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Acknowledgements

This research would not have been possible without the help of many people. I am very grateful to all those who supported me throughout my PhD, and would like to mention the following people in particular.

Firstly, thank you to the participants who took part in this project and were so generous with their time. I was often humbled by the thoughtful and sincere way in which they responded to questions. Thank you, too, to the stroke unit team at St Mary's hospital, who were supportive of this research, and made me feel welcome on their ward. Thank you also to Alice Lamb, who collected data at the stroke unit at the Royal Free Hospital, London.

A heart-felt thank you to my supervisor, Katerina Hilari. It feels like a long journey that we have gone on together in completing this PhD, starting with Katerina encouraging me to embark on an MSc, and then inspiring me to start the PhD. It was a fantastic opportunity to work on this project together, and I have learnt so much from our supervisions. Thank you for all the insightful guidance.

Thank you, also, to Jane Ritchie, who was the other big influence in my academic journey over these last few years. I loved learning about qualitative research, and could not have found a more inspiring, humane or perceptive teacher.

I am also grateful to Shashivadan Hirani, for his advice and enthusiasm when working on cluster analysis. Thank you also to Nicola Botting, Jane Marshall and Madeline Cruice, who have all given me suggestions and advice at various times, and shown interest in the progress of the study.

I also want to acknowledge the Consortium for Healthcare Research of the Health Foundation whose grant funded the project.

It is said that a stroke is really a family illness. In a similar vein, this PhD has been a family affair. I would never have completed it without the love, support and generosity of my family, in particular, my wonderful husband, Ben, who made it all possible. Thank you also to both my parents and my mother-in-law for the devoted care they gave my daughters in order to give me time to study. Thank you to Sara, or 'Granny', for your generosity and optimism, and to Richard for all the cakes. Thank you to my parents for your unwavering belief in both me and the project and for giving me that 'secure base' from which to explore the world. Thank you to Karen for your exceptional care of my children. And thank you to the daughters themselves, Emily and Isabel, who accompanied me through most of this PhD journey, and gave me so much happiness, perspective, as well as plentiful distraction.

Declaration

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Abstract

Background

The social consequences of having a stroke can be severe, with social isolation a reported problem. It is little explored, however, what factors predict who will feel well supported and retain a strong social network after a stroke, nor is it well understood why friendships and other social contacts are lost.

Aims

This thesis explored: 1) how social support and social network change over time following a stroke, and whether this is different for those with aphasia; 2) what factors predict perceived social support and social network six months post stroke; 3) why people lose contact with friends, and whether there are any protective factors; 4) how the changing dynamics within the family unit are perceived by the stroke survivor.

Design and setting

Repeated measures cohort study. Participants were recruited from two acute stroke units and assessed at two weeks (baseline), three months and six months post stroke. A subset of participants was selected for in-depth qualitative interviews 8 – 15 months post stroke.

Measures and methods

Stroke Social Network Scale; MOS Social Support Survey; General Health Questionnaire; National Institute of Health Stroke Scale; Frenchay Aphasia Screening Test; Frenchay Activities Index; and the Barthel Index. Multiple regression, ANOVA, correlation and t-tests were used as appropriate.

Results

87 participants were recruited of whom 71 were followed up at six months. At six months, 56% of participants were male, 16% had aphasia, and the average age was 69 years old. 29 participants took part in qualitative interviews. Perceived social support at six months was not significantly different from pre-morbid levels; social network, however, did significantly reduce ($p = .001$). Those with aphasia had comparable levels of perceived social support but significantly reduced social networks ($p < .05$) compared to those without aphasia.

Concurrent predictors of perceived social support at six months were: a person's social network, their marital status, and their level of psychological distress (adjusted $R^2 = .37$). There was only one baseline predictor of social support at six months: perceived social support prior to the stroke (adjusted $R^2 = .43$). Concurrent predictors of social network at six months were: perceived social support, ethnic background, aphasia and extended activities of daily living (adjusted $R^2 = .42$). There were two baseline predictors: pre-morbid social network and aphasia (adjusted $R^2 = .60$).

There was a significant reduction in the Friends factor of the social network measure ($p < .001$). The main reasons for losing friends were: changing social desires especially a sense that many participants were 'closing in' on themselves; aphasia; loss of shared activities; reduced energy levels; physical disability; environmental barriers; and unhelpful responses of others. Family were generally robust members of the social network post stroke. The spouse was the main provider of all support functions. Nonetheless, beneath the apparent stability of the quantitative data there were changes in how family relationships functioned, including some distressing role shifts, for example, receiving rather than providing support.

Conclusion

Contact with family and perceived social support remained stable post stroke. In contrast, a person's social network, in particular contact with friends, was found to reduce, especially for those with aphasia. Indeed, aphasia was the only stroke-related factor at the time of the stroke that predicted social network six months later. Intervention aimed at addressing social isolation may be most effective if it takes into account the multiple reasons for friendship loss, including new language and physical disabilities, as well as changing social desires.

Chapter One: Introduction

Stroke is the most common cause of adult disability in England[1], and the social consequences of having a stroke can be severe. Studies have found that following a stroke people take part in fewer social activities[2-4], and contact with friends and the wider network is vulnerable[5-8]. There is also evidence that poor social support post stroke is associated with psychological distress[9-11], reduced health-related quality of life[12-14], and worse physical recovery[15-17].

This PhD explores functional and structural aspects of a person's social support system over the first 12 months following a stroke, using both qualitative and quantitative methodologies. Factors which predict who will feel well-supported and have a strong social network are analysed. The impact of the stroke on the family unit, as well as on friendships and the wider network, are also explored. Finally, a social network typology is developed, and the support provided by different network members is examined. Both those with and without aphasia were recruited into the project, allowing a direct comparison to be made between their different experiences.

This introductory chapter will cover the following topics: health service priorities in relation to the stroke population; brief historical overview of the concept of social support; the link between social support and health; and theoretical models which could potentially explain the role of social support following a stroke. A systematic literature review of social support after a stroke is the topic of Chapter Two.

1.1 Stroke and aphasia

1.1.2 Definitions, prevalence and importance

A stroke is caused by disruption of the blood supply to the brain. There are two main types of stroke: ischaemic, where a clot narrows or blocks a blood vessel resulting in brain cells dying from lack of oxygen; and haemorrhagic, where a blood vessel bursts and damage is caused by bleeding in the brain.[18] Ischaemic strokes are more common, accounting for around 85% of strokes. A further 10% of strokes are due to primary haemorrhage and 5% due to subarachnoid haemorrhage[19].

According to the National Audit Office, each year around 110,000 people in England have a stroke and of these, around 30% will die in the first month, making stroke the biggest cause of death after heart disease and cancer[20]. Of those who survive, it is estimated that around one third will have a long-term disability[21], and about 5% will be admitted to long-term residential care[22]. Although those who are older are more at risk, around 25% of those who have a stroke are under 65[20]. Further, it is estimated that each year 10,000 people under 55 years of age, and 1,000 people under 30 years of age will have a stroke[23]. In total there are more than 900,000 stroke survivors living in England, and of these, 300,000 are living with moderate to severe disability, making stroke the leading cause of adult disability[20].

The impact of having a stroke on individuals' lives is described as 'devastating and lasting' in the National Stroke Strategy[1]. The nature of the disability following a stroke is determined by which part of the brain has been damaged, and on the extent of the injury. Common difficulties

following a stroke include difficulties with movement, balance, walking, reduced sensation, swallowing, cognitive difficulties, incontinence, and reduced energy levels. These can impact on an individual's ability to carry out activities of daily living, for example, dressing, feeding, and maintaining personal hygiene. They may also restrict participation in social activities and limit community integration.

Another common sequela of stroke is aphasia. Indeed, it is estimated that around one third of stroke survivors will have aphasia[24], and for 15% of stroke survivors aphasia will persist in the long-term[25]. Aphasia is a language disability, caused by damage to the communication centres of the brain. Although the most common cause of aphasia is stroke, it can also be caused by other brain damage, such as traumatic brain injury or tumour. Aphasia can affect all language modalities, thus a person with aphasia may have difficulty speaking, understanding, reading or writing. As observed by Connect, a charity for people living with aphasia, the consequences of having aphasia can affect day to day life and relationships profoundly: 'Everyday activities such as having a conversation, answering the phone, watching television, may suddenly become a source of profound frustration and anxiety both for the person with aphasia and for their families, friends and carers.'[26]

The emotional impact of having a stroke is considerable. A systematic review of depression post stroke estimated that around 33% of stroke survivors show depressive symptoms[27]. For people with aphasia this figure is higher, reported at 62-70%[28]. In comparison, it is estimated that between

10-15% of the general elderly population (aged over 65) have depression, with more severe depression affecting around 3-5%[29].

A further consideration is the cost of care. The financial cost to the NHS and the economy has been estimated at £8billion in 2008-9, of which £3billion was direct care costs to the NHS, making it more costly than heart disease. Informal care (for example, nursing home fees paid for by family members) and cost to the wider economy (for example, through lost productivity) accounted for a further £5billion.[30]

In summary, given the physical, emotional and financial costs to the individual, their family and the nation, stroke should be a high priority for the health service. In fact, in 2005, the National Audit Office noted that the Department for Health had focused on cancer and heart disease in terms of setting priorities and allocating resources, and had accorded stroke a lower priority. Since then, however, the National Stroke Strategy (2007) has been published, outlining a 'quality framework against which local services can secure improvements' (p10)[1], and setting out actions and measures to improve services over a ten-year time frame. A more recent report from the National Audit Office (2010) documented significant improvement in stroke care since the publication of the National Stroke Strategy, including better emergency response and acute hospital care. Still, there are concerns that long-term support of stroke survivors remains inadequate[30].

1.1.2 Shifting conceptions of health

Over the last half decade, there has been a shift in the way society views health. Rather than conceptualising health in the traditional medical model, where it is seen as the absence of disease or infirmity, there has been a move

towards the positive concept of well-being, including physical, mental and social components[31]. Thus, for example, the World Health Organisation's current definition of health, first stated in 1948, is as follows:

'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.'[32]

This broader conception of health is mirrored in many of the aims of the National Stroke Strategy. For example, the main aim of healthcare intervention after the acute stage is 'to achieve a good quality of life and maximise independence, well-being and choices' (p34)[1]. Similarly, the National Clinical Guidelines of the Royal College of Physicians (RCP) states that: 'the goal of healthcare is to help a person integrate back into the community in the way that they want' (p126)[33]. Thus there is consensus that the aim of healthcare goes beyond assisting physical recovery. Further, best practice in stroke care recognises the long-term needs of the stroke population, with recommendations that stroke survivors are reviewed annually to monitor physical and emotional needs[1].

Another shift in how healthcare is provided is the increasing importance accorded to the patient's perspective on both their health and treatment priorities. In 1999, the Patient Partnership Strategy aimed to improve service delivery in part through involving patients in making informed decisions about their care[34]. More recently, one of the key recommendations in the RCP National Clinical Guidelines is that the views of stroke patients and their carers should be taken into consideration when evaluating a service[33]. The National Stroke Strategy has as one of its top ten priorities that people with stroke should be involved in service planning[1]. Further,

there is a consensus that stroke survivors become ‘informed partners’ in their own rehabilitation pathway. This process has arguably contributed to the holistic nature of the health service aims described above.

If the aim of health service interventions is improving quality of life and well-being, then it follows that consideration should be given to the social support systems surrounding the stroke survivor. Of note is that as far back as 1948, ‘social well-being’ was considered integral to health in the WHO definition[38]. The National Stroke Strategy acknowledges the importance of both close family as well as the wider social network as important components in living successfully with stroke. The central supportive role of the carer is emphasised, such that the health and well-being of the carer is an aim of service delivery in itself (p44)[1]. Further, one of the top ten priorities is participation, in particular, provision of ‘assistance to overcome physical, communication and psychological barriers to engage and participate in community activities.’[1] (p8)

Conceptualising health in such a broad and far reaching way has implications for how services need to be configured. If the aim of healthcare intervention is participation, then this will potentially affect how leisure, transport, housing, education and employment are organised. The RCP observe that ‘Most healthcare focuses on improving a person’s capacity to undertake activities. The wider task of achieving community integration also depends upon additional factors such as availability of suitable and accessible social settings and appropriate training for community providers of leisure and social activities’ (p126)[33]. Both the RCP and the National Stroke Strategy conclude that services need to work together, and that

specialist voluntary sector services and peer support groups may play an important role. It is anticipated that the findings from this thesis will inform health service provision in this broadest sense, including the interface between health, social care, and the third sector.

1.2 Concept of social support

1.2.1 Historical perspective

Back in 1624 the English poet John Donne wrote 'No man is an island, entire of itself'[35]. Before him, stretching back to Aristotle and his exposition on the role and value of friendship[36], philosophers and artists have mused on the meaning of social connections and the seemingly innate need to belong. Thus reflections on the meaning of social bonds are not a modern phenomenon. Nonetheless, current understanding of social support and social networks is informed by developments in sociology, psychoanalytic theory, anthropology and psychology that have taken place over the last 150 years. The major developments in this area are briefly outlined below.

Emile Durkheim (1858-1917)

Over 100 years ago, Durkheim (1897, trans 1952)[37] argued that even an apparently 'individual' act such as suicide could be explained by failure of social integration. He found that suicide rates were lower in societies where individuals were more embedded or integrated into the social groups around them. Durkheim theorised that in understanding suicide it was therefore important to understand the role of social integration and the ways in which an individual may be influenced by social relationships. It has been argued that his work led the way to others to establishing similar links between

social ties and mortality, and more generally, considering the explanatory power of social context in relation to an individual's behaviour.[38]

John Bowlby (1907-1990)

Berkman (2000) recently described Bowlby as 'one of the most important psychiatrists of the twentieth century'[39] for his influential work in the 1960s and 70s on attachment. Bowlby believed that there is a universal human need to form close, affectionate bonds, and that this is a 'primary motivational system'[40] (ie not secondary to physical needs such as hunger). His attachment theory suggested that the healthy psychological development of an infant was dependent on the infant experiencing a warm, intimate and continuous relationship with a responsive carer. From this secure base, the infant would be given the safety and emotional security to explore the world. These intimate bonds created in childhood would then form the basis of subsequent loving and lasting adult relationships. In particular, Bowlby saw marriage as the equivalent 'secure base' or 'protective shell' from which the individual could flourish in the world[41]. Berkman suggests the strength of his theory lies 'in its articulation of an individual's need for secure attachment for its own sake, for the love and reliability it provides, and for its own "safe haven".' (p844)[39]

1.2.2 Functional social support

From Bowlby to concepts of functional support

Influenced by the work of Bowlby, in 1974 Weiss developed a model of social provision: different functions which he suggested were essential if an individual was to feel supported rather than alone[42]. He described six

provisions of support, performing both expressive and instrumental functions for the individual. These were: attachment (as described by Bowlby); social integration (or a sense of belonging to a group); guidance (for example, receiving advice when needed); reliable alliance (a belief that others can be relied upon); reassurance of worth (feeling valued by others); and opportunity for nurturance (the belief that one is needed by others).

Two years later, in 1976, Cobb defined social support as follows[43]:

'Social support is defined as information leading the subject to believe that he or she is loved, esteemed and belongs to a network of mutual obligation'.

By the 1980s a number of theorists were defining a variety of supportive functions that were hypothesised to be of importance, such as House (1981)[44]. In their review of the social support literature in 1985, Cohen and Wills documented the most common supportive functions that had been assessed in the studies reviewed (p313)[45]. These were:

- *Esteem support*: which Cohen and Wills define as supporting a person to feel esteemed, accepted and valued. This type of support is now usually referred to as *'Emotional support'*, and is also termed expressive support, and self-esteem support. Commonly it may also refer to feeling loved, valued, and cared for; encouragement; feeling there is someone to confide in who will be understanding; sympathy; and reinforcement of positive self-appraisal[46-49].

- *Instrumental support*: defined by Cohen and Wills as 'provision of financial aid, material resources, and needed services.' Berkman

(2000) defines instrumental support as 'help, aid, or assistance with tangible needs such as getting groceries, getting to appointments, phoning, cooking, cleaning or paying bills'[39]. It may also mean personal care. This sort of support is also known as practical support, tangible support or material support.

- *Informational support*: Cohen and Wills define this as help in 'defining, understanding, and coping with problematic events.' More commonly, it is understood to mean feedback, guidance, advice, or provision of information that may help provide a solution to a problem.[48, 50] It may also include help in deciding which course of action to take[39]. It is sometimes referred to as advice support.

- *Social companionship*: defined by Cohen and Wills as spending time with others, for example, in leisure and recreational activities. Sherbourne and Stewart define a similar concept, 'positive social interaction', as 'the availability of other persons to do fun things with.'[48]

Received versus perceived functional social support

A further development in the field has been to disentangle *received* support (sometimes known as enacted support) from *perceived* support. Ditzen and Heinrich (2013)[51] define received support as 'an intended and observable act of help (including all functional types)' whereas perceived support is 'understood as a general expectation of being supported.' While received support may vary according to life circumstances, perceived support is

understood to remain relatively stable[52]. Thoits (2011)[53] suggests that the perception of being supported is 'probably generalised from daily, mostly invisible supportive exchanges occurring over time'. By invisible, she means commonplace support exchanges that are so minor as to be taken for granted. By contrast, with received support, the supportive act becomes visible.

It is of interest that perceived support is only weakly associated with actual support received: in a meta-analysis of 23 studies, Haber *et al.* (2007)[54] found the association to be r = .35.[54] They observe that perceived support is more strongly and consistently associated with physical and mental health than received support. Thoits (2011)[53] suggests that this is because visible support (ie received support) may be less acceptable and welcome, particularly if it cannot be reciprocated. Sherbourne and Stewart (1991)[48] also point out that 'received support is confounded with need', and that 'the fact that a person does not receive support during a given time period does not mean that the person is unsupported.'

Lack of conceptual clarity and consistency

There is a lack of consensus regarding terminology and definitions. For example, emotional support has been conceptualised in a variety of ways. It is instructive to take three measures of social support that have been widely used in recent stroke studies (see Chapter Two), and compare how they define emotional support.

In the Social Support Questionnaire, developed by Sarason (1983)[52], the conceptual basis for defining 'emotional support' is Bowlby's work. Specifically, it probes whether there are people who can be relied upon to

care about, love and value the participant. By contrast, in the Medical Outcomes Study Social Support Survey (MOS SSS)[48] the emotional support items probe whether there is someone to whom the person can confide about worries and problems, and who will listen and be understanding. This is a narrower definition of emotional support that does not include the concept of feeling valued or loved. Finally, in the Family Social Support Scale, developed by Tsouna-Hadjis *et al.* (2000)[17] specifically for their study, emotional support is defined as: 'involvement of family members' for example, how many hours they spend with the stroke survivor.

These three diverse definitions of emotional support illustrate how this term lacks consistency in the literature. A similar analysis could be undertaken with any of the other support functions described above. A number of writers have commented on the lack of conceptual clarity in studies of social support, arguing that this situation makes it hard to compare and interpret results, assess how social support links to other outcomes, or gain insight into the social support process[45, 49, 55].

For the present thesis, functional social support was measured using the MOS Social Support Survey[48]. This measure categorises five functions of support: emotional, informational, tangible, social companionship and affectionate. These functions are defined fully in Chapter Three.

1.2.3 Social networks

The development of social network theory

As identified earlier, one of the earliest writers to consider the relationship between social structures and individual behaviour was Durkheim. In terms of collecting fieldwork in order to investigate social networks, influential early works were written by anthropologists, such as Bott (1957)[56] and Barnes (1954)[57]. Subsequent developments in the study of social networks have come from a variety of disciplines, including sociology, psychology, mathematics, and health sciences.

Defining a social network

A 'social network' can be conceptualised as the structural element when considering interpersonal relationships. Bowling (1997)[49] defines a social network as 'the web of identified social relationships that surround an individual and the characteristics of those linkages'. Thus each individual is seen as a node in the network, with each exchange between network members constituting a link. Aspects of social network structure identified in the literature [39, 49, 58] include: size of network; geographic dispersion; density (how much network members are in each other's networks), homogeneity (the extent to which network members are similar to one another) and composition of members (for example, whether the members are friends, neighbours, children, other relatives). Characteristics of individual network ties may include: frequency of contact (face to face, phone, mail, social media), reciprocity, and duration (length of time people have known each other). Many social network indices also include

frequency of participation in community or religious organisations, or some other indication of community integration.

Conceptual clarity

As with functional support, definitions and conceptions of social network vary from author to author. Thus Pinquart and Sorensen (2000)[59] use 'social network' as an umbrella term to cover both structural and functional support. Due *et al.* (1999)[55] make a distinction between 'social network' (defined as linkages between individuals who feel affection and/or are close family) and 'formal relations' (defined as 'a dentist, teacher or lawyer… along with acquaintances like neighbours and the parents of one's best friend'). They use 'structure' as the umbrella term to cover both concepts. More commonly social network is defined as including both close and 'weak' ties, although the exact dimensions of the social network measured varies from scale to scale (see McDowell and Newell (1996)[60] or Bowling (1997)[49] for an overview). The terms 'social integration', 'social structure' 'social quantity' and 'embeddedness' are also sometimes used interchangeably with 'social network'.

In the present study, the term social network was used to describe structural aspects of social relationships, such as composition of network, frequency of contact and proximity.

1.2.4 Structure and function: two different concepts?

Social networks can be seen as the structure through which perceived social support is provided (Lin *et al.*, 1981)[61]. However, as O'Reilly (1988) states

‘[Social] networks have a variety of functions of which the provision of social support is but one’[62]. Seeman and Berkman (1988)[63] confirm that the two concepts are independent, finding that the characteristics of someone’s network and social support are not so highly correlated as to make them interchangeable. This is supported by a literature review by Cohen and Wills (1985)[45] where they note that the correlation between the two concepts ranges from r = .20 to .30. They explain this finding by pointing out that ‘adequate functional support may be derived from one very good relationship, but may not be available to those with multiple superficial relationships’.

1.3 Social support and health

1.3.1 Social support and physical health

Back in 1979, Berkman and Syme measured the social networks of 4,775 adults in Alameda County, California[64]. Their study was the first to measure social networks using a complex measure (ie not a single-item indicator such as marital status). Their results were compelling: those with strong social networks had a reduced mortality risk of nine years. House *et al*. (1982)[65] conducted a similar study in Michigan (2754 adults), where they also measured social network, but included a baseline medical examination in order to control for various health factors, such as high blood pressure. They were able to replicate the Berkman and Syme results. These large-scale epidemiological studies paved the way for numerous other research

which has consistently come to the same conclusion: social relationships appear to be protective for a person's health.

A number of recent reviews in this area have drawn together this evidence[39, 66 67, 68]. In particular, Holt-Lunstad and Smith (2012)[66] conducted a meta-analysis following a systematic search of all prospective studies that measured both social relationships and illness-related mortality. They included 148 studies, with 308,849 participants, who were followed up on average for 7.5 years. Participants with stronger social networks had a 50% increased likelihood of survival compared with participants with weaker social relationships. They suggest that since most of the studies tracked initially healthy individuals, it is unlikely that these results can be explained by reverse causality. They then transformed the data to make it comparable with other risk factors, and found that 'the influence of social relationships is equivalent or greater than that of most leading health indicators including physical activity, overweight and obesity, tobacco use, alcohol abuse, immunizations for influenza and air pollution (p43).' They observe that having few social ties was the equivalent of smoking 15 cigarettes a day.

Holt-Lunstad and Smith (2012) also compared the comparative influence of functional support versus structural support. Complex measures of social integration were found to have the highest effect sizes (associated with 91% increased survival rate, OR: 1.91). Binary measures, such as living alone, had the lowest (OR: 1.19). Generally, structural aspects had stronger effect sizes than functional aspects. In terms of functional support, perceived support (OR: 1.35) had a larger effect size than received support (OR: 1.22).

There is also evidence that those with restricted social ties are more at risk of developing an illness, and less likely to survive or make a good recovery following the onset of diseases[67, 69] for example myocardial infarction[70] or cancer[71]. To complete the circle, those who are disabled are likely to have smaller social networks[72, 73], as are those who are older[73-75]. The longitudinal work of Wenger (1994)[75] suggests illness and the frailties associated with advancing age are causes for people to develop more restricted social networks[75].

1.3.2 Social support and mental health

Considerable evidence has accumulated to suggest that social support, and to a lesser extent aspects of the social network are associated with mental health in both the general population [53, 73, 76], and the chronically ill population[77, 78].

In terms of risk of developing depression, a recent study (Teo *et al*., 2013)[79] followed up a cohort of 4,642 American adults ten years after baseline social support data were collected. Their outcome variable was past-year depression at follow up, and they controlled for a variety of baseline covariates (including sex, age, physical and mental health, alcohol misuse). They assessed social isolation (whether lived with partner, and frequency of contact with family, friends and neighbours); supportive quality of relationships (based on questions such as: “How much does your spouse or partner really care about you?” which would seem close to many definitions of emotional support); and straining aspects of relationships (for example, “how often does your partner criticise you?”). They also created a

composite measure: overall quality of relationships, combining both supportive and straining aspects of relationships. They found that the strongest predictor of depression was baseline overall relationship quality (OR: 2.60); then social strain (OR 1.99); then lack of social support (OR 1.79). Those with the highest quality of social relationships (top decile) had a 6.7% chance of developing depression, whereas those with the lowest quality (bottom decile) had a 14% chance. Of interest was that social isolation did not predict future depression.

A review by Pinquart and Sorensen (2000)[59] examined the link for older people between social relationships and three aspects of subjective well-being (SWB): life satisfaction, self-esteem and happiness. They included 129 studies looking at aspects of social network (such as size of network or frequency of contact); and 55 studies examining 'quality' of relationships (defined as 'emotional support or feeling close to someone', thus likely to be measures of functional support). Again, they found that quality of contact explained more variance than quantity of contact in all three aspects of SWB, particularly life satisfaction (3.4 times more variance explained).

1.4 Proposed mechanisms through which social support effects health

Although it is widely accepted that social relationships are associated with both mental and physical health, there is still considerable controversy about the mechanisms through which this occurs[53, 68]. This section will firstly outline the influential Cohen and Wills 1985 model[45]. It will go on to

explore possible behavioural, psychological and physiological pathways. The debate over whether the effect is 'direct' or 'indirect' will also be summarised.

1.4.1 Cohen and Wills (1985): a theoretical framework for analysing social support

Cohen and Wills (1985)[45] discuss the mechanism through which social support associates with good mental and physical health. They put forward two models:

1. *Stress buffering*, where social support reduces stress, which in turn has a positive impact on health and well being
2. *Direct effect*, where social support directly impacts on health and well-being.

In the 'direct effect' model they describe a scenario where a person is not experiencing acute stress. In this scenario, they hypothesise that the person will benefit most from 'social networks'. They suggest that large social networks promote a sense of social integration which leads to well-being.

In the 'stress-buffering' scenario, a person is experiencing an acutely stressful situation. Here they hypothesise that the person will benefit most from perceived social support, particularly the functions of emotional and informational support. They define stress as arising 'when one appraises a situation as threatening or otherwise demanding and does not have an appropriate coping response'. They then go on to suggest various mechanisms by which perceived social support may alleviate this stressful response, and reduce the impact on health. Firstly, they suggest that 'the

perception that others can and will provide necessary resources may redefine the potential for harm posed by a situation'. Thus social support may prevent a stress response occurring in the first place. However, even if stress is experienced, appropriate support may reduce the likelihood of stress resulting in poor health through reducing the perceived importance of the problem, by facilitating healthy behaviours, by providing a solution, or by tranquillising the neuro-endocrine system. They term this type of social support 'stress-buffering'.

Cohen and Wills, 28 years later

The Cohen and Wills model is still influential, described in recent theoretical overviews[53, 68, 76], and also forming the basis of hypothesis testing in recently published studies[80].

