planning for each day has already been mentioned. Jim also talked about how he set goals to work towards but also how these helped him take and maintain control. June also talked about the self-determination needed but also the need to be in control.

*“So I always say you’ve got to have goals. Set yourself a goal. I remember my first goal when I came in this house because my wife moved to here while I was in hospital and my goal was to go, can you see that little wall down there with the green things on, I do, yes. I want to do this and I want to do that, and right at the beginning it was like re-learning to boil an egg you know. You need this and you need, and abc or 123, little tiny steps. And that’s how I used to do things. And still do things. If I’m going to do something like DIY or something like that, I kind of go through it in my head, I even write it down sometimes. All the steps, I’ll do this and I’ll do that, and when I’m gardening I do that. Go to bed at night with a goal for the next day.”*

Jim, 376

*“You’ve got to do what you want to do. Not what other people want you to do: To be determined and do things. You got to do what you can do. And um you know, so speak to everybody and I mean you’ve got make an effort, everybody’s busy, but go and sort of, it helps if you’ve got visitors coming, but if not mix with other people you see, you’ve got to sort of help yourself, not letting other people do it for you. And do what you want to do, but don’t do anything silly.”*

June, 210

People's progression was not linear and periods of no change or setbacks occurred. People described bad days or periods of slower or no progress. People learnt their own strategies for managing these as described above. Wood and colleagues (2010) who interviewed ten people on five occasions in their first year after their stroke described how it was people's fluctuating confidence for community living that contributed to a non-linear progression of the process of community reintegration after stroke. Whenever participants were transitioning to a new goal, for example, gaining physical function while in rehabilitation or establishing independence within the community, the experience was marked by a decrease in confidence. This decreased confidence was the result of being faced with challenges not experienced since their stroke. Over time people's confidence gradually increased as they gained experience and were exposed to other confidence building sources (Wood et al. 2010). In this current study many people described an ongoing fragile self-confidence that was easily eroded but didn't describe the decreases in relation to goal transitions that were found in Wood's study; possibly due to the fact that this study was carried out many years later and Wood and colleagues (2010) were also able to interview people many times and therefore capture such detail.

Six of the people in the current study also talked specifically about how rehabilitation staff hadn't made them work as hard as they had hoped or needed. The issue was specifically related to the frustration of incompatible expectations.

*"I walked every day and every day I walked just a little bit further and just a little bit further every day and eventually I could walk along the whole promenade. That came from me and my family and not from the physios'. They didn't push me enough at all you only got the odd half an hour."*

Charles, 649

*“I suspect that many victims might not know, might not be interested & almost certainly would not be offered information, regarding the latest thinking or outcomes of stroke rehabilitation. I was fortunate in that I had a job which required me to keep abreast of my field and gave me an awareness of medical terminology, so I had an idea of where to start searching & what the information (that I found) was saying. My brother is a research virologist so I could also rely on him to leave no stones unturned. I know that I would not have had near as much to aspire-to and try-for if I had not uncovered this information. I feel that this has helped greatly in the physical recovery that I’ve made so far. My experience of the stroke has made me think that the current standard of care/rehab. Makes victims feel more helpless, more hopeless and more “patientified” (my word! You know what I’m trying to say?). Having said that, I think that the advent of the dedicated stroke wards must have been a great improvement on the previous standard of stroke care & rehabilitation?”*

Raymond, 620

He continued

*“You need to take control of your stroke and not take too much notice of physio’s and the speech therapist’s you know it’s your body you’ve got to get on with it and unless you do make an effort you are not going to get on with it and really your recovery or as far as it will go will take a long time and it will be very frustrating because it will take a long time, but it is up to you it’s on you and you alone”*

Raymond, 646

*“The stroke units just don’t set high enough expectations, there is not enough positivity.”*

Jim, 281

This finding was also described by Bendz and colleagues (2003) and Burton (2000) who both reported how rehabilitation staff tended to set very different goals from their patients. The rehabilitation staff mostly focused on physical tasks or functional ability with concrete end points. People after their stroke on the other hand reported less concrete goals and more those pertaining to personal identity, finding new roles or defining a new sense of normal. For these people, the process of adaptation and reconciliation, including the development of new ways to interact with the social world, seemed to be the focus for recovery rather than physical or functional ability alone.

People in the current study all described completely individual approaches, meanings, goals and timescales based on their own circumstances and these needed to be supported and respected by their family, close friends and rehabilitation staff. This was also found in other studies (Robison et al. 2009; Barnard et al. 2010). Barnard and colleagues (2010) found that people downplayed their real goals or didn't tell others about their aspirations because other people thought they were impractical or impossible to achieve and when professionals (Alaszewski et al. 2004; Barnard et al. 2010) or families (Evans et al. 1994) believed the goals were unrealistic, they did not provide help. These studies found that successful involvement in activities related to the degree to which other people allowed the person to set their own goals and go along with them.

### 6.5.3 *A new, evolving social world*

The majority of people had fewer social contacts and social groups than before their stroke and so these few relationships were important. For those people who had negotiated relationships outside of their families, most had made new friendship groups networks and had not reintegrated back into old ones. Only three of the thirty people in the current study returned to previous social groups outside of their homes: Jean to her church; Patricia, somewhat reluctantly, to her social dining group as previously discussed and Jim had also just reconnected with some old air force friends which he met monthly.

*"I now see again my friends in the area who I knew from before, because I was in the Air Force, and there are a lot of Air Force guys round here, and we meet once a month and of course all we ever do is reminisce. And I used to find it very difficult, but now it doesn't bother me. I can sit there and it's just like because it's like talking about what are your achievements, or when you are college, all different stages in your life. Now they are all coming to a different stage, and you realise that and you understand it."*

Jim, 427

For the majority of people, they described how their social world took on a new shape with new groups filling some of the empty space. Importantly, almost all of the participants talked about a new life and not a return to the old.



*“Well, your life is never the same, but you’ve got other things that you can do. If you only just go along different lines. I mean at one time, we would never go and sit down on the seafront. We were always up on the hills. That was so different, although I have always liked the sea.”*

Fred, 222

The term integration as opposed to reintegration felt appropriate as nearly all the people were integrating into new groups or networks and not reintegrating or returning into old networks; although they were all reintegrating at some levels back into society. This new social world had emerged from a process of a growing self-awareness of needing to change. People all described how they found different meanings within their own personal discourses. They also talked about regaining control and an improved understanding of themselves. This didn’t necessarily mean an acceptance, instead more often a form of reconciliation or truce that allowed a new social world to emerge. They had started to integrate their stroke into their life and the realisation that their life was continually evolving.

*“I mean life has continued to evolve from the day it happened up to this point and it will continue to evolve. I mean, I suppose it’s life itself, you know you do change, you’re constantly changing.”*

Stephen, 531

*“So I suppose really this integration thing is a life thing, not a stroke thing. It’s probably now I just feel that getting out isn’t so bad after all.”*

David, 566

People also commented how, in this evolving world, improvements were also still happening even after many years.

*“You can improve, you notice things, you do improve with practice but it may be one year to the next. After 8 years it is only this year that I can use a tooth brush with my right hand. There are certainly improvements but not on a day to day basis”*

Raymond, 472

When asked, the people in the current study were keen to offer their advice to others newly experiencing a stroke and they often mentioned things that they

wished someone had told them. Many felt that a disproportionate focus had been on the physical effects of their stroke and not on the social and psychological resources needed and as such some people felt that they had let their own social networks restrict whilst they were focused on getting physically better. Many people commented, with the benefit of hindsight, on the long never ending journey.

*“Well I would certainly say you know try and get social skills re-learnt and to make the effort to get out. Keep up your support network, whether it’s the family or their friends and recognise where that support is and keep it going. It’s actually quite a long journey and think what you want to do. If something’s important to you then plan it out first to make sure you know, you’re going to get there. I do things under my own conditions.”*

David, 567

Some people highlighted the importance of talking about feelings, something that so few of them had ever had an opportunity to do.

*“Talk about feelings, you can see people who are so full of despair that just go downhill so rapidly but no one talks to them or asks them to talk.”*

Marilyn, 238

Some people also mentioned the terminology that people in wider society used and how potentially damaging it can be.

*“You have got to call us survivors and then we will act like one. Until you can learn you are a survivor and you can change your lifestyle. You have to stay busy, there are people so much worse than I was; do something constructive and do something to help someone else. I am alive. You are going to get depressed so take the tablets the doctor gives you. You have just lost part of yourself that you depended on and needed and you just have to find a way around it. You could sit at home and feel sorry for yourself but what is the point, you are not a victim, you have to get up and go do something.”*

Richard, 561

Asking for, or accepting help, but maintaining control was a key theme of advice that many of the people used and has already been discussed. They described that it had taken them years of fighting against this and they wished they had understood that accepting help didn’t mean you were a failure. Developing a

positive construct of interdependency was a crucial step forward. Some people realised that this might be a necessary process that would take time to work through, others felt that they would have benefited from more help from the rehabilitation staff.

*“I would say mainly don’t be afraid to go out and integrate with people, accept people, if they want to help you accept their advice or help that they can offer or give you, take that, and above all get, you know, don’t shut yourself away, I think that is the worst thing you can do, you know get out.”*

Jean, 259

The realisation, that there was no end but this was an ongoing process of change needing renegotiating, was hard to come to terms with and people talked about the effort needed to simply keep going. The hard work described throughout people’s journeys was pervasive and had become existential in its existence. People had to put effort and thought into their social world like never before.

*“So often we don’t show we care, it’s tough it’s really tough and I would want to say to them to fight the dumb down feeling and the temptation to do bugger all, you won’t necessarily get better, you may have to pace yourself and that is bloody agony, and pushing the extra mile is just going to make things worse. There is no end, you need to go with the flow, I am having a tough time myself.”*

David, 431

*“You have to have other people views on the weather, on politics, on sport even if you want to say sod off you silly old bugger that’s rubbish you have got to have opinions on various parts of life. I never had to work as hard at it before my stroke but now I have to think about socialising all the time.”*

Stephen, 460

*“Don’t give up because there are, there is a life afterwards although it’s totally different. You’ve got to face the facts and adjust to it, which I’m trying to do but I would advise them not to get too depressed about it because there are things which you can do plus the things that you can’t but there are an awful lot of things that you can do and take an interest in. So it’s not the be all and end all. It’s a very dramatic change in life of course.”*

Roy, 284

Only two of the people interviewed talked directly about acceptance. David talked about accepting the labels or views of others. Jim was able to reflect on the eight years since his own stroke and described two stages of acceptance.

*“I think acceptance helps this. I remember the first time that somebody said that I was disabled, and I got really upset about that and angry and said I am NOT disabled. I’ve got a medical problem, but I’m not disabled. And now I’m thinking it doesn’t bother me the fact that I’ve got this particular label because I’ve accepted it.”*

David, 423

*“I would say it would be nearly two years before I kind of had some kind of acceptance. Um and then there’s acceptance of about five years later when you think okay then, I’ve got to think that’s pretty much who I am now, this will be pretty much my life from now on.”*

Jim, 517

Jim also talked about how he no longer experienced conflict and was able to reflect back on his life.

*“I don’t have conflicts in terms of myself anymore, I don’t. Maybe it because of what I’ve done before, like I had a period when I was at college, a period when I was in the Air Force, a period when I was teaching and a period when I was here doing this. And you know they’re different stages. So I can look back, can talk about it and it’s a compartment if you like. I can take it out and read it again and do the same with other parts of my life. And you know it doesn’t trouble me. But I think most people want to be able to do that. I know there are some people that can’t do that. I think most people want to”*

Jim, 539

Some of the literature identified pointed to a stronger overarching pattern of acceptance over time than has been found in the current study. Some of the studies were carried out in a closer timeframe to people’s stroke, and with younger people with milder strokes, which may provide a partial explanation of the difference (Clarke & Black 2005; Ch’ng et al. 2008; Green et al. 2009; Brown et al. 2010). Sarre et al. (2013) highlighted in their recent systematic review that there seemed to be a fine line between acceptance and resignation and that acceptance could lie somewhere on a continuum between resignation, despair and adjustment. Such words are powerful and used widely in the qualitative stroke literature and yet connotations and understandings may be

complex. Sarre and colleagues (2013) propose a genuine challenge for researchers in escaping the use of a moral interpretation of people's responses. This will be discussed further in the next chapter. Wood et al. (2010) highlighted that the process of community reintegration would probably continue for the duration of the people's lives and as found in this current study; there was no end.

Whilst two people used the term acceptance, other people spoke about the fact that although they had been told by rehabilitation staff and family members that after a period of time they would come to terms with what had happened and accept it, that simply wasn't the case in their own experience. Although things had changed with time there was, for most people, no such thing as acceptance of what had happened, people described feelings of reconciliation and regaining control or a form of resignation; comfortable or uncomfortable, but not an acceptance. This finding was also supported by a study by Alaszewski and colleagues (2004) who carried out interviews with 30 people who had experienced a stroke and then separate interviews with 17 health professionals involved in their care. They found that whilst the bereavement model was used in professional accounts of adjustment after stroke it was completely absent from those who had experienced a stroke. Whilst people in their accounts of life after a stroke did acknowledge the ways in which stroke disrupted their life and resulted in losses and disabilities, their perception of such losses and disruption was shaped by the context of their every-day life. They found that most people sought to actively manage their recovery by setting goals and they wanted professional support in achieving their goals. Interestingly, Alaszewski and colleagues also found that the bereavement model was often being used by professionals in situations where there was a conflict over goals and they explained this by saying that people had become 'stuck' and their goals unrealistic (Alaszewski et al. 2004).