Many aspects of the Cohen and Wills hypothesis have stood the test of time. Functional support, particularly emotional support has been shown to be beneficial in times of stress[51, 76, 81]. Further, well-developed social networks have been repeatedly found to be associated with reduced mortality and morbidity and to a lesser extent psychological well-being (see 1.3 above). Other parts of the hypothesis are now more controversial, however. Firstly, there has been considerable evidence in the last 20 years that functional support *does* relate to good mental health and to a lesser extent physical health even for those not experiencing acute stress[59, 66, 82]. There is also doubt as to whether the association between functional support and health/ well-being is mediated solely through the stress response[68, 80].

Nonetheless, the main thrust of their hypothesis still stands: people may need different things from their support networks in times of stress as

opposed to ‘ordinary’ life. This is likely to have implications for the stroke population.

1.4.2 Behavioural and psychological pathways

Following from this early work of Cohen and Wills (1985) the mechanisms through which social relationships influence health and well-being has been the subject of study and also controversy. In a recent review Thoits (2011)[53] drew together evidence on this topic. She identified seven possible mechanisms:

1. Social influence/ social comparison

People have been found to modify their own behaviour in order to match the norms of the group. Thus attitudes to risk behaviours versus health behaviours (for example, alcohol consumption, drug use, exercising) are likely to be influenced by a person’s ‘reference group’.[39, 83]

2. Social control

Social control is where the influence of the social group is more explicit, ie family or friends encourage, pressure or persuade an individual to adopt a healthier lifestyle[83-85].

3. Behavioural guidance, purpose and meaning (mattering)

Thoits (2011)[53] defines roles as ‘positions in the social structure (for example, husband-wife, parent-child, doctor-patient, friend-friend) to which are attached reciprocal sets of normative rights and obligations.’ Roles, with their attendant responsibilities, are thought to be a constraining influence.

Thoits argues that roles confer 'behavioural guidance', thus roles imply expected behaviours, 'and in conventional roles this means conventional (non-deviant) behaviour' (p148).

There is also the argument that knowing one is important to others gives life purpose and meaning, which in turn influences both psychological well-being and self-care[83, 85, 86].

4. Self-esteem

Thoits (2011) cites evidence that an individual's evaluation of their own performance in valued roles is reliably associated with global self-esteem. Similarly, feeling that one 'matters' and is connected to others in reciprocal supportive relationships is thought to influence self-esteem[39]. Self-esteem is in turn associated with increased life-satisfaction[87], and improved mental health outcomes[88]. Thus self-esteem is considered to be one route 'mediating' the relationship between social support and physical and mental health. There is some evidence of this both for the general elderly population[89], and for those with a chronic illness [90].

5. Sense of control or mastery

Thoits (2011) argues that successful role performance also links to concepts of self-efficacy, and the belief that a person has control over their life. There is some evidence in the literature of the mediating role that self-efficacy may play between social support and psychological health, including in stressful situations[91].

6. Belonging and companionship

A sense of belonging, or feeling included by a group, and the sense that there are others with whom one can have enjoyable social experiences with, have been shown to be associated with good mental and physical health. Feeling attached to one's community is also considered to be beneficial [39, 53, 92]. Cohen and Wills (1985)[45] suggest that feeling integrated and embedded in one's social network 'provide(s) positive experiences… positive affect, a sense of predictability and stability in one's life situation, and a recognition of self-worth,' which they suggest is beneficial for health and well-being.

7. Functional social support

Thoits (2011) discusses the potential mechanism whereby functional social support may influence health in non-acute situations. She suggests that 'routine or everyday emotional, informational and instrumental acts are helpful in themselves'. These reciprocal patterns of giving and receiving are what leads to the perception of feeling supported, feeling one matters and is valued. This, she suggests, leads to improved self-esteem, self-efficacy and psychological health, indirectly affecting physical health. She contrasts this to functional support received in times of acute stress, where social support becomes more 'visible' and deliberate, focused on the individuals' situation, and expectations of reciprocity are temporarily suspended.

1.4.3 Physiological pathways

Ditzen and Heinrich (2013)[51] review the physical mechanisms through which social support has been found to influence health. Firstly, social support has been found to affect the autonomic nervous system. This has

often been measured through indirect markers such as cardiovascular reactivity. An early experiment was conducted by Kamarck *et al.* (1990)[93]. Participants were exposed to a public speaking task. Half the participants were told support was available if needed, although no support was in fact provided. Nonetheless, those who perceived themselves to be supported had lower blood pressure both before and during the public speaking event. In similar tasks, this protective effect was more pronounced when the participants knew the support person well (for example a close friend)[94]. Further, the more stressful the task became the more noticeable the effects of social support[95]. There is thus evidence of social support 'buffering' the physiological impact of a stressful event in laboratory situations. In everyday life, too, ambulatory blood pressure has been found to be lower when with 'supportive' network members such as family than with strangers[96].

There is also evidence linking social support to both the immune system and the endocrine system. Lack of support is associated with elevated levels of stress hormones (norepinephrine, epinephrine, and cortisol)[97], and compromised immune systems (see DeVries *et al*., 2007 [98], for an overview).

Evidence also comes from animal studies. Berkman *et al*. (2000)[39] cite research suggesting that animals living in isolated circumstances experience accelerated aging. Thus monkeys housed on their own have more extensive atherosclerosis than less isolated animals; and rats who were separated from their mothers in early life had a number of markers of early aging, such as hippocampal cell loss and cognitive impairment. This accumulated evidence

led Berkman (1988)[99] to put forward the proposition that being socially isolated is 'a chronically stressful condition to which the organism responded by aging faster'.

1.4.4 Social support: direct or indirect effect? Innate and universal?

The mechanisms outlined by Thoits (2011)[53] in section 1.4.2 describe how the effect of social support on health may be mediated through a variety of pathways such as lifestyle, self-esteem, self-efficacy, and other psychological mediators, which in turn are thought to work through the physiological pathways described in section 1.4.3. However, there is increasing evidence that social support may also *directly* impact on health via the cardiovascular, neuroendocrine or immune systems. This is discussed in a recent review by Uchino *et al.* (2012)[68]. They summarise the results from laboratory studies which have found that social support alters physiological processes during stressful tasks, but not psychological processes (ie 'supported' participants may have had reduced blood pressure compared to non-supported participants, but reported similar levels of distress, anger or stress). Similarly, there are studies which have found that social support is associated with cardiovascular activity[100, 101] and immune function[102] even after controlling for a range of psychological processes, such as stress, life satisfaction and depression. While the failure to find psychological mediators may be due to measurement error or design issues, an alternative explanation is that, at least in part, social support may *directly* affect health.

The argument that there is something intrinsically health-giving about social relationships may tie in with those who suggest the need to form meaningful attachments is a universal, innate characteristic. Baumeister and Leary (1995)[103], like Bowlby, argue that there is likely to be an evolutionary basis for this basic human need: those able to form and maintain bonds would have been more able to care for their children, hunt for food, and protect themselves from adversity. Their literature review found that this need to feel meaningfully connected to others appears to be universal across cultures; that dissolution of bonds is generally avoided, and where it occurs is a cause of emotional distress; and that lack of belonging leads to psychological and physical health problems, as documented above. From this they put forward the following hypothesis: 'the need to belong is a fundamental human motivation… the belongingness hypothesis is that human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships.'

1.5 How do concepts of social support relate to the stroke population?

In understanding how social support may operate post stroke, it is perhaps helpful to re-examine the proposed mechanisms whereby social support is thought to influence mental and physical health in section 1.4.2 above. The psychological benefits of 'norm-referencing' may be lost post stroke, as self-esteem may be negatively affected if a person compares themselves

with their non-disabled peers. It may also be harder, both physically and arguably psychologically, to take part in pre-stroke social or community activities. Further, the purpose, meaning, self-esteem and self-efficacy associated with successful accomplishment of social roles is likely to be challenged post stroke: the pain associated with lost roles is documented in the stroke literature[6, 104]. Even the benefits of receiving functional support may be compromised. Functional support is likely to become more 'visible' and less reciprocal post stroke. Thoits (2011)[53] cites evidence suggesting that 'deliberate helpfulness', particularly when accompanied by inability to reciprocate, can lead to feeling indebted, dependent, over-controlled or incompetent. Thus arguably many of these 'beneficial' pathways are compromised post stroke.

As a person struggles to continue in community roles, or take part in community activities, it may be expected that there will be some shrinkage of the social network. Further, the role shifts in the family unit, combined with difficulty in accepting help and becoming 'dependent', may be expected to lead to family disharmony. Thus a stroke may be anticipated to constitute a 'threat' to successful social relationships, which is of concern given the importance of feeling meaningfully connected to others described above (see 1.3.1, 1.3.2 and 1.4.4).

So what social support might help a person following a stroke? Turning first to the Cohen and Wills[45] model, it might be predicted that functional support, particularly emotional support, may help to 'buffer' the negative psychological and social consequences of the stroke. For the chronically ill, emotional support has been shown to bolster a person's sense of self-

worth[90]. Where functional support, particularly tangible support, must become 'deliberate', 'visible' and unreciprocated post stroke, there is the concern that it may carry some negative psychological costs. However, there is limited evidence that this need not be the case so long as it is *responsive* (defined as support which made the recipient feel understood, valued and cared for)[105]. Further, it may be hypothesised that where a stroke survivor succeeds in reciprocating support, or is able to resume former (or new) social roles, even if only partially, this may help them to feel more satisfied with their social relationships.

So what is the role of the wider network post stroke? The Cohen and Wills model suggests that the benefits of the wider network are most apparent when an individual is not facing an acutely stressful situation. The issue of when a person ceases to be 'stressed' by having a stroke is not clear cut. In a recent systematic review, rates of depression were estimated at 33% in the acute (within one month) and medium term (between one and six months), and *rose* to 34% in the long-term (post six months)[27]. A study looking at generalised anxiety disorder post stroke found the prevalence rate to be 28% in the acute stages, and this rate did not significantly decrease through the 3 years of follow up[106]. Nonetheless, in theory part of adjusting to post stroke life in the long-term might be considered to be reintegration into the wider community, or at least finding companionship and a sense of belonging, with the social and psychological benefits this would confer.

Thoits (2011)[53] suggests that an additional role of the extended social network is to provide access to experientially similar others (for example, network members may have gone through a similar event, or know someone

who has). Alternatively, peer support groups may provide this function. Thoits suggests that 'experientially similar others' may be in a better position to understand and empathise and may be able to validate that what a person is experiencing is 'normal'. They may also be in a better position than other network members to provide valuable information, advice or guidance, and potentially can act as role models, giving hope. Thoits[53] makes the persuasive case that they are less likely to be threatened or distressed by the person's emotions and worries. She compares this to significant others, who, she suggests 'are invested in the problem being resolved as quickly as possible to alleviate their own and their loved one's distress. Invested supporters therefore may minimise the threatening aspects of the problem, insist on maintaining a positive outlook, or pressure the person to recover or problem solve before he or she is ready.' She therefore argues that while significant others may be best placed to provide love, concern and companionate presence, 'experientially similar' others also have a valuable and distinct role in supporting an individual following a stressful event.

1.6 Learning from models of loss

Lacking from the above analysis is a framework in which to view a person's post stroke adjustment. In order to understand the role of social support more fully, it may be helpful to consider whether a model exists which might explain the 'journey' a person is likely to go on following this stressful life event. In the stroke literature, models of loss and grief have been suggested as having explanatory power. This section firstly outlines

two models of grief cited in the stroke literature: Parkes' model of psychosocial transition[107], and the Dual Process Model of bereavement[108]. It then examines how social support may interact with these models. Finally, it comments on how this knowledge may apply to the stroke population.

1.6.1 Stroke as a psycho-social transition

Glass and Maddox (1992)[109] suggest it is helpful to see an individual's response to stroke as a grief reaction, and therefore consider recovery from stroke as a 'psycho-social transition'. They argue that stroke occurs suddenly, and challenges existing assumptions a person may hold about their identity, self-concept and role capability. The person who has had a stroke, then, 'must adjust to new definitions of self, and new limitations in physical, psychological and social capacity', and ultimately they suggest the challenge of transition is in achieving acceptance.

The conceptual model cited for this paper is that proposed by C. Murray Parkes (1971)[107]. Parkes explores a temporal dimension to such grief (the Phase model of grief, see also Bowlby, 1980[110]). He suggests that a person adapting to a major loss, such as bereavement or loss of a limb, may go through various stages. Firstly, they may experience shock, disbelief, and numbness. This is often followed by a chaotic period of anger, distress, and restlessness. They may then experience disorganisation and despair. Finally, they may reach a stable phase ('restitution'), achieving some sort of reorganisation or acceptance.

1.6.2 Dual Process Model of bereavement (DPM)

An alternative 'grief' model that has been found to be helpful in relation to the stroke population is the Dual Process Model of bereavement (DPM). In a qualitative study, Ch'ng *et al.* (2008)[111] explored how people come to terms with loss following a stroke, and move towards acceptance and successful 'adjustment'. They identified that the DPM model 'captured the experiences of participants' in their study.

Stroebe and Schut (1999)[112] developed the Dual Process Model (DPM) of coping with bereavement as they were concerned that the focus on 'grief work' of either the Phase model[110, 113], or Task Model[114] (the most widely adopted models at the time) did not adequately explain adaptive patterns of coping with bereavement. In particular, they were concerned that they did not take into account different cultural patterns of grief, did not acknowledge the need for 'respite' from grief or 'dosage' of grief, focused on the loss of the loved one neglecting other potential sources of stress (for example, bringing up children as a single parent), and did not acknowledge that different subgroups appeared to be helped by different types of "working through".

The DPM model aimed to 'better describe coping and predict good versus poor adaptation to this stressful life event.' The authors acknowledge the influence of both Cognitive Stress Theory[115], and also the work of Parkes and Bowlby. However, the DPM differs from previous models of grief in conceptualising two categories of stressors. The first is loss-orientation: focusing on the loss experience, and thus incorporating 'grief work', which, like earlier models, they suggest is important in coming to terms with the

loss. The second is 'restoration-orientation' which focuses on the secondary stressors 'reflecting a struggle to reorient oneself in a changed world without the deceased person.' A third component of the DPM model is 'oscillation': a sense that this is a dynamic process, and a person will fluctuate between confronting loss, while at other times avoiding it; similarly they will oscillate between restoration work and also 'time out'. The model proposes that adaptive coping is brought about by oscillating between the two types of stressors (ie between loss and restoration).

The DPM moves away from the idea of set 'stages', although the broad pattern of moving from grief work to 'restitution' described by Parkes is acknowledged. Thus the authors note 'there will gradually (and unevenly) be less attention to loss-oriented and more to restoration-oriented tasks… Furthermore, as time goes on the total amount of time spent on coping with loss and restoration tasks will diminish.'

They suggest their model also provides a clear framework for understanding 'complicated grief': thus chronic grievers have been found to focus extensively on loss, and absent grievers on restoration, without oscillating between the two.

1.6.3 Models of grief and the role of social support

As in other times of distress, measures of perceived social support have been found to be associated with 'positive' outcomes for those who are bereaved. These include better adjustment[116]; enhanced sense-making and benefit-finding[117]; and improved posttraumatic growth[118].

In terms of what functions of support are most likely to help, Hogan and Schmidt (2002)[119], in their model of grief to personal growth, hypothesise that a bereaved person will benefit most from a supportive person who will listen to their thoughts and feelings in a non-judgmental manner. In this way, they may be supported in 'making sense' of their grief. Parkes (1996)[113] suggests that different support functions may be beneficial dependent on what 'stage' a person is at. Thus in the first stage of grief, when a person is numb and in shock, tangible support may be most useful, for example, helping with practical matters. As the person begins to experience distress, he suggests emotional support may be valuable: 'Such communal expressions of sorrow make the bereaved person feel understood and reduce the sense of isolation he or she is likely to experience…the important thing is for feelings to be permitted to emerge into consciousness.' Informational support can be helpful in providing reassurance that what they are experiencing is 'normal'. Parkes suggests that in the later stages of grief, the grieving person should be helped to establish their own autonomy, and it is important for them 'to give up their withdrawal from life, and to start to build a new identity'. He describes personal accounts of 'turning points' which have included going to an evening class or going on holiday. This would seem to tally most closely with the perceived social support function of social companionship or becoming integrated into a wider network.

A recent qualitative study explored how support from family and social networks was perceived by 21 bereaved individuals following the death of a family member from a road traffic accident[120]. The support that was found to be most valued was 'when people listened and allowed them to talk

openly about their feelings and their deceased loved ones, or were "just there" for them'. More commonly, however, they encountered avoidance, which was either implicit (others feeling uncomfortable talking about the deceased, and changing the topic; or dismissing the feelings of the bereaved by false cheerfulness); or explicit (for example, others turning around and walking away when encountering them in public places). They also described their distress when others felt they should have 'moved on', or that grief was a linear process that needed to be 'worked through'. Instead, their patterns of grief were reported to be more similar to the DPM model of oscillation described above. They also reported the deterioration of many relationships, including both family and close friends.

1.6.4 How the bereavement literature may relate to social support after a stroke

The purpose of considering grief models was to examine whether they could provide a useful framework for exploring the role of social support after a stroke. The 'tasks' described by the DPM model would seem to be a promising starting point. Thus the role of support could be to facilitate the following:

1. 'loss-oriented tasks' (such as 'painful dwelling on… the loss experience'[112]). The function of emotional support may be most likely to be helpful.
2. 'restoration-oriented tasks' (such as 'rethinking and replanning one's life' including developing new roles and identities[112]). Again, emotional support is likely to play a role. Further, the wider network

may start to become increasingly beneficial as a person adjusts to a new post stroke life.

3. ‘time out’: the DPM model suggests a person may need ‘respite’ from grief/restoration. This may suggest a role for ‘social companionship’: having one’s mind taken off one’s worries, being distracted, sharing enjoyable times with family and friends.

While the DPM model suggests that in the early stages the focus will likely be on loss rather than restoration, the concept of oscillation is perhaps helpful: that it may be considered natural and adaptive to oscillate between processes if successful adjustment is to take place.

The conclusions drawn from the social support literature and the bereavement literature in terms of the stroke population have much in common. In particular, both suggest that emotional support, for example, listening to a person’s experiences in a non-judgemental way, will be beneficial. While this may sound ‘easy’, indeed obvious, the bereavement literature suggests that in fact it may be more natural for others to want to avoid becoming involved in such raw and distressing emotions. This links to Thoits (2011)[53] observation that significant others may find it threatening or too upsetting to tolerate expressions of extreme distress.

In considering the relevance of the bereavement literature, a couple of observations should be made. Firstly, the bereaved person has by definition lost a member of their social network. Indeed, much of the literature focuses on the experiences of those who have lost a spouse. The stroke survivor, however, is likely to still have their close family to support them. In particular, the role of the spouse or partner in facilitating recovery and

adjustment may be more important for the stroke survivor than is reflected in the bereavement literature. A second difference lies in the expectation of recovery: a stroke survivor may spend much of their first few months seeking to improve their physical functioning, with the continuing hope of 'getting better' or 'back to normal'. Accepting the limits to recovery is likely to take place months post onset, and is often a painful process[121]. Thus it may be expected that some of the 'grief work' may take place at this later stage. Finally, having aphasia may complicate some of the support processes described.

1.7 Relationship between theoretical models and current thesis

A distinction discussed in the social research literature is between theoretical research and 'applied research'. Rather than stemming from theory, research questions in applied research tend to be informed by the need to understand or explain contemporary issues, often in the context of policy development or evaluation[122]. However, Ritchie (2003)[123] argues that it is unhelpful to consider applied research as necessarily a-theoretical. Firstly, all social research can potentially contribute to theory, through providing new insights and understanding. Further, good quality applied research 'requires an understanding of social theory to provide context to, and more fully interpret, the evidence generated.' (p25)

In the current thesis, the research questions were derived primarily through gaps identified in the literature, as explored in Chapter Two. Thus the

research questions have not been explicitly derived from hypotheses aimed at testing specific theories, and as such the thesis is not ‘deductive’. Nor was the aim at the outset necessarily to build theory (inductive). Rather, it was felt that through addressing under-explored areas in an exploratory manner, the thesis was likely to generate results potentially useful to researchers, clinicians and service providers.

So how has theory informed this thesis? Firstly, the theoretical definitions of functional social support and social network guided the literature review, the research questions, the choice of measures, and the topic guide. Further, both theories of social support and of bereavement suggest that a person may benefit from different support functions dependent on the stage of ‘recovery’ they have reached. This informed the decision to conduct a longitudinal study that recruited in the acute stage and followed people over the first year. Further, the theoretical constructs described in this chapter will provide the framework in which to interpret the results. Finally, the findings will be used to assess the usefulness of the described theories in explaining the experiences of the participants in this project.

1.8 Summary

This chapter has described how social support can be viewed in terms of its function and structure. The link between social support and both mental and physical health is well described: those with well-developed social ties can expect to live longer, and are more likely to feel satisfied with their lives. It is likely that in times of acute stress functional support, particularly

emotional support, will be most useful; while a well-developed social network confers most benefits to those who are not acutely stressed. The bereavement literature, in particular the Dual Process Model of bereavement, may be a useful framework in which to consider the role of support in facilitating a person in adjusting to their post stroke life.

Having examined theoretical models of social support in Chapter One, the next chapter will explore the literature on social support after a stroke, ending with the research questions which form the basis of the current thesis.

Chapter Two. Social support after a stroke: a systematic review

2.1 Rationale for conducting a systematic review

Health care professionals and those that design services should be guided by the best available evidence[123]. However, it can be difficult for an individual practitioner to filter the most relevant information, given the large number of studies published. Further, studies may be biased or flawed, misrepresented, or give conflicting results[124]. As such, it may not always be clear which results are most reliable, and should form the basis for healthcare service provision. It has therefore been argued that systematic reviews are essential tools in order not only to summarise evidence from relevant studies, but also to evaluate research[125], thus 'making the available evidence more accessible to decision-makers' (preface, v)[124].

In conducting this systematic review, the aim was to follow best practice guidelines[125], making the design and decision-making processes of the review as transparent, specific and reproducible as possible. Not only was the aim to identify, evaluate and summarise the study findings, but also to reveal areas where there is as yet little or contradictory evidence, thus paving the way for the research questions which will form the basis of this thesis.

To date there is no systematic review of what happens to social support and social networks after a stroke; nor what factors are associated with social support. This systematic review aimed to: (1) describe what happens to

functional social support following a stroke; (2) describe what happens to a person's social network, including relationships with family, friends and the wider network ; (3) identify what factors are associated with or predictive of functional social support and social network post stroke; (4) review the quality of the relevant studies.

2.2 Rationale for including qualitative and quantitative studies

Dixon-Woods *et al.* (2001)[126] observe that qualitative research has 'tended to be excluded or marginalised in systematic reviews' (p125), a situation which they argue stems in part from unease about whether it counts as rigorous 'evidence' on the part of quantitative researchers. It may also reflect the on-going debate in the qualitative research community about the appropriacy of conducting reviews at all[124, 127]. There is concern that qualitative studies may be specific to the particular context and study participants involved, and that in synthesising or combining research, the original findings will be wrongly de-contextualised and inappropriately considered commensurable[128]. Further, in comparison to well set out procedures for conducting systematic reviews of quantitative studies, methods for reviewing qualitative studies are considered to be still emerging and contested[127, 129].

However, a number of authors have made the case that qualitative research can and should inform policy and practice[130, 131], and in this context Thomas and Harden (2008)[127] argue that the research community needs to

‘recognise that methods are required to bring its findings together for a wide audience’ (p3). The authors go on to make the case for conducting sensitive syntheses of results that preserve and respect the ‘essential context and complexity’ of the original studies.

There is the further argument that qualitative evidence should be considered alongside quantitative evidence in order to inform health care decision making. Dixon-Woods *et al.* (2001)[126] give a variety of examples where qualitative research has helped to explain, augment or highlight the inadequacies of quantitative findings. Further, qualitative research is able to answer questions which are difficult to address through quantitative methodology alone, such as the patients’ perceptions of healthcare, or the ‘lived-in’ experience of a health condition, such as stroke and aphasia[104]. Dixon-Woods *et al.* (2001)[126] argue that the influence of qualitative research will have the greatest impact when ‘all available qualitative evidence from relevant studies is brought more directly into conjunction with the synthesis of other evidence in systematic reviews.’ (p126)

The focus of the current review is social support from the perspective of the stroke survivor. This would seem to be a review question which lends itself to inclusion of both qualitative and quantitative evidence. Thus qualitative evidence might be expected to explain trends found in the quantitative evidence (for example, reduced contact with friends), and interpret significant associations (for example, between social support and recovery).

2.3 Methods

The PRISMA guidelines formed the basis of the conduct and reporting of this systematic review of the literature. [125, 132] Where there is debate in the literature about the degree to which aspects of accepted systematic review methodology can be 'translated' to qualitative studies, this is briefly discussed.

2.3.1 Eligibility criteria

Studies were considered eligible for this review if they explored the following aspects of social support:

Functional social support:

- adequacy or availability of functional social support (perceived or received)
- analysis of the different functions of support, such as emotional or tangible
- satisfaction with functional social support;
- the related concept of loneliness was also considered

Social network:

- size, composition, frequency of contact, and the related concept of social isolation
- functioning of different elements of the network post stroke (for example, family, friends)
- group membership/ social activities

- satisfaction with social network

Social factors not included in review

There are a number of terms and concepts closely related to social support which were not the focus of this review. Thus studies that examined the following concepts were not included: social dysfunction (which typically also measures ability to work[133]); participation (which is generally conceptualised as including daily activities as well as social roles)[134]; and social exclusion (which encompasses concepts of poverty, poor skills, high crime as well as social factors such as family breakdown and reduced social capital)[135]. Further, the review did not consider support received from professionals as the focus of the current thesis is informal social networks. Finally, the review did not include studies where the only social indicator was either marital status or living arrangements: single indicators such as these have been found to be less predictive of outcome than more complex measures[66].

Participant characteristics

Participants had to be adults (≥ 18 years old) who had had a stroke. Studies reporting exclusively on people with aphasia were included, as were studies who excluded those with aphasia. Studies reporting on the perspective of the caregiver or other family members were excluded unless they also reported on the perspective of the stroke survivor. Additionally, studies were excluded if they reported on mixed populations, for example stroke and spinal cord injury populations, unless stroke results were reported separately. Finally, those studies reporting exclusively on right hemisphere stroke or subarachnoid haemorrhage stroke were excluded.

Study design and characteristics

There was no restriction on sample size or duration of follow up. The focus of the review was observational studies (as defined by STROBE[136]): both cross-sectional and longitudinal designs were considered.

Reports based on cohort of participants used in current thesis

Three reports were excluded as they stemmed from the cohort of participants who are reported on in this thesis[7, 137, 138].

Additional criteria

Only studies that reported in the English language were included. Further, only studies that had been peer-reviewed were included. However, there was no restriction in terms of geographical location or date.

2.3.2 Additional considerations in selecting qualitative studies

There is debate about whether qualitative reviews should select papers purposively rather than exhaustively. A proponent of this view is Doyle (2003)[139] who suggests that the purpose of a qualitative synthesis is interpretive explanation rather than prediction, thus the reviewer should aim to include papers that achieve 'conceptual saturation'. This approach was adopted in a review of patients' perspectives of diabetes[130]. An alternative way of limiting the number of papers is to include only those considered to provide 'rich description' or which have 'conceptual clarity'[124]. Other authors have argued that this form of sampling may lead to the inadvertent exclusion of relevant data, and recommend including all papers that meet set criteria[140 129].

For this project, the decision whether or not to include a paper was made on pre-determined and clearly specified criteria as set out above. An additional criterion which only applied to qualitative studies was that the data should be analysed using an established method (a criterion also used by Hilari *et al.*, 2012[141]).