From the current study, Richard described his thoughts on acceptance and his own journey six years after his stroke.

*“Yeah I feel that bereavement stuff is nonsense um I think it’s dangerous because I think people try and impose it upon you, it may apply to some people but it certainly didn’t apply to me um I can’t think of anything in that whole process that resembled any sort of grief and acceptance. You need to take control and it will take time.”*

Richard, 590

## **6.6. Summary**

These findings highlight the complexity and uniqueness of people’s experiences in the process of developing a new and personally meaningful social world after a stroke. Developing these new relationships seemed less dependent on levels of disability and more on the ability of people to actively utilise internal resources in the mobilisation of external resources to make and sustain these new connections. The current study showed how the entanglement of stroke sequelae can mean that negotiation towards a new social world is long and relentless with numerous setbacks needing pervasive hard work and energy. People experienced gaps in their own identity and for some an internal conflict and yet were driven by a need to belong. Some people managed to muster enough confidence to take a conscious decision to meet and interact with new people outside of their homes and regain some personal control. Each journey was highly individual with its own personal meaning and was continuing to evolve even many years after the experience of stroke. The next chapter will discuss some of the key findings and will compare and contrast these within the current literature to show how this study has created new knowledge.

## Chapter 7. Discussion

### 7.1 Introduction

*“I never had to work as hard at it before my stroke but now I have to think about socialising all the time.”*

Stephen, 462

*“Before the stroke you never thought of these things. You don’t equate integration with anything because we were part and parcel of anything that ever went on. I don’t think you ever stopped to think.”*

Jean, 301

*“Nobody can do it for you; the only person that can do it is yourself”*

Raymond, 509

The previous two chapters introduced the substantive theory *from indecision to volition*, described in detail the four major categories, and situated them within the current literature. A metaphor and model of travelling on an underground train system was developed to help the reader gain further insight and draw on shared understandings to highlight some of the main qualities from the findings and to add a visual and embodied representation to the process and meaning of social integration in older people following a stroke.

The aim of this study was to understand the meaning and process of social integration from older people, addressing a gap in knowledge. The majority of people in the current study did not recognise the term social integration and did not use it as part of their vocabulary; instead terms such as social world, social life, relationships and getting out and about were used by the people interviewed and adopted by myself as these were more meaningful to these people. Furthermore, they described the importance of social interactions and the impact of their stroke on previously established groups and networks and the challenging process of building new, meaningful social worlds. In this

chapter, the impact of being an older person after stroke in relation to the people in this current study will be discussed initially, in order to add context. Five key findings from this study will then be considered with a proposal of how these offer new richness or a different perspective to current thinking and understandings in the literature which has been reviewed up to 2014. These five areas are: *Prevailing effort and hard work; A never ending journey; A conscious decision to act; The impact of the empty social space* and lastly; *New, changed, unique social worlds*. Finally, the study limitations will be considered.

## **7.2 The experience of being older**

The people in this study had a mean age of 76 years with ages ranging between 68 and 88 years. This mean age was higher in all but one paper of the supporting stroke literature that was reviewed since 2007 (Eilertsen et al. 2010). Eilertsen and colleagues (2010) carried out a longitudinal study with six older women in Norway looking at the process of recovery after their stroke. These women were of a similar age range (68-83 years) to the current study. The majority of the literature reviewed to the current date, has studied people of mixed ages who had all experienced a stroke and hence people's mean ages in these studies were significantly lower and the age ranges wider. In the current study I purposely chose older people in order to add new insights and additional richness to understanding the specific experiences of older people following a stroke.

The current study confirmed that the biological process of ageing had brought particular issues and increased challenges to the process of integrating into a new social world. Ten people were widowed and for half of them this had happened after their strokes. The impact of loss of a spouse and other close network members caused additional strains and challenges to people. In addition to loss of loved ones, the major factor in determining the frequency of seeing and having contact with relatives is physical proximity. Intergenerational contact, is greatly affected by geographical distance between households, with more distant children interacting less often with parents (Pillemer et al. 2000; Fiorillo & Sabatini 2011), often leading to reported loneliness amongst older



people (Victor and Bowling 2012). Within the current study, the issue of geographic mobility, in particular children moving away for study or work, was also problematic for some people. This reduction in social contact from family members caused two different issues: Firstly, people felt it directly affected their social worlds as their family were less able to fill the increased social space following their stroke. Secondly, people were less able to draw on family members for the external resources that they needed, in order to move forward and tentatively build their new social world. Subsequently, these people had to access resources from elsewhere. Another issue found in this study was that despite the ages of the people interviewed, seven people were in employment at the time of their stroke. As a result, these people potentially experienced the same impact of loss of their job that younger people would, including the sudden loss of their occupational social network. With an increasing retirement age and people continuing to carry on working into their late sixties and seventies in the UK (Victor and Bowling 2012), the impact of people losing their occupation and experiencing a sudden, unplanned and imposed retirement, needs to be considered in both older and younger people following a stroke.

Age is not only a biological process but also an interpretive one. In this study the majority of people, many years later, continued to describe their stroke as sudden, dramatic and with lasting impact on their lives. A significant disruption was described by over 20 of the people. This finding is contrary to others who have theorised that older people specifically may downplay their experience by minimising or normalising their stroke (Bury and Holme 1991; Pound et al. 1998; Hinojosa et al. 2008). There are many possible explanations for this as age is only one area of contextual importance in relation to the experience of their stroke. All of the people in the current study had experienced lasting social, physical and psychological changes to their lives and all but one person would be considered, from a physical perspective, of having experienced a moderate to severe stroke. Additionally, despite their age, only four people reported any longstanding or significant illnesses prior to experiencing their stroke. This meant that for all people in this study they reported their stroke as the most significant illness within their life context and a key turning point or transition

along their own process of ageing; one where it was simply no longer possible to carry on as before.

Significant restrictions in people's social worlds meant that their focus changed from activities outside of the home to predominantly those centred around the home. All the people in this study had managed to return to their homes after their stroke and had managed to continue living there; often with additional support. The ageing literature highlights how older people want to remain living in their own homes for as long as possible, and they wish to be active and participate in their communities on their own terms (Valdemarsson et al. 2005; Oswald et al. 2007; Haak et al. 2007). Haak and colleagues (2007) found that across the ageing trajectory, participation in older people changed from performing more physically and mentally demanding activities to them carrying out less strenuous activities. Furthermore, the location of the activities shifted over time from outside of the home to those within the home environment. Desrossies and colleagues (2006) also found that some restriction in older people's participation after a stroke may be partially attributed to normal ageing and not solely due to their stroke. This needs to be considered within the context of the current study findings.

From an ageing theoretical perspective, a link to the theory of place integration (Cutchin 2003; 2004) can be considered. Place integration conceptualises how older people, through their activities, are integrated within their homes in an evolving, changing and transactional process (Cutchin 2004; Dickie et al. 2006). Place integration embraces the homes in which people live and spend their life, and proposes that to be able to understand a person's actions it is necessary to consider the context through which an individual lives their life (Cutchin 2001; Haak et al. 2007). In addition, place integration theory recognises the constant instability amongst older people in relation to their increasing frailty, and how this instability will affect all actions taken within the context of their place of living. Cutchin (2003,2004) explains how these actions are the result of people's struggle to maintain independence but also the negotiations that they carry out to consider what is important or not important in their lives (Cutchin 2003; Cutchin 2004; Haak et al. 2007). The findings in the current study resonate with

the conceptualisations of place integration although whilst the model developed by Cutchin (2001) recognised increasing frailty and instability it does not explicitly consider the concept of people experiencing a sudden turning point or transition such as a stroke. This sudden turning point in the current study could be seen to govern the hard work, effort, dissonance and negotiation processes that have been described in the previous chapter and thus would be an important concept to consider for place integration. Some of the ageing literature identified does describe how an older person can experience such turning points or transitions and how they act in relation to them as a result of the social and cultural demands posed upon (Bennett 2010), and also as a consequence of personal preferences and motivation (Oswald et al. 2007). Turning points are also nearly always related to some sort of health issue, in this case stroke, even though they are often articulated in terms of social events or environmental changes (Bennett 2010). The current study findings support those found in the ageing literature in relation to how older people will experience a continuous negotiation between the world they are living in, their state of mind, and the concept of turning points in life. Furthermore, this current study has presented and described a complex and dynamic process and if older people are to be supported to develop meaningful social relationships then this process of constant negotiation needs to be fully considered within the entire context of ageing, health, home, community and self.

### **7.3 Five key findings**

Five key areas have been identified from the study findings that have added new depth and richness to current understanding and knowledge. These five areas are: *Prevailing effort and hard work*; *A never ending journey*; *A conscious decision to act*; *The impact of the empty social space* and; *New, changed, unique social worlds*. Although they are all intertwined, each will be discussed separately for ease of reading.

### 7.3.1 *Prevailing effort and hard work*

An important theme running through all the people's experiences in the process of building new social worlds was one of persistent, overwhelming effort and hard work. The effort and work that was described was all encompassing and included both the pure physical effort people required to carry out simple daily tasks since their stroke and the mental energy needed to deal with the often overwhelming challenges that they had to face. This effort and hard work prevailed throughout people's narratives; working at an existential level that linked to their sense of their new lives and existence of self that they had simply never experienced before. A daily struggle ensued in which people needed to expend energy in living and managing. People described what hard work it was to leave their home to make new social connections outside of their family and to also sustain these; their lives were an effortful existence.

The people in the current study were older people living in their own homes, 13 people were living by themselves, managing the consequences of their stroke and dealing with ageing bodies and minds. A recent multi-site study of older people living in the community, within their own homes, highlighted this daily struggle that older people experienced in order to participate in meaningful activities (Haak et al. 2011). Successfully managing this struggle contributed to people maintaining a preserved picture of independence and an ability to participate in life according to personal choices (Haak et al. 2011). During this process, Haak and colleagues (2011) described how people were constantly trying to maintain a balance between their own frailty and health, their demands on themselves and from others, the demands from their home environment and also carrying out activities in which they needed or hoped to participate. In the current study many people also described a daily struggle and the effort and hard work required in order to get out and about and maintain independence and choice. In contrast, other people were unable to sustain or potentially confront this struggle and needed to resign to a more dependent existence. In addition, for many people, being able to do everything they wanted was not possible as they simply didn't have the energy. They needed to negotiate and prioritise and, for those who were successful in forging new relationships, they

needed to be able to work out how they could optimise their energy. Asking for help was a crucial part of this and constructing a new framework of interdependence and letting go of previous independence by swallowing their pride was an important progression for some people, but this took time.

Whilst the ageing literature supported some of the findings related to the prevailing effort and hard work required, less explicit findings were identified in the stroke literature. Some papers reported lack of energy after a stroke (Kirkevold 2002; Kouwenhoven et al. 2011; Pallesen 2014) and described the hard physical work and effort of mental adjustment needed in recovery after a stroke (Burton 2000; Kirkevold 2002; Erikson et al. 2010; Wood et al. 2010). However, unlike the effortful existence found in the current study, these factors were often described in more general terms in the papers, and commonly within the context of the initial early phase after people's strokes. One study, with younger people only eight to fifteen months after their stroke, described how some people were exhausted and how the hard work caused some to close in on themselves (Norcott and Hillari 2010), which directly restricted their participation in activities.

In the current study, people described the overwhelming and ubiquitous effort and hard work that was needed from immediately after their stroke but also for many years later. People talked in those terms even eight years later. This seemed to be independent of gender, time after their stroke or severity of their stroke. People would use different terms and language to describe it but it prevailed through all of the people's experiences and journeys; as Stephen explained that prior to his stroke he never had to work so hard but now he had to think about socialising all the time; the hard work was constant. The metaphor proposed in chapter five painted a picture of a complex journey on an underground train. The hard work and effort described by the people every day simply to exist could relate in this visual picture to someone having to take the train journey every day; dealing with broken escalators or closed lines and negotiating all challenges, day in, day out.

This finding needs to be considered in relationship to supporting older people to manage and negotiate new social paths after a stroke. People need to be supported to find strategies in order to be able to conserve energy to participate in chosen and meaningful activities. Rehabilitation staff also need to understand the effortful existence that older people living in their own homes after a stroke may experience, by listening to their stories and considering how they can provide support to help mitigate against the risk of social isolation.

### 7.3.2 *A never ending journey*

For the people in this study, their journey was ongoing and the process of developing meaningful relationships was dynamic; there were no dramatic moments that involved feelings of acceptance, reconciliation, integration, adjustment or attainment. Instead, people described an ever changing social world that included changes of track; pausing or (re)negotiating different directions. Life was evolving as Stephen said, “*as life does*”. Even people who had managed successfully to negotiate new social networks and relationships didn’t feel that they were socially integrated and that they were still working hard to sustain networks or considering testing new groups. It was what mattered to these people at a personal level that was most important. This brings into question the challenge of being able to successfully measure and capture optimal social integration or participation due to its complex and important subjective qualities but also due to its evolving and dynamic nature. Despite a minimum of four years and a maximum of eight years after their stroke, some people described how they were still striving and moving forward. The narrative of their stroke remained central in their lives despite many years having passed, but they described a process over the years of a shift in their understanding and priorities. A significant, growing body of qualitative literature since the initial literature review in 2007 was examined in the experience and meaning of life after stroke, but the majority of studies identified remained focused on the initial year or 18 months after people’s strokes. Fewer studies were located that considered people’s experiences greater than three years after their stroke (Ch’ng et al. 2008; Kessler et al. 2009; Pallesen 2014). The findings in the current study also describe a complex and dynamic process which have been

presented in phases within a loose time trajectory, where people may take years to move forward, may pause, or move backwards. The process of developing new relationships and maintaining friendships was non-linear.

In addition, terminologies of adjustment, recovery and acceptance after a stroke were found to be prominent in the literature and timescales for reaching or attaining acceptance, or adjusting and recovering, were often variable. In the literature acceptance was related and felt to be influenced by many different contexts such as age, severity of stroke and time since stroke. As discussed in the previous chapter, the use of this term may also be linked to people's or researchers' insights into the complexities and nuances of people's stroke experiences and therefore be ascribed different meanings. Sarre and colleagues (2013, p.9) argued that acceptance "*lay somewhere on a continuum between despair, resignation and adjustment*" and that there was a wide scope for researcher interpretation, which may include a moral judgement on successful adjustment.

The term acceptance in this current study was only used by two people, but not within the construct of bereavement frameworks that some rehabilitation staff may still adopt (Kubler-Ross 1969; Doyle 1980). Additionally, as the model described is dynamic, people's thoughts and feelings changed with time and context. For example, Jim described two levels of acceptance, one at two years and another one at five years. These findings may help explain why other studies may have identified concepts of acceptance at earlier times after people's strokes. More importantly they highlight the risk of supposing that acceptance has taken place rather than taking into account the dynamic nature of experience and the differing meanings that people will have. Acceptance is often perceived as an end point or as a positive outcome and yet an acceptance of not being able to carry out previous activities could also be interpreted as being closer to a resignation whilst this may actually be a pause with further progression happening many years later.

What is most important is in the understanding of people's unique journeys, that what may be of value and meaning to one person may be different for others,

and that there is no predictable illness trajectory of phases. This finding supports the shifting perspectives model (Thorne and Paterson 1998; Paterson 2001). Thorne and Paterson (1998) carried out a meta-synthesis of qualitative studies and developed an insider perspective of chronic illness, one that shifted away from loss and burden and instead viewing health within illness. Paterson (2001, p.4) supported this further by viewing the experience of chronic illness:

*“As an ongoing, continually changing process in which people experience a complex dialectic between themselves and their world.”*

Paterson (2001) described how shifts will constantly occur and a person may move from a focus of suffering and loss to one of control and looking ahead and back again. In the current study, even many years after their stroke, people also described such shifts as part of their many narratives. Some people described how they managed their constantly evolving world and the often daily challenges that it presented by taking each day as it came. People described how they focused on the present and didn't look too far into a future which was uncertain and could cause a resurgence of fear and anxiety. This approach allowed people to manage their uncertain future but also helped them to construct continuity in a more contained timeframe.

Paterson (2001) also discussed how rehabilitation staff still commonly refer to the terms acceptance and denial when describing a person's response to a stroke without understanding that there will be constantly fluctuating feelings. These professionals risk relying on their own, often incorrect, interpretations and instead they need to ensure they encourage people to tell their own unique stories, otherwise this dissonance could potentially stall or halt progress in rehabilitation. Moreover, if staff use terms loosely or without realising that the person hearing them may internalise them (particularly coming from a person with authority), then people's progress may also be affected and the therapeutic relationship damaged.

The concept of the never ending journey found in this current study challenges traditional models for the delivery of rehabilitation services and recognises that older people after a stroke may well need support to build new friendships



groups and networks many years after their stroke. These findings also offer hope to many people and their families in that people do continue to develop meaningful social worlds often many years after their stroke; not something that is often acknowledged.

### 7.3.3 *A conscious decision to act*

This study has explicitly highlighted a conscious decision to act and build new relationships outside of the home as a central component and subsequently the core category. This concept of a conscious decision has been presented in this study as being situated within a complex framework that made the process difficult and challenging for the older people. This was a new and different experience as prior to their stroke people explained that they didn't have to consciously think about getting out and meeting people; as Jean said, in the quote at the start of the chapter, previously they were simply "*part and parcel of everything.*"

This need for people to exercise a conscious choice in order to meet new people and build new social worlds is not mentioned in such explicit detail in the identified stroke literature and adds some supplementary granularity. In a recent analysis of the literature in relation to social participation following a stroke, Woodman and colleagues (2014) described a process in which people re-appraised their situation by thinking about their options and subsequently made personal choices about what they wanted to do. They enhanced this by adding that after the re-appraisal, people made personal choices to either resume an activity, to focus on a new activity or adapt an activity. This current study adds richness to the process they described, emphasising how the choice had to be actively considered. The present study also challenges the concept of choice. The older people were often unable to fully realise their choices due to lack of both internal and external resources, the wrong timing and the hard work and effort required.

In the current study, the driver for this conscious decision was, for most people, a growing awareness of a need to belong and meet people outside of their own families as opposed to staying within the safety of a social world simply

revolving round their home and close relatives. An often long period of indecision occurred until this conscious decision was enacted. Erikson and colleagues (2010) identified a process of belonging in 11 people during their first year following a stroke, partially driven by feelings of being a burden. Other studies have described the choice to take action and increase participation after a stroke, as being driven by a need for regaining control (Kessler et al. 2009), as described in section 6.4, or a right for people to exercise personal choice (Hammel et al. 2008). Hammel and colleagues (2008) developed a model of participation from insider perspectives of people with a range of disabilities including stroke and described a right to exercise personal choice based upon respect of difference and dignity of personhood; something that some people in this current study continued to struggle with even after many years. This right to decisional autonomy or regaining of personal control was often seen by people in this current study as an outcome of this conscious decision but was not described as a driver.

The current study found important variation, both in people making a conscious decision to act and those that did not mention it, but also a variation in the time it took those that did act to make the decision. The indecision and cognitive dissonance I described in the previous chapter was often present for many years, with the balance slowly changing from feelings of *"I am okay as I am, aren't I?"* to the growing and pervasive drive of needing to belong, filling people's thoughts with increasing recognition. As Raymond said above, *"the only person that can do it is yourself."* David was still thinking about making the decision four years after his stroke. The need to belong in this study grew, for many, from feelings of loneliness, feeling disconnected, feeling a burden, and a lack of reciprocity in family relationships. Although many people described how supportive their families were, for many, they didn't fully satisfy this need to belong and forge new relationships outside of their home, in addition to those with close relatives. This finding is supported in the literature in that feelings of loneliness are much more closely tied to our networks of optional social connections than to those handed to us at birth (Pillemer et al. 2000; Christakis and Fowler 2008).

This key finding is important in relation to people's experiences after a stroke as the conscious decision to act happened at very different times after people's strokes, which does not naturally fit with current models of rehabilitation or access to community services. Rehabilitation approaches for people after a stroke remain focused on physical outcome and less on social outcomes and this can be linked to the timing of the provision which is weighted heavily to the initial few months after a stroke. In England it is often difficult to re-access specialist stroke services after months or years and so for the older people in this current study who sometimes took many years to reach a decision, they often described minimal access to such services. Whilst some people may need additional specialist support from occupational therapists or psychologists in order to enact the conscious decision, support must be tailored to people's own needs and requirements and the traditional model of rehabilitation services may not be the only or best option. Offering opportunities in people's local communities that encourage participation and integration by building confidence and allowing people to build new social connections outside of their homes also need to be considered. This current study showed there was a limited choice outside of local stroke groups and the need for older people to belong and forge relationships outside of their families is often not fully understood or considered by health and social care professionals. Therefore people may be considered well supported if cared for by close relatives and assumed that they are having all their needs met.

#### *7.3.4 The impact of the empty social space.*

The people in this study all described how, after their stroke, they experienced an immediate shrinkage of social groups, relationships or networks causing a restriction in their social worlds and the emergence of an empty social space. Although, for most people their families stepped in to fill this empty space, this still led to people spending an increasing amount of time on their own. This was an enforced time alone as opposed to a chosen solitude. Over half of the people subsequently described how, within this space, an energy draining fear grew and took hold. This described fear consumed people and left them frozen and inactive, and increasingly vulnerable. In turn these feelings caused people

to further withdraw and caused even greater erosion to their self-confidence. This sense of fear and vulnerability was instrumental in constraining social opportunities. A downward spiral leading to introspection and, for many people, further social isolation was subsequently created. Although this fear-filled empty social space was most noticeable in the initial time after their stroke, for some people this was described as continuing for years and not months. For those able to break the spiral, as their social space re-filled with people and social opportunities as time progressed, the fear for most people receded. However, anxieties remained which ebbed and flowed; at times the fear would come to the fore again when they didn't expect it.

This concept adds to the stroke literature in respect of identifying a relationship between fear and the impact of a stroke on people's social worlds. Fear and anxiety following a stroke have been identified in the literature relating to psychological impacts of stroke (White et al. 2008; Bergersen et al. 2010; Lincoln et al. 2013), but less explicitly within a broader psychosocial framework. Additionally, this study has also highlighted that psychological morbidity after stroke is a broader construct than post stroke depression (which is most frequently measured or described) and that fear and anxiety are equally important to study within this broader context (White et al. 2008). One other stroke study identified, described in more detail how people after their stroke became more introverted and withdrew from their wider social world due to becoming increasingly self-conscious and closing in on themselves (Northcroft and Hillari 2011). Northcroft and Hillari (2011) also highlighted how some people found going out and meeting people was a cause of anxiety or fear. In contrast, this current study found that rather than meeting people causing fear and anxiety, it was fear and anxiety that prevented them taking a step forward and meeting new people. Further understanding of the directional or bidirectional causation of this relationship could help support people experiencing such fear.

Over time, people in the current study described how they learnt to manage and navigate the fear filled space. It required an ability to fill the social space with meaningful activities, energy, as well as the capability to utilise internal and

external resources to gain reassurance and social support from the family or health care workers. For those people that struggled to re-fill the social space, they became increasingly socially isolated leading to an even greater space and time alone for the fear to continue its hold. People described different strategies for dealing with the fear and anxiety. Keeping active and busy was important but Stephen, who was less physically able, found that focusing on a book, and not letting himself get wrapped up in the fear, a helpful approach. The people who continued to live with fear and uncertainty of reoccurrence described how a shadow had cast over them and they showed a reduced confidence in moving forward.

The metaphor in the last chapter described someone arriving in London for the very first time and standing in front of a huge topographical tube map; an array of colours, lines and names of stations that they have never heard of. All they can identify on the map finally is the “*you are here*” arrow, but they can’t find where they need to go. They feel totally overwhelmed by the enormity of the task in hand and whilst all around them people are rushing about with a purpose, they stand there feeling vulnerable and inactive. This highlights why this finding is important in relation to rehabilitation, as people could be given early reassurance that the feelings they are experiencing are common, and be given practical information and knowledge to allay some of their fears. Filling people’s empty space with simple activities or positively valued company could help to reduce the feelings. Helping them to find things that they can do to allay their fear and teaching people techniques to handle their feelings as they emerge will also be beneficial. Some people who continue to describe feelings over a longer period of time will be at a higher risk of isolation and they will need more focused support than others. Stephen explained how he wished people had told him about these feelings and that they would recede with time, whilst Jim described how at times they would return many years after his stroke and that he needed ongoing reassurance.

### 7.3.5 *New, changed, unique social worlds*

In the current study, all the people described a changed social world after their stroke; one that was smaller and for those with relatives, mostly concentrated around their families and their homes. For those people that had renegotiated relationships outside of their home and close family, all but three of the people had done so by developing new social groups or networks and not by returning to their pre-stroke groups. People in this study described three predominant reasons why they lost previous networks. Firstly, some networks were instantly lost due to the immediate physical or cognitive changes of the stroke. Secondly, people described how they withdrew from established groups or networks initially to focus on physical recovery but then the impact of the empty social space caused a subsequent erosion of self-confidence as described earlier and made them less likely to ever return. Finally, some social groups simply withered over time, and so no longer existed even if the person ever decided to return. No one in this study talked about being shunned or rejected by others.

Many people described how their stroke had led to gaps in their own identities that over time they attempted to fill and find some continuity of self. This process was time consuming and required energy that kept them inwardly focused and needing to take one day at a time. Slowly people described how they began to fill the gaps in their identity and started a complex period of negotiation. They needed to test out their new self and so doing this with new groups and acquaintances made total sense; allowing them to look forward and not backwards. They saw themselves as different and they needed to find new people to relate with. The stroke literature identified often focused on recovery and return to pre-stroke life as a goal. Only a few studies identified, explicitly highlighted the significant formation of new social groups as opposed to the return to old but did not explore the process of this (Greveson and James 1991; Murray and Harrison 2004; Northcott and Hillari 2011; Woodman et al. 2014). Murray and Harrison (2004) described how the experience of a stroke often left people with reconstituted personal and social identities in which their old relationships did not fit, and this resulted in a search for new friends such as those found in stroke support groups, although they found that other people in

their study remained socially excluded. The time of the interviews in this current study may also have influenced this finding as, immediately after a stroke, people may still be comparing and looking back to their previous lives as opposed to constructing new narratives many years later.