Determining whether a quantitative paper had analysed social support was relatively straightforward (for example, scanning through measures carried out in a study). The process was less obvious with qualitative papers. Firstly, the terms 'social support' or 'social network' were less commonly used. Qualitative findings are often reported using participant language which may differ from academic terminology, as discussed by Dalemans *et al.* (2010)[5]. Examples of reported main themes relating to social support were 'people'[142] or 'making a good time'[143]. Secondly, an aspect of social network could appear as a minor subcategory of a theme, making the paper less useful to the review. The strategy decided upon was that papers would only be included if an aspect of social support/network was included in the title, research question, key words, or was reported as a main finding. It was decided that to be considered a 'main finding', social support/network needed to appear in the abstract and in at least two paragraphs in the results section of the paper (ie 'rich description'). It was unclear whether this latter criterion was somewhat arbitrary. To counter this, the concept of 'saturation' was used. Thus papers that met all the inclusion criteria, but where social support was reported on only briefly, were put to one side and not included in the initial analysis. Once an initial thematic framework had been completed (described below), these papers were then reread to see if

they added any new themes or concepts. None of them did, which would seem to justify the decision not to include them.

2.3.3 Additional considerations in selecting quantitative studies

When assessing subjective feelings, there is a strong case to be made that well-constructed validated scales with sound psychometric properties will give more reliable results[144]. Thus initially, it was decided that since functional social support is a subjective and potentially difficult construct to measure, only studies using validated scales would be included. It was considered that aspects of social network could more reliably be assessed without using a validated scale, as they are potentially more 'objective'. Further, many key studies (Astrom *et al.*[9], Code *et al.*[145], Cruice *et al.*[3]) made use of non-validated social network scales or items, and excluding them could weaken the review. In the event, the concepts of social network and functional social support were so intertwined in many studies, that in practice it was difficult to justify excluding non-validated measures of functional social support while including non-validated measures of social network. Thus, reflecting the heterogeneous way in which social support is conceptualised and assessed in the stroke literature, studies were included that used non-validated scales. However, a distinction was made when reporting and interpreting the results.

2.3.4 Information sources and search strategy: qualitative and quantitative

In order to find relevant studies, the following search strategy was undertaken. Firstly, the following electronic databases were searched: Academic Search Complete; CINAHL Plus; E-journals; Health Policy Reference Centre; MEDLINE; PsycARTICLES; Psychology and Behavioral Science Collection; PsycINFO; and SocINDEX. These databases were searched for peer-reviewed journal articles. Articles were found from the following search strategy:

- Field: Title. Search terms: 'stroke' OR 'aphasia'
- Field: Abstract. Search terms: 'social support' OR 'social network' OR 'social activity' OR 'social satisfaction' OR 'isolat*' OR 'lonel*' OR 'social participation'

Search results were stored on EBSCOhost. Further studies were considered from following up references, or through recommendation by expert advisors. Where a peer-reviewed article was subsequently turned into a book, this was also considered for review. Finally, relevant recent systematic reviews were consulted for additional references.

2.3.4 Screening and data collection: qualitative and quantitative

The abstracts of all journal articles that came out of the above search strategy were screened against the eligibility criteria. Reasons for excluding

or including studies were recorded. Where it was not possible to assess the eligibility based on the abstract alone, the full text was reviewed.

For those studies which were considered eligible, a data extraction process was undertaken. For each eligible study the following information was recorded:

- Publication details, including title, authors, journal, date
- Study design
- Study aims
- Country/ setting
- Timing of assessment(s)
- Study population (sample size, sex, age, ethnic background, presence/ severity of aphasia, severity of stroke. In addition major exclusion criteria were recorded and in the case of longitudinal studies, rate of follow up)
- Measures used (both social support and other measures)
- Main results

2.3.5 Critical appraisal: qualitative studies

The assessment of qualitative research is another contested area[124, 127]. Researchers from different theoretical backgrounds may have different perspectives on what makes research of high quality[128], and thus attempting to codify, or prescribe a set formula for assessing validity and reliability of qualitative research is argued to be fraught with difficulty. Indeed, many reviews of qualitative papers do not include any critical appraisal. A recent

review of papers synthesising qualitative studies relating to health care found that 60% of the 42 reviews included did not report on any appraisal of studies[146].

Despite the inherent difficulties, there are sound arguments for including a critical appraisal of included papers. Thomas and Harden (2008)[127] argue that the 'quality of qualitative research should be assessed to avoid drawing unreliable conclusions' and to 'assess the possible impact of study quality on the review's findings' (p48).

For this study, the critical appraisal process was not used to exclude papers (although the decision only to include studies which analysed data using an established methodology excluded some poor quality research). Instead, at the end of the synthesis, an analysis was undertaken to see whether anything substantially different was found in the weaker studies, as done by Noyes and Popay (2007)[129] in their synthesis of tuberculosis treatment.

The tool chosen to appraise quality was the Critical Appraisal Skills Programme (CASP) tool for qualitative research[147]. This tool was developed by the Public Health Resource Unit in order to assist readers of research to judge whether it is reliable, trustworthy and relevant. It has been widely used in health care reviews[129, 130, 141]. No major adaptations were made to the CASP tool. There are ten sections in this tool which address the appropriacy of the research design, recruitment strategy, validity and rigour of data collection and analysis, ethical issues, role of the researcher, and the value of the research

A copy of the CASP tool for appraising qualitative research is provided in Appendix One.

2.3.6 Critical appraisal: quantitative studies

All included quantitative studies were critically appraised using the Critical Appraisal Skills Programme (CASP) tool for cohort studies[148]. As with the qualitative CASP, the purpose of the cohort study CASP is to appraise the rigour, validity and value of research.

One potential problem of using the CASP for cohort studies is that the review also included cross-sectional studies (for which there is no CASP tool). This meant that not all the sections were applicable to studies of cross-sectional design, specifically Section 7 (follow up of subjects). Further, the CASP is a generic tool, rather than stroke specific. It was therefore modified to make it more sensitive to the stroke population. In particular, items from the critical appraisal tool developed by Counsell and Dennis (2001)[149] were incorporated into it.

The Counsell and Dennis tool was developed for the authors' own systematic review of prognostic models in stroke[149] and has subsequently been used by other authors conducting systematic reviews of the stroke literature (health related quality of life in aphasia[141]; predictors of depression after stroke[150]). It was not an appropriate tool to use for the present review, however, as it is designed to evaluate prognostic models: there was only one study included which looked at predictors of social

network (Code *et al.*[145]) and none that examined predictors of functional social support.

The ways in which the Counsell and Dennis tool was incorporated into the CASP is outlined below. The relevant sections from the Counsell and Dennis tool are indicated (for example, Ai).

CASP Section 3: Was the cohort recruited in an acceptable way?

Three quality markers were taken from Counsell and Dennis.

- Ai) Population-based studies are considered the least biased studies, as they include stroke patients not admitted to hospital at the acute stage. Those recruited from hospitals, and particularly those recruited from rehabilitation units, could be considered to be less representative of the stroke population as a whole[150].
- Aiii) Major exclusion criteria could limit generalizability of the findings. In practice, almost all studies excluded those with poor cognition, who lived in a residential care home prior to the stroke, and who had severe or terminal co-morbidity. Further, most studies excluded those who had had a previous stroke. These exclusion criteria were not noted on Table 2. Counsell and Dennis[149] suggest that generalizability will be limited if a study excludes on the basis of age, sex or type of stroke. Other major exclusion criteria noted included: aphasia, stroke severity and mobility.
- Bi) Time post onset stated. Part of the purpose of the review was to examine whether functional social support and network change over time following a stroke, thus it was important to know at what stage

post stroke the study took place. Where this information was not provided, it was hard to interpret and generalise findings.

CASP Section 6A: Have the authors identified all important confounding factors?

- Bvi) Counsell and Dennis[149] argued that a model is likely to be more reliable if stroke severity is included as a potential predictor/ confounder.

CASP Section 7B: Was the follow-up of subjects long enough?

- Bv) Follow up of over 30 days is considered more meaningful following a stroke.
- Bv) Fixed points used. In order to study how social support changes over time, it is necessary to know at what stage assessments have been carried out. In order to compare participants, assessments should be made at similar time post onset (or post discharge home if the focus is on adapting to living at home).

CASP Section 10 (Do you believe the results?)

In order to address the believability of results, six markers of quality and reliability were used. Since the Counsell and Dennis framework was designed for predictive models, it does not apply to markers B and E.

A. Population may be biased:

- Bii) where inadequate numbers are followed up. Where over 40% were lost to follow up, it was considered the results may be biased.

- Postal: where under 50% agreed to participate in study if postal, it was considered problematic. Bowling (2004)[151] argues that 75% should be considered a minimum acceptable level to avoid bias in postal surveys. However, a recent review found that mean response rate to postal surveys in the related area of health services research was 56%, with only 16% of studies achieving 75% or more[152]. For the purposes of this review, a study based on postal surveys with a response rate of over 50% was considered acceptable.
- Face to face: Singleton and Straits (1999)[153] suggest that a 70% response rate is a minimum acceptable level.

B. Study did not take into account confounding factors (for example, presents only univariate associations)

C. (Biv and Bvii) Reliance on non-validated scale for perceived social support

D. (Ci) Where multiple regression techniques used, results considered unreliable if events per variable ratio insufficient (>10 considered acceptable for multivariate analysis)[149]

E. Effect size/ power not reported where ANOVA or similar study design used. Tabachnick and Fidell (2007)[154] argue that it is important to report on the degree of association between variables (effect size), over and above a statistically significant result, 'to avoid publicizing trivial results as though they had practical utility' (p54).

F. Study design, methods or analysis flawed in other specified manner which could potentially lead to unreliable results

CASP Section 11: Can the results be applied to the local population?

- Aiv) where a description of the cohort is provided, it is possible for the reader to assess how similar it is to their local population. As a minimum, Counsell and Dennis suggest that age and sex details should be provided.

Finally, CASP Section 12 (do the results fit with other available evidence?) was addressed in the results tables and narrative account.

A copy of the CASP tool and the Counsell and Dennis tool are provided in Appendix One.

2.3.7 Data Analysis: qualitative

Meta-ethnography was chosen as the method for synthesising findings. This involves the interpretive integration of findings from qualitative studies[128]. Through 'translating' concepts from one study into another, the aim is to go beyond individual accounts to produce new interpretations. This method was developed by Noblit and Hare in 1988[155], and, as suggested by the name was devised initially to synthesise ethnographic studies. However, as discussed by Aveyard (2010)[156], it is now widely used with many qualitative methods, and as such 'meta-ethnography can be applied to all qualitative studies.' (p126).

The initial stage involved deciding what constituted the ‘data’ to be analysed. In a meta-ethnographic synthesis, the data is the findings of the research papers. Thus a decision needs to be made about what constitutes ‘findings’[127]. Sandelowski (2007)[128] suggest that findings are distinct from the data from which they are based. Further, the researchers’ conclusions, externally sourced data, and methods do not constitute ‘findings’. In the present study, this meant the data was any findings that related to social support/network including interpersonal relationships with family, friends and the wider network.

Having conceptualised what constituted the ‘data’, the next step was to read and reread the reports, in order to become familiar with the findings. The subsequent analytic steps were similar to those described in Campbell *et al.* (2003)[130]. Findings that related to social support were summarised, using the terms and concepts found in the studies. Key concepts were then identified. The process of ‘translating’ concepts from one study to another was an iterative process, involving mind maps, continual review and refinement of concepts, and returning to both the summarised and the original data. Concepts were ‘grouped’ to construct ‘descriptive’ themes[127], a thematic framework evolving through this process. At this stage, a systematic search was conducted of the data, to ensure that all relevant material had been included in the framework, and that the integrity of original findings had been maintained, a process also described by Brown *et al.* (2012)[157]. As discussed by Noyes and Popay (2007)[129], this iterative process has much in common with analysing primary research in qualitative studies. Finally, a narrative synthesis was written.

2.3.8 Data Analysis: quantitative

The quantitative studies included in this review were not homogenous in study design, measures used, study aims, or participant characteristics. This made it inappropriate to conduct statistical meta-analysis[158]. Instead, a narrative synthesis of the evidence is presented.

2.3.9 Reporting results: combining qualitative and quantitative

When reporting the results of a review that includes both qualitative and quantitative research, there are concerns about how to combine the findings, given the different research 'paradigms'[159]. One option, chosen by Thomas *et al.* (2004)[160] and recommended by Mays *et al.* (2005)[158] is to present the syntheses separately, and then seek to combine and interpret the results. Mays *et al.* (2005) suggest this will 'preserve the unique contribution of qualitative and quantitative evidence while also providing a way for each type of evidence to help interpret the other, in order to form a more comprehensive and useful answer to the review question.' (p17-18).

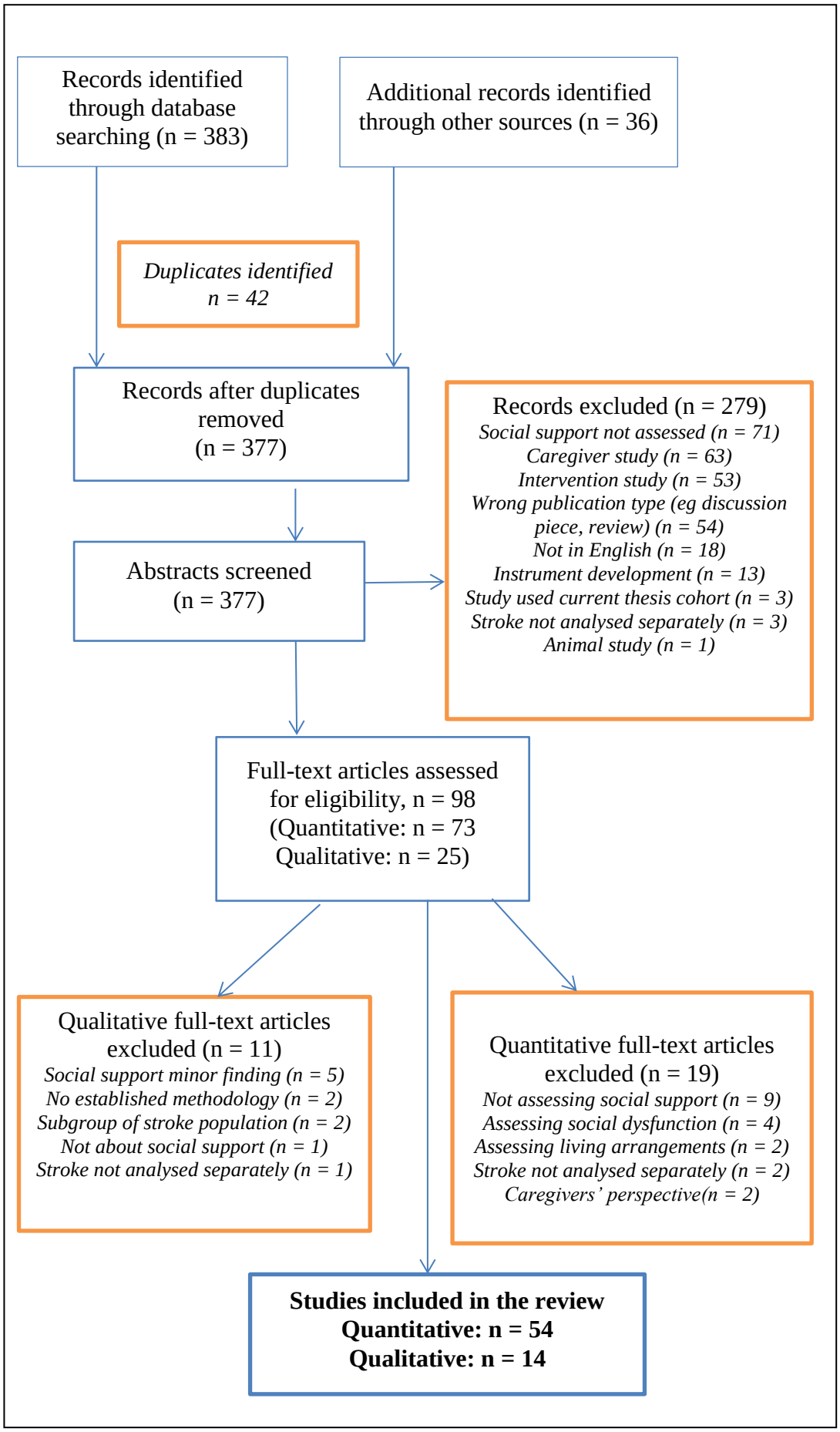
2.4 Results

2.4.1 Study selection

Electronic database searches were conducted in February 2013 and resulted in 383 references. An additional 36 references were identified through other sources, such as reference lists. A flow diagram (Figure 2.4.1) shows the reasons for exclusion at each stage. Only one reason is given for why a study was excluded in the flow diagram, although in some cases there were

several reasons for exclusion. After deduplication, 377 studies remained. A further 279 studies were excluded after screening abstracts, leaving 98 reports, of which 73 were quantitative studies, and 25 were qualitative. The full text of all 98 reports were read, and a further 19 quantitative reports and 11 qualitative reports were excluded (reasons again provided in the diagram). The most common reason for exclusion at this stage was: study not assessing social support (n=9) (quantitative studies); study not reporting on social support as a 'main' finding (n = 5) (qualitative studies). The review therefore includes 68 reports: 14 qualitative reports and 54 quantitative reports.

Figure 2.1 Flow diagram illustrating the review process



2.4.2 Study characteristics

Qualitative studies

The 14 qualitative reports are based on 13 studies (participants were the same in both reports by Brown *et al.*[143, 161]). Brief study details are provided in Table 2.1. The method of data collection most frequently used was semi-structured interviews (10/13), although this was supplemented by additional methods in three cases (diary[5, 162]; participant photographs[143, 161]; observation[162]; stimulated recall of a video[162]). One study used focus groups[111], one study ethnography[163], and one study used an ethnographic account of published data[164]. Participants for eight studies were drawn exclusively from people who had aphasia. The remaining five studies recruited from the general stroke population, and either do not make clear whether people with aphasia were included[6, 165], or give no indication as to how they were facilitated[111, 166, 167]. The studies took place in the UK (5), Australia (4), USA (1), Canada (1), and the Netherlands (1). Three studies additionally interviewed care-givers or close relatives[5, 6, 168]; and one study observed controls as well as people with aphasia[162] .

Sample size in the qualitative studies ranged from nine to 77. In total, 165 participants were recruited for aphasia studies; and 208 participants were recruited into the stroke studies. Additionally, 38 care givers or close relatives were interviewed (although their data is not analysed in this review); and 15 controls were recruited.

All studies were cross-sectional in design apart from Haun *et al.*[165], which interviewed participants on three occasions over the first 12 months. Only

two studies interviewed participants in the acute stage post stroke: Grohn *et al.*[169] at three months, when many participants were still in active rehabilitation; and Haun *et al.*[165] (initial interview took place one month post stroke). The remainder of the studies collected data at least six months post onset, and in some cases many years post onset (for example, Parr *et al.*[104] sought to recruit participants five years or more post stroke).

Quantitative studies

The 54 reports are based on 48 studies. Participants were the same in four reports by Astrom *et al.*[2, 106, 170, 171], two reports by Cruice *et al.*[3], two reports by Hilari *et al.*[172, 173], and two reports by Glass *et al.*[16, 109]. Brief details about the studies are provided in Table 2.2, where they are grouped into three categories: those including only people with aphasia (n = 5); stroke studies that included people with aphasia (n =18), although in many cases, only those with mild aphasia; and stroke studies that either do not mention aphasia at any point in the article (n = 5), or that specifically exclude people with aphasia (n = 20).

Of the 48 studies, 29 were cross-sectional, defined as studies which 'assess all individuals in a sample at the same point in time (p807)'[136] Five studies of these studies also reported on controls[3, 4, 174-176]. The majority of cross-sectional studies interviewed people at least six months post stroke (n = 16), and four studies interviewed people in the acute stage. The remaining nine studies were either unclear about the timing (for example, Adeniyi *et al.*[177], who gives no information about time post onset), or recruited both those in the acute and chronic, often including a wide range of time post onset (for example, Friedland and McColl[178], where participants were between two

and twenty-four months post discharge, yet are treated as one group for analysis).

There were 19 cohort studies (where participants are followed over time)[136], one of which also reported on a comparison group[2]. The study which followed people over the longest period of time was Boden-Albala *et al.*[179] which tracked stroke survivors for five years recording recurrent stroke, death or myocardial infarction. There were also two studies which assessed stroke survivors on a range of measures for over two years post stroke (Astrom *et al.*[170], which recruited people two days following the stroke and followed them for three years; King *et al.*[10] followed stroke survivors from discharge for two years). More commonly, stroke survivors were followed up over a six month period.[16, 17, 79, 180-184]

Sample size ranged from 20[175] to 1417[176]. In total, data from 6456 stroke survivors were included in the studies, as well as 1983 controls. The aphasia studies reported on 209 participants. Studies took place in the USA (n = 20), Australia (n = 6), UK (n = 5), China (n = 5), Canada (n = 3), Nigeria (n = 2), Taiwan (n = 2), other (n = 5).

2.4.3 Risk of bias within studies

Qualitative studies (Table 2.1)

Table 2.1 presents the results of the critical appraisal of included papers. Qualitative methodology was appropriate in all cases, and the research design was justified. 12/14 additionally had clearly focused research questions.

In terms of recruitment, the process by which studies were recruited was explained and justified in 12/13 studies. Seven studies gave their criteria for purposive sampling, suggesting they succeeded in recruiting a diverse sample (considered appropriate for qualitative methodology[185]). Only one study Haun *et al.*[165] provided no information as to how the sample had been recruited.

In terms of generalizability, there were concerns about the pool from which a number of studies drew their participants. Haun *et al.*[165] recruited only men. The published accounts that form Hinckley's[164] data set are written by well educated, motivated, and younger stroke survivors, thus the extent to which findings may be 'transferable' to the more general stroke and aphasia population is questionable. For two studies[5, 168], a requirement for inclusion was a willing care-giver or significant other to take part in the study, potentially excluding the most isolated participants. Finally, three studies recruited either through stroke or aphasia groups exclusively[111, 168] , or in combination with a university clinic and research register[143, 161]. Results based on those who attend groups or have chosen to be part of a university aphasia community may not transfer to those who are either unable or do not want to attend such groups. A further observation is that only three of the studies included participants who lived in care home settings.[163, 167, 169]

In terms of data collection, the methods used were appropriate, and on occasion displayed imaginative extensions of the semi-structured interview (for example use of participant photography)[143]. Data was collected in a prospective manner in 12/13 studies. The exception was Haun *et al.*[165], where data was collected as part of a larger project, suggesting that probing

of areas specific to the report's research question may not have taken place. Only one study discussed saturation of data[111].

In terms of data analysis, 13/14 reports provided sufficient information as to how the data was analysed; the exception was Hinckley (2006)[164]. Some indication that rigour was incorporated into study design was evident in 12/14 reports: three reports used respondent validation; in eight reports there was more than one analyst involved; one study referred to triangulation of data; and two reports to establishing an 'audit trail'. Two reports[104, 166] however, did not provide sufficient information. Reflexivity of the researcher about their own potential biases was not considered in any of the stroke studies, but was considered in 6/9 of the aphasia studies.

In summary, the studies were on the whole well-constructed. The main concern related to the samples recruited, which could potentially limit generalizability of results. In particular, those most isolated (without a care-giver, not attending groups, or living in a nursing home) may be under-represented.

As specified in the methods, a brief analysis was undertaken to see if the 'weaker' studies contributed substantially different results to the 'stronger' studies. The two weakest studies were considered to be Hinckley *et al.*[164] (population which makes the transferability of results problematic; insufficient detail as to analytic process; weak credibility as it is unclear which stages of the analytic process the second analyst was involved in), and Haun *et al.*[165] (secondary analysis; very limited participant information provided; exclusion of women). Neither of these papers contradicted the findings of the other reports, nor did they contribute new themes. They did,

however, provide additional insight into themes (for example, over the contribution of the spouse in facilitating recovery).

Table 2.1 Study details and critical appraisal of qualitative studies (based on CASP)

	Studies with PWA only						
	Brown et al (2010)[161]	**Brown *et al.* (2013)[143]**	**Dalemans *et al.* (2010)[5]**	**Davidson *et al.* (2008)[162]**	**Grohn *et al.* (2012)[169]**	**Hinckley *et al.* (2006)[164]**	**Le Dorze & Brassard (1995)[168]**
Study details	Australia	Australia	The Netherlands	Australia	Australia	Various	Canada
Timing of data collection: mean (SD)	≥2yrs TPO	≥2yrs TPO	16mths – 11 yrs	9mths – 9 yrs	3 mths	>2 yrs	2-14 yrs
Number of stroke participants	25	25	13	15	15	18	9
RQ topic	Living successfully	Role of friendship	Social participation	Friendship	Living successfully	Living successfully	Aphasia & ICF
Quality assessment							
1 Clearly focused RQ	✓	✓	✓	✓	✓	✓	✓
2 Qualitative methodology appropriate	✓	✓	✓	✓	✓	✓	✓
3 Research design justified	✓	✓	✓	✓	✓	✓	✓
4 Recruitment strategy							
Recruitment process explained/justified	✓ purposive	✓ purposive	✓ purposive	✓	✓	✓	✓
Participants appropriate for RQ	Through stroke groups and university	Through stroke groups and university	✓ needed willing care-giver	✓	✓	Not representative	✓needed willing care-giver
5 Data collection							
Method selected (eg focus group, in-depth interview, published data)	Interviews + participant photos	Interviews + participant photos	Diary + semi-structured interviews	Observation + diary + stimulated recall interview	Semi-structured interview	Published accounts	Semi-structured interviews
Data collected in a way that addresses RQ	✓	✓	✓	✓	✓	✓	✓
Methods used clearly explained	✓	✓	✓	✓	✓	✓	✓
Saturation of data discussed							
6 Researcher/ participant relationship							
Researcher considered own influence	✓	✓	✓	✓		✓	Not considered
7 Ethical issues							
Consideration of ethical issues	✓	✓	✓			N/A	✓
Approval from ethics committee	✓	✓	✓		✓	N/A	
8 Data analysis							
Analytic method used (where specified)	IPA	IPA			Thematic analysis		
In-depth description of analysis process	✓	✓	✓	✓	✓		✓
Rigour (clarity as to how themes derived from data; sufficient data presented)	✓	✓	✓	✓	✓		✓
Contradictory data taken into account	✓	✓	✓	✓	✓		✓
9 Findings							
Clear statement of findings	✓	✓	✓	✓	✓	✓	✓
Credibility discussed	✓ >1 analyst; audit trail	✓ >1 analyst; audit trail	✓ respondent validation	✓ triangulation + respondent validation	✓ >1 analyst	✓ >1 analyst	✓> I analyst
10 Value of the research							
Contribution to knowledge discussed	✓	✓	✓	✓	✓	Brief	✓
Transferability of findings discussed	Specific to group attendees?	Specific to group attendees?	✓ (only 1 PWA living alone)	Only 3 PWA interviewed	✓	Limited	Belonged to Aphasia Association

Table 2.1 (con) p2/2	PWA only		General stroke population studies				
	Parr *et al.* (1997)[104]	**Parr (2007)[163]**	**Ch'ng *et al.* (2008)[111]**	**Dowswell *et al.* (2000)[6]**	**Haun *et al.* (2008)[165]**	**Pound *et al.* (1999)[166]**	**Sumathipala *et al.* (2011)[167]**
Study details	UK	UK	Australia	UK	USA	UK	UK
Timing of data collection	>5 yrs	9mths – 15 yrs	4.4 yrs (3.08)	13-16mths	1, 6 & 12 mths	10mths	1-11yrs
Number of stroke participants	50	20	26	30	77	40	35
PWA included	✓	✓	✓ (?recovered)	Not specified	Not specified	×severe	✓mild
RQ topic	Experiencing aphasia	Social exclusion	Challenges of recovery; coping	Psychosocial difficulties	Connectedness and isolation	Social and practical strategies	Long-term needs using ICF
Quality assessment							
1 Clearly focused RQ	✓	✓	✓			✓	✓
2 Qualitative methodology appropriate	✓	✓	✓	✓	✓	✓	✓
3 Research design justified	✓	✓	✓	✓	✓	✓	✓
4 Recruitment strategy							
Recruitment process explained/justified	✓ purposive	✓ purposive	✓	✓	No	✓ consecutive	✓ purposive
Participants appropriate for RQ	✓	✓	Through stroke groups only	No participant info provided	Men only; limited participant info	✓	✓
5 Data collection							
Method selected (eg focus group, in-depth interview, published data)	Semi-structured interviews	Ethnography	Focus groups	Semi-structured interviews	Semi-structured interviews	✓	Semi-structured interviews
Data collected in a way that addresses RQ	✓	✓	✓	✓	Retrospective	✓	✓
Methods used clearly explained	✓	✓	✓	✓	No	✓	✓
Saturation of data discussed			✓				
6 Researcher/ participant relationship							
Researcher considered own influence	Not considered	✓	Not considered	Not considered	Not considered	Not considered	Not considered
7 Ethical issues							
Consideration of ethical issues raised by study	✓	✓		✓	No	✓	✓
Approval from ethics committee	✓				No		✓
8 Data analysis							
Analytic method used	Framework	Framework					
In-depth description of analysis process	✓	✓	✓	✓	✓	✓	✓
Rigour (clarity as to how themes derived from data; sufficient data presented)	✓	✓	✓	✓	✓	✓	✓
Contradictory data taken into account	✓	✓	✓	✓			
9 Findings							
Clear statement of findings	✓	✓	✓	✓		✓	✓
Credibility discussed		✓ respondent validation	✓ respondent validation	✓ 2 analysts	2 analysts for coding only		✓
10 Value of the research							
Contribution to knowledge discussed	✓	✓	✓	✓	✓	✓	✓
Transferability of findings discussed	✓	✓	Specific to stroke group attendees?	No participant info provided	Men only; limited participant info	Specific socio-economic group	✓

Quantitative studies (Table 2.2)

Most reports had a clearly focused research question (48/56), and used appropriate methodology (51/56).