The importance of continuity of social identity that others have highlighted was not realised in the majority of people in this study. Haslam and colleagues (2008) highlighted the importance of people maintaining social identity continuity in facilitating well-being following stroke. They found that those people who had multiple social groups and networks prior to their stroke were more likely to retain a few after their stroke and thus were able to sustain and continue their social identity (Haslam et al. 2008). It is possible that this continuity was not found within this study, because few of the older people described diverse and multiple social groups prior to their stroke and therefore simply didn't have the breadth of groups present that Haslam and colleagues (2008) identified for maintaining continuity. An alternative explanation is that people in the current study did search for continuity but paradoxically, for some, their previous groups challenged their new identity and they were subsequently unable to bring their past into the future. They needed to look forward and make a conscious decision to develop new, different relationships. A great deal of variation in relation to development of new groups was found within the findings of this current study. Some people described how they continuously strove to expand their social worlds; other people contained their worlds within the safety net of their family inside their own homes. Some of these people described making active choices to not strive further, whilst for others a less comfortable resignation occurred as they did not have the energy or ability to mobilise the resources needed to go further; this felt hard and difficult.

This finding, that people may look to forge new social relationships and groups, is an important concept for the process of stroke rehabilitation and how older people and their families can be best supported after their stroke. Consideration needs to be balanced between helping to maintain people's social identity continuity by sustaining previous social groups, and recognising that some people will need support and encouragement to join new groups because they

need to establish a new identity within new social groups. For the people that had made the initial move to get out and about, they described a new evolving world with successes and setbacks requiring focus and hard work. Although integration back into society is not carried out alone, the data obtained using this grounded theory approach revealed that people after a stroke viewed social integration as having a significant personal component which needed to be realised at a private level. The recognition of the value of meaningful yet personal integration can have important implications for respecting the rights of people forging a new life after their strokes.

The literature has suggested that people can choose a new refined, smaller social world and this concept has been underpinned by socio-emotional selectivity theory (Carstensen et al. 1999). The theory suggests that when time in life is perceived to be limited, social motivations change and goals in the present that relate to emotional meaning are prioritised. Thus frailer, older people or those with terminal illnesses have been shown to prefer contact with immediate family and close friends. Whilst this may hold true for a few of the people in this study, significant caution would be advised in making such an assumption as this wasn't the case for the large majority of people in the current study. Woodman and colleagues (2014) have suggested that it is the perceived value of activities that could also contribute to the reasons why people with stroke prioritise certain activities over others. In the current study, people described the enormous hard work and energy needed to manage day to day and the process of getting out and meeting new people was complex and shrouded with an existential effort. This often meant they were simply unable to muster the required resources to act. There were also limited opportunities for the older people in this study to meet with new people within their local communities.

People in this present study described how they forged new, personal and unique social worlds. Very few people managed to maintain their pre-stroke groups and for most their experience and emergent identity led them to test and establish new groups and friendships. Many healthcare staff perceive the need



for social identity continuity and reintegration into previous social networks as the panacea for rehabilitation. Support needs to be given to people in allowing both a return to previous groups or ensuring opportunities to forge new relationships, as driven by the person and not by the assumptions of rehabilitation staff.

#### 7.3.6 *Summary*

Five key findings from this study have been identified, discussed and considered within the current literature. For the older people in this study, there was no perception of successful social integration. Instead, people described an ongoing dynamic process through which they attempted to develop and exercise their capacities for personally meaningful social connections and progression towards a new and unique social world.

### **7.4 Study limitations.**

There are limitations with all theoretical frameworks and corresponding research methods (Holloway 2005). Four main limitations for the current study have been identified; the first of which is consistent with studies using grounded theory and three more specific to the actual methods used for this study.

#### 7.4.1 *Generalisability of the theory*

Grounded theory aims to develop a substantive theory that is grounded in people's experiences and therefore consistent with the grounded theory method used. The emergent theory identified has predictive power within the specific context only (Strauss and Corbin 1998). In the case of this study the substantive theory was developed with older people living with a stroke in the South of England. Two different geographical areas covering three counties were used for different phases of the study, which may help to enhance the theory but there can be no assumption of generalisability of the theory to other contexts. However, this substantive theory does aim to generalise the process and meaning of integration in older people after a stroke and predict some patterns in behaviour (Glaser 1992). These patterns and processes will require further

exploration within other population groups. The theory is presented here for further development in other contexts that may allow for transferability and for further refinement and enhancement. In addition, in this study a combination of a detailed explanation of the study methods (chapter four); a description of the characteristics of the people involved (chapter five); a reflexive account (chapters one, four and five) and a rich description of findings including many direct quotations and explanation of variation (chapters five, six and seven), offers the reader enough detail to allow an audit trail. It is the individual's judgement of whether this theory is relevant and applicable in other contexts.

#### *7.4.2 Recruitment of people*

The recruitment approach in phase one of this study was with people who had already taken part in a randomised controlled trial (RCT). The intervention was a twice weekly exercise and education programme held in local community venues over a six week period. At the end of the trial all people within the control group were also offered the opportunity to attend the programme. This recruitment approach was used as people had agreed to further contact and I was able to work with the previous trial research co-ordinator who had access to the database. These people were therefore a more selective group from the beginning. Unlike other trials (Kersten et al. 2010) this RCT had deliberately set out to be as pragmatic and inclusive as possible (section 4.3.1) and the data collected as part of the RCT had shown the people to display diverse characteristics. In order to minimise the possible impact of the RCT, all the people who were selected to be approached for this current study had finished the intervention a minimum of three years previously (and it was over five years since they had been initially recruited to take part in the RCT) so the trial wouldn't be fresh in their minds. Phase two of the current study, recruited people from a large inclusive database of people who had been discharged from three large stroke units in another county of Southern England and therefore widened the recruitment and allowed me to test the findings of phase one with different people.

### 7.4.3 *Theoretical sampling*

Theoretical sampling within this study was hindered due to access of people to join the study. In the first phase, people were recruited over five years since they were initially selected to take part in a trial evaluating exercise and education schemes. It felt insensitive due to this long gap in time and awareness of their ages, to contact people more than once. This meant a limited response. In phase two, some purposeful sampling was able to occur to increase the number of women in the study and to interview people who were perceived to be socially integrated, but once again a more pragmatic approach was needed due to the limited number of older people that were able to be identified.

### 7.4.4 *Study design*

This study aimed to gain a greater understanding of meaning and process of social integration in older people following a stroke. A key strength was the opportunity to interview people between four and eight years after their stroke and being able to hear their stories so many years later. However, a series of interviews with each person may potentially have provided a greater insight into the actual process of integration during this period. Pragmatically, this approach would have reduced the number of people that could have been involved within the context of the current study. Thus, although the use of multiple interviews for individuals would have allowed for a greater exploration of individual's perspectives, this would have been at the expense of the breadth that was gained by interviewing 30 people in two different geographical locations.

## 7.5 **Summary**

This chapter has discussed the five key findings of the present study and set these within the context of ageing. The new findings were also situated within the literature, to understand how they may bring new perspectives to current thinking and understanding. The limitations of the study within its theoretical framework were also considered. The next chapter will now conclude by

reviewing the study aim and objectives in relation to these findings and explore implications for practice and research.

## Chapter 8. Conclusion

### 8.1 Introduction

This chapter will review the study aim and objectives in relation to the findings and explore the implications for practice and recommendations for future research. It will conclude by highlighting the contribution to knowledge development.

### 8.2 Review of study aim and objectives

The aim of this study was:

To gain a greater understanding from older people of the meaning and process of social integration following a stroke:

Specific objectives were to gain an understanding of:

- Whether people felt they had successfully integrated following their stroke.
- How people had (or had not) integrated and what factors had helped or prevented the process of integration.
- What factors could have improved their and perhaps other people's experience of integration.

The study has successfully managed to meet its aim and objectives. It was found that people did not feel they had managed to attain social integration; instead they described a more restricted but evolving social world. People described the process within the context of a personal journey to establish meaningful relationships. Everyone's social world was unique. After people's strokes an empty social space unfolded from the loss of friendship groups and social networks. Within this space, feelings of fear emerged and people experienced increasing self-consciousness and an erosion of self-confidence. The journey described was encompassed within a complex framework that required some of the people to make a conscious decision to act in order to forge new relationships outside of their families. This conscious decision was

driven by an increased awareness of a need to belong that grew out of an internal conflict. People also described how their journeys were shrouded within continuous effort and hard work. Many factors were identified that were needed in order to make this conscious decision to act; in order to test new relationships, to build new social networks, to manage setbacks and sustain new social worlds. These factors were identified as internal and external resources, and key ones included; a positive outlook; resilience; planning; social support from others who provided knowledge and advice; and asking and accepting help.

This study identified variation in the process of social integration; people described differing social progression. Whilst some people were content for their new world to be centred around their home and close family, other people resigned less comfortably. Those that were able to make progress and take a tentative step forward needed to access and utilise some or all of the resources described but at the right time for them. By dipping a toe in the water people began to test new groups and build confidence. Only a few people returned to previous groups and instead, for the majority, they slowly built new friendships and groups and a new social world began to emerge; one that was often fraught with setbacks or pauses. People identified the need for them to be able to lead this process and set their own meaningful goals, as opposed to those set by rehabilitation staff or close friends and families. They were also able to reflect on their own journeys after many years, recognise their progress and offer advice for those who were setting off on their own.

### **8.3 Implications for Policy, Education and Practice**

This research has highlighted several areas which have implications for those commissioning stroke services, health and social care professionals in practice and training and also people working within the third sector of voluntary and charity services. As it cannot be assumed that the findings are generalisable, the following suggestions are made tentatively and may not be applicable for all situations.

Four key areas in relation to the current study will be highlighted:

- The *terminology* that people use.
- The *provision of services* that are responsive to individual needs and timescales.
- The *education and training* of health and social care staff in the importance of social needs and process for social integration.
- The need to *support older people* to find an individual balance between their old and a new social world.

### 8.3.1 Terminology

This study showed that the term social integration did not resonate with people and no one recognised themselves as socially integrated. Alternative terms such as community reintegration and participation are also often used but again these may not be meaningful to people. Health and social care staff working with people after a stroke may subsequently use terms that have little meaning for the people they are working with, which may potentially cause confusion or distance in the therapeutic relationship. In the current study, people described the prevailing effort and hard work that was needed to develop new relationships and social groups they also described increasing conflict and a growing need to belong. Although their stroke had left them with a restricted social world and relationships that mostly revolved around their homes, many people continued to strive to make new relationships outside of their homes. In this context it would be useful for health and social care staff to ensure that they address people's needs for developing relationships both within and outside of their homes. In the case of the current study the findings would suggest the use of the phrase *personally meaningful social relationships both within and outside of people's homes* to be more helpful than social integration. In addition the use of the term *social world* would also incorporate the range of groups, relationships, and activities both inside and outside of the home into a more meaningful term for people.

### 8.3.2 *Provision of services*

Commissioners of services need to work across health and social care boundaries and with the voluntary sector, to maximise opportunities for those people living with a stroke. This study highlights that people's social needs are unique and a single model of commissioning will not be effective; one size simply does not fit all. Recent policy changes within the UK should support this need, with greater integration of health and social care at local government level now in place. New, local Health and Wellbeing Boards have been established with a responsibility to lead the delivery and implementation of fully integrated health and social care strategic plans, which include a significant shift of service delivery into community settings (Department of Health 2012). The older people in this current study also described how they needed to make their own decisions within their own timescales, which were sometimes many years after their stroke. Services need to be made available to reflect this need and to offer a significant degree of flexibility in their structure. A pathway focused approach is required that will allow people to access services when they are needed and not only when they are available.

Recent national guidelines (Intercollegiate stroke working group 2012) have recommended that all people have a formal six month and subsequent annual review after their stroke and many clinical commissioning groups in England are now procuring services to deliver these reviews. There is a genuine opportunity to optimise these reviews; shifting the sole focus from medical issues (secondary stroke prevention and pharmacology) to more holistic reviews that also include understanding of the psycho-social consequences that this study has highlighted. The reviews do not need to be carried out solely by health care staff but trained voluntary workers could carry them out; including people who have also previously experienced a stroke who could bring an insider knowledge and understanding. If these reviews are to be successful, people will need to be appropriately identified as needing further support and be able to re-access services as required whether this is formal health services such as occupational therapy or psychology, or informal groups or community activities.



This current study highlights that people's needs are unique and so it is important to not simply commission more of the same in terms of current models of service delivery but instead it is important to think differently. By working with local charities and community groups, new groups or community activities need to be developed and offered to people in order to reduce isolation and optimise personally meaningful social relationships within their local communities.

### *8.3.3 Education & training*

Whilst service delivery needs to be flexible and responsive, the education and training of staff is also crucial. All professionals working with older people after a stroke need to develop a greater understanding of social needs after a stroke and the impact and implications of social isolation on people's health and lives. This learning needs to be embedded during training, and continued as part of on-going professional development. The theory and model generated from this study present some potential phases that a person may experience in order to develop a new, meaningful social world. The training of health and social care staff should not only focus on the importance of social needs but also on the complex process of developing a new meaningful social world for people that this study has identified. This training would, for example, include an understanding of the impact of people's empty social space and the fear that may fill it. Simple techniques such as reassurance and understanding the specific tenets of the person's fear would help. Later, staff could also support by discussing techniques for managing the fear and the empty space. Equally, staff awareness of the significant loss of confidence, the overwhelming effort and work that this study showed, will help to build an understanding and allow the setting of shared realistic goals both in the stroke unit and more importantly, over time, in the community. By understanding further the process towards social integration, health, social care and voluntary sector, staff will also be able to help identify those people who are at higher risk of isolation or need more specialist support, and ensure it is accessed in a timely manner.

The findings from the current study would support the use of a lifeworld led approach to rehabilitation and the specific support for older people after a stroke that rehabilitation workers could offer by helping to focus on their lived experiences (Dahlberg et al. 2009). This approach to rehabilitation highlights that it is insufficient to focus solely on people's physical or medical needs. By embracing a lifeworld approach this would deepen the understanding for all staff of the complex, often ambivalent natures of people's meanings. It would also highlight the fact that disability is encountered by people within a broad context of relationships, previous history, family context and people's aspirations and includes both the subjective and social realms of the lifeworld, which all need consideration.

#### *8.3.4 Support for older people*

In this study only a few older people returned to the friendship groups that they had prior to their stroke. Whilst people's social worlds after their stroke were mostly centred around their home and families, for those who made a decision to act, they tended to forge new relationships and groups and not return to their old groups. There needs to be far greater support from health, social care and voluntary sector staff in understanding people's social worlds prior to a stroke. They need to work with people and their families, as appropriate, to identify previous social groups or activities that they may wish to return to, in order to provide some social identity continuity. However, a balance needs to occur and staff need to recognise that many people will also need new opportunities in order to develop new groups and friendships. The wider community, along with health and social care commissioners, need to come together to ensure that there are opportunities for people to access new groups, activities and settings; perhaps, for example, a visit to a museum or an invite to coffee. All health and social care staff and those people working within the third sector need to be aware of these groups or of potential activities, and help signpost or offer support to people (at the right time) to access them. A fine balance needs to be attained between understanding people's old social worlds and helping people to maintain continuity, and supporting them to develop new, personally meaningful relationships.

## 8.4 Implications for research

The present study revealed a number of salient findings that point towards several lines of enquiry for future research that can test and extend the substantive theory generated.

It would seem reasonable to suggest that this theory may have relevance in other geographical and cultural settings and in different groups of people after a stroke, but this will need to be tested. Specific areas for further testing and extending of the theory would be with:

- People from more diverse populations and backgrounds. A greater diversity of people in background and ethnic diversity would help to extend this theory. People could be theoretically sampled to include; people living in more challenging financial environments, people for whom English may not be their first language, those who have differing cultural needs or people living in large inner cities. Additionally, people who live alone and have no close relatives living nearby could be selected specifically to study due to their greater risk of social isolation.
- People with different outcomes following a stroke. For example, conducting a study of people with moderate to severe aphasia.
- Older people living in residential or nursing home accommodation who may experience additional challenges in forging new meaningful relationships.
- Younger people following stroke and in particular understanding the process of social integration in those with occupations.

Alternatively, a longitudinal prospective qualitative study design could be used in order to gain further insight into how and why the changes happened at certain times after people's strokes, and to gain a greater understanding of potential transition points. I am aware of one such long-term longitudinal qualitative study currently being carried out by Sandy Rutherford and Professor Kath McPherson in Auckland and collaboration could help to explore cultural differences.

## 8.5 Contribution to Knowledge Development

This study adds to the contribution of original knowledge through an increased understanding that:

- Older people need to make a conscious decision in order to start to build new relationships, social groups and networks after their stroke. Many people will need support during the process but the decision needs to be directed and led by the person themselves.
- After a stroke, people are left with an empty social space due to the sudden restriction of previous social groups and networks. Within this empty space, feelings of fear emerge which can overwhelm people and prevent them from being able to take steps forward, potentially leading to greater social isolation.
- An all-encompassing and overwhelming effort and hard work is required by people to manage their day to day life after a stroke.
- Many older people following a stroke will not return to previous friendship groups or social networks outside of their home but instead will slowly build new changed, social worlds.
- People did not perceive themselves as socially integrated. Instead they described a journey that was ongoing and the process of building personally meaningful relationships both within and outside of their homes as dynamic and evolving.

## 8.6 Summary and concluding comments

This thesis presented the findings of a grounded theory study that investigated the meaning and process of social integration in older people following a stroke. It was found that people did not see themselves as socially integrated but instead described an ongoing journey and a unique and evolving social world. For those people who developed new relationships outside of their homes, they described how they needed to make a conscious decision to act. A substantive theory, *from indecision to volition* was generated to explicate how people forged new social worlds after their strokes and the factors that supported or hindered this progress. The current study findings help to elaborate on a growing literature of the social impact of experiencing a stroke. It remains crucial to not only understand how older people develop personally meaningful relationships after a stroke, but to equally be cognisant of the consequences of people not being supported or given such opportunities; social isolation and ill health. This substantive theory has shown that the process is complex, variable and can occur over many years. Targeted and effective interventions that recognise and understand people's individual social needs have been suggested. These and opportunities for further research will continue to build a greater understanding, enabling people to move from uncertainty and indecision to an active volitional choice in order to form new and personally meaningful social worlds.

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World Health Organisation (WHO), 2002. *Towards a Common Language for Functioning, Disability and Health. International Classification of Functioning, Disability and Health*. Genève: WHO.

# Appendices

## Appendix A-1: Ethical approval (phase 1)



### National Research Ethics Service

#### Bath Research Ethics Committee

Room 11, John Apley Building  
Research Ethics Office  
Royal United Hospital  
Combe Park  
Bath  
BA1 3NG  
Tel/Fax: 01225 825725  
vanessa.bishop@ruh-bath.swest.nhs.uk

3 December 2007

Dr Caroline Ellis-Hill  
Senior Lecturer  
University of Southampton  
School of Health Professional and Rehabilitation Sciences  
Highfield  
Southampton, SO17 1BJ

Dear Dr Ellis-Hill

**Full title of study:** Developing a greater understanding from older stroke survivors of their own meaning of integration following a stroke  
**REC reference number:** 07/H0101/172

Many thanks for forwarding the further information requested by the Committee. This has now been reviewed and approved by the Chair, Dr Brian Robinson.

#### Approved documents

The documents reviewed and approved by the Chair were:

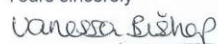
Document	Version	Date
Letter of response	N/A	19/09/2007
Revised Follow up letter	2	Not dated
Revised Participant Information Leaflet	2	Not dated
Letter from PBSPCRC	N/A	16/10/2007
Letter from PBSPCRC	N/A	16/10/2007
Letter from Taunton & Somerset R&D Consortium	N/A	08/10/2007
Letter from Swindon PCT	N/A	24/10/2007
Letter from Wiltshire PCT	N/A	24/10/2007
Letter from Sponsor		21/09/2007
Letter of Indemnity		20/09/2007

**07/H0101/172** Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

Yours sincerely



**Vanessa Bishop**  
**Committee Coordinator**  
 vanessa.bishop@ruh-bath.swest.nhs.uk

Copy to:	<p><i>Miss Rachel Harrington</i>  <i>PhD Student</i>                  University of Southampton                  School of Health Professional and Rehabilitation Sciences                  Highfield                  Southampton                  SO17 1BJ</p> <p><i>Dr Martina Prude</i>                  Research Governance Manager                  University of Southampton                  University Road                  Southampton                  SO17 1BJ</p>
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## Appendix A-2: Sponsorship form (phase 2)



School of Health & Social Care

Ref: indemnity letter/RHarrington

26<sup>th</sup> July 2011

Dear Sirs,

— **RE: Rachel Harrington**

**Title: Gaining a greater understanding from older stroke survivors of what integration means for them**

On behalf of Bournemouth University, School of Health & Social Care, we are very happy to be the sponsors for the above project.

Please find enclosed evidence of our Indemnity.

Yours faithfully

A handwritten signature in black ink that reads 'Jonathan Parker'.

**Professor Jonathan Parker**  
**Deputy Dean of Research and Enterprise**  
**School of Health & Social Care**  
Bournemouth University

## Appendix A-3: Ethical approval (phase 2)



**NRES Committee South East Coast - Brighton and Sussex**  
 Charing Cross Hospital REC Centre  
 Room 4W/12, 4th Floor  
 Charing Cross Hospital  
 Fulham Palace Road, London  
 W6 8RF

Telephone: 020 33 110108  
 Facsimile: 020 3311 7280

10 November 2011

Ms Rachel Harrington  
 Acute workstream lead (PhD student)  
 Medical Directorate  
 South East Coast Strategic Health Authority  
 SEC Strategic Health Authority  
 York House,  
 Horley, Surrey  
 RH67DE

Dear Ms Harrington

**Study title:** Gaining a greater understanding from older stroke survivors on what integration means for them: A qualitative study.  
**REC reference:** 11/LO/1741

The Research Ethics Committee reviewed the above application at the meeting held on 03 November 2011. Thank you for attending to discuss the study.

### Ethical opinion

- 1 Members agreed that this was a well presented and worthwhile study.
- 2 Members did not raise any major ethical issues with the submission but felt the study needed minor clarifications.
- 3 Members noted that you intended to record non-verbal responses and were of the view that if you intended to do this you needed to include this information in the relevant section of the information sheet. You indicated at the meeting that you would not do this in front of the participant but would make notes immediately after you left the premises when you got into your car.
- 4 Members queried if the mobile number provided was your personal mobile number. You assured the committee that it was your work mobile number.
- 5 Members asked about the role of East Kent Strokes Group in this study. You indicated that the Chair of this group was a clinical psychologist who had agreed that you could recruit participants through this service. You agreed at the meeting that recruiting this group of participants may introduce potential bias into the research but indicated that in qualitative research this was not of primary importance and that you intended to acknowledge this in your write-up. Members accepted the explanation provided.
- 6 It was noted that you would provide the support needed should any of the participants become distressed as a result of taking part. However, members were not sure how this support would be provided. You indicated at the meeting that you would ask them to

visit their GP and refer them on in person if you felt that it was necessary. Members indicated that it may be a good idea to provide them with written information about where further support could be obtained. You indicated that the East Kent Strokes had a very good support mechanism and all their members knew where they would obtain further support if they needed it.

7 It was noted that the invitation letter and the information sheet would go out together. Members asked whether the letters would go out by post or by email. You indicated that 30% would go out as letters and 70% would go out as emails. You also indicated at the meeting that potential participants would also be recruited by sending the invitation letter and information sheet along with the Christmas leaflets that would be sent out to all stroke survivors shortly. Members did not have any objections to this method of recruitment.

8 As the carers/partners may also be present during the interviews members wanted to know if you intended to include their contribution as well in the study. They indicated that if you intended to do this you needed to obtain consent from the carer/partner. At the meeting, you assured the committee, that you intended to concentrate on the voice of the stroke participant and would not use the voice of the carer/partner.

9 Members wanted to know how you would ensure that the patient had not died before they were contacted. You accepted that this was always a risk but assured the committee that the service had a very good up to date list and that the service was always in contact with all its members to keep its records up to date.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Ethical review of research sites**

##### **NHS Sites**

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

##### **Conditions of the favourable opinion**

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

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

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

Other conditions specified by the REC:

- 10 Amendments requested in the information sheet:
  - 10.1 A clear paragraph to indicate what will happen to them if they take part including some information about the type of questions that would be asked during the interview was also required.
  - 10.3 A statement to indicate that brief notes would be taken about the interviews, which would be used in the study.
- 11 Amendments requested in the consent form:
  - 11.1 The following standard statement to be included "I understand that the research data collected during the study, may be looked at by individuals from (sponsor name) and from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records".
  - 11.2 A specific statement to be included to obtain consent for the use of direct anonymised quotes in any write-up

If you would find it helpful to discuss any of the matters raised above or wish to seek further clarification please contact the committee co-ordinator Mrs Nischinth Cherodian.