The most representative stroke studies are those that are 'population-based'[150]. Only four (of 48) studies in the present review had 'population-based' samples, while a further eight studies were 'community-based' (ie drawn from the community via stroke groups, advertisement etc), including 4/5 of the aphasia studies. Thus the majority of studies were either recruited from hospitals (n = 18), stroke units/ rehabilitation settings (n = 12), or clinics/ outpatients (n = 4). The majority of studies seeking to recruit chronic stroke survivors chose to do so via hospital records (n = 10), rather than through the 'community'. Only two studies[174, 186] gave no information as to where they recruited participants from.

Half of the included studies (24/48) had no major exclusion criteria which would limit generalizability. Two included TIAs[9, 187], which has been argued to be problematic as TIAs have a different prognosis to stroke[149]. Thus 24/48 studies had a variety of exclusion criteria relating to age, severity of stroke, mobility, recovery, type of stroke (for example,excluding haemorrhage), and availability of a willing care-giver.

Twelve studies did not use either a validated functional social support or social network measure. It was of particular concern that five studies relied on non-validated measures of perceived social support, potentially leading to unreliable results.

In terms of confounding variables, only nine studies considered stroke severity. Of the 54 reports, 10 failed to consider the influence of confounding variables in their design.

The cohort studies all followed stroke participants beyond 30 days. 17/19 used fixed points post stroke onset for assessment. Rates of follow up were extremely variable, ranging from 0% lost to follow up[184], to 53% lost to follow up[186]. There was also much variability between studies in terms of the transparency with which this information was provided. An example of good practice was Astrom *et al.*[9, 170], who gave a clear breakdown including causes of lost follow up. Conversely, four studies gave no information at all[109, 180, 181, 188].

43/48 studies provided sufficient information about the age and sex of their participants. Five, however, provided no participant information.

Finally, in terms of reliability of results, 27/54 reports were considered to be unreliable. Six reports were considered to have biased populations due to poor response rate (this figure could be higher: not all studies reported on response rates); seven reports failed to take into account confounding factors, for example, through conducting univariate analyses only; six reports relied on non-validated measures of perceived social support; three reports had insufficient subjects to variable ratio for multiple regression; six reports give ANOVA results without reporting effect size; and six were considered flawed in design, methods or analysis in some other specified manner.

In summary, the studies were of variable quality. Study weaknesses will be considered when interpreting the results, particularly where there are conflicting findings.

Table 2.2 Study details and critical appraisal of quantitative studies (based on CASP)

Table 2.2; p1/4	Studies with PWA only (± age-matched controls)							Stroke studies including PWA						
	Code *et al.* (2003)[145]	Cruice *et al.* (2003)[189]	Cruice *et al.* (2006)[3]	Hilari *et al.* (2003)[172]	Hilari & Northoctt (2006)[173]	Ross & wertz (2003)[174]	Vickers *et al.* (2010)[8]	Astrom *et al.* (1992A)[2]	Astrom *et al.* (1992B)[170]	Astrom *et al.* (1993)[171]	Astrom (1996)[106]	Belanger *et al.* (1988)[180]	Boden-Albala *et al.* (2005)[179]	Colantonio *et al.* (1993)[15]
Study details	UK	Australia	Australia	UK	UK	USA	USA	Sweden	Sweden	Sweden	Sweden	Canada	USA	USA
Study design	x-sec	x-sec	x-sec	x-sec	x-sec	x-sec	x-sec	Cohort	Cohort	Cohort	Cohort	Cohort	Cohort	Cohort
Time of assessment(s) (for x-sec: mean (SD) where provided)	36.5 (29) mths	41 (25.6) mths	41 (25.6) mths	3.5 (3.1) yrs	3.5 (3.1) yrs	>6 mths	81.4 (45.8) mths	4d/3mths	4d-3yrs	4d-3yrs	4d-3yrs	7d-6mth d/c	2d-5yrs	Premorbid-6wks
Number of stroke participants	38	30	30	83	83	18	40	80	80	80	80	129	655	87
PWA included	✓	✓	✓	✓	✓	✓	✓	Proxy	Proxy	Proxy	Proxy	✓	Proxy	✓
Quality assessment														
1 Clearly focused RQ	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2 Appropriate methodology for RQ	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓		✓	✓
3 Cohort/ sample recruitment														
Community based	✓ (via charity)	✓	✓	✓	✓	?	✓	Stroke unit	Stroke unit	Stroke unit	Stroke unit	Hospital	Population	Hospital
No major exclusion criteria	✓	×↓mobility ×<55 yrs	×↓mobility ×<55 yrs	✓	✓	×<40 or >80 yrs	✓	✓ (TIAs ✓)	✓ (TIAs ✓)	✓ (TIAs ✓)	✓ (TIAs ✓)	×<50 >80 yrs ×mild stroke	×haemorrhage	✓
TPO stated	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
4 Exposure accurately measured														
Valid, reliable assessment of social support/network	×SN	SN✓ Soc Act ×	SN✓ Soc Act ×	✓	✓SS ×SN		✓							✓SN ×SS
5 Outcomes accurately measured														
Valid, reliable assessment of other measures	✓	✓	N/A	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓
6 Confounding factors identified														
Stroke severity considered													✓	✓
Confounding factors taken account of	✓	✓	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓
7 Follow up (% lost to follow up)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	5% lost	39% lost	39% lost	39% lost	?	2% lost	21% lost
>30 days	N/A	N/A	N/A	N/A	N/A	N/A	N/A	✓	✓	✓	✓	✓	✓	✓
Fixed points used	N/A	N/A	N/A	N/A	N/A	N/A	N/A	✓	✓	✓	✓	✓	✓	✓
8 Results of the study	Table 2.7	Tables2.4& 2.7	Table 2.3	Tables2.3& 2.4	Tables2.3 &2.4	Table 2.3	Table 2.3	Table 2.3	Table 2.3	Table 2.5	Table 2.5	Table 2.3	Table 2.6	Table 2.6
9 CIs reported						✓							✓	
10 Reliable results (see end of table for key)	✓	✓	✓	✓	B & E	C & F*	✓	✓	✓	✓	✓	F*	✓	✓
11 Applicability of results														
Age details provided	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sex details provided	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 2.2; con p2/4	Stroke studies including PWA												
	Clark & Smith (1999)[190]	**Glass *et al.* (1992)[109]**	**Glass *et al.* (1993)[16]**	**King (1996)[12]**	**King *et al.* (2002)[10]**	**Michael *et al.* (2006)[191]**	**Norris *et al.* (1990)[192]**	**Owolabi (2010)[193]**	**Perry & MacLaren (2004)[193]**	**Robinson *et al.* (1983)[194]**	**Sharpe *et al.* (1994)[187]**	**Townend *et al.* (2007)[11]**	**Teoh *et al.* (2009)[195]**
Study details	Australia	USA	USA	USA	USA	USA	USA	Nigeria	UK	USA	UK	Australia	Australia
Study design	Cohort	Cohort	Cohort	x-sec	Cohort	x-sec	x-sec	x-sec	x-sec	x-sec	x-sec	Cohort	Cohort
Time of assessment(s)	Rehab- 12 mth d/c	1-6mth	1-6mth	1-3yrs	d/c – 2y	6-166 mths	2-13 mths	>1mth	6mths	<2wks	31-64 mths	2d-3mths	BL:11.7(4.9) mths
Number of stroke participants	60	46	46	86	97	53	47	100	206	103	60	125	135
PWA included	×severe	proxy	Proxy	×severe	×severe	×severe	×severe	Proxy	Proxy	×severe	✓	×severe	×severe
Quality assessment													
1 Clearly focused RQ	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
2 Appropriate methodology for RQ	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
3 Cohort/ sample recruitment													
Community based	Rehab unit	Hospital	Hospital	Hospital	Rehab unit	✓	Rehab	Hospital	Hospital	Hospital	Population	Hospital	✓
No major exclusion criteria	×live alone ×<2 wks rehab	×haemorrhage	×haemorrhage	✓	×living alone	×haemorrhage	✓	✓	✓	✓	✓ (TIA✓)	✓	✓
TPO stated	✓	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓
4 Exposure accurately measured													
Valid, reliable assessment of social support/network	✓	✓	✓	✓	✓	✓	✓		✓	✓		✓	✓
5 Outcomes accurately measured													
Valid, reliable assessment of other measures	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
6 Confounding factors identified													
Stroke severity considered		✓	✓			✓						✓	
Confounding factors taken account of		✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
7 Follow up (% lost to follow up)	26%	?	?	N/A	45% lost	N/A	N/A	N/A	N/A	N/A	N/A	17%	9%
>30 days	✓	✓	✓	N/A	✓	N/A	N/A	N/A	N/A	N/A	N/A	✓	
Fixed points used	✓	✓	✓	N/A	✓	N/A	N/A	N/A	N/A	N/A	N/A	✓	✓
8 Results of the study	See Table 2.3	Table 2.6	Table 2.6	Tables 2.3&4	Tables 2.3&5	Table 2.7	Table2.6&7	Table 2.4	Tables 2.3&4	Table 2.5	Table 2.5	Tables2.3&5	Tables2.3&4
9 CIs reported											✓	✓	
10 Reliable results(see end of table for key)	B, E	E	E	✓	A	D	A & C	C	✓	B	D	✓	A
11 Applicability of results													
Age details provided	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sex details provided	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 2.2; con p3/4	Stroke studies incl PWA		Stroke studies excluding PWA										
	Tsouna-Hadjis *et al.* (2000)[17]	**White *et al.* (2007)[196]**	**Adeniyi *et al.* (2012)[177]**	**Beckley (2007)[197]**	**Chang *et al.* (1999)[175]**	**Chau *et al.* (2010)[198]**	**Dayapoglu (2010)[199]**	**De Sepulveda (1994)[200]**	**Feibel & Springer (1982)[181]**	**Friedland & McColl (1987)[178]**	**Glymour *et al.* (2008)[182]**	**Griffen *et al.* (2009)[201]**	**Huang *et al.* (2010)[202]**
Study details	Greece	Australia	Nigeria	USA	China	China	Turkey	USA	USA	Canada	USA	N/AUSA	Taiwan
Study design	Cohort	x-sec	x-sec	x-sec	Case control	x-sec	x-sec	x-sec	Cohort	x-sec	Cohort	x-sec	x-sec
Time of assessment(s)	1-6mth	1/3/5 yrs	?	3-6mth	On rehab ward	6mths d/c	>3mths	1-12 mths	10d-6mth	2-24 mths d/c	c. 18d -6mth	48.4(63.8) mths	29.8 (73.4) mths
Number of stroke participants	50	90	104	95	20	210	70	75	91	85	272	90	102
PWA included	Proxy	Proxy	?	×	×	×	×	?	?	×	×	×	×
Quality assessment													
1 Clearly focused RQ	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓
2 Appropriate methodology for RQ	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
3 Cohort/ sample recruitment													
Community based	Hospital	Hospital	Hospital	Rehab	Rehab	Rehab	Neurology OP clinic	Rehab	Hospital	Hospital	Hospital	✓	Hospital OP
No major exclusion criteria	✓	✓	✓	✓	✓	✓	✓	×≤ 62 yrs	×full recovery in 2 mths	×>65	×mild stroke ×severe stroke	×non-driver pre-stroke	×haemorrhage
TPO stated	✓	✓		✓		✓	✓	✓	✓		✓	✓	✓
4 Exposure accurately measured													
Valid, reliable assessment of social support/network	✓	✓	✓	✓	✓	✓	✓	✓		✓	SS✓ SN×	✓	✓
5 Outcomes accurately measured													
Valid, reliable assessment of other measures	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
6 Confounding factors identified													
Stroke severity considered	✓										✓		
Other confounding factors	✓		✓	✓		✓		✓	✓	✓	✓	✓	✓
7 Follow up (% lost to follow up)	14% lost	N/A	N/A	N/A	N/A	N/A	N/A	N/A	?	N/A	22%	N/A	N/A
>30 days	✓	N/A	N/A	N/A	N/A	N/A	N/A	N/A	✓	N/A	✓	N/A	N/A
Fixed points used	✓	N/A	N/A	N/A	N/A	N/A	N/A	N/A	✓	N/A	✓	N/A	N/A
8 Results of the study	Tables2.3&6	Table 2.3	Table2.7	Table 2.7	Table 2.7	Table 2.5	Table 2.4	Table 2.5	Table 2.5	Table 2.5	Table 2.7	Table 2.7	Tables2.4&5
9 CIs reported						✓					✓		
10 Reliable results (see end of table)	E	✓	F*	✓	B	✓	B	✓	F*	✓	✓	✓	✓
11 Applicability of results													
Age details provided	✓	✓		✓		✓	✓	✓		✓	✓	✓	✓
Sex details provided	✓	✓		✓		✓	✓	✓		✓	✓	✓	✓

Table 2.2; con p4/4	Stroke studies excluding PWA													
	Kim *et al.* (1999)[203]	**Kishi *et al.* (1996)[186]**	**Knapp & Hewison (1998)[184]**	**Labi *et al.* (1980)[4]**	**Lam *et al.* (2010)[204]**	**Li *et al.* (2003)[205]**	**Mackenzie *et al.* (2002)[14]**	**Morris *et al.* (1991)[206]**	**Osberg *et al.* (1988)[188]**	**Sit *et al.* (2007)[183]**	**Spencer & Tompkins (1995)[207]**	**Stephens *et al.* (1987)[208]**	**Ueki *et al.* (1999)[209]**	**Wyller *et al.* (1998)[176]**
Study details	Canada	USA	UK	USA	China	Taiwan	China	Australia	USA	China	USA	USA	Japan	Norway
Study design	x-sec	Cohort	Cohort	x-sec	x-sec	x-sec	Cohort	Cohort	Cohort	Cohort	Cohort	x-sec	x-sec	x-sec
Time of assessment(s)	1-3yrs	Acute – 24mths	<1mth – 6mth d/c	?chronic	?post d/c from hosp	28.9 (31.5) mths	2d - 3mths acute d/c	2-14mths	1-12 mth d/c	2d-6mth	c3mths – c9mths	0-12mth post d/c	2-3yrs	Any
Number of stroke participants	50	301	30	121	50	106	215	76	89	112	162	48	47	1417
PWA included	×	×	×	?	×	×	×	×	×	×	×	×severe	×	?
Quality assessment														
1 Clearly focused RQ	✓		✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2 Appropriate methodology for RQ	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
3 Cohort/ sample recruitment														
Community based	Hospital	Hospital	Hospital	?	Day clinic	Hospital OP	Rehab	Rehab	Rehab	Rehab	Hospital	Rehab	Population	Population
No major exclusion criteria	×<60 yrs	?	×no willing caregiver	× ADL dependent	×<65 yrs	×<65 yrs ×↓mobility	✓	×no-one to turn	×mild stroke	✓	×no caregiver	?	×<40	✓
TPO stated			✓			✓		✓		✓	✓		✓	
4 Exposure accurately measured														
Valid, reliable assessment of social support/network	✓	✓	✓		✓	✓	✓	✓		✓		✓		
5 Outcomes accurately measured														
Valid, reliable assessment of other measures	✓	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	
6 Confounding factors identified														
Stroke severity considered									✓	✓				
Other confounding factors	✓	✓		✓		✓	✓	✓	✓	✓	✓	✓	✓	✓
7 Follow up (% lost to follow up)	N/A	53% lost	0%	N/A	N/A	N/A	26% lost	42% lost	?	15%	25%	N/A	N/A	N/A
>30 days	N/A	✓	✓	N/A	N/A	N/A	✓	✓	✓	✓	✓	N/A	N/A	N/A
Fixed points used	N/A		✓	N/A	N/A	N/A	✓	✓	✓	✓	✓	N/A	N/A	N/A
8 Results of the study	Table 2.4	Table 2.5	Table 2.5	Table 2.6	Table 2.5	Table 2.5	Table 2.4	Table 2.5	Table 2.6	Table 5	Table 2.5	Tables2.6&7	Table 2.5	Table2.4
9 CIs reported														
10 Reliable results (see end of table)	A & D	A & E	B	F*	B	✓	✓	A	✓	✓	C & F*	✓	C	C
11 Applicability of results														
Age details provided	✓	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓
Sex details provided	✓	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓

KEY to abbreviations:
ADL: activities of daily living
d: day; mth: month; y: year
OP: outpatient
PWA: person/people with aphasia
Rehab: rehabilitation unit/ hospital/ ward/ institute
SS: functional social support
SN: social network
x-sec: cross sectional
?: not specified/unclear

KEY to Section 10 of CASP (Reliable results). Results considered unreliable if:

A. Population may be biased:
- >40% lost to follow up
- Postal: <50% agreed to participate in study if postal
- Face to face: <70% agreed to participate

B. Study did not take into account confounding factors (for example, presents only univariate associations)

C. Reliance on non-validated scale for perceived social support

D. Where multiple regression techniques used, results considered unreliable if events per variable ratio insufficient (>10 considered acceptable for multivariate analysis)

E. Effect size/ power not reported where study compares groups (for example, ANOVA)

F. Study design, methods or analysis flawed in other specified manner

This applied to the following studies:

*Adeniyi *et al.* (2012)[177] 99.8% participants reported to perceive their social support as low on the MOS SSS, which is at congruence with all other studies, including in Nigeria. This statistic is deemed an error and not included in Table 2.3

* Belanger *et al.* (1988)[180] Unclear how many variables entered into each multiple regression equation; measures not clearly defined

* Feibel & Springer (1982)[181] Non-validated measures used for both IV (social activities) and DV (depression)

* Labi *et al.* (1980)[4] No participant information, limiting generalizability. Over-reliance on non-validated measures. Disparity between text of results and Table 8 p564 (whether having a friend as significant other increases (table) or decreases (text) likelihood of reducing social activities);

*Ross and Wertz (2003)[174] Authors do not make clear in results that Item 22 labelled 'social support' refers only to satisfaction with support received from friends

*Spencer and Tompkins (1995)[207] Measures not clearly defined in methods; unclear how many IVs entered into multiple regression

2.4.4 Synthesis of results

As described in the methodology, this review leads with the qualitative synthesis, followed by the quantitative synthesis. There then follows a section comparing and interpreting how the qualitative and quantitative strands of the review relate to one another.

2.5 Qualitative meta-ethnographic synthesis

The meta-synthesis begins by examining the impact of having a stroke on the family, including relationships with a spouse/partner, children, and other relatives. It goes on to explore how the stroke affects friendships and social acquaintances. Reasons for reduced participation post stroke are explored, as well as factors facilitating social contact. The role of new friendships, including groups, is analysed. Finally, the functions of support received post stroke are outlined, and the synthesis concludes by looking at what aspects of social support have been associated with positive outcomes, such as 'living successfully'.

Although some meta-syntheses do not refer to individual studies when narrating the results of the meta-analysis[129], a decision was made that referencing primary studies lends greater transparency. In order to do so efficiently, the studies have been numbered alphabetically using square brackets, starting with the stroke studies ([1] to [5]), and then the aphasia studies ([6] to [14]). These numbers will be referred to throughout the synthesis. For ease of reference, they are listed below. Where a particular

theme appears exclusively in either the aphasia studies or the stroke studies this is commented upon.

List of studies included in the meta-ethnographic synthesis

[1] Ch'ng AM, French D and McLean N (2008)[111]

[2] Dowswell G, Lawler J, Dowswell T, *et al.* (2000)[6]

[3] Haun J, Rittman MR and Sberna M. (2008)[165]

[4] Pound P, Gompertz P and Ebrahim S (1999)[166]

[5] Sumathipala K, Radcliffe E, Sadler E, *et al.* (2012)[167]

[6] Brown K, Worrall L, Davidson B and Howe T (2010)[161]

[7] Brown K, Davidson B, Worrall LE and Howe T (2013)[143]

[8] Dalemans RJ, de Witte L, Wade D (2010)[5]

[9] Davidson B, Howe T, Worrall L, Hickson L and Togher L (2008)[162]

[10] Grohn B, Worrall LE, Simmons-Mackie N and Brown K (2012)[169]

[11] Hinckley JJ (2006)[164]

[12] LeDorze G and Brassard C (1995)[168]

[13] Parr S (2007)[163]

[14] Parr S, Byng S and Gilpin S (1997)[104]

2.5.1 Family

As one participant wrote, a stroke 'is actually a family illness' [11, p29], and the impact of the stroke on family relationships was explored in 12 of the studies. The main themes that came through the data were: disruption to family relations; factors which make family life more harmonious; strains on the marital relationship; the valued roles played by a spouse; and the impact of the stroke on relationships with children and other relatives.

2.5.1.1 Disruption to family relations

The stroke was described as the cause of stress and disharmony within the family in a number of studies [1, 2, 11, 12, 13, 14]. Only one study [4] considered that the stroke did not disrupt close family relationships as the family structure had already adapted due to pre-existing frailty or ill-health. As such the stroke represented more a need to 'rearrange' supportive structures, and find a new balance of 'giving and receiving'. Even in this study, however, it was acknowledged that 'In cases where the onset of disability was more sudden it was possibly more difficult to achieve a new balance in the relationship.' [p123]

The reasons for the disruption were explored and fall into the following main categories:

Lost roles/ change in roles [1, 2, 12, 14]

The stroke could cause people to be unable to fulfil previously valued roles. These included the roles of provider and worker, protector, carer, husband or wife. The stroke could challenge their ability to take on the parental role, and participants describe losing authority over their children [12], and being unable to support their children at key milestones [14]. It could also make it

hard for participants to support their own aging parents, and fulfil the role of son or daughter [14]. In particular, it could be hard for people to lose 'giving' roles, and instead have to be in the position of 'receiving' [2]. For some, after a lifetime spent looking after others, such role changes were reported to be associated with helplessness and frustration, and disruption to self-identity [2].

Dependence/ inability to contribute [1, 2, 3, 14]

Some stroke participants were reported to feel they were a burden, felt unable to contribute, and could have a sense that they were ruining other people's lives.

Changes to the 'fabric of the day' [4, 13, 14]

Post stroke, the 'fabric of the day' could change, and instead of being focused around work or other out-of-house purposeful activities, it could consist of washing, feeding, lifting and managing other ADLs [4, 13, 14]. Spending large amounts of time in the house together could cause tension [13, 14].

Dealing with strong emotions [14]

Emotions post stroke could be strong: anger, depression, frustration. These could be difficult for the family members to deal with [14]

Aphasia [6, 13, 14]

Difficulty communicating could disrupt family relationships, and be a further cause of stress. Further, it could make it harder for a person to negotiate and come to terms with their lost roles and new dependence. Through making conversation difficult, aphasia could take away a source of

comfort, reassurance, and a sense of shared experience, at a time when it was most needed, namely after the 'trauma' of a stroke. [14]

2.5.1.2 Factors which made family life more harmonious

A number of studies explored what factors enabled people to find successful ways of living within their family post stroke [3, 4, 6, 11, 13, 14]. The main themes to emerge were:

Being able to contribute/ maintain roles [3, 4, 6]

Caring for others, maintaining relationship roles where possible, and finding ways to 'contribute' to family life were all seen as protective: they could make the person feel valued [6] and connected [3]. Being able to reciprocate, and engage in 'mutual help and support' was also found to be positive [4]

Negotiating support and independence [3, 4, 11, 14]

Those who were able to communicate their need both for assistance and independence throughout their recovery perceived themselves to be more 'connected' [3].

Being able to express and receive intimacy and love [1, 3]

Being able to express love, whether to a partner or other family member, was associated with feeling 'connected' [3], and successful 'coping' [1].

2.5.1.3 Marital relationship post stroke

Impact on marital relationship [1, 3, 8, 11, 12, 14]

Although mostly people stayed together post stroke, there were also examples of the stroke being the catalyst for divorce or separation [1, 11, 14]. Friction and marital strain was reported [1, 12]. Partners could be perceived as being unable to cope [1], not able to understand [12], or unable to accept their post stroke identity [11]. In addition, spouses could become 'over protective', taking over and making all the decisions [3, 8, 14], which could impact negatively on recovery and feelings of competence. More rarely, having a disability could leave someone vulnerable to more serious negative interactions, such as being dominated, ignored, rejected or exploited by their partner [14].

There was also an awareness of the strain that was placed on the spouse. This could lead to a complex 'layering' of emotions on the part of the stroke survivor: concern, guilt, resentment, and wariness [p49, 14]. Sex life could also be disrupted [3, 14].

Valued roles of the spouse

Despite the strain placed on the marital relationship described above, the spouse generally played a key role in making the stroke survivor feel valued and loved [11, 14]. They were likely to be the main source of tangible and emotional support following a stroke [1], as well as companionship [3], and married participants were less likely to feel isolated [3].

There was a 'paradox' that was described in three studies [3, 11, 14]: that spouses of stroke survivors needed to provide essential tangible support

while at the same time fostering independence and recovery. An account of this happening successfully is provided in [11]: ‘As the story progresses, the married pair successfully negotiates the paradox of becoming more tightly intertwined while maintaining independence.’ [p29] Study [14] describes this as finding the ‘delicate balance’ [p48]. It appears that where a couple can successfully negotiate this balance, then it was likely to lead to more harmonious family relations and greater adjustment and recovery.

The spouse could also play a key role in facilitating engagement and participation [8, 13, 14]. For example, spouses could organise meetings with friends, make contact with community activities, facilitate others’ successful communication (for people with aphasia). Indeed, for those with severe aphasia [13] the main examples of successful social inclusion (for example, joining a bowling club) were as a result of ‘a lot of careful work and attention on the part of the wives.’ [p112] This phenomenon is reported in the aphasia studies rather than the stroke studies.