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

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation**

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Evidence of insurance or indemnity	01/08/2011 to 31/07/2012	26 July 2011
Investigator CV		
Letter from Sponsor		
Other: CV of Dr Caroline Ellis-Hill		
Other: Reply slip	1.0	01 August 2011
Other: Invitation letter	1.0	07 October 2011
Participant Consent Form	1.0	01 October 2011
Participant Information Sheet	1.0	01 August 2011
Protocol	1.0	30 September 2011
REC application		10 October 2011

**Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of conflict of interest from any of the members present

**Statement of compliance**

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

**After ethical review**Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- **Notifying the end of the study**

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

Feedback

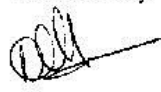
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**11/LO/1741** Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

  
 Dr Simon Walton  
 Chair

Email: ncherodian@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*  
*"After ethical review – guidance for researchers"*



## NRES Committee South East Coast - Brighton and Sussex

## Attendance at Committee meeting on 03 November 2011

## Committee Members:

Name	Profession	Present	Notes
Dr Jill Adams	GP	No	
Dr Duncan Angus	Consultant Psychiatrist	Yes	
Dr John Bull	Consultant Physician (retired)	Yes	
Mr Gerard Cronin	Business Development Manager	No	
Dr Sue Eckstein	Lecturer in Clinical and Biomedical Ethics	Yes	
Prof Angie Hart	Professor of Child, Family & Community Health	No	
Mr Stuart Heatherington	Mathematician	Yes	
Dr Puneet Kakar	Specialist Registrar in Medicine & Geriatrics	No	
Mr Bill Kent	Retired Civil Servant	Yes	
Miss Samantha Lippett	Lead Microbial Pharmacist	Yes	
Mr Maurice Marchant	Public Health Information Specialist	Yes	
Ms Nicola Mason	Specialist Midwife - Practice Development	Yes	
Dr Martin Parry	Consultant Paediatric Anaesthetist	Yes	
Dr Paul Seddon	Consultant Paediatrician	Yes	
Mrs Kathy Stoll	Pharmacist	No	
Dr Simon Walton	Consultant in Anaesthesia and Intensive Care	Yes	In the Chair
Mrs Susan Waton	School Librarian	Yes	
Dr Stuart White	Consultant Anaesthetist	Yes	
Ms Dobra Young	Head of Midwifery	No	

## Also in attendance:

Name	Position (or reason for attending)
Mrs Nischinith Cherodian	Co-ordinator

## Appendix A-4: Indemnity- Bournemouth University (phase 2)

Hasilwood House  
60 Bishopsgate  
London EC2N 4AW  
Tel: 020 7847 8670  
Fax: 020 7847 8689




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TO WHOM IT MAY CONCERN

8<sup>th</sup> July 2011

Dear Sir/Madam

**BOURNEMOUTH UNIVERSITY  
AND ALL ITS SUBSIDIARY COMPANIES**

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:-

**PROFESSIONAL INDEMNITY**

Certificate of Entry No.	UM044/99
Period of Cover	1 August 2011 to 31 July 2012
Limit of Indemnity	£10,000,000 any one claim and in the aggregate except for Pollution where cover is limited to £1,000,000 in the aggregate.
Cover provided by	U.M. Association Limited and Excess Cover Providers led by CNA Insurance Company Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Susan Wilkinson  
For U.M. Association Limited



U.M. Association Limited  
Registered Office: Hasilwood House, 60 Bishopsgate, London, EC2N 4AW  
Registered in England and Wales No. 2731799

## Appendix A-5: Risk assessment Southampton University



University  
of  
Southampton

School of Health  
Professions and  
Rehabilitation Sciences

**RISK  
ASSESSMENT  
FORM**

To be completed in accordance with the attached guidelines

**Title of Project:**

**Developing a greater understanding of integration for older people following a stroke. A qualitative study.**

**Activity:**

This study will involve the researcher (Rachel Harrington) contacting by letter, stroke survivors living in the Bath area. If in agreement she will subsequently interview up to 30 stroke survivors. The data will be collected via audio tape and analysed.

**Location(s):**

The interviews will be taking part in the stroke survivors' homes.

**Significant Hazards:**

Although this is extremely unlikely the stroke survivors may find the interview upsetting.

The researcher will be working on her own.

**Who might be exposed/affected**

Stroke survivors and researcher

**Existing control measures:**

In the unlikely event of a stroke survivor becoming upset in the interview, the researcher who is a qualified physiotherapist will ensure that they do not leave until they are sufficiently calm. If the researcher is concerned the participants will be encouraged to allow the researcher to call a friend or a family member and in extreme circumstances the General Practitioner. Recording of the interview will be terminated. The researcher will ensure that no participant is left in a distressed state and where necessary additional local information on stroke support groups, family support workers and stroke coordinators will be given out and left with the participants.

The researcher will adhere to the University of Southampton lone working policy for visiting people in their own home. Detailed information left in a sealed envelope, in order to protect confidentiality, will be left with a designated person with separate interview times. If the researcher has not phoned or texted this

person by a specified time, after it is projected the interview will have been completed, then, initially the researcher will be phoned on their mobile and then their home number, if there is no reply, the envelope will be opened and the stroke survivor will be called. If the designated person at the University remains concerned, then the police will be called.

In addition a code word will be agreed as a trigger for an emergency response if used in a conversation between the researcher and person at the University.

**Risk evaluation:** **Low**

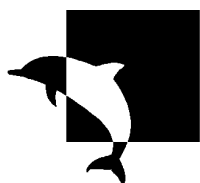
**Can the risk be further reduced:** **No**

**Further controls required:** **None**

**Date by which further controls will be implemented:**

**Are the controls satisfactory:** **Yes**

**Completed by:** Rachel Harrington .....

**Appendix B-1: Initial letter and Information sheet (phase 1)**

**University  
of Southampton**

**School of Health  
Professions and  
Rehabilitation Sciences**

Tel Number 01225 383621

Dear

You may remember me as the coordinator from the community stroke scheme. I am writing to invite you to take part in a small research project being carried out by my colleague Rachel Harrington as part of her PhD at the University of Southampton. I have enclosed an information sheet explaining this new project in more detail.

As the information sheet stresses, you are under absolutely no obligation to take part, but if you would like to, or find out more details please either return the reply slip on the next page in the stamped addressed envelope provided or ring Rachel or I at the number given above. If no one answers please do leave your name and a contact number and Rachel will ring you back.

With my best wishes

Mary Read  
Project coordinator

**Information Leaflet****Developing a greater understanding of integration  
following a stroke**

You are invited to take part in this research study which is being carried out by Rachel Harrington, a PhD student at the University of Southampton. Before you decide to take part it is important for you to understand the purpose of the study and what taking part will involve. Please take time to read the information below and talk to family and friends. If something is not clear or you would like some more information, please do not hesitate to contact Rachel. Contact information is given at the end of the leaflet. Thank you for reading this.

**What is the purpose of the Research Study?**

We are aiming to look at how you and others who have experience a stroke adapt to life once you return home. We want to hear how you have adjusted to life after your stroke in your own words.

**Who is organising the study?**

This study is being carried out by Rachel Harrington as part of her PhD research and is supervised by Dr Caroline Ellis-Hill and Dr Paula Kersten at the University of Southampton.

Rachel has recently been leading the community stroke project which you were involved in. She is a qualified physiotherapist, with a special interest in working with older people.

**Why have I been chosen?**

We are asking a number of people who took part previously in the Community Stroke Project for permission to take part in a further study. We want to ask a range of people who have experienced a stroke, both men and women, younger and older, with different disabilities.

**Do I have to take part?**

No. You do not have to take part in this study if you choose not to; this will have no effect on any other treatment arranged by your own doctor or the hospital.

**What will happen if I agree to take part in the study?**

If you wish to take part then return the reply slip in the stamped addressed envelope provided. Following this the researcher (Rachel Harrington) will contact you and arrange a time which is suitable for her to come and visit you at home or another suitable venue. It is expected that the interview will take no longer than an hour. You will be asked about how you have found life following your stroke. With your consent the interview will be recorded onto an audio tape to allow easier future analysis. You are free to request that both the interview and/or the taping are stopped at any point with no consequences to yourself.

### **Where will the interview take place?**

Rachel can visit you in your own home or a local community venue, such as a private room in your local health centre, community hospital or another nearby place depending on where you live.

### **What are the possible benefits of taking part?**

You will not necessarily gain any direct benefit by taking part. Sometimes people have found spending time discussing the issues that affect your day to day life helpful.

### **What are the possible risks and disadvantages of taking part?**

It is not expected that there are any undue risks in taking part in this study. The meeting and interview will take up some of your time.

Some people may find that spending time talking about difficulties you have found following your stroke upsetting. The researcher is experienced in working with people who have had a stroke and will try and make the interview as comfortable as possible.

### **Will my taking part in the research study be kept confidential?**

Yes. All information that you provide will be entirely anonymous. The actual tapes and notes from the interviews will be stored in a secure manner in accordance with the Data Protection Act. It will not be possible for the information you provide during the interview to be linked back to you.

### **What will happen to the results of the research study?**

The information gained from the interviews will form part of a PhD project. In addition the study will be published in a scientific journal and presented at conferences. The results of the study can be sent to you if you wish

**Who has reviewed this study?**

The study has been reviewed by the School of Health Professions and Rehabilitation Sciences and has approval from the Bath and Swindon Local research ethics committee

**Contact Information**

Please feel free to contact me and ask any more questions you may have, by returning the reply slip or phoning me:-

Rachel Harrington -Telephone number 01225 383621 (please leave a message on the answer phone if there is no answer.)

Email [rh3@soton.ac.uk](mailto:rh3@soton.ac.uk)

**Thank you for reading this information sheet.**



## Appendix B-2: Initial letter and Information sheet (phase 2)



Chairman: Robin Cant, 199 The Street,  
Adisham, Canterbury, Kent, CT3 3LE  
☎ (01304) 840196  
email: eastkentstrokes@btinternet.com

Ethics No.

Version 1.0  
October 7<sup>th</sup> 2011

Dear East Kent Stroke Survivor

I am writing to invite you to take part in a small research project being carried out by a researcher called Rachel Harrington as part of her PhD at the University of Bournemouth.

If you do choose to take part it would involve a single interview with you at home or at a venue of your choice. However, you are under absolutely no obligation to take part, but if you would like to please read the information pamphlet enclosed. To find out more details, please either return the reply slip (attached – Rachel will refund your postage costs) or ring Rachel on 07909960797. If no one answers please do leave your name and a contact number and Rachel will ring you back.

Very best wishes

**Robin Cant**

EKS Chair



## **Information Leaflet**

### **Gaining a greater understanding from stroke survivors of what integration means for them**

You are invited to take part in this research study which is being carried out by Rachel Harrington, a PhD student at the University of Bournemouth. Before you decide to take part it is important for you to understand the purpose of the study and what taking part will involve. Please take time to read the information below and talk to family and friends. If something is not clear or you would like some more information, please do not hesitate to contact Rachel. Contact information is given at the end of the leaflet. Thank you for reading this.

#### **What is the purpose of the Research Study?**

Rachel is looking at how you and others who have experienced a stroke adapt to life once you return home. She wants to hear how you have adjusted to life after your stroke in your own words.

#### **Who is organising the study?**

This study is being carried out by Rachel Harrington as part of her PhD research and is supervised by Dr Caroline Ellis-Hill and Dr Paula Kersten at the University of Bournemouth. Rachel is a qualified physiotherapist, with a special interest in working with older people. She is currently working at the strategic health authority.

#### **Why have I been chosen?**

Rachel is asking a number of people living in Kent, through East Kent strokes.

#### **Do I have to take part?**

No. You do not have to take part in this study if you choose not to; this will have no effect on any other treatment arranged by your own doctor or the hospital.

**What will happen if I agree to take part in the study?**

If you wish to take part then either return the reply slip or phone Rachel on 07909960797. Following further discussion with Rachel, if you are still happy then she will arrange a time which is suitable for you, for her to come and visit you at home or another suitable venue.

The study will involve a single interview which should take no longer than an hour. Rachel will ask you questions about how you have found life following your stroke and what things have helped you to get out and about. She will also ask you some questions about your life before your stroke.

With your consent the interview will be recorded onto an audio tape to allow easier future analysis. You are free to request that both the interview and/or the taping are stopped at any point with no consequences to yourself. After the interview, Rachel may also make some brief notes. These notes will not mention your name and will be stored securely with the tapes. Any use of information that you have told Rachel that she uses in her research will always be made anonymous.

**Where will the interview take place?**

Rachel can visit you in your own home or a local community venue, such as a private room in your local health centre, community hospital or another nearby place depending on where you live.

**What are the possible benefits of taking part?**

You will not necessarily gain any direct benefit by taking part. Sometimes people have found spending time discussing the issues that affect their day to day life helpful.

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

It is not expected that there are any undue risks in taking part in this study. The meeting and interview will take up some of your time. Some people may find that spending time talking about difficulties you have found following your stroke upsetting. The researcher is experienced in working with people who have had a stroke and will try and make the interview as comfortable as possible.

**Will my taking part in the research study be kept confidential?**

Yes. Contact details will be kept until the questionnaire is returned and a code assigned, then all details will be destroyed. All information that you provide will be entirely anonymous. The actual tapes and notes from the interviews will be stored in a secure manner in accordance with the Data Protection Act. It will not be possible for the information you provide during the interview to be linked back to you.

**What will happen to the results of the research study?**

The information gained from the interviews will form part of a PhD project. In addition the study will be published in a scientific journal and presented at conferences. The results of the study can be sent to you if you wish.

**Who has reviewed this study?**

The study has been reviewed by Bournemouth University and has approval from the Kent research ethics committee

**Contact Information**

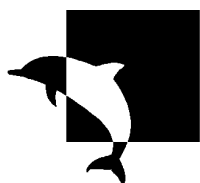
Please feel free to contact Rachel and ask any more questions you may have, by returning the reply slip or phoning her on:-

Rachel Harrington -Telephone number **07909960797** (please leave a message on the voicemail with your phone number if there is no answer.)

Email [i7914794@bournemouth.ac.uk](mailto:i7914794@bournemouth.ac.uk)

**Thank you for reading this information sheet.**

## Appendix B-3: Consent form (phase 1)



**University  
of Southampton**

**School of Health  
Professions and  
Rehabilitation Sciences**

### Consent Form

**Title of project:** Developing a greater understanding of integration following a stroke

**Name of researcher:** Rachel Harrington

**Patient identification number:**

*Please initial boxes*

I confirm that I have read and understand the accompanying letter or I have had the accompanying letter fully explained to me for the above study and have had the opportunity to ask questions

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without medical care or legal rights being affected.

I consent to the interview being audio taped

I agree to take part in the above study

I consent for the data collected to be used for a PhD study

Name of participant:

Date:

Signature:

Name of researcher:

Date:

Signature:

Two forms to be signed at interview in presence of interviewer and interviewee: 1 to participant & 1 to researcher

**Appendix B-4: Consent form (phase 2)****Consent Form**

**Title of project:** Developing a greater understanding of integration following a stroke

**Name of researcher:** Rachel Harrington

**Patient identification number:**

*Please initial boxes*

I confirm that I have read and understand the accompanying letter *or* I have had the accompanying letter fully explained to me for the above study and have had the opportunity to ask questions

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without medical care or legal rights being affected.

I understand that the research data collected during the study may be looked at by individuals from Bournemouth University and from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I consent to the interview being audio taped and that anonymised quotes may be used when writing up the PhD study

I agree to take part in the above study

Name of participant	Date:	Signature:
Name of researcher:	Date:	Signature:

Two forms to be signed at interview in presence of interviewer and interviewee: 1 to participant & 1 to researcher



## **Appendix C-1: Interview schedules / frameworks (initial, post pilot, interviews 7 to 23)**

### ***Interview schedule for initial for pilot on colleague***

As is normal practice when using grounded theory methodology, the research areas remain the same but the questions and the focus for those questions will change over time. The Interview schedule will be informed by responses from previous interviews, that is grounded in the data. This schedule will therefore develop and change over the course of the study.

- What do you understand about the term integration?
- How would you define it?
- How important is it to you?
- Do you feel you were integrated prior to your stroke?
- Do you feel you have successfully integrated since returning home after your stroke?
- What are your reasons for this?
- What factors and issues have helped / prevented your successful integration?
- What factors and issues could have improved your own integration?
- Can you give any advice to other stroke survivors to help their own integration?
- What do you think about the actual term/word integration?

### ***Interview schedule for pilot Interview with participant and then for interviews 1-6 (Nov 07).***

- How long have you been home?
- What has it been like people and getting out and about since you have been home?
- Researchers have used a term integration to capture some of the things that we have just been talking about.
- Do you have a feel for what the researchers would like to include/capture?
- Do you have an idea what term you would use?
- Is there anything else you think that people would like to know about?

***Interview framework/schedule for Interviews 7-23.***

- How long ago was your stroke? What side, how did it affect you?
- Can you tell me a little about your life before you had your stroke?
- Prompt – working, roles, family, social networks, hobbies, social environment.
- Tell me about what happened to all of this when you had your stroke?
- Prompt- what changed?-changes in roles, family, networks.
- How did it make you feel?
- Prompt – what made up their time, did they have free time, how did they feel, some people said their family did more, how did that feel?
- That was x years ago, tell me a little about what you are doing now?
- Build up picture of before, at the time of stroke and now and then try to explore the process depending on answers given.
- Can you explain a little about what made you start going out to x? Did you need to plan going to y? Do you know why it took x years to start going to z?
- Explore empty social space – restriction
- Effort, hard work
- Conscious decision making process or just happened, anxiety, fear.
- Some people said they felt a need to belong did you experience this (If not brought up) etc
- How do you feel now about your social life?
- Would you like to be busier, get out and about more?
- Are you comfortable within your own social world? Lonely, reconciled?

## **Appendix C-2: Interview framework/schedule (final interviews)**

Listen and question around these areas if they come up – prompt if need be but let people lead at all times – use previous framework but add in these as appropriate.

### **The shrinking social world and new social space and its effects**

- Early stages and its often dramatic impact
- Loss of role, networks, confidence
- Impact of this space: fear, isolation, anxiety
- Just letting life happen, blank, dull feelings

### **Conscious Decision – Internal conflict**

- What are the drivers here – is it control or is that an outcome
- What about the need to belong
- Internal conflict, breaking the cycle, trust and confidence in self
- Inner voice – I can versus I can't
- Role of family

### **Dipping a toe in the water – exploring and negotiating**

- Length of time – people are describing long time to often get to this testing
- Testing things out and coping with failure or additional hurdles
- Opportunities in the community / barriers

### **Ongoing / evolving world**

- Fit with supposed bereavement cycle – do they use term acceptance?
- Never ending – integration doesn't happen
- Hard work and energy – listen for clues

## Appendix D-1: Examples of memos from logbook

## Phase 1

Memo - April 08

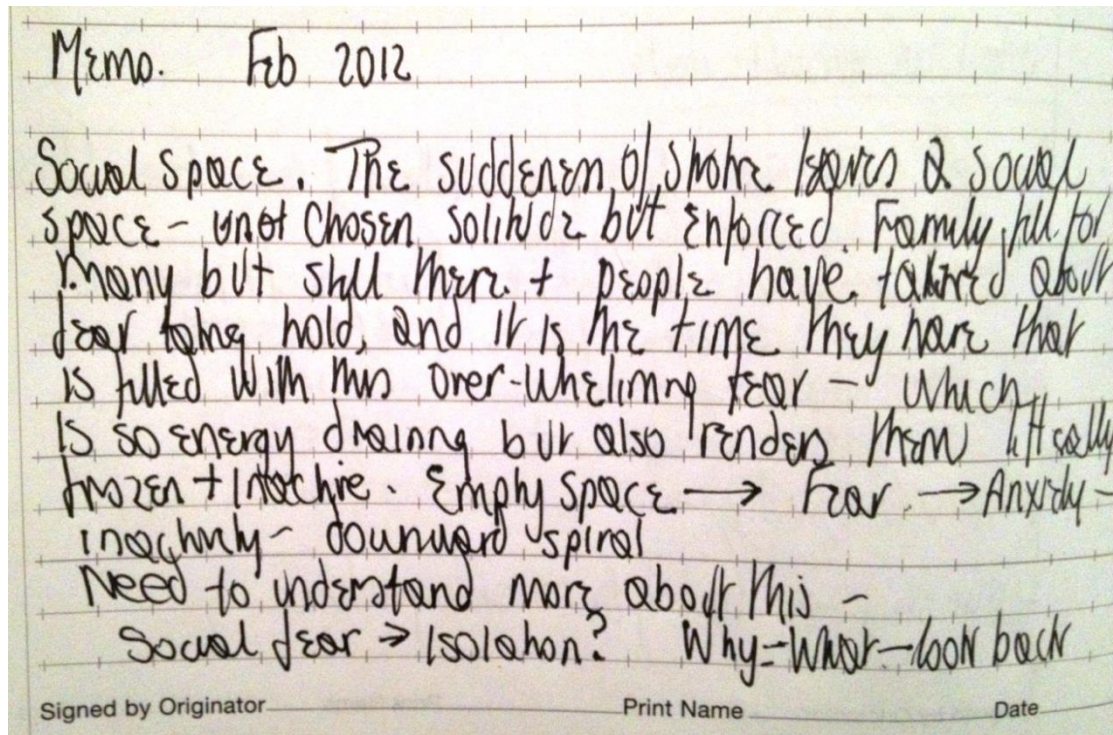
I am really interested in the decision needed to start getting out again. I have gone back to some earlier interviews + it is there in many.

It was ~~me~~ that talked about the fact that you never had to think about socialising but now you do all the time.

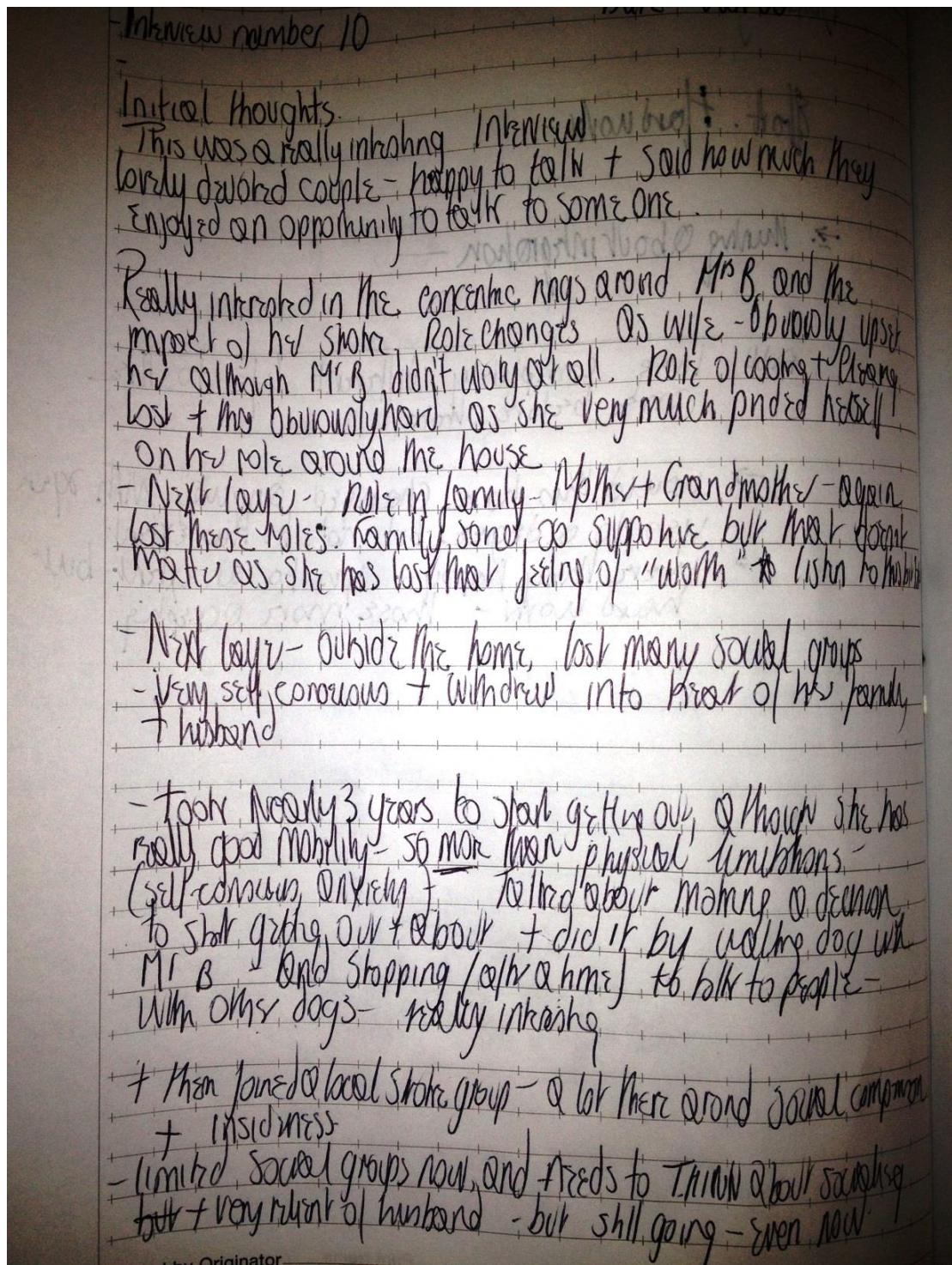
This is hard work + needs a real conscious effort. I can't find anything in the literature around a conscious decision I need to make sure I ask about this in the next interviews.

Do people who don't recognise this - integrate or are they staying within family support mechanism - what does this conscious decision? What resources are needed?

## Phase 2



## Appendix D-2: Example of field note from logbook



**Appendix E-1: Example of transcript page**

254 Patricia ...No, I wasn't, and I didn't feel I needed the support  
255 because I was managing. I didn't feel that I needed to go  
256 there to discuss how I would do this, or how I would do  
257 that because I'd already sorted that or worked it out  
258 myself.

259 Rachel Um, can you tell me more {name};some people have said  
260 to me, you know, before their stroke, they never thought  
261 about having to get out and about. They never thought  
262 about integrating or seeing other people, and then after  
263 their stroke they didn't necessarily want to but they almost  
264 had to think about it and make themselves do it?

265 Patricia Yes, yes, you see because I had a horse and I knew all  
266 the horsey group, I had my own group. I used to go up  
267 and look after my horse and meet all my friends up there.  
268 Once I had to give up riding and my poor horse had to go  
269 to heaven anyway, that was one of the things I did lose,  
270 and then where do you go then? What, how do you find  
271 another group that has the same interests as you? It's  
272 certainly not easy, and you do have to think about it. And  
273 um I didn't. I'd rather given up. I don't really care whether  
274 I belong to a group or not. I just, I do go out once a  
275 month with a group, two lots of different groups, for a  
276 dinner, once a month and I'm supposed to go to one  
277 tomorrow, and I can think up excuses because I don't  
278 really want to go. And I'm not going. I don't want to go  
279 because although they are all very nice, I find it all, you  
280 have to dress up and you think oh God, what am I going  
281 to wear, and how to get there and how to get home. So I  
282 find that, I don't find it easy and often don't bother  
283 because of it. But the other group, where I go out and I  
284 don't find them difficult at all. It's a smaller group and I  
285 chat away to them and it's fine. [pause] But, this one I'm  
286 supposed to be going tomorrow, they are a big society  
287 group, you know they're all yakking away about how  
288 much this cost and what, and I feel, oh for goodness  
289 sake. If you were me you'd think, I don't care. Um, It is  
290 different in the day as well [Pause]

291 Rachel And what about day to day [name]? Do you meet up with  
292 people in the day, and get out and about?

293 Patricia Sometimes, I've got a friend down the road, two friends  
294 down the road who I see, and I've got another friend in  
295 the village, but some days I'll go for days and not see  
296 anyone, I make, I go out a lot you see, take the dog for a  
297 walk and I usually find I can chat to somebody, but I don't  
298 {know} many people in this village really in {village name}  
299 I know a few I've known for years, but I don't, I, but I, if  
300 I'm fed up I go out.