Finally, it was reported that the support provided by the spouse facilitated the process of adjusting to a new life post stroke [1], could play a ‘vital role’ in recovery [3], and in some cases ‘is portrayed as being a consistently positive force in a return to successful living.’ [11, p29]

2.5.1.4 Stroke and other family members

The evidence is ‘thinner’ about the impact of the stroke on other family relationships compared to the ‘thick’ evidence relating to the marital relationship.

Children [4, 5, 12, 14]

Grown up children could provide tangible support, in some instances being the primary care-giver [4, 14], although some children were unwilling or unable [3]. Study [4] describes examples of children interweaving support (such as regularly preparing meals and shopping) with formal services to enable an elderly parent to live alone in the community. Study [5] documents that some stroke survivors moved house specifically to be closer to their grown up children in order to receive needed support. How tangible support provided by children is perceived by the stroke survivor is only briefly addressed in one study [14], which comments that most welcomed the support, although people could be 'wary of adding to the pressure of their offspring's busy lives', and that support from children could underline their own limitations and arouse feelings of jealousy [14, p55]

In terms of other types of support provided by children, study [4] briefly described how children also took their elderly parent on outings (social companionship support).

In terms of frequency of face to face contact with grown up children, this is not reflected upon in the qualitative literature. Study [14] observes that aphasia could make it more difficult to keep in contact with children overseas, if both writing and using the telephone have become difficult.

Those stroke survivors with young children describe how feelings of love and responsibility could help them 'to weather the effects of the stroke' [p52, 14]. It is also documented how the stroke could present challenges in fulfilling the parental role, as discussed above [12, 14].

Other relatives [1, 4, 5, 12, 14]

There was mixed evidence as to what happens to relationships with other relatives. One study found that the stroke survivor had reduced contact with their brothers and sisters [12]. 'Unhelpful' responses of relatives were documented in two studies [5, 14]. Relatives could be over-protective [5], or 'controlling' [14]. They could also 'talk over' or make it hard for the aphasic person to join in conversations [14]. It was also possible to feel 'overwhelmed' by plentiful extended family [14].

An alternative more positive picture is also provided by study [14], which reported that although the stroke could have a negative impact on relationships with relatives (as described above), it could on occasion bring relatives closer together, even be a catalyst to end long-standing feuds, and that relatives could take the place of lost friends. Study [4] found that relatives could supplement the support from the primary caregiver following the stroke, and gave the example of brothers and sisters cooking and eating with the stroke survivor on a regular basis.

Finally, young stroke survivors report that their mother was the main provider of support [1]. Young stroke survivors could move back home to be cared for by their parents. Some describe their gratitude, others their frustration at losing their independence, and returning to a 'previous' relationship [14]

2.5.2 Friends, acquaintances and the wider social network

All 14 studies explored non-kin contact post stroke, be that friendships, social activities, group membership, or, more broadly, social participation. The main trend was that following a stroke people lost contact with friends, were not so engaged in social activities, and reported reduced social participation. Areas explored in the studies included: the nature of the reduced social contact; how this loss was perceived; barriers and facilitators to social participation; and the value of friendships and social activities including the role of stroke and aphasia groups.

2.5.2.1 What happens to friends, acquaintances and social activities?

All studies that report on what happens to friendships found that stroke survivors had difficulty maintaining contact with their pre-stroke friends. They reported losing friends [8, 12, 13, 14], were in less frequent contact with friends [9], and participated in fewer community and social activities [1, 2, 3]. Stroke survivors were also found to engage in fewer interactions with acquaintances and strangers than controls [9]

The study exploring severe aphasia found that all participants had 'experienced social constriction' [13]. Other studies reported a range of experiences: that although reduced social contact was the most prevalent story, there was also a small subset of people who reported a reasonably varied social life [2, 8]. To maintain pre-stroke levels of social and community activity, however, was reported to be rare [3, 8].

In so far as people with aphasia did attend groups, the type of groups they attended was found to be different from controls. Controls went to education classes, joined in sports and crafts activities, went to senior citizen clubs. By

contrast those with aphasia were found primarily to go to respite centres and therapy groups [9].

The trajectory post stroke was commented on by two studies who found that while there might be an initial rallying around, contact then dropped off [7, 14].

2.5.2.2 Isolation and exclusion [3, 8, 13]

The consequence of losing friends and social activities was that many participants felt isolated and lonely [8, 13]. It was described how participants were left sitting for hours on their own, not leaving their house, not interacting with anyone [3, 8, 13].

One study [3] created a typology, categorising those who were 'connected', and those who were 'isolated' from a sample of 77 men. They found that those who were isolated were: more likely to live alone; less likely to be married; perceived their support to be unsatisfactory including from family who were either unable or unwilling; they received few visits and lacked the 'physical presence' of anyone else most of the time; they were not involved in their community; found it difficult to express intimate feelings such as love; and were unlikely to feel they were making a contribution to anyone else in either their family or community, instead they perceived themselves as a 'burden'. They could find the point of discharge from hospital (where they were helped) to home (where they perceived themselves to be on their own) to be difficult. The authors found, unsurprisingly perhaps, that those who were 'isolated' made a less satisfactory adjustment to their post stroke lives than those who were 'connected'. In terms of prevalence, 31% (24/77 participants) were moderately isolated, and 13% (10/77) were very isolated

at 12 months post stroke, although these figures should be interpreted with caution since it is not made clear how participants were recruited.

A further finding was that participants could feel isolated and alone even when surrounded by others [8, 13]. Both studies reporting this finding explored the experiences of those with aphasia, and document the distress of being surrounded by people, yet unable to engage in the conversation. Conversely, one study [2] did note that some participants were 'ferociously independent' and 'suggested they wanted no social life' [p511], highlighting the individual variation in what makes a social network satisfying.

2.5.2.3 Perceived causes of reduced social participation

In many instances it was unclear whether 'social contact' or 'social participation' referred collectively to the entire social network, including family, or specifically related to friends. This section, therefore, groups together all the reasons given for reduced participation in the broadest sense. Where results refer specifically to friends, this is made clear. No study provided a definition for the term 'friend'.

Physical and cognitive disability [2, 7, 8, 13, 14]

New physical difficulties such as pain, loss of balance, fatigue, or fear of falling could make social participation more difficult [2, 8]. Memory [8] and 'thinking' [2] were also cited. Increased dependency could make it harder to see friends independently [7].

Relocation [2, 4, 5, 14]

Relocation due to physical difficulties was not uncommon post stroke. People either moved in order to have more suitable accommodation (for

example, ground floor) [4], or in order to be closer to children [5]. Of the four studies that mention relocation, two suggest that it could disrupt social networks [2], and make it hard to keep in touch with formerly local friends [14]. This is not discussed in the other two studies [4, 5].

Lack of access / driving cessation [1, 2, 3, 5, 8]

Not having a driving licence could make it harder to participate or access social support [1] or feel 'connected', particularly if there was no family member available to give lifts [3]. Lack of transport [2, 3, 5], or difficulty accessing transport, for example, difficulty telling driver when to stop due to aphasia [8] were also cited as barriers to participation.

Situation specific [2, 7, 8, 13, 14]

When a person gave up an activity, for example, work [2, 7, 8, 14], or sport, or going to a particular pub [2], they could lose contact with friends. One study [14] described how work colleagues would come over in the early days after the stroke, but that these visits would decline. This was perceived as resulting partly from the work colleague being unsure how to deal with the aphasia, and partly because they no longer shared the work place pressures and interests [14]

Financial [13, 14]

For working age people, the stroke could mean a sudden end to employment, which in turn could lead to financial pressures. Reduced income was cited as a reason why it was harder to participate, for example, harder to afford a round of drinks, harder to belong to an expensive golf club, harder to afford travel costs to visit someone [13, 14].

Internal barriers [2, 7, 8, 12, 13, 14]

A range of emotions were cited as negative influences on whether a person participated. These included feeling depressed, frustrated, sad and disappointed [8]. Two studies described a sense that participants seemed to be withdrawing into themselves following the stroke and avoiding contact [8, 13]. There was a sense that some participants were frightened to go out, especially on their own [13, 8]. Another reported response was feeling they no longer felt they 'belonged' [8].

Several studies found that a proportion of participants were embarrassed or ashamed about their disabilities, including aphasia [2, 8, 12, 14], and most went on to make a direct link between this sense of shame and a reluctance to socialise or participate [2, 8, 14]. Study [2] found that 'many respondents were uncomfortable with their current disabled states… and did not wish to burden their friends, relatives or former acquaintances with their post-stroke "new selves".' [p511]. They also observed that some participants made moral judgements about illness generally: 'it [illness] only happens to slackers, idlers and loafers. For these individuals, illness did not happen to people like their pre-stroke selves.' [p513]. In the discussion, they made a connection between these pre-morbid beliefs and subsequent sense of shame. A further link could arguably be made between these beliefs and post stroke withdrawal from socialising.

In contrast, the only study specifically to look at friendship found that participants did not express any reduced desire to socialise with friends [7]. This may reflect the pool from which participants were drawn in this study:

predominantly from aphasia groups. Alternatively, it may reflect the focus on friendship.

Communication difficulties [6, 7, 8, 9, 12, 13, 14]

Almost all the aphasia studies described the negative impact aphasia could have on participation: the difficulty of joining in group conversation [8, 12] and needing too much time to respond or think what to say [8].

Some studies looked specifically at the difficulties of communicating with friends post stroke [7, 9, 14]. It was observed that friends were exposed to the language difficulties on early visits before they knew how to deal with it [14]. Maintaining friendships then became hard when the participant was no longer able to join in fast-paced conversations, have the same in-depth discussions as they had done prior to the stroke [6, 7, 14], or make jokes as they used to [9, 14]. In addition, for friends that did not live close by, difficulties writing letters and speaking on the phone could make it hard to continue the friendship [14].

Unavailability of friends [14]

Only one study [14] found that in some instances a friend could become unavailable. Thus a friend could become ill themselves, or find them themselves in a new life situation, such as caring for a young family. This study interviewed people who had had their stroke at least five years previously, which may have enabled more time for the personal circumstances of friends to change.

The attitude of friends and members of the community [5, 7, 8, 12, 13, 14]

Many of the aphasia studies described situations where friends had abandoned or rejected the person with aphasia. Friends were described as feeling awkward, embarrassed or frightened of the aphasia [13, 14]; of staying away because they did not know how to handle it [8]; of being too impatient or busy [14]; not being able to understand or show empathy or acceptance [7, 8]; unwelcome pity [7]; and of male friends, used to competitive friendships, not knowing how to show concern [14].

There was a sense of stigma attached to the aphasia. People with aphasia described their friends treating them as though they were simple minded or deaf [14]; that aphasia was seen as a mental illness [7, 12]; that there was prejudice in the community where they were thought crazy or stupid [8].

This sense of stigma is less well described in the non-aphasia stroke studies, although two studies [4, 5] found that some participants attempted to conceal their strokes, for example by not using necessary walking aids [4, 5]. However, only one of these studies [5] said this was due to fear of stigma and not wanting to appear vulnerable due to 'negative attitudes from others in the neighbourhood' [p40]. The other study [4] attributed it to preserving self-esteem.

Unhelpful communication styles [7, 8, 13, 14]

A variety of unhelpful ways of interacting were reported in the aphasia studies, which hampered participation. People with aphasia could be ignored, talked over, side-lined, not acknowledged [13, 14], not involved [8]. Others could take on the unwelcome role of 'teacher', insisting on words being repeated, and correcting the person's attempts to speak, which

was often perceived negatively by the person with aphasia [13, 14]. People with aphasia also described others having no patience, and not being prepared to adapt their communication style [8]. Finally, a stigmatising manner of communication was sometimes reported: teasing, mocking, treating the aphasic person as stupid [7, 8, 13, 14]

2.5.2.4 Changes to the substance of friendships

Participants were observed to be more passive than controls, less likely to initiate plans, take control or actively organise their day [9]. They were more likely to receive visits than to make visits [2, 9]. Control thus shifted from the stroke survivor to the other person. [2].

The substance of conversations was altered for those with aphasia. There were more communication break downs, interactions were briefer, and they were less likely to engage in lengthy anecdotes or have in-depth debates and conversations [8, 9]

2.5.2.5 A new selectivity

A different angle on the loss of friends, relatives and other social contacts was discussed by two studies [2, 11]. They both observed a new 'selectivity'. There was a sense that people needed to be selective, make 'careful choices' [2] about which friends and family they invested energy in, and surround themselves with individuals they perceived to be helpful [11]. This arguably links to a finding in [8]: that 'doing things' did not necessarily make people feel more integrated. Thus participants did not necessarily want to be doing more, but wanted what they did do to be more satisfying. Hence it was argued that *quality* of social experiences was more important than quantity in enabling people to feel included rather than isolated.

2.5.2.6 How the loss of friends and social activities was perceived

Two studies explored how this loss of friends was perceived by participants [7, 14], and found a range of responses. The loss of friends could make participants feel sad and distressed, and also angry [7, 14]. Friends' lack of understanding, for example addressing them as if they had a 'mental disorder' could be particularly distressing [7, 8, 13, 14]. Other participants were not angry, but more accepting [7] or resigned [14]. The loss of social activities was also described as distressing [1, 14].

Losing friends and social activities could make participants lose confidence and become withdrawn and isolated [14], or focus contact on the family instead [14]. Alternatively, participants could take a more proactive stance, seeking to replace lost contacts with new friends [7].

It is not discussed in the literature whether the circumstances of the friendship loss (ie whether stemming from lost activities, or explicit rejection by the friend, or 'selectivity' on the part of the stroke survivor) impacted on the level of emotional distress experienced by the participant.

2.5.3 Factors which facilitated social participation

Attitude of the stroke survivor

The need to be proactive in going out and making new friends and join in social activities was emphasised in study [7]. This was reported to facilitate participants' adjustment to the loss of pre-stroke friends. Similarly, study [8] documented that the motivation and attitude of the stroke survivor was a key facilitator of social participation: 'Those persons [who participated] wanted

to stay active, to be part of something bigger and to act upon that: they were driven by motivation' [8, p542]. In addition, it was observed that those who succeeded on participating persevered and 'kept on trying, despite the reaction of others.'

Facilitative role of the spouse[8, 13]

As discussed above, a spouse could play a key role in facilitating social participation [8, 13], particularly for those with aphasia.

Living in a small rural community [8]

Living in a quiet environment like a village was found to be more facilitative than living in an urban environment [8]. Participants would be more likely to know people well in their community, thus found it easier to shop and walk around alone. By contrast, living in the city there was more background noise and distraction, and people were less likely to know each other. No other study considered the impact of living in a rural as opposed to urban area.

Positive interaction styles [7, 8, 9, 14]

The aphasia studies identified some helpful interaction styles. These included others having patience [8] and allowing time [9, 14]; sharing humour [9]; sharing common interests in conversation [9]; making an effort and being prepared to find out about aphasia and how to adapt conversational styles [8]. Finally, positive interaction meant relating directly to the person with aphasia, treating them with respect, and showing acceptance and understanding [7, 8, 14].

In some instances it was the person with aphasia who took the initiative in explaining what they needed to make successful conversation [7, 8, 14]; on other occasions it could be a spouse who took this role [8, 13].

Factors which facilitated preserved contact with pre-stroke friends [8]

This issue was only touched on briefly in one study [8] which reported that the closer the friend was prior to the stroke, the more likely it was that they would keep in touch after the stroke.

2.5.4 The value of friendships and activities

Participants who regained social and community activities post stroke described the positive value of this in several studies [1, 3, 6, 8, 13]. Firstly, there was the sense of enjoyment [1], a chance to catch up with old friends and acquaintances [13], a motivation to get out of the house [8], it could make participants 'feel alive' [8]. It could also confer a sense of achievement and confidence [1], and that they were contributing and were valued members of their community [3]. Two studies [1, 13] mention the social companionship and sense of community that could come from attending church services.

One study [7] specifically focused on the contribution of friendship to living successfully with aphasia. Almost all the participants in this study found friendship to be an important component of 'successful living'. Having lost many pre-stroke friends, the friends they retained were especially appreciated. The study explored which aspects of friendship were particularly valued post stroke, and found three main themes in their data:

‘making a good time’ (spending time with friends, doing things together); laughter and engaging in positive interactions; and emotional support from friends (constancy, encouragement, making them feel valued).

2.5.5 The role of new friends and stroke/aphasia groups

The findings in relation to the role of groups were varied, and appeared to be dependent to some extent on the manner in which the sample had been recruited. Those studies that recruited exclusively or predominantly through groups or aphasia associations [1, 6, 7, 12] found that group membership was a significant factor in successfully adjusting to post stroke life. Those studies that did not recruit through stroke groups (for example, used population-based registers of stroke survivors [4, 5]) reported more mixed results, both in terms of the value of groups for the participants (variable), and in terms of the proportion who went to groups (for example, in study [5], only 5/35 participants attended day centres or stroke groups). Finally, time post onset could be a factor: 2/3 of those studies exploring the experience of stroke in the first 12 months [3, 4] did not report on groups. The exception was study [10], which discussed the social role of early hospital therapy groups.

In terms of new friends made since the stroke, these appeared to be predominantly made through stroke or aphasia groups (“Now my stroke survivors are my friends” [6, p1282]), although participants did also describe meeting new friends through other community based activities [7, 13]. The process of going out and making new friends was not found to be easy, however. It was reported that participants with aphasia felt they had

fewer opportunities for making social contacts [12] and that it was effortful meeting new people post stroke [12].

The role of new friends is discussed exclusively in terms of groups in the literature. These findings are divided into two sections: the positive contribution of group membership; more negative experiences of groups.

2.5.5.1 Positive contribution of attending groups

Several studies stressed the value of meeting others 'in the same boat'[1, 6, 7, 14]. Participants reported feeling understood [1, 7], feeling accepted [6], and encouraged [1, 10, 14]. There was a sense that other stroke survivors could understand in the way that people who had not had a stroke could not [1, 7]. The value of mutuality was also described: participants were able to help each other, and learn from one another [7].

Participants also described the enjoyment and fun they had at groups, and the value of laughter [1, 6, 7]. For those with aphasia it could be a relief to be in a situation where communication was 'easy' and aphasia the norm [7, 14].

Groups were a way of making new friends [7, 9, 10], and being in contact with others [2, 5, 8, 14]. Two studies [7, 12] found that friendships formed with other stroke survivors could help a person adjust to the loss of pre-stroke social contacts.

Finally, several studies found that group membership facilitated adjustment to post stroke life. Meeting other stroke survivors could help 'normalise' the stroke experience and facilitate successful coping [1], could help a person construct a positive post stroke identity [14], and assist a person to 'live

successfully' with aphasia [7]. Two studies observed that when asked what advice they would give, many participants emphasised the importance of meeting others with aphasia [7, 14].

2.5.5.2 Negative experiences of group membership

For some, entering a stroke group could be a difficult or painful process: some did not want to identify with others who had a stroke [13, 14]; could find it depressing comparing their recovery with others [14]; young stroke survivors could be put off by a room full of older people [13, 14]. Study [13] described participants attending day centres, where they were 'unwilling members'. This was in part because the activities could feel inappropriate (for example, craft activities more suited to young children); in part because of stigmatising attitudes of staff and volunteers. The experience of group attendance for those with severe aphasia, as described in study [13] did not appear to be positive. Study [14] observed that some people 'simply do not like being in a group' [p121, 14].

A further theme reported in studies was of access. Study [5] found that lack of access to suitable transport prevented some participants from attending groups. Once at the group, access to participation could be compromised for those with severe aphasia: study [13] found that many of the activities (for example, paper and pen games) at day centres and volunteer-led groups excluded people with severe communication difficulties.

2.5.6 Functional support

The functions of support received by stroke participants can be categorised as: tangible; emotional; and social companionship.

Tangible support [1, 3, 4, 5, 6, 10, 14]

Most participants appeared to be able to mobilise tangible support post stroke [3, 5], especially in the acute stages. A variety of tangible support was described in the studies, including: medical (for example, accessing medical care; picking up medicine; helping with homework activities); help with ADL and IADL (for example, cooking, shopping, banking); and help to get outside the house (for example, walking outside, giving lifts).

Emotional support [1, 3, 5, 6, 7, 10, 11, 14]

Again, most participants appeared to be able to mobilise emotional support post stroke. Types of emotional support found to be helpful were: encouragement [1, 6], and others believing in them [11]; making the person feel valued and loved [3, 6, 7, 14] and competent [10]; providing reassurance [10] and acceptance [6]; and the idea of 'constancy', the belief that they would always be there for the stroke survivor [6,11].

Social companionship [1, 6, 7, 9, 10, 14]

The importance of this type of support post stroke was emphasised in many studies [1, 6, 7, 9, 10, 14]. Participants spoke of the value of laughter and having fun [1, 6, 9], being distracted from ruminating on their difficulties [1], 'making a good time' with family and friends [6, 7] through doing activities together.

Informational support

No study reported on the provision of informational support by friends and family. This may reflect this type of support was less probed in interviews, or was less valued by participants. Alternatively, it may be that it is more often provided by professionals than family or friends.

2.5.7 Social support, adjustment and successfully living with stroke and aphasia

Three studies looked at facilitators to 'coping' [1, 4, 12]; four examined what factors contribute to 'successfully living with aphasia' [6, 7, 10, 11]; and successful adjustment and acceptance were key themes in three studies [1, 3, 14]. All these studies identified that meaningful relationships were key to successfully living, adjusting and 'coping' with stroke and aphasia. The aspects of social support found to be most valuable are as follows:

- Feeling valued and loved
- Encouragement
- Constancy/ knowing someone is there
- Acceptance and understanding
- Receiving needed tangible care in a way that fosters independence
- Social companionship including humour, distraction, spending positive time with family and friends
- Being able to make a contribution/ maintain roles
- Meeting other stroke survivors

2.6 Synthesis of results: quantitative studies

2.6.1 What happens to social support and social network following a stroke?

Table 2.3 summarises descriptive statistics relating to social support and social network. There were 21 reports relating to 19 studies that explored this area. In total, 1737 stroke participants took part in these studies.

Table 2.3 Social support and social network after a stroke: descriptive statistics

Table 2.3; p1/2		Studies reporting on PWA only					Stroke studies including PWA				
	SUMMARY OF RESULTS	Cruice *et al.* (2006)[3]	Hilari *et al.* (2003)[172]	Hilari & Northoctt (2006)[173]	Ross & Wertz (2003)[174]	Vickers *et al.* (2010)[8]	Astrom *et al.* (1992A)[2]	Astrom *et al.* (1992B)[170]	Belanger *et al.* (1988)[180]	Clark & Smith (1999)[190]	King (1996)[12]
Study details		Australia	UK	UK	USA	USA	Sweden	Sweden	Canada	Australia	USA
Number of stroke participants		30	83	83	18	40	80	80	129	60	86
Social support/network measure used (where applicable)		SOCACT	MOS SSS	MOS SSS		Friendship Scale; SNCI				FAD	SSE
Functional social support											
Good/ high	7/7		✓	✓							✓
Stable over time	5/5										
Satisfied	2/3										✓
Social Network											
Size											
Reduced post stroke	1/1					✓					
Less than controls	1/1	✓									
Family: overall											
Family functioning deteriorated since stroke	2/2									✓	
% 'dysfunctional' families post stroke	33-58%									58.3%	
Availability of close, attachment relationship	2/2										
Children											
Frequency of contact stable	2/2			✓			✓	✓			
% see children at least x1/wk	78-87%						78%		87%		
Contact comparable to controls	1/1						✓	✓			
Other relatives											
Frequency of contact reduced post stroke	2/2			25% less; 42% same		✓*	✓*				
Contact less than controls	1/1						✓*				
Friends and other social contacts											
Number reduced since stroke	2/2					✓*					
Number less than controls	2/2	✓					✓*	✓*			
Frequency of contact reduced since stroke	3/3			✓		✓*	✓*	✓*			
% see friends at least x1/wk	28-40%							28% (at 2&3 yrs)	39.8%		
% no contact/ no friends				30% no friends					46% no contact		
Social activities/ groups											
Number reduced since stroke	4/4						✓	✓	✓		
Number less than controls	1/1	✓									
Dissatisfied with social contacts/activities compared to controls	2/2	✓			✓						

* Friends and close relatives analysed and reported on together

	Stroke studies including PWA						Stroke studies excluding PWA				
Table 2.3; con p2/2 – see page 1 above for summary of results	**King *et al.* (2002)[10]**	**Perry & MacLaren (2004)[13]**	**Sharpe *et al.* (1994)[187]**	**Teoh *et al.* (2009)[79]**	**Tsouna-Hadjis *et al.* (2000)[17]**	**White *et al.* (2007)[196]**	**Chau *et al.* (2010)[198]**	**Knapp & Hewison (1998)[184]**	**Labi *et al.* (1980)[4]**	**Lam *et al.* (2010)[204]**	**Spencer & Tompkins (1995)[207]**
Study details	USA	UK	UK	Australia	Greece	Australia	China	UK	USA	China	USA
Number of participants	97	206	60	135	50	90	210	30	121	50	162
Social support/network measure used	FAD; ISEL	MOS SSS		MOS SSS	Family & Social Support Scale	MSPSS	SSQ6	ISSI		SSQ6	
Functional social support											
Good/ high		✓		✓	✓	✓					✓
Stable over time	✓			✓	✓	✓ (stable across 3 cohorts)					✓
Satisfied							✓			×only 'a little satisfied'	
Social Network											
Size											
Reduced post stroke											
Less than controls											
Family: overall											
Family functioning deteriorated since stroke	✓										
% 'dysfunctional' families post stroke	33%										
Availability of close, attachment relationship			✓					✓			
Children											
Frequency of contact stable											
% see children at least x1/wk											
Contact comparable to controls											
Other relatives											
Frequency of contact reduces											
Contact less than controls											
Friends and other social contacts											
Number reduced since stroke								✓			
Number less than controls											
Frequency of contact reduces											
% see friends at least x1/wk											
% no contact/ no friends											
Social activities/ groups											
Number reduced since stroke									✓		
Number less than controls											
Dissatisfied with social contacts/activities compared to controls											

Functional social support after a stroke was rated as good in 7/7 studies [12, 13, 17, 79, 173, 196, 207]. It was also found to be stable across time in 5/5 studies[10, 17, 79, 196, 207] (from 1 month to 2 years), although no study included a pre-morbid measure of perceived social support. In terms of satisfaction with perceived support, 2/3 studies reported participants were satisfied[12, 198]. In the study that found participants on average 'only a little satisfied', the size of network was unusually impoverished (on average 1.14 in total), suggesting a particularly isolated population[204]. No study compared levels of perceived social support with controls. In summary, stroke participants generally felt themselves to be well supported, and this did not change over time.

Studies measured a variety of elements that comprise a social network. Only two aspects of the social network (reduced contact with friends; reduced number of social activities) were measured by four reports (relating to three studies); the remainder of the items were assessed by three or fewer studies. Nonetheless, the studies were unanimous in their findings.

Turning first to the family unit, in terms of children, frequency of contact was stable following a stroke (2/2)[170, 173], and comparable to controls (1/1)[2]. The availability of a close attachment person also appeared to be stable (2/2)[184, 187]. Despite this apparent stability, the two studies reporting on family functioning both found that it deteriorated post stroke. The proportion of stroke participants living in 'dysfunctional' families was found to be between 33%[10]-58%[190].

Contact with relatives was analysed together with friends in 2/3 studies. Where analysed with friends, it was found to have reduced (2/2)[2, 8], and be

less than controls (1/1)[2]. The only study to analyse contact with relatives separately found that it was less stable than contact with children: 42% saw relatives the same as before the stroke, 25% less and 33% more[173]. This compared to 71% who saw their children the same amount.