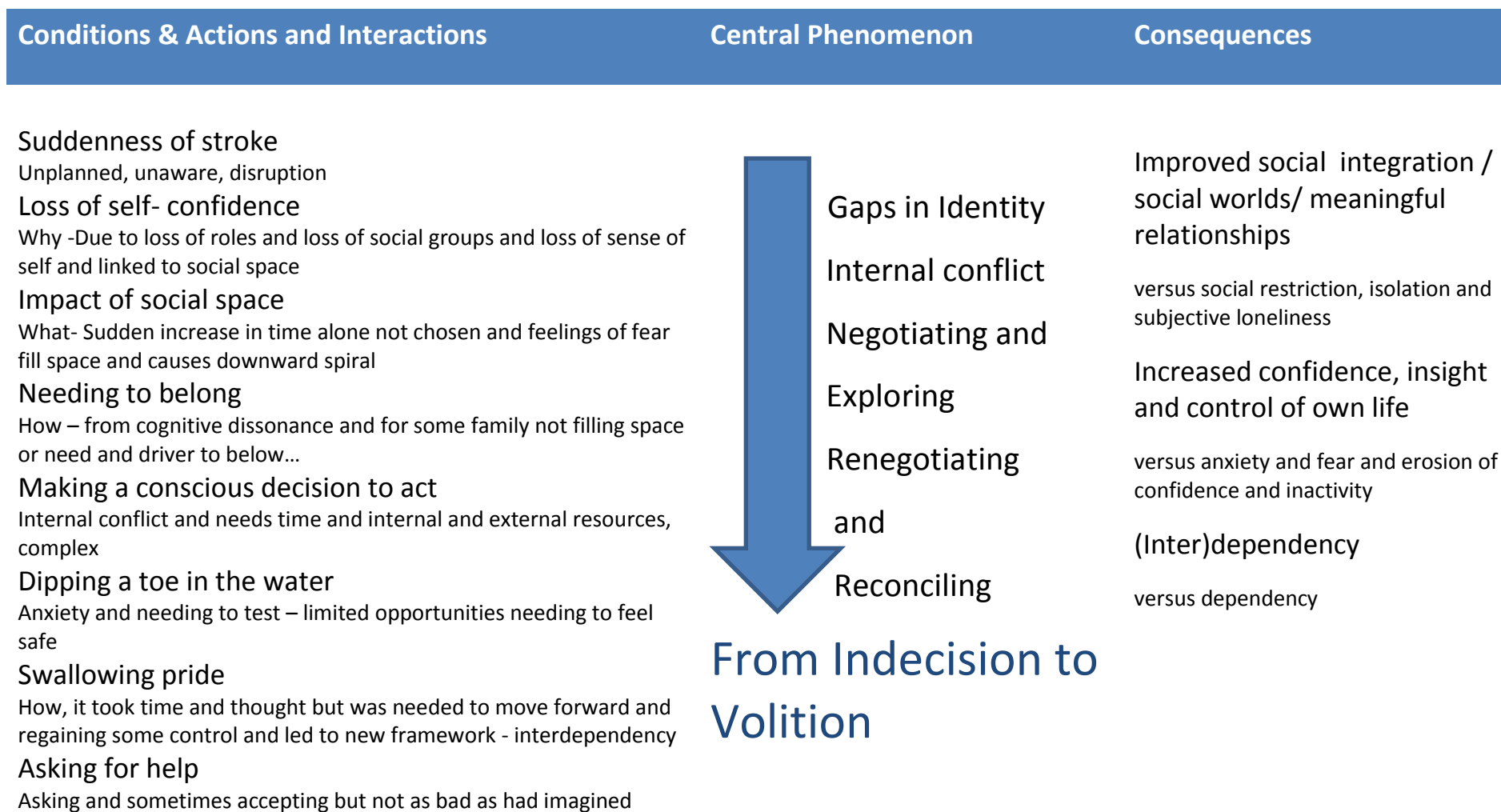
## Appendix F-1: Visual representation of process of analysis (illustrative example).

Snap shot of data is taken from three different transcriptions to show code and concept development

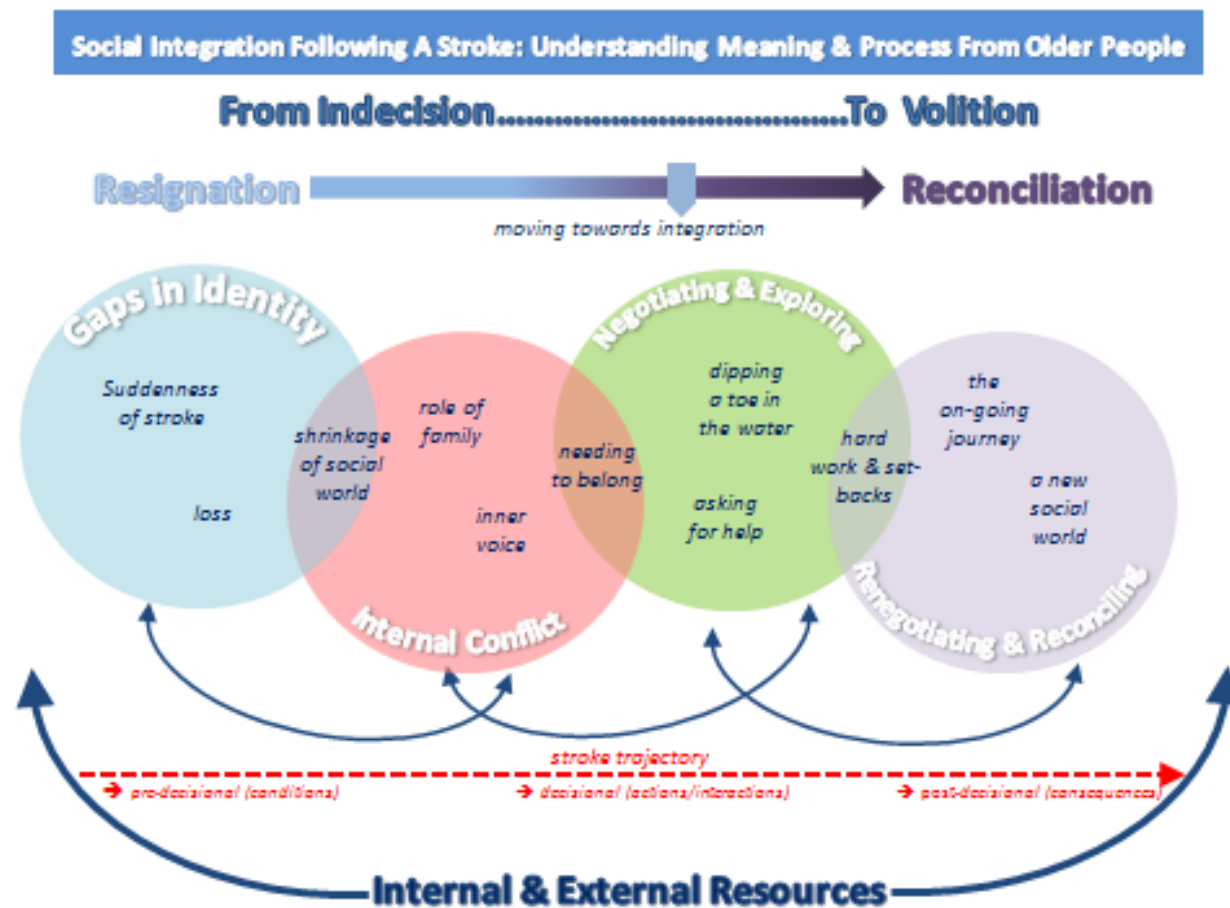
Snap shot of Data	Example of Codes	Concepts	Emerging Categories
<p>Provided I've got <b>something to do</b> and go out the following morning, which I do, I know it sounds stupid, but I think to myself tomorrow I've got to go out and <b>I've got to do something, you know</b>. It might only be shopping, or it might only be going down the town, but I've got to do it. And if I get up and shower and clean up things and go out, I'm alright. But it's when I think to myself oh, I've got a day off I'll do nothing today, I'll sit here for about an hour and a half, I'll think Jesus Christ, I'm going bonkers here. So that's it. So if I <b>make my mind up</b> to do something... so I <b>always go to bed at night with generally what I'm going to do first thing in the morning</b></p> <p>At the beginning, I found it really useful to be with others stroke survivors, just seeing the others worse off than me. I used it as a <b>positive</b> as I think most people do and, it is rather cruel but I <b>compared my situation</b> with a couple of men there who you know I was a lot better off. In the back of your mind, you are thinking the person is worse or better than you and that <b>tempers your feeling</b> and you can't feel woe is me, you have to temper that with they are worse than me so yes you do do that when meeting stroke survivors I suppose the real reason I would say it has to be a stroke group is because, it sounds a bit callous to say this, it is in actual fact <b>mostly helpful to see people who are in a different situation, or a worse situation</b> I think though more broadly I am lucky in that I have got a balance in the things I do. I have got other stroke survivors but I have also got quite a bit of my life which is not about them which is <b>with normal people</b>- I have got my family and my kids when I see them occasionally so it's a <b>balance</b> if I was <b>institutionalised with just stroke survivors I would go around the bend</b> I think you know.</p> <p>I think different people behave in different ways but I think one thing it does do is um uh help try and provide the contacts in which a person <b>can rebuild their self-confidence their self-esteem um feel better about themselves</b> and often that is a lead to other activities you know <b>if I feel OK</b> in the pub with that lot on Tuesday I will be alright with the fishing group on Friday night or whatever so in that sense I think your use of the term stepping stones is really apt yeah.</p> <p>Sometimes I feel I don't want to be there at the group, I'd <b>rather be here with people who are normal</b>, rather than people who are suffering like I am. It keeps my mind away from my problem. But we do go to Stroke Club. <b>We get to learn all sorts of things</b> about various bodies that are out there to help people who are in trouble. And we do get some very interesting speakers and activities too which the club itself is called the Active Stroke Group and active is a very prime word, primarily to make us become as active as possible. All things are related to that, round the club activities. In that way it's very good. I think you have got to learn to, uh, <b>swallow your pride a bit um not to the point where you give up all pride</b> but for example um when I go on holiday and you get to the airport and you let them know you are disabled. I can remember Gatwick once they offered to give me a wheelchair I wouldn't have a wheelchair I would rather hurt badly because being in a wheelchair is a very negative experience but now um ..... I am <b>a little less proud</b> in that sense and um in fact in the spring we went abroad for 3 or 4 days and we went to museum and I was very happy for x to push me around in a wheel chair nobody knew me there so it didn't matter and it was certainly <b>more comfortable</b> seeing the paintings there is a bit of swallowing of pride but yeah ..... You start to <b>modify your pride</b> yeah to cope with and I spose that would be a good thing to encourage people to do after a stroke not to be so proud to <b>be more willing to accept help</b> and not not to the point where people help you across the road even if you don't want to get across the road you know it has got to be done in moderation but its ok to accept the fact that people are going to open doors. Yeah it's not people taking you over it's you letting them think ...yeah they are ...it's a <b>power thing</b> I suppose which is interesting to know whether that's different from men and women because men traditionally in society have had more power haven't they than women? You can <b>still take control</b> but actually you can do that in a way that you <b>are letting go but you are in control of letting go</b> of some of the things so you can still be in control and modify you know.</p> <p>Swallow your pride and <b>accepting help</b>, I find it so difficult, I have a volunteer driver pick me up for my lunch club, he is such a chauvinist and horrible man but I have to try so hard not to lose my rag as I need him to take me to the lunch club, so I can get out. <b>Regaining control</b> was crucial and the <b>awareness that although others could advise and support, it was your body and your life and you needed to be in charge</b>.</p> <p>You need to <b>take control of your stroke</b> and not take too much notice of physios and the speech therapist you know it's your body you've got to get on with it and unless you do <b>make an effort</b> you are not going to get on with it and really your recovery or as far as it will go will take a long time and it will be very frustrating because it will take a long time, but it is <b>up to you it's on you and you alone</b></p>	<p>Something to do every day  <b>Making mind up</b>  <b>Initially being with other stroke survivors</b>  <b>Comparing with people in a worse position</b>  <b>Tempering feelings</b>  <b>Being with normal people</b>  <b>Being institutionalised with stroke survivors</b>  <b>Rebuilding self-confidence and self esteem</b>  <b>Being with normal people</b>  <b>Learning and education</b>  <b>Helping</b>  <b>Swallowing pride but not giving up</b>  <b>Being seen</b>  <b>Comfort</b>  <b>Becoming less proud / modifying</b>  <b>Willing to accept help</b>  <b>Power</b>  <b>Taking control</b>  <b>Letting go but taking control</b>  <b>Accepting help</b>  <b>Regaining control of your stroke</b>  <b>Taking charge</b>  <b>Awareness that others could advise and support but it was your own life</b>  <b>Making an effort</b>  <b>It's up to you and you alone</b></p>	<p>Planning          Consulting          Seizing control          Self-Awareness          Creating a new sense of self          Redefining normal          Finding new groups          Dipping your toe in the water          Safety with others          Comparing and contrasting          Inter-dependency</p>	<p>Negotiating          And          Exploring</p>



## Appendix G-1: Adapted visual paradigm model



Appendix H-1: Further iterations of visual model.



Appendix H-1: Further iterations of visual model.