Non-kin contacts appeared to be more affected than family by having a stroke. Studies found that people had fewer friends and acquaintances (2/2)[8, 184] and were in less frequent contact with them (3/3)[8, 170, 173] than before the stroke. They also had fewer friends than controls (2/2)[3, 170]. One study (exploring more severe strokes) found that 46% of stroke participants had no contact with friends at all after the stroke[180]. Similarly, studies found involvement in social activities was reduced (3/3)[4, 170, 180], and that people were involved in fewer social activities than controls (1/1)[3]. Satisfaction with friends and social activities was less than for age matched controls (2/2 studies, both examining those with aphasia only)[3, 174].

Given the reduction in the number of friends, it was unsurprising to find that the only study which analysed size of network prior to the stroke and post stroke concluded that the size of network was significantly smaller[8]. Further, the only study to compare the network size to age matched controls found that stroke participants had significantly smaller networks, which concentrated on the ‘inner core’ (predominantly immediate family) rather than the ‘outer core’ (predominantly friends and other social contacts)[3]. Both these studies focused exclusively on those with aphasia.

In summary, stroke participants appear to perceive themselves to be well-supported following a stroke, and this is stable over time. Further, contact with the most immediate family (children/ close ‘attachment’ figure) is

stable. However, family dynamics appear to be adversely affected by the stroke. Furthermore, contact with friends and involvement in social activities is significantly reduced.

2.6.2 Relationship between social support and other variables

Social network was the dependent variable in only one study, and even then, it was a very specific element: hours spent out of the house. Functional social support was not the dependent variable in any study. Therefore, this analysis is only able to assess studies exploring social support as an independent variable, associated with a variety of other variables, in either univariate or multivariate analyses.

2.6.2.1 Health-related Quality of life (HRQL) (Table 2.4)

The relationship between perceived social support and HRQL was not straightforward, comprising both positive and negative results.

Turning first to the acute stage, the only study examining the relationship between HRQL and functional social support at two weeks found no significant relationship[14]. However, the same study found a significant association at three months. The only study measuring the relationship at six months also found a positive relationship[13].

The picture for chronic stroke survivors is mixed, and may be dependent on the choice of social support measure. The three studies that look at perceived *availability* of support (using the MOS SSS) or *receipt* of support (using the ISSB) found weak results in the chronic phase. Thus Teoh *et al.*[79] found no significant relationship; Huang *et al.*[202] reported a negative result for three of the four support subscales; and Hilari *et al.*[172] also reported a

non-significant result for overall social support, although in a subsequent report on the same study (Hilari & Northcott, 2006)[173] found that two subscales were significantly associated, albeit weakly (r = .24, r = .26). In contrast, studies looking at *satisfaction* with or *quality* of perceived social support found strong correlations: Mackenzie *et al.* (2002)[14], King[12], Kim *et al.*[203]. The negative finding of Teoh *et al.*[79] may also reflect their sample and methodology (68% male; 15% response rate to postal questionnaire). The one study using an unvalidated scale with no information about what support was being measured found only an association with a HRQL subdomain rather than overall HRQL[193]. This study also provided no information as to what time post onset the data was collected.

Only one study[14] looked at whether baseline perceived social support (satisfaction with emotional and tangible support) could predict future HRQL (at three months), and found it to be a significant predictor. They did not find the baseline number of social contacts to be predictive, however.

In terms of the concurrent association between number of social contacts/ size of network and HRQL, the picture is again mixed. Hilari & Northcott[173] found it significant only for women ($p<.05$); Mackenzie *et al.*[14] found it significant at three months (univariate only: it drops out of multivariate analysis) but not at two weeks post stroke; Cruice *et al.*[189] found it significantly associated with only some HRQL domains (change in health; environmental mastery); Kim *et al.*[203] found it not significant.

Only one study[173] looked at frequency of contact, and found that those who saw their children and relatives the same amount as before the stroke had higher HRQL than those who saw them either more or less.

Finally, one study assessed the relationship of perceived social support and loneliness (single items only) with subjective well-being, and found both to be significant predictors[176].

In summary, the relationship between functional social support and HRQL is more evident three to six months post stroke. In the chronic phase, quality and satisfaction with perceived social support were associated with HRQL; whereas the evidence that availability or receipt of social support was associated with HRQL was weak. In addition, there is limited evidence that some aspects of social network may be related to HRQL.

Table 2.4 Relationship between health-related quality of life (HRQL) and social support/network after a stroke

	SUMMARY OF RESULTS	Cruice *et al.* (2003)[189]	Hilari *et al.* (2003)[172]	Hilari & Northoctt (2006)[173]	King (1996)[12]	Owolabi (2010)[193]	Perry & MacLaren (2004)[13]	Teoh *et al.* (2009)[79]	Dayapoglu (2010)[199]	Huang *et al.* (2010)[202]	Kim *et al.* (1999)[203]	Mackenzie *et al.* (2002)[14]	Wyller *et al.* (1998)[176]
Study details		Australia	UK	UK	USA	Nigeria	UK	Australia	Turkey	Taiwan	Canada	China	Norway
Study design		x-sec	x-sec	x-sec	x-sec	x-sec	x-sec	Cohort	x-sec	x-sec	x-sec	Cohort	x-sec
Chronic (>6mths) or acute		chronic	chronic	chronic	chronic	>1mth	6mths	chronic	>3mths	chronic	chronic	2d-3mths	Any
Number of stroke participants		30	83	83	86	100	206	135	70	102	50	215	1417
HRQL measure used		SF-36; Dartmouth COOP charts	SAQOL-39	SAQOL-39	QLI	HRQOLISP; SF-36	QLI	SIS; SF-12; AQOL	SF-36	QLI	QLI	SIP	
Social support/network measure		SOCACT; Convoy model	MOS SSS	MOS SSS	SSE		MOS SSS	MOS SSS	PFS	ISSB (modified)	SSIPAD	SSQ6	
Health-Related Quality of Life													
SS associated with concurrent HRQL	**9/10**		×overall	✓ Social companionship ✓Information ×Emotional ×Tangible ×Affectionate	✓✓	✓ (ecosocial domain only)	✓✓	×	✓SS from family	✓Tangible ×Emotional ×Appraisal ×Information	✓✓quality	✓✓ 3mths × 2 wks	✓✓ (DV: subjective well-being)
T1 SS associated with T2 HRQL	**1/1**											✓	
Loneliness associated with subjective well-being	**1/1**												✓✓
SN associated with concurrent HRQL	**3/4**	✓✓ (social activity*/ SN[¥] with specific domains of HRQL only)		✓ size of network for women only ✓same frequency of contact with children and relatives							×quantity	✓ 3mths × 2 wks	
T1 SN associated with T2 HRQL	**0/1**											×	

✓significant; ✓✓ significant in multivariate analysis (DV: overall HRQL unless otherwise specified); ×no significant relationship

*Role functioning; General Health [¥] Change in health; Environmental mastery

2.6.2.2 Social support and depression (Table 2.5)

A diagnosis of depression is made by using the DSM-IV criteria in a psychiatric assessment. This is the case in 4/20 studies reported here. 15/20 studies relied on validated scales, assessing depressive symptoms or psychological distress. Only one study[181] used nurse ratings, rather than a validated scale or psychiatric assessment.

There is strong evidence that functional social support is associated with depression following a stroke in both the acute and chronic stages (10/11 studies). For those that reported individual subscales: 2/3 emotional support to be significantly associated[17, 205], and 1/3 found no significant association[183]; 2/2 found informational support to be correlated[183, 205]; and 0/3 tangible support to be significantly associated [17, 183, 205].

There was also evidence that some elements of the social network were associated with depression. These were: family functioning (1/1, chronic)[10]; availability of close confiding relationships (2/2, acute[184] and chronic[187]); and social activities (2/2[181, 209]). Generally, satisfaction with social network was also found to be associated with depression (two studies found a significant association[10, 207]; one study reported non-significant results)[184]. The one study[200] to use a validated social network scale assessing overall network functioning found only a weak significant association, r = .24 (assessed 1-12 months post stroke).

The relationship between depression and contact with the wider network (friends, relatives, community contacts) was mixed. Friedland and McColl (1987)[178] reported significant results for both the friends/relatives subscale, and the community subscale (timescale: 2-24 months post stroke). Astrom *et*

al. (1993)[9] also found contact with friends and relatives was significantly associated at three months, one, two, and three years post stroke. Knapp and Hewison (1998)[184] found that availability of loose network contacts was associated with depression at one month, but not six months post stroke. One explanation is that the Knapp and Hewison (1998) study was underpowered (n = 30); the correlation reported at six months was r = -.26.

Living alone was associated with depression at discharge only (1/1)[171]. Finally, social network was not associated with suicidal ideation (1/1)[186].

In terms of studies looking to see if baseline social factors were associated with subsequent depression, 2/3 studies found that functional social support predicted future depression. The two studies finding a positive correlation explored satisfaction/perceived social support [10, 206], whereas the study reporting a negative result[17] was measuring received social support. Further, (1/1) studies found that pre-morbid availability of loose network contacts and confiding, close relationships were both associated with subsequent depression at 6 months; satisfaction, however, was not[184].

Only two studies followed a cohort from acute to the long-term (over two years post stroke): Astrom *et al.* (1993)[9] and King *et al.* (2002)[10]. Both used multivariate predictive models of depression and assessed a range of measures including physical functioning. In both studies a variety of factors were significant predictors at the point of discharge (aphasia and living alone[9]; social support and two coping scales[10]). However, by two years the only significant predictor in both studies were social factors. In the Astrom *et al.* (1993) study it was ‘few social contacts outside the house’. In King *et*

al.'s (2002) study, the only two significant predictors were family functioning, and 'belonging' support.

A final observation is that no aphasia study reported on depression.

In summary, it appears that functional social support and depression are closely related at all stages post stroke, and that functional social support measured at around the point of discharge may predict future depression. Further, there is evidence that some aspects of social network such as taking part in social activities, the availability of close, confiding relationships, and contact with the wider network (friends, relatives, community contacts) are associated with depression. However, *number* of social contacts does not appear to be significantly associated.

Table 2.5 Relationship between social support/network and depression or depressive symptoms after a stroke

		Stroke studies including PWA								Stroke studies excluding PWA		
	SUMMARY OF RESULTS	**Astrom *et al.* (1993)[171]**	**Astrom (1996)[106]**	**King *et al.* (2002)[10]**	**Robinson *et al.* (1983)[194]**	**Sharpe *et al.* (1994)[187]**	**Teoh *et al.* (2009)[79]**	**Townend *et al.* (2007)[11]**	**Tsouna-Hadjis *et al.* (2000)[17]**	**Chau *et al.* (2010)[198]**	**De Sepulveda (1994)[200]**	**Feibel & Springer (1982)[181]**
Study details		Sweden	Sweden	USA	USA	UK	Australia	Australia	Greece	China	USA	USA
Study design		Cohort	Cohort	Cohort	x-sec	x-sec	Cohort	Cohort	Cohort	x-sec	x-sec	Cohort
Time of assessment(s)		4d-3yrs	4d-3yrs	d/c – 2y	<2wks	3-5yrs	6-24mths	2d -3mths	1-6mth	6mths d/c	1-12 mths	10d-6mth
Number of stroke participants		80	80	97	103	60	135	125	50	210	75	91
Depression measure used		DSM-III	DSM-III-R for Generalised Anxiety Disorder	CES-D	Zung; Hamilton	DSM-III-R	CES-D	HADS	Zung	GDS	CES-D	Nurse rating
SS/SN measure used				FAD; ISEL	Social Ties Checklist		MOS SSS	MSPSS	Family & Social Support Scale	SSQ6	ISEL; Lubben SN scale	
Depression												
SS associated with depression/ depressive symptoms	**10/11**			✓✓at d/c: SS ✓✓2yrs: belonging ✓2yrs: SS				✓✓ (at 1 & 3 mths)	✓ Emotional × Compliance ×Tangible	✓✓	✓ (except for those severely disabled)	
T1 SS associated with T2 depression/ depressive symptoms	**2/3**			✓✓ belonging SS					×			
SS distinguishes depressed vs non-depressed	**2/2**						✓					
SN associated with depression/ depressive symptoms	**8/10**	✓✓ (at d/c) living alone ✓✓ (3mth – 3 yrs) few social contacts	✓✓ (at d/c) living alone ✓✓ (3mth – 3 yrs) few social contacts	✓✓2yrs: family functioning ✓✓2yrs: satisfaction with quantity	✓	✓having close personal relationship				× quantity	✓	
T1 SN associated with T2 depression/ depressive symptoms	**1/1**											
SN distinguishes depressed vs non-depressed	**2/2**											✓ (social activities)

✓significant; ✓✓ significant in multivariate analysis (DV: depression/depressive symptoms); ×no significant relationship

	Stroke studies excluding PWA									
Table 2.5; con p2/2 (see p1/2 above for summary of results)	**Friedland & McColl (1987)[178]**	**Huang *et al.* (2010)[202]**	**Kishi *et al.* (1996)[186]**	**Knapp & Hewison (1998)[184]**	**Lam *et al.* (2010)[204]**	**Li *et al.* (2003)[205]**	**Morris *et al.* (1991)[206]**	**Sit *et al.* (2007)[183]**	**Spencer & Tompkins (1995)[207]**	**Ueki *et al.* (1999)[209]**
Study details	Canada	Taiwan	USA	UK	China	Taiwan	Australia	China	USA	Japan
Study design	x-sec	x-sec	Cohort	Cohort	x-sec	x-sec	Cohort	Cohort	Cohort	x-sec
Time of assessment(s)	2-24 mths d/c	?2.5yrs	Acute – 24mths	<1mth – 6mth d/c	?	10wk-10yrs	2-14mths	2d-6mth	c3mths – c9mths	2-3yrs
Number of participants	85	102	301	30	50	106	76	112	162	47
Depression measure used	GHQ—28	CES-D	Psychiatric interview	HADS	GDS	GDS	DSM-III	CES-D	CES-D	GHQ-60
Social support measure	SSISS	ISSB (modified)	Social Ties Checklist	ISSI	SSQ6		ISSI (partial)			
Depression										
SS associated with depression/ depressive symptoms	✓✓Satisfaction	×SS (however, Tangible SS partially mediates association between ADL and depression)			✓	✓ Emotional ✓Information ✓Affirmation ×Tangible	✓	✓✓Social companionship ✓✓ Information ×Emotional ×Tangible		✓
T1 SS associated with T2 depression/ depressive symptoms							✓ (poor T1 SS associated with longer lasting depression)			
SS distinguishes depressed vs non-depressed	✓ (Satisfaction; quality)									
SN associated with depression/ depressive symptoms			× not associated with suicidal ideation	✓1 & 6 mths: attachment relationship ×satisfaction reln ✓1mth: wider network ×6mth: wider network & satisfaction network	✓				✓ satisfaction with amount of contact	✓return to social activities
T1 SN associated with T2 depression/ depressive symptoms				✓3mths/×6mths attachment relationship ×satisfaction reln ✓3&6mths: wider network ×satisfaction network						
SN distinguishes depressed vs non-depressed	✓ (personal; relative/friends; community) ×overall quantity									

✓significant; ✓✓ significant in multivariate analysis (DV: depression/depressive symptoms); ×no significant relationship

2.6.2.3 Social support and physical outcomes (Table 2.6)

Whether there was a positive relationship between aspects of social support/ network and physical measures depended on the timescales, and the precise research questions.

In terms of concurrent associations, functional social support was not correlated with either ADL (four studies found non-significant results[192, 200, 206, 208]; one reported significant association[202]) nor neurological deficits (0/1)[182]. The only exception to this finding was a single study (Huang *et al.*, 2010)[202] that found tangible support to be associated with ADL, but not emotional, appraisal, or information support. Since this study was using the ISSB, which measures received support, this may reflect the increased need.

Strong social support at the time of the stroke improved functional outcome in 2/2 studies, and this was particularly the case for more severe strokes, and particularly emotional support[17, 109]. Further, both studies found that the relationship between social support and recovery did not become evident until after one month: those with worse support showed decline between three to six months in comparison with the continued improvement of the well-supported groups. Both these studies use ANCOVA to assess the relationship, controlling for stroke severity. However, neither study reported effect size.

Colantonio *et al.* (1993)[15] reported that pre-morbid social network (using a validated scale administered to a population-based sample prior to the stroke) was strongly associated with functional recovery at six weeks. A single item from the same study on functional social support did not predict

functional outcome at six weeks, however. This may reflect the inadequacy of trying to assess social support with a single item.

In terms of the association between concurrent social networks and physical outcomes, there was some evidence that those more severely disabled by the stroke spent less time out of the house[145], and engaged in fewer social activities[4]. However, Labi *et al.* (1980)[4] found that even those who had made a full recovery still did not regain pre-stroke levels of activity. Glymour *et al.* (2008)[182] found that a measure of social ties was not associated with stroke severity at 20 days post stroke. None of these studies used validated scales.

Finally, Boden-Albala *et al.* (2005)[179] found that stroke survivors who had fewer than three friends were more likely to go on to have an adverse outcome (defined as recurrent stroke; death; or myocardial infarction).

In summary there is some evidence that strong social support and social network (measured either prior to the stroke, or shortly after the stroke) may facilitate better recovery, and reduce the likelihood of a future stroke. There is also some evidence that in the chronic phase, those with more severe disability may spend less time out of the house, and engage in fewer activities.

Table 2.6 Relationship between social support/network and physical variables (including Activities of Daily Living and neurological deficits)

		PWA only	Stroke studies including PWA						Stroke studies excluding PWA						
	SUMMARY OF RESULTS	Code *et al.* (2003)[145]	Boden-Albala *et al.* (2005)[179]	Colantonio *et al.* (1993)[15]	Glass *et al.* (1992)[109]	Glass *et al.* (1993)[16]	Norris *et al.* (1990)[192]	Tsouna-Hadjis *et al.* (2000)[17]	De Sepulveda (1994)[200]	Glymour *et al.* (2008)[182]	Huang *et al.* (2010)[202]	Labi *et al.* (1980)[4]	Morris *et al.* (1991)[206]	Osberg *et al.* (1988)[188]	Stephens *et al.* (1987)[208]
Study details		UK	USA	USA	USA	USA	USA	Greece	USA	USA	Taiwan	USA	Aus	USA	USA
Time of assessment(s)		>5mths	2d-5yrs	Premorbid-6wks	1-6mth	1-6mth	2-13 mths	1-6mth	1-12 mths	c. 18d - 6mth	?2.5yrs	?chronic	2-14mths	1-12 mth d/c	At d/c
Number of stroke participants		38	655	87	46	46	47	50	75	272	102	121	76	89	48
Physical measure used			NIHSS	Katz	BI	BI		BI	BI	NIHSS	BI	Kenny	BI	BI or Kenny	Multilevel Assessment Instrument
Social support measure used		SNAP		SNI	ISSB	ISSB		Family & SS scale	ISEL; Lubben SN scale	ISSB (partial)	ISSB (modified)		ISSI (partial)		
Physical Variables															
Activities of Daily Living associated with concurrent SS	**1/5**						× SS (✓✓negative social interactions)		×		✓ Tangible ×Emotional ×Information×Appraisal		×		×
Activities of Daily Living associated with SN	**1/2**	✓time out of house*							×						
Neurological deficits associated with SS	**0/1**									×					
Neurological deficits associated with SN	**2/3**	✓ time out of house**								×		✓social activities			
Adverse outcome (death/ ADL dependent) associated with SN	**1/1**													✓✓In-house SN ✓out-of-house SN	
Social factors associated with future physical outcomes															
Pre-morbid SN associated with adverse physical outcomes	**2/2**		✓✓	✓✓											
SS associated with better physical recovery trajectories	**2/2**				✓ (esp. Emotionl SS)	✓ (esp. severe strokes)		✓ (esp. severe strokes)							

✓significant; ✓✓ significant in multivariate analysis (DV: physical variable); ×no significant relationship
*mobility considered only; **hemiplegia considered only

2.6.2.4 Other significant factors (Table 2.7)

The relationship between a variety of other variables and social support/network was also assessed. These are discussed briefly in turn.

Severity of Aphasia: Severity of aphasia predicted time spent out of the house[145], social activities[189] and the social functioning domain of SF-36[189]. The only study to look at the relationship between perceived social support and aphasia severity found no significant association[173].

Cognition: there was little evidence that concurrent social support was associated with cognition (two studies found no association[192, 206]; one study found significant association[208]). However, one study[182] (Glymour *et al.*, 2008)[182] found that social factors, particularly emotional support, predicted 'cognitive recovery' in the first six months post stroke. The aspect of improved cognition most associated with social support was working memory.

Fatigue: only one study assessed this[191], and found a significant univariate association, although social support was not a significant predictor in multivariate analysis.

Physical activity level: 1/1 studies[177] found social support to be a significant predictor of physical activity level.

Self-esteem: only one study[175] explored the relationship between self-esteem and social support in the stroke population. This was a pilot study, and had a small sample size (20 participants, 20 controls). It considered univariate analyses only. Its results should therefore be interpreted cautiously.

Nonetheless, it found that trait self-esteem (also referred to as global, characteristic or 'unchanging') was not associated with social support. However, performance self-esteem (one aspect of state, ie changeable, self-esteem) was associated with social support. Other aspects of state self-esteem (appearance and social) were not associated however.

Community integration: both quality and quantity of social support was found to be associated with community integration[197]. Further, social support partially mediated the relationship between driving cessation and community integration: those who could drive and were well supported had higher levels of integration than those who could not drive (regardless of social support), and those who could drive but lacked social support[201].

Table 2.7 Relationship between social support/network and aphasia, cognition, fatigue, self-esteem and community integration

			PWA only		Stroke studies including PWA		Stroke studies excluding PWA						
	SUMMARY OF RESULTS	**Code *et al.* (2003)[145]**	**Cruice *et al.* (2003)[189]**	**Hilari & Northoctt (2006)[173]**	**Michael *et al.* (2006)[191]**	**Norris *et al.* (1990)[192]**	**Adeniyi *et al.* (2012)[177]**	**Beckley (2007)[197]**	**Chang *et al.* (1999)[175]**	**Glymour *et al.* (2008)[182]**	**Griffen *et al.* (2009)[201]**	**Morris *et al.* (1991)[206]**	**Stephens *et al.* (1987)[208]**
Study details		UK	Australia	UK	USA	USA	Nigeria	USA	China	USA	USA	Australia	USA
Chronic or acute		Chronic	Chronic	Chronic	Chronic	2-13 mths	?	3-6mth	On rehab ward	c. 18d -6mth	Chronic	2-14mths	At d/c
Number of stroke participants		38	30	83	53	47	104	95	20	272	90	76	48
SS/SN measure		SNAP		MOS SSS	MOS SSS		MOS SSS	SSIPAD	SSQ6	ISSB	SPS	ISSI	
Aphasia													
Severity associated with reduced SN	**2/2**	✓ time out of house	✓ social activities										
Severity associated with social functioning (SF-36 domain)	**1/1**		✓										
Severity associated with SS	**0/1**			×									
Cognition													
Associated with SS	**1/3**					×						×	✓
Cognitive change predicted by SS	**1/1**									✓✓ Emotional × Tangible			
Cognitive change predicted by SN	**1/1**									✓✓			
Fatigue													
Fatigue associated with SS	**1/1**				✓								
Physical activity level													
Low level associated with SS	**1/1**						✓✓						
Self-esteem													
Self-esteem associated with SS	**1/1**								✓ (performance state self-esteem) × (trait self-esteem)				
Community integration													
Community participation associated with SS	**1/1**							✓✓					
Community participation associated with SN	**1/1**							✓✓					
SS partially mediates impact of driving cessation	**1/1**										✓		

✓significant; ✓✓ significant in multivariate analysis; ×no significant relationship

2.7 Synthesis of qualitative and quantitative findings

There is a striking degree of congruence between the qualitative and quantitative findings. Both syntheses found that the family unit is likely to 'hold together' following a stroke, albeit with increased tensions and strains. The 'disharmony' within the family was measured using the Family Assessment Device in two studies; the qualitative research was able to explore reasons for the tensions, and how it was perceived.

Both syntheses also documented the trend for people to lose contact with friends and the wider network post stroke. The quantitative findings demonstrated that there was a significant reduction in number of friends and social activities, and that people were dissatisfied about the level of contact. The qualitative findings were able to explore some of the barriers and facilitators to social participation from the perspective of the stroke survivor.

The quantitative synthesis also showed that the perception of feeling supported appears to remain stable following a stroke. Given that the family were more stable network members than friends/the wider network, a possible explanation is that it is the family who were the main providers of emotional and practical support. Who provided what support was not analysed in any of the quantitative studies, and was not the focus of any of the qualitative studies. Four of the qualitative studies, however, suggested that the main provider of emotional, practical and social companionship support was indeed the spouse. Thus it

would appear that despite the marital strains, the level of support provided by the spouse was fairly constant.

One area of divergence between the syntheses lies with how variables were conceptualised. The qualitative studies focused on concepts such as successful living, coping, acceptance and adjustment. The quantitative studies measured variables such as depression and HRQL. Functional social support was found to be strongly correlated with depression and to a lesser extent HRQL. Successful living/ coping / adjustment was considered to be facilitated by eight social support factors (see 2.5.7), and six of these could largely be conceptualised in terms of functional social support, in particular, emotional support (feeling valued and loved, encouragement, constancy, acceptance and understanding) and social companionship (humour, distraction, spending positive time with family and friends). The extent to which 'successful living' is a similar or related concept to HRQL or psychological well-being is clearly debateable. Still, the findings clearly do not contradict one another, and arguably there is a form of weak triangulation here.

A more direct 'translation' may relate to the finding that depression was associated with reduced social activities and few contacts with friends and relatives. The qualitative findings also document the distress that could be caused through losing friends and activities. Further, there is the suggestion that depression (and the sense of withdrawal and social avoidance) was sometimes seen as part of the reason for lost contact with friends. One interpretation of this might be that a potentially vicious cycle could be set up: depression leading to

social avoidance, which in turn could lead to feeling isolated and so more depressed. This is not explicitly described or tested in any of the 68 studies, however.

A rationale for including qualitative studies is that they might be able to explain significant associations found in quantitative studies[159]. One such association is that Emotional support facilitated more complete physical recovery. Tangible support was either found not to be associated with recovery, or that 'too much' tangible support was found to be less beneficial than moderate levels of tangible support. The findings of the qualitative synthesis help to explain this pattern. Tangible support was only found to be facilitative to recovery when it was provided in such a way as it fostered independence. Where the stroke survivor felt that their spouse/ family member was 'taking over' or being 'over protective', this impacted negatively on feelings of competence. Emotional support, in the form of making the stroke survivor feel valued/ loved, encouraged, and understood, was perceived as facilitating recovery. It is intriguing that one study[182] found a similar pattern in relation to cognitive recovery. These findings underline the importance of Emotional support in recovering from a stroke.

2.8 The question of aphasia

There appeared to be a divide in the literature. On the one hand, there were aphasia studies, which did not recruit stroke survivors without aphasia. On the

other hand, there were stroke studies which either excluded people with aphasia (PWA) or only inadequately included them. Thus it is difficult to make direct comparison between those with and without aphasia.

Turning first to the quantitative literature, the five aphasia studies make clear how people were facilitated, and excluded generally only those with severe receptive aphasia, as measured by a specified and validated scale. These studies also demonstrated that it is possible for even those with moderate-severe aphasia to be included in lengthy interview-based assessments, provided that their responses are suitably facilitated.

Of the remaining studies (n = 43), 20 excluded all those with aphasia, and five do not mention aphasia. Of the 18 stroke studies that included people with aphasia seven used proxies. However, there are concerns that proxy responses are not commensurable with self-report, particularly for less observable, more subjective constructs. Proxies tend to score PWA as more severely affected than the PWA scores themselves[210, 211]. A further eight studies excluded those with 'severe' aphasia (although only King *et al.* [12] assessed severity). Of these eight studies, none describe what measures they took to facilitate people with aphasia. Finally, Belanger *et al.* do not specify what approach they took[180], and for the remaining study, Colantonio *et al.*[15], social network information was collected pre-morbidly. To summarise, in the stroke studies PWA are at best under-represented (only mild aphasia, with no indication as to how facilitated) or proxies used; and at worst excluded altogether.

The qualitative studies also are divided in terms of inclusion of PWA. Again, there are aphasia studies that have not recruited stroke survivors without aphasia (n = 8); and stroke studies that either do not make clear whether people with aphasia were included (n = 2), or give no indication as to how they were facilitated (n = 3). Only one of the general stroke studies reports briefly on the impact of aphasia, and then only in the acute stage[111]. Again, this makes it difficult to make direct comparisons between those with and without aphasia.

An alternative way to assess the impact of aphasia on social support is to look at measures of severity of aphasia. There is evidence that those with severe aphasia spend less time out of the house[145], and take part in fewer social activities[189]. Severity of aphasia was not associated with perceived social support, however[173].

Finally, it is possible to examine whether similar trends are found in the stroke studies and aphasia studies. Turning first to the quantitative synthesis, patterns reported in the aphasia papers appear to be similar to those found in the stroke studies: relatively high levels of perceived social support, stable contact with children, but a reduction in the number of friends and social activities. No aphasia study explored the relationship between social support and depression, nor the impact of social support on physical or cognitive recovery. In terms of HRQL and mobility, aphasia study findings were not dissimilar to the general stroke population.

In terms of the qualitative literature, again, many of the same themes emerge in both the stroke studies and the aphasia studies. However, there were some

findings that appeared to be specific to those with aphasia. These were: the attitude of friends and those in the community, in particular the sense of stigma that appeared to be attached to having aphasia; the changes to the 'substance' of relationships brought about by changed communication patterns; feeling isolated and excluded even when surrounded by others; the increased role of the spouse in facilitating successful communication and participation; and possibly the role of aphasia groups and aphasia friends.

2.9 Gaps in the literature

There were a number of gaps identified through this literature review. These are addressed in turn.

Firstly, no study has facilitated the inclusion of people with moderate-severe aphasia in a general stroke study exploring social support. Including PWA would allow direct comparisons to be made, and explore the possibility that those with aphasia may be more adversely affected on measures of social network and support than those without.

Secondly, although perceived social support has been found to be stable over time, no study has assessed pre-morbid levels of perceived social support, nor confirmed that this trend is true for people with aphasia.

This review has shown the importance of social support in recovering from a stroke, and yet it is not known what factors predict who will feel well supported

or who will have a strong network post stroke. Although two studies have examined predictors of related concepts (social dysfunction[212]; participation[134]), and one study has explored predictors of social support in a mixed population (stroke and spinal cord injury[213]), no study has explored predictors of perceived social support or social network, as measured by a validated scale, in the stroke population.

In terms of friendships, it is well-demonstrated that people lose contact with friends following a stroke. However, it has not yet been explored what factors might protect pre-stroke friendships. Further, although the causes of reduced participation have been examined in a number of studies, it is not clear how these relate to friendships specifically.

Furthermore, both the quantitative and qualitative literature have tended to analyse contact with relatives and friends together[5, 6, 171, 178]. Yet the literature on the general elderly population suggests that relatives and friends occupy different roles within a person's social network, and provide different sorts of support[75].

In relation to relatives, there are contradictory patterns reported in both the qualitative and quantitative literature, with some participants reported to see relatives more than before the stroke, and some less. Yet reasons for these patterns, and how they are perceived, have not yet been studied.

Contact with children is reported to be stable. However, no study has explored the 'meaning' of this stability, or how contact and receipt of support from children is perceived by the stroke survivor.

In addition, it has been little explored which members of the social network provide which functions of support, and how this is perceived by the stroke survivor.

Finally, social network typologies have been used in the general elderly population, and found to be a useful way of conceptualising social network patterns and change. Yet no stroke study has yet developed a social network typology.

2.9 Research questions for current thesis

The research questions for this thesis stem directly from the gaps identified through the literature review. They are listed below:

RQ1: Do pre-morbid levels of perceived social support change over time following a stroke?

RQ2: Does a person's pre-morbid social network change over the time following a stroke?

RQ3: Are stroke survivors with aphasia different from those without aphasia on measures of social support and social network?

RQ4: What concurrent factors predict perceived social support six months post stroke?

RQ5: What baseline factors predict perceived social support six months post stroke?

RQ6: What concurrent factors predict social network six months post stroke?

RQ7: What baseline factors predict social network six months post stroke?

RQ8: What happens to friendships following a stroke?

RQ9: What happens to family relationships following a stroke?

RQ10: What are the reasons why a person shifts from one social network type to another following a stroke?

RQ11: Which network members provide what functional support following a stroke?

2.10 Summary and conclusion

This chapter has documented the different stages involved in carrying out a systematic review of both the quantitative and qualitative literature on social support after a stroke. The conduct and reporting were based on PRISMA guidelines. 54 quantitative reports (based on 48 studies) and 14 qualitative

reports (based on 13 studies) matched the eligibility criteria. Use of the CASP critical appraisal tools suggested that the qualitative studies were on the whole well carried out, although there were concerns that the most isolated may be under represented. The quality of the quantitative studies was variable: only 27/54 were considered to report reliable results. Further, as predicted, choice of measures reflected a variety of ways of conceptualising functional social support and social network, making comparison more difficult. The majority of studies did not report the individual subscales of functional support, making it hard to determine their relative importance (for example, emotional versus tangible support). Of more concern, there was an overreliance on non-validated scales to measure social support/network, and in many instances, single items were used. These limitations limit the strength of the findings.

As discussed in section 2.7, the qualitative and quantitative studies found similar patterns. Further, the findings were shown to complement and explain each other, which would seem to justify the decision to include both data sources in this review.

The main findings can be summarised as follows. The aspects of social support/ network which remained stable following a stroke were: functional support (for example, perceiving that there is someone who can give emotional or tangible support); and contact with family (for example, contact with children remained stable). The aspects of social support/ network which changed were: family functioning (a sense that the stroke was a cause of disharmony and strain within the family unit); and contact with friends and the wider network, including

participating in social activities. Isolation was reported to be a significant concern post stroke.

Functional social support was strongly associated with depression/depressive symptoms at all stages post stroke, as were aspects of the social network particularly in the chronic phase (social activities; availability of close confiding relationships; contact with friends, relatives, and those in the community). Number of contacts did not appear to be associated, however.

HRQL was associated with functional social support at three and six months. In the chronic phase, HRQL was most strongly associated quality or satisfaction, rather than with perceived availability or receipt of functional support. The evidence for social network factors being associated with HRQL was more mixed.

In terms of physical disability post stroke, there was some evidence that in the chronic phase, those with more severe disabilities as a result of the stroke engaged in fewer activities, and spent less time out of the house. In terms of physical recovery and psychological adjustment, emotional support was found to play an important role.

The review ended with an analysis of gaps identified through this literature review, which led to specific research questions, forming the basis of this PhD.

Chapter Three. Methodology

This chapter will outline how the design of the project matches the research questions outlined at the end of Chapter Two. It will then give information about how participants were recruited, the procedure for collecting data, measures used, and how people with aphasia were included.

3.1 Design

The research questions for this thesis are diverse and in order to address all of them a mixed methodology was employed, incorporating a longitudinal design.

In order to assess whether there was any change in pre-morbid levels of support and social network, it was necessary to interview participants shortly after their stroke while in hospital, so they could still remember their pre-stroke life clearly. To then track whether support changed over time, a longitudinal design was necessary. In this project participants were interviewed three and six months post stroke, during which time the majority would be discharged home: the time around discharge is reported as a challenging period[111, 165]. Through again interviewing at around one year post stroke it was anticipated that a person would have begun the adjustment of living with a stroke into the longer term. The only study to track social factors annually over three years found little change past one year[170].

A further aim was to examine predictors of social support and network. For this, validated measures of both the dependent variables (support and network) and potential independent variables needed to be assessed on a sufficiently

large population. Further, since a particular aim of the project was to compare the experience of those with and without aphasia, it was necessary to recruit from the general stroke population, but ensure measures were taken to make the project accessible to those with language difficulties.

In order to explore the impact of stroke on both the family and friends, qualitative data was collected in addition to quantitative data. Qualitative data can provide insight into the 'lived experience' of a health condition, and give insight into how change is perceived by the individual[126]. It was also anticipated that it might help to interpret trends found in the quantitative data[159]. It would also facilitate the creation of a social network typology.

From these considerations, a two-stage design was developed.

Stage One of the project was a repeated measures cohort study, and interviews took place at two weeks (baseline), three months and six months (± one week) post stroke. Stage One formed part of a wider research project, evaluating the psychometric properties of the Stroke and Aphasia Quality of Life Scale in the general stroke population (SAQOL-39g)[214]. Although Stage One was designed by the principal investigator of the SAQOL-39 project, the research questions addressed here did not form part of this larger project. Thus various aspects of the design were decided by the PhD candidate (for example, choice of social support measures, decision to measure pre-morbid social factors).

Stage Two of the project was not part of the larger project and it was designed by the PhD candidate. It consisted of qualitative interviews with a subset of

participants who were selected from the overall sample using purposive sampling. These took place between eight and 15 months post stroke.

3.2 Participants

People were eligible to be included in Stage One of the study if they met the following requirements:

- Over 18 years old
- Admitted to hospital following first ever stroke
- Stayed in hospital for at least three days as a result of the stroke

Potential participants were excluded for the following reasons:

- Did not live at home prior to the stroke
- Known history of mental health problems or cognitive decline before the stroke
- Other severe or potentially terminal co-morbidity
- Unable or too unwell to give informed consent
- Did not speak English prior to the stroke (an assessment was made by the interviewer in consultation with the potential participant, their family, and medical staff)

Participants for Stage Two were selected using purposive sampling: criteria used are outlined in section 3.6 below.

3.3 Procedure

The procedure for the project is described in detail in the following two sections. Figure 3.1 below provides an overview of the stages involved.

3.3.1 Stage One: repeated measures cohort study

The study was approved by the relevant National Health Service (NHS) Local Research Ethics Committees (see Appendix Two). Potential participants were initially approached by a member of the hospital staff, with brief details about the project, in order to gain consent for the researcher to discuss the project with them and access their medical notes. On receiving this initial consent form, the researcher would examine their medical records to confirm they met the eligibility criteria for the project. The researcher then went through an information sheet with the participant (see Appendix Three), explaining what the project involved and what the aims were. Any queries were discussed, and written information left with the participant. At least 24 hours were allowed between this initial contact and first interview in order to give the participant time to reflect and discuss the project with their families. For those who agreed to take part, they were asked for written consent.

Participants were interviewed initially in the hospital. Prior to commencing the first interview, the National Institute of Health Stroke Scale (NIHSS)[215] was calculated from hospital medical notes, and the Barthel Index[216] was scored via discussion with nursing staff (asking an informed nurse has been shown to be as reliable as testing, and is quicker)[217]. At the three month and six month interviews the researcher carried out both these assessments.

At the start of the two week (baseline) interview, the Frenchay Aphasia Screening Test[218] was administered. Those who scored ≥ 7/15 on the receptive domains were able to self-complete the Stroke and Aphasia Quality of Life Scale (SAQOL-39)[219, 220]. Where people scored lower than 7/15, indicating severe receptive aphasia, they were asked to nominate a proxy to complete the questionnaires on their behalf. Proxy responses are not analysed in this project. Ability to complete the SAQOL-39 was considered relevant since the research team (consisting of trained SLTs) considered the linguistic load of the other measures to be comparable to the SAQOL-39.

Those who had adequate comprehension skills then completed a number of measures in interview format, in the same order. The interview comprised: a case history, the SAQOL-39; the General Health Questionnaire-12 (psychological distress scale)[221]; the Stroke Social Network Scale[222]; the Medical Outcomes Study Social Support Survey[48]; and the Frenchay Activities Index (extended ADL measure)[223]. The two social support measures and the extended ADL measure asked participants to consider the month(s) prior to the stroke during the baseline interview.

At three months and six months, interviews took place at a location chosen by the participant, usually the participant's home, alternatively, a public space such as a cafe, or in hospital or rehabilitation setting. With one participant where there were safety concerns, the researcher requested the interview take place in a public space (at three months a café, and at six months, a station). Where appropriate, permission was also gained from medical staff in rehabilitation

settings for the researcher to come in and carry out the interview on their premises.

Participants were recruited from two sites: two acute stroke units based in London teaching hospitals. Recruitment took place over 15 months in the first hospital (Site One), and six months in the second hospital (Site Two). Three researchers carried out the survey questionnaire interviews: all three were trained speech and language therapists. At Site One the principal investigator and PhD candidate carried out the interviews. Participants recruited through Site Two were interviewed by the third researcher, who was mentored by the PhD candidate to ensure consistency of approach. Approximately 75% of the interviews were conducted by the PhD candidate.

3.3.2 Stage Two: qualitative interviews

At the six month interview participants recruited in Site One were asked if they consented to being contacted again by the PhD candidate for a final follow up interview. The different nature of the interview was explained. Nearer the time, they were then sent a letter explaining about the format and aims of the qualitative project, before the PhD candidate phoned or emailed them (as agreed with them before hand). Participants again gave written, informed consent prior to the interview (see Appendix Four).

Interviews took place between eight and 15 months post stroke. All interviews were audio tape-recorded, with the permission of the interviewee. Reassurances about confidentiality and what would happen to the recording were given. Interviews took on average 65 minutes (ranging from 38 minutes to two hours

and six minutes). Although participants were given the option of completing the interview over two sessions, all participants elected to conduct the interview in one sitting. Interviews took place at a venue chosen by the participant, usually their own home.

Field notes were made shortly after each interview, allowing me to reflect on how the interview had gone, for example, how topics were presented, and make a note of anything that would not be on the audio-tape, such as the mood of the participant prior to commencing the interview. All qualitative interviews were carried out by the current author.

Figure 3.1 Time line of assessments

Two weeks post stroke (± one week)

Potential participants identified and given information on the project.

Assessments carried out for those who consented to take part:

NIH Stroke Scale (from medical records); Barthel Index (from nursing staff)

Face to face assessments:

Frenchay Aphasia Screening Test*; General Health Questionnaire-12; Stroke Social Network Scale; MOS Social Support Survey; Frenchay Activities Index

*participants scoring less than 7/15 on receptive domains of FAST took part in proxy stream of the project, and their results are not reported here

↓

Three months post stroke (± one week)

Face to face assessments:

NIH Stroke Scale; Barthel Index; Frenchay Aphasia Screening Test; General Health Questionnaire-12; Stroke Social Network Scale; MOS Social Support Survey; Frenchay Activities Index

↓

Six months post stroke (± one week)

Assessment protocol as for three months

↓

12 months post stroke (± 4 months)

Subset of participants purposively selected for in-depth interviews

3.4 Stage One: Measures

The following section describes in more detail the different scales and measures that participants completed in this project. For all the measures used in the project, copies of their scoring forms are presented in Appendix Five.

3.4.1. Perceived social support: MOS Social Support Survey

Participants' perception of functional support was assessed using the Medical Outcomes Studies (MOS) Social Support Survey (SSS)[48]. This scale includes 19 functional support items hypothesised to cover five dimensions:

- Emotional support: feeling there is someone to confide in, someone to share your private thoughts and fears with
- Informational support: someone to give advice, information
- Tangible support: practical support, such as behavioural assistance
- Social companionship: the availability of other people to do fun things with
- Affectionate support: someone who will show you love and affection

The response format is a 5-point scale with the participant rating the support item as available 'none of the time' (1) to 'all of the time' (5). The scale does not ask who provides the support. It was tested on a group of chronically ill ambulant outpatients (n = 2,987), and the items are designed to be short, simple,

and easy to understand. The scale has previously been used with those who have chronic aphasia following a stroke[173, 224].

The scale has good psychometric properties: excellent internal consistency (for the overall scale α = 0.97; subdomains range from α = 0.91 to 0.96); and reasonable construct validity. Test retest reliability was only tested at a one-year interval (one year stability coefficient was 0.78). Responsiveness to change has not been formally assessed. Factor analysis suggests the items can fit reasonably into an overall scale, although the authors recommend that in order to determine which functions of support lead to different outcomes, the subscales could be used separately.

3.4.2 Social network: Stroke Social Network Scale

An aim of the project was to measure people's social networks, and analyse how these change over the months following a stroke. Since there is no social network measure that has been validated in a stroke sample including those with aphasia, a subsidiary aim of the project was to develop and psychometrically evaluate a new patient-reported measure. This measure is the 19 item Stroke Social Network Scale (SSNS), and its development is reported in detail in Northcott & Hilari (2013)[222]. A copy of this paper is included in Appendix Six.

The content of the Stroke Social Network Scale was derived from three sources: a set of questions forming a preliminary version of this questionnaire, used in previous research with those who have chronic aphasia following a

stroke[173, 224]; a review of the literature; and a review of existing instruments. A conceptual model was developed which had five core subdomains: size of network; composition of network; frequency of contact; proximity; satisfaction with network. Twenty-two potential items were then adapted by expert clinicians so that they were accessible to those with aphasia. Of these initial 22 items, three were eventually deleted as they failed a number of psychometric criteria.

Principle axis factor analysis with varimax rotation was used to identify a subdomain structure with sound psychometric properties and conceptual integrity. The final model for the 19 item Stroke Social Network Scale explained 63% of the variance, and included five factors: Satisfaction with network; Children; Relatives; Friends; Groups. All items loaded >0.40, and there was no cross loading on different factors.

The scale demonstrated good internal consistency ($\alpha = 0.85$ overall score; $\alpha = 0.74$ to 0.87 subdomains); acceptability (low item non-response and no floor/ceiling effects); and convergent ($r = 0.34$; $r = 0.53$) and discriminant validity ($r = -0.10$; $r = -0.19$). It was also able to differentiate between known groups: those who felt better supported (scored ≥ 4 on the MOS Social Support Survey, $n = 42$) had higher SSNS scores, than those who felt less well supported (scored < 4, $n = 30$); $t(70) = -2.60$, $p = 0.01$. In terms of responsiveness, there were moderate changes from two weeks to six months ($d = 0.32$; standardised response mean (SRM) = 0.46), with the Friends factor, as

expected, showing more change than the Children's factor (Friends factor: *d* = 0.46; SRM = 0.50; Children's factor: *d* = 0.06; SRM = 0.19).

In terms of scoring the measure, some items were not applicable: for example, for people who had no children, items relating to contact with children were not applicable. In these situations the imputed score given was 0 ('not at all'). Equally participants were not asked to rate their satisfaction with an element of their social network that was absent. In this situation, the overall satisfaction score was imputed. Finally, in order to reduce the effect of outliers, a decision was taken to cap the number of friends, relatives and groups. The rationale for where to place was the cap was that aggregate endorsement frequencies should be >10% [225]: ie that adjacent response options for an item should together account for at least 10% of the respondent answers. Raw scores were converted to have a range of 0 – 100. The overall score is the mean score of all items. Lower scores are indicative of a participant having fewer social ties.

In summary, the SSNS demonstrated good internal consistency, validity and responsiveness to change. It can be used to measure the social networks of both those with and without aphasia following a stroke: those with mild-moderate receptive aphasia and even severe expressive aphasia are able to complete the questionnaire.

Validation of the Stroke Social Network Scale was part of the larger project, and as such, used the same participants. To avoid circularity, all psychometric analyses other than responsiveness were conducted on the three month data set. When the Stroke Social Network Scale was used in multiple regression

analyses (see Chapter Five), only the baseline and six month data sets were used.

3.4.3. Psychological distress: General Health Questionnaire-12

Psychological distress was assessed using the General Health Questionnaire – 12 item version (GHQ-12) [221]. The GHQ is a screening device, designed to identify psychiatric disorders in the general population. It focuses on two main areas: the inability to carry out normal functions, and the appearance of new and distressing phenomena[226]. It assesses a person's current state, and asks if that is different from their usual state: as such, it is sensitive to short-term psychiatric disorders rather than long-standing difficulties. There are four versions, of which the GHQ-12 is the shortest.

The GHQ has been extensively validated with different population groups (see McDowell and Newell, 1996, for an overview[60]), including with people who have had a stroke. Johnson *et al.* (1995) compared the GHQ to the Hospital Anxiety and Depression Scale (HADS)[227] and found it to have better specificity, sensitivity and predictive validity with those who have had a stroke[228]. Indeed, the GHQ-12 is one of the tools recommended in the National Clinical Guideline for Stroke to screen for depression[33].

In this project, the GHQ-12 was chosen rather than any of the longer versions. The GHQ-60 includes questions relating to physical symptoms, which were answered positively by people who were physically unwell regardless of their mental state[221] . The GHQ-12 has psychometric properties comparable to the GHQ-30 and GHQ-28, and yet it is shorter, thus reducing respondent burden.

There are four response options per item (example response options: not at all; no more than usual; rather more than usual; much more than usual). Goldberg recommends that replies are coded 0-0-1-1, thus each problem is identified as absent or present[221]. Scores range from 0-12 with higher scores indicating greater distress. A cut-off score of two or three can also be used in order to identify those with high psychological distress and in need of further evaluation[27]. It has been previously used with those who have chronic aphasia, and found to be acceptable[172].

3.4.4. Activities of daily living: Barthel Index

The Barthel Index (BI) was used to measure activities of daily living [216]. The BI was originally designed to be used with long-term hospital patients, in order to monitor their functional independence in personal care and mobility. In the 50 years since its development its psychometric properties have been widely assessed, including being tested for validity with stroke patients, with good results[229]. Its predictive validity with this population has also been tested: BI score at admission can be used to predict length of stay, and subsequent progress[230, 231]. It is limited in scope, however, including items relevant to a hospital setting and omitting activities necessary to live independently once in the community, such as cooking or shopping.

The BI is a rating scale to be completed by a health professional or other observer, although it can be self-administered. There are ten activities assessed. Each item assesses how much help an individual needs to carry out that activity. For example, if a person is independent at feeding themselves, they

score 10; if the need help, for example, having food cut up, they score 5; if they are unable to feed themselves, they score 0. Scores range from 0-100, with higher scores indicating better ability to function.

3.4.5. Extended activities of daily living: Frenchay Activities Index

Extended ADL was measured using the Frenchay Activities Index (FAI)[223]. The FAI focuses on general activities rather than personal care, and consists of 15 items. There are three subdomains in the FAI: domestic; leisure/work; outdoors. The validity and reliability of the measure was tested on a sample of 976 stroke patients, who were seen just after their stroke, and then at six months and 12 months post onset. The original study demonstrated good validity, inter-rater reliability and sensitivity to change[223]. Subsequent studies have also demonstrated excellent internal consistency[232], and good test-retest reliability[233]. The activities are those relevant to stroke patients, thus for example there is less emphasis on employment. This scale has been used with those with aphasia in a previous project and found to be acceptable to this population[172].

The scale asks participants to consider how frequently they performed each activity in the last three or six months. Thus at baseline participants were considering their life prior to the stroke. Scores range from 0-45, with higher scores indicating better functioning. There is one item in the FAI which relates to gardening, which was usually not applicable to participants without a garden. In these cases, this item was imputed using the participant's mean score on the measure.

3.4.6. Aphasia: Frenchay Aphasia Screening Test

The Frenchay Aphasia Screening Test (FAST)[218] was used to screen whether participants had aphasia. The FAST has four subscales which measure: comprehension; verbal expression; reading; writing. The FAST was designed to be administered quickly and easily by non-specialist health practitioners, taking between 3 and 10 minutes to administer[234]. It has been shown to have good reliability[234, 235], and also validity: excellent correlations were reported between the FAST and the Functional Communication Profile[236] at both 15 days post stroke (r = 0.87) and for those with chronic aphasia (r = 0.96)[237] and also between the FAST and the Sheffield Screening Test for Acquired Language Disorders[238] (r = 0.89)[239]. Although responsiveness has not been formally evaluated, Enderby *et al.* (1987) did find that FAST scores changed significantly in the expected direction during repeat administrations of the test[234].

Although the FAST has reasonable sensitivity (Al-Khawaja *et al.* (1996) report it as 87%[239]), its specificity can be adversely affected by the presence of visual field deficits, visual neglect, illiteracy, deafness or poor concentration.[234, 239, 240] Thus it was used and interpreted cautiously with participants who demonstrated these conditions.

It has 30 items, and scores range from 0 to 30, with higher scores indicating better language function. Scores can also be calculated for a shorter version which comprises only the comprehension and expression sections, for a score that ranges from 0 – 20. The sensitivity of this shortened version of the FAST is

reported to be comparable to administering the complete assessment[234], and has the advantage of not being affected by either illiteracy or motor difficulties with writing.

3.4.7. Stroke severity: National Institute of Health Stroke Scale (NIHSS)

Stroke severity was measured using the National Institute for Health Stroke Scale (NIHSS)[215]. It is a 15-item scale, used to examine neurological impairment. It assesses: level of consciousness, extraocular movements, visual fields, facial muscles, arm and leg motor strength, sensory function, coordination, language, speech, and neglect[241]. Each item is scored from 0 -2, 0 -3, or 0-4. Total scores on the NIHSS range from 0 – 42 with higher scores reflecting more severe strokes. It is also possible to categorise people into mild, moderate or severe strokes using their NIHSS scores[242, 243]. Those with mild strokes (scoring 0 – 5) are associated with discharge home; those with moderate strokes (scoring 6 – 12) associated with acute inpatient rehabilitation needs; those with severe strokes (scoring over 13) likely to be discharged to a care setting.

The NIHSS has established reliability and validity. For example, inter-rater reliability has mostly been reported as excellent[244], although less good where raters were not trained[245]. Studies have also demonstrated adequate to excellent test-retest reliability[215]; excellent convergent validity (high correlation between NIHSS scores and infarct volume)[215]; and good predictive validity (predictive of clinical outcome, recovery, discharge destination)[243].

The examination takes less than 10 minutes to complete[215], although it can also be estimated from medical notes detailing neurological examination at admission[246]. In order to be able to administer this assessment at the three and six-month assessments, all those involved in data collection on this project watched a 45 minute instructional video, a training method with established reliability.[247]

3.4.8. Health-related Quality of life: Stroke and Aphasia Quality of Life 39g

A primary aim of the broader study that this project was a part of was to validate the Stroke and Aphasia Quality of Life 39-item scale[220] in a generic stroke population. This measure was not used in multiple regression analyses in the present study in order to avoid issues of circularity. Further details of the psychometric validation of this scale are provided in Hilari *et al.* (2009)[214]. It was not used in the data analysis of the current thesis.

3.4.9. Other information collected

In addition to the measures outlined above, further information was gathered both from the case history, and from the medical notes. The following demographic information was collected: age, sex, ethnic group, employment prior to the stroke. The number of co-morbid conditions was collected initially via the medical records, and then corroborated with the participant during the case history. The medical notes were also used to classify whether the participant had suffered an ischaemic or haemorrhagic stroke.

3.5 Data Analysis: Stage One

Descriptive statistics are provided for the different scales used in Chapter Four. To analyse how levels of perceived social support and social network change over time (RQ1 and RQ2), one-way repeated measures ANOVAs were used. Post hoc tests were carried out using Bonferroni correction. To examine whether stroke survivors with aphasia are different from those without on social support measures (RQ3), independent t-tests were used on the six month data. To explore predictors of social network and social support (RQs 4-7), standard multiple regression was carried out and the methods are detailed in Chapter Five. Finally, to explore which network members provide what functional support (RQ11), Pearson product-moment correlation coefficient was used. Other research questions were addressed using qualitative data analysis, which is described below (see 3.8).

All statistical analysis was carried out using IBM SPSS Statistics 19 for Windows, and statistical tests were 2-tailed.

3.6 Stage Two: Sampling procedure for qualitative interviews

3.6.1 Designing a sample

Purposive sampling was used to ensure that participants chosen for Stage Two symbolically represented the stroke population. The aim was to include

individuals who had key characteristics that were of relevance to the study, such as good or poor support systems[185]. In addition, less common combinations of characteristics were sought to explore the diversity of experience (for example, feeling well supported even though living alone and elderly; feeling poorly supported despite a large social network). The aim was to recruit enough participants in order to represent the range of experiences.

3.6.2 Selection criteria

Deciding who to include in Stage Two was determined by pre-set selection criteria. These selection criteria were used to create a sampling matrix (see below, Figure 3.2). The purpose of the matrix was to ensure that selection was systematic, and captured the different patterns of social support experienced.

Primary criteria used to create matrix

Social support. This was determined according to their score on the SSS at six months. Participants were grouped according to whether they scored in the top, middle, or bottom third of the sample population.

Aphasia. Since a primary aim of the project was to compare the different social experiences of those with and without aphasia, a decision was made to over-represent those with aphasia. Thus while people with aphasia are reported to make up 15% of the long-term stroke population [25], the aim was that 30% of participants at Stage Two should have aphasia. People were defined as having aphasia from their FAST scores, using the cut-off scores described by Enderby *et al.* (1989)[218]. There was one exception: a participant who scored in the

‘normal’ range, but where both clinical judgement and participant perception indicated the presence of aphasia.

Severity of stroke: Stroke severity was another primary selection criterion. Stroke severity was measured using the NIHSS. Participants were divided into three groups according to their NIHSS scores at baseline: mild (≤ 5), moderate (6-10), and moderate to severe (11+), the cut-off points derived from studies examining the predictive validity of the NIHSS[243, 248]. Those scoring 13 or over are reported to be more likely to experience poor outcomes (either death or long-term nursing facility). A decision was made not to include targets for recruiting these more severe strokes, as the primary focus of the research was not investigating social support on going to a nursing home.

Age: A young person with work and family responsibilities will face different challenges to an older retired person following a stroke. This meant age was another primary criterion for selection. The two main categories were over 65, ie retired, or 65 and under. Furthermore, targets were set to ensure that the oldest old (over 80) and the youngest stroke survivors (under 50) were also included so that a range of different age groups were represented.

Secondary criteria

In addition to the primary selection criteria outlined above some further criteria were set. These were:

Additional social support factors (using data collected six months post stroke): these included size of network, number of close friends, whether living

alone, marital status. Specific targets were set, which are displayed in the sampling matrix (Figure 3.6.2), for example, the target of recruiting at least two people with no friends.

Gender: The number of men and women recruited was monitored to ensure the project represented both perspectives.

Ethnic background: The ethnicity of the sample was monitored to ensure it mirrored the ethnic make-up of the larger stroke population from which it was being drawn. Thus those from ethnic backgrounds were over-represented compared with the general population.

3.6.3 Deciding who to interview

As participants became eligible for qualitative follow up (ie at least eight months post stroke) their characteristics were checked against the matrix. Participants were contacted if they fulfilled the requirements to fit into a vacant cell in the sampling matrix, with further consideration given to secondary selection criteria. Those with aphasia and the youngest stroke survivors were preferentially included to ensure they were adequately represented.

All participants with aphasia from Site One were potentially eligible to take part, including those who had scored <7/15 on the receptive domains of the FAST at baseline, and had remained involved in the project via their proxies. Where there were additional concerns about health status (for example, end stage cancer) or level of consciousness, participants were not invited to take part in Stage Two.

Figure 3.2 Sampling matrix

	Moderate-Severe stroke NIHSS 11+		Moderate stroke NIHSS 6-10		Mild stroke NIHSS 0-5		
Good social support SSS≥ 4.2 (at 6 months post stroke) At least 5: network ≥12 At least 2: network <7 At least 3: > 4 friends At least 2: living alone	≤ 65 yrs;	>66 yrs	≤ 65 yrs;	>66 yrs	≤ 65 yrs;	>66 yrs	
	1-2	1-3	1-2	1-3	1-2	1-3	8-12
Moderate social support SSS >3.5 <4.2 (at 6 months post stroke) At least 5: network 7-11.5 At least 2: network <7 At least 2: network≥12 At least 3: living alone At least 3: not living alone	1-2	1-3	1-2	1-3	1-2	1-3	8-12
Poor social support SSS ≤ 3.5 (at 6 months post stroke) At least 5: network 0-6.5 At least 2: network≥ 12 At least 2: 0 friends At least 3: not living alone	1-2	1-3	1-2	1-3	1-2	1-3	8-12
Gender	At least 4 ♀		At least 4 ♀		At least 4 ♀		
	At least 4 ♂		At least 4 ♂		At least 4 ♂		
	8-12		8-12		8-12		c. 30

Monitoring:
People with aphasia: at least 10
Age: Over 80: At least 5
Under 50: At least 3
Ethnic background: 20-25% of sample to come from non 'White British' background

3.7 Stage Two: Data Collection

3.7.1 Content of the interviews

A topic guide was used, providing a loose structure for the interviews (see Appendix Seven). The guide did not include specific questions, but flagged up areas to be covered. The order in which topics were discussed varied from participant to participant, following in an organic way from participant responses.

The following areas were covered during the qualitative interviews:

- **Social network.** A 'map' of current social contacts was constructed: who they were in contact with (face to face, telephone, other), what they do together, where they saw them, how this was arranged.

- **Changes.** A considerable part of all interviews was exploring how social contacts and relationships had changed since the stroke, and reflect on the causes and impact of the change. This could include discussion of other factors, such as stroke related disability, depression, or their aphasia.

- **Friendships.** Since the literature suggests that friendships may be particularly vulnerable post stroke[170, 173], an aim of the interviews was to unravel what was causing the disintegration of friendships, when and how it was happening, and what it meant to the participants. An additional aim was to explore whether there were protective factors, or ameliorating circumstances. The interviews also included discussion of

what makes a ‘good’ friend, what could be expected from a friend, and what role they had played post stroke.

- **Family.** The literature suggests contact with family is generally maintained[2]. The qualitative interviews aimed to explore how having a stroke had impacted on family relationships and family roles, and how this was perceived by the individual. A subsidiary aim was to explore the different expectations that are placed on family versus non-family members when chronically unwell.

- **Wider social contacts.** The social ‘map’ constructed at the beginning of the interview was used to find out about the more distal parts of a person’s social network, such as shopkeepers, wardens, hairdressers, volunteers, stroke groups. Part of the interview explored the value placed on this contact with the wider community, and whether this had also been compromised by having a stroke.

- **Professional support.** Part of the post stroke experience is generally increased contact with various professionals, both health professionals, and others such as social services and carers. This was often a new element to a person’s support system, and its role in the person’s life was discussed. This material was not analysed in the present thesis, however.

- **Types of support**. The different functions of support were probed during each interview. In particular, the participants were asked about the support functions that comprise the Social Support Survey

(emotional, tangible, informational, and 'social companionship' support). For example, there was discussion about who provided it, what it meant to them, whether it had been helpful since the stroke. The interview also explored whether there were types of support they didn't receive, or support that was unhelpful.

- **Adjusting to post stroke life.** The interviews explored the role of others in facilitating participants' recovery and adjustment to post stroke life and identity.

Four pilot interviews were carried out.

3.7.2 Style of interviews

A key aim in conducting the interviews was to ensure that participants felt relaxed and able to talk about the topics in depth. Various techniques were employed to this end. From the start, participants were encouraged to amplify and expand upon their answers. Careful consideration was given to how questions were asked: the aim was to use open questions, with clear language, where possible using the participants' own expressions. Lengthy preambles, double questions, or complex or technical language was avoided. Content-mapping questions were asked to achieve breadth of coverage and 'open up' an area (for example, 'Can you tell me about who you saw last week?'), and content mining and a variety of in-depth probing techniques to achieve depth[249] (for example, 'When you say you felt stuck, can you tell me a little bit more…?'). Plenty of time was allowed for people to reflect and reply.

The interview was formulated in different stages[250, 251]. As stated by Legard *et al.* (2003), 'the researcher's task is to ease the interviewee down from the everyday, social level to a deeper level at which they can together focus on a specific topic' (p144)[249].

In the initial stage the aim was to set the scene, negotiate the terms of the interview, and facilitate a relaxed atmosphere. Initial questions were not controversial or taxing to answer, but were a chance to show the 'rules' of the interview: ie fluid structure, open ended answers. Since I had extensive knowledge about the interviewees prior to the interview, I could tailor these initial questions to avoid introducing upsetting topics at this early stage. The interview then moved on to mapping the participants' current social network. In particular, they were asked who they had been in contact with during the previous week, or if that was not a typical week, then who they'd see in a typical week. Talking about their current life, what they do and who they see now, is potentially more straightforward than, for example, asking them about life 12 months earlier. It also provided me with various leads for later in the interview (for example, the shopkeeper they chat to every morning). It was also relatively factual and not emotional, unless the interviewee chose to expand on how they felt.

In the second stage of the interview, I started to explore with participants potentially more painful topics: how their life had changed, how they felt about that, what had caused the changes. From this stage onwards, I started to probe answers, and explore emotions and meaning. As the interviews progressed, and

most topics had been covered, I would return to any inconsistencies, 'puzzles', areas left unresolved, or areas that had been previously evaded, and explore them further.

In the final stage of the interview, I signalled that we were coming towards the end. The aim of this final part of the interview was to 'restore' the participant, to bring them up to the surface once more. It was also a chance for the interviewee to bring up any final issues or thoughts. I chose questions that were relatively positive, to leave the interview on an upbeat note: asking them for advice, and asking them what had really helped since their stroke. At the end of the interview, I gave further reassurances about confidentiality, and discussed what would happen next, and engaged in more normal 'social' conversation, ensuring that the participant was left, as much as possible, feeling 'well'[249].

3.8 Stage Two: Data Analysis

All the interviews were transcribed verbatim. Pauses were marked, as was tone of voice. For those with aphasia who chose to write their responses, this was also included in the transcripts. Participants' non-verbal gestures, especially those of people with aphasia, were described as the interview took place, and were also transcribed for analysis.

The method used for analysing the data in this project was the 'Framework' method[252], developed at the National Centre for Social Research. This method has been successfully used when analysing interviews with people who have

had a stroke, including those with aphasia[104]. Initial themes and concepts were identified through reviewing the data. These were then used to construct a thematic index (see Appendix Eight). All the material was then indexed, such that each phrase or sentence was assigned a label. Thematic charts were constructed, the chart headings evolving from the indexing process. The labelled data were then summarised and synthesised into these matrices. This matrix based method of analysis allows both thematic and 'case' based analysis, enabling systematic exploration of the range and pattern of views and experiences. A copy of Charts Two (Family) is presented in Appendix Nine as an example.

A descriptive account of the data is given in Chapters Six to Nine. Explanatory analysis is also presented, for example, identifying patterns and developing explanations[253].

3.9 Stage Two: Ensuring quality and lack of bias

Data collection stage: Various strategies were used to avoid biasing participants' responses. In terms of questioning techniques, leading questions were avoided and a conscious effort was made not to finish off sentences. Although participants were often asked to expand, clarify, or explore their responses, an attempt was made not to summarise or comment on their answers to avoid communicating judgements or assumptions, which could in turn shape future responses. I listened back to recordings of interviews throughout the data

collection stage to monitor my interviewing techniques. Furthermore, two early interviews were listened to by a senior researcher who gave feedback helping to ensure that the interviews were non-biased and open-ended. I also received specialist training in carrying out in-depth qualitative interviewing.

Writing field notes after each interview gave an opportunity for me to reflect on how the interviews related to my own life and values. This potentially enabled me to identify any issues which could influence my response to the data.

Data analysis stage: all the different stages in the iterative analytic process were carried out through discussion between myself and a senior researcher, helping to avoid bias and subjectivity. For example, the senior researcher selected a portion of charted material in order to give feedback on themes that I had drawn out of the data.

3.10 Including people with aphasia (PWA)

A focus of my research was to compare the life experiences of people with and without aphasia following a stroke. It was therefore important to facilitate the participation of people with aphasia (PWA).

3.10.1 Stage One: Questionnaires

Ensuring that people with aphasia could self-report on all the measures used was a key part of the project, and therefore all measures were reviewed for their linguistic complexity. The content of the measures remained unchanged to avoid invalidating their psychometric properties; however, changes were made to presentation and administration, using methods that have been tested and

recommended in previous studies[195, 219, 254]. A variety of adaptations were made. Participants both heard and saw all the questions. The written version was designed to be easily comprehended: use of white space, large font size (14 - 16pt), key words emboldened, pre-prepared pictures to support comprehension of key concepts where appropriate. Possible answers were displayed so that participants could point to an appropriate response. Practice items were introduced to enable participants to understand the format of each questionnaire. Only a few items were presented on each page. The presenter's forms for the Social Support Survey and the Stroke Social Network Scale are provided in Appendix Ten. The information sheet and consent forms were similarly adapted to be accessible to people with aphasia (see Appendix 11).

The Stroke Social Network Scale was specifically developed for use with people with aphasia. Further, three of the measures used had previously been adapted to be accessible to people with aphasia (the SSS, FAI and GHQ-12) for use in a previous project[173, 224]. There was minimal missing data reported, suggesting that they were acceptable to this population. The presenter's forms used in this former study were adopted in the present project.

The interviews were carried out by aphasia-specialist speech and language therapists. All modalities of communication (for example, gesture, drawing, writing) were used to facilitate both comprehension and expression of participants. The only limitation was that participants needed moderate comprehension: only those scoring $\geq$ 7/15 on the receptive domains of the FAST were able to complete the measures used in Stage One. As indicated

above (3.3.1), those scoring less than 7/15 were invited to nominate a proxy, and their results are not reported here.

3.10.2 Stage Two: Qualitative interviews

Conducting qualitative interviews presented different challenges. As Legard, Keegan and Ward (2003) describe, 'The interviewee's role is to give fulsome answers, to provide more depth when probing questions are asked, to reflect and to think… their role involves opening up and talking as opposed to giving simple answers.'[249] Traditionally, then, an interviewer will ask open questions. This approach, however, creates problems for some PWA. In this project, the following decisions were taken:

Firstly, a booklet (see Appendix 12) was brought to the interview with the topics laid out, using simple language, with key words emboldened, and making use of font size, colour and white space to aid comprehension. This book was used flexibly, thus preserving the ability to cover topics as they came up, while still giving a level of 'scaffolding' to the interaction to aid comprehension.

More controversially, this booklet also included possible answers. Answers were generated from previous interviews carried out in the project, and from the literature, for example, Parr *et al.* (1997)[104] . This resource was used judiciously for people with severely reduced expressive output, who used it both as a short cut in providing/clarifying answers, but also as a springboard for further discussion.

In addition, the following measures were used to facilitate PWA:

- **Time.** Extra time was allowed for the interview. This meant that participants felt they had as much time as they needed to convey whatever was important to them. For example, one participant was asked why his friends were important to him. It took him over six minutes to write his reply: 'They are the only think [thing] I have.' Writing was a challenge for this participant, both physically (use of non-dominant hand) and linguistically. This sentence about his friends was an emotional moment for the participant, and arguably required support and sensitivity to make the silence comfortable as he attempted to write. The interview as a whole took over two hours, with the participant repeatedly assuring me he wished to continue.

- **At participants' home.** Interviews were all carried out in the participants own home, so they could refer to objects in their environment, for example photographs and calendars, and had ready access to any communication aid, such as a communication passport.

- **Total communication.** I carried out all the interviews myself. As a trained SLT with experience of working with this client group, I took care to modify my own language, and use and be responsive to any communication modality favoured by the participant, for example writing, gesture etc.

- **Careful choice of questions.** Where possible, simple, clear, open questions were used. However, on occasion, greater use of closed

questions was made for PWA than would normally be the case during an in-depth qualitative interview. Every effort was made, however, to avoid introducing bias.

- **Familiarity.** I already knew participants by the time the qualitative interview was carried out, as I had met them on at least two, and mostly three previous occasions to conduct the survey questionnaires. This arguably aided my ability to unpack the issues that were important to them, as well as giving me familiarity with their family structure, names of significant people and so on, which helped to reduce the load of information they needed to impart to me during the interview.

- **No proxies.** For both those with and without aphasia, the interviews were conducted directly with the individual, where possible in a one to one setting. This was perhaps particularly important, however, for those with aphasia, as it circumvented the tendency for others to speak for them.

- **Verbal feedback.** During the interviews, I verbally commented on the participants' non-verbal gestures, which ensured their meaning was correctly understood, and also meant there was a verbal record on the transcript to be analysed later. In addition, field notes were made shortly after all interviews, making reference to non-verbal occurrences.

The following excerpt demonstrates some of the issues involved in interviewing PWA. Chris was only able to say yes, no, counting and some swear words. He was not able to write.

> SN: Is there anyone who you feel you can relax with and have fun with?
>
> Chris: No
>
> SN: And why is that? [pause] Is that the same reason for the emotional support, to do with the language?
>
> Chris: No
>
> SN: It's not particularly to do with the talking.
>
> Chris: No
>
> SN: To do with the walking? That you're not sharing those activities, like sports?
>
> Chris: Yes, yes.
>
> SN: So that kind of companionship you used to get that through going to see, looking at Arsenal or looking at cricket?
>
> Chris: Yes, yes, yes, yes, yes, yes, yes, yes.
>
> SN: OK. Do you feel like I've understood what you were trying to say for those different types of support?
>
> Chris: Yes.

Several points are illustrated. Firstly, that although Chris only says 'yes' and 'no', he is able to be expressive and give emphasis, for example, through repeating 'yes' eight times when he felt I had understood correctly. Secondly,

the only open question used (line 4) does not get any response, and I needed to use closed questions to move the interview forward. Thirdly, the time I spent prior to the interview showing an interest in Chris' communication book was helpful, in that it made me aware of his interest in Arsenal and cricket. Fourthly, I clarified whether I had understood correctly. In other parts of the interview when asked a similar question, Chris felt able to tell me that I hadn't understood. Although it is not usual in an in-depth interview, constant checking was helpful with this participant.

While Chris does not provide the richness of detail typical of a qualitative interview, he does, nonetheless, manage to convey both factual information and how he feels. Clearly there are issues relating to the greater role the interviewer plays in assisting, and so potentially shaping, his responses. Nonetheless, it was arguably a compromise worth making in that it meant his story could be heard alongside those with no language difficulties.

3.11 Ethical considerations

Ethical approval was obtained from City University, London, and also the participating National Health Service Local Research Ethics Committees (see Appendix Two). Informed, written consent was gained for each stage of the project, including giving potential participants accessible information about the project, and time to consider and discuss whether or not to take part with their families. No pressure was put on potential participants to take part, and they were reassured that their care would not be affected in any way if they declined or withdrew.

Issues of confidentiality and privacy were respected at all times. When interviews were carried out in hospital, where possible, they took place in a private side room. For those who were bed bound and unable to leave the ward, they were given the option of pointing to responses to protect their privacy. All data was anonymised and kept confidential. Names and identifying details have been changed throughout this thesis, as well as in other forms of dissemination.

Respondent burden was considered. Where possible, shortened versions of scales were used (for example, the GHQ-12). Where there was a choice of appropriate measures, shorter scales were chosen (for example, the SSS). Participants were given the option of completing interviews over several sessions, if they preferred, or, indeed, withdrawing their involvement in the project at any time.

Of particular concern in the present project was the potentially distressing nature of the interview material, combined with the prevalence of depression in the post stroke population[27] . In order that the interviews were a positive part of their post stroke journey, various supportive measures were put in place. Firstly, I allowed flexibility in how long each interview took, depending on how much the participant wanted to reflect upon and discuss their responses so that participants felt supported rather than rushed as they considered how the stroke was affecting their lives.

Relevant support material was also provided. This included:

- Written material and leaflets, such as leaflets from Age Concern and the Stroke Association (for example, explaining what a stroke is, about depression following stroke, about reducing the risk of future strokes)

- Contact numbers of relevant charities and support groups. I also made contact with local branches and organisations to discuss what services they provided prior to commencing interviews. The researcher compiled a list of potentially useful telephone numbers and passed these on to participants as appropriate: for aphasia (Connect, Speakability); for stroke (Stroke Association); for support as an older person (Age Concern, Counsel and Care for the Elderly; Contact the Elderly; The Community Network for Older People); for depression (Depression Alliance, Saneline, Mind Info Line, Good Samaritans, British Association for Counselling and Psychotherapy); for carers (Carers National Association; Princess Royal Trust, Cross Roads).

- Information about local services, for example, local groups, Good Neighbour Schemes, personal alarm systems, transport schemes such as dial-a-ride

- Services based in both the acute hospital and rehabilitation units

Participants were also facilitated in accessing other services, such as the Citizen's Advice Bureau, further rehabilitation, negotiating benefit helplines, or contacting the Camden Volunteer Bureau to enable a participant to take up volunteering in his community. On occasion, with the consent of the

participant, and where I had serious concerns about the participant's mental health, their local GP was contacted.

As pointed out by Lewis (2003)[255], a researcher is not a counsellor, and this distinction in roles was maintained, hence the emphasis on putting participants in touch with people and organisations who could provide on-going support. The following quote illustrates the potentially unsettling nature of the interview process, however, and the consequent sensitivity required of the interviewer: *'You're the only person who listens to me, really. ...you're the only person I've talked to about this sort of stuff… how the situation is right now. The first person.'*

3.12 Summary

This chapter described the approach taken in order to examine perceived social support and social networks following a stroke. It outlined the two-stage design: a repeated measures cohort study in the first six months post stroke, followed by in-depth qualitative interviews roughly one year post stroke. The measures used to quantify social support were discussed, and included an established measure of perceived social support, the MOS Social Support Survey, and a newly developed measure of social network, the Stroke Social Network Scale. Details of the other measures used as potential predictors of perceived social support and social network were also provided. In terms of the qualitative arm of the project, information was given about the sampling procedure, topic guide, and how the data was analysed. Finally, the ways in which the interviews, both qualitative and quantitative, were modified so as to

include people with aphasia was discussed, as were the ethical considerations in conducting such potentially sensitive interviews.

Chapter Four. Participant characteristics and descriptive statistics

This chapter presents participant characteristics for both Stage One and Stage Two of the project. Descriptive statistics for the measures used are also provided, and change over time is analysed. In addition, the social support and social network of those with aphasia is compared to those without.

The following research questions are addressed in this chapter:

RQ1: Do pre-morbid levels of perceived social support change over time following a stroke?

RQ2: Does a person's pre-morbid social network change over the time following a stroke?

RQ3: Are stroke survivors with aphasia different from those without aphasia on measures of social support and social network?

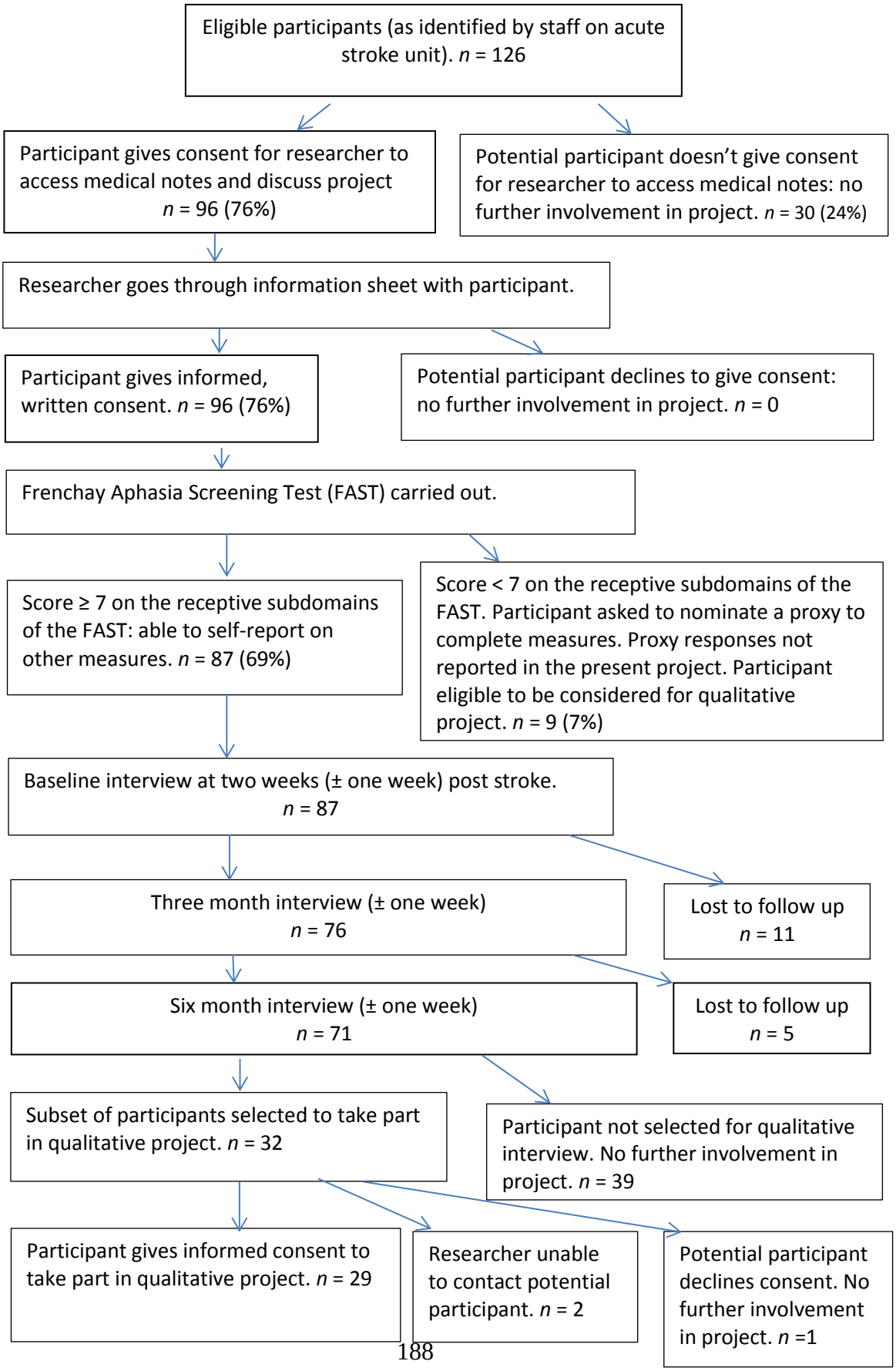
4.1 Participant characteristics: Stage One

The sample in this study is the same as that reported in Hilari *et al.*(2009)[214]. Of 126 eligible people, 96 (76%) agreed to take part. For those who decided not to take part, the researchers did not have consent to access their medical records, therefore it is not possible to determine whether their characteristics differed from those who did agree to participate. Nine participants of the 96 had severe receptive aphasia and for those participants proxy respondents were

used: these results are not reported here. Of the 87 remaining participants, 76 (87%) were followed-up at three months, and 71 (82%) were followed-up at six months. There was no significant difference between those who were followed up, and those who were not, on any baseline variable (demographics, stroke severity, ADL, aphasia, psychological distress, perceived social support and social network).

Figure 4.1 summarises the different stages of the project.

Figure 4.1 Participant flow in the project



Demographic characteristics

Table 4.1 presents the characteristics of the 87 people who participated in this study. The majority were white (75%) and male (60%). Roughly half were married or had a partner (52%), and the majority of participants were living with someone (55%). The average age was 70, with the youngest participant aged 18, and the oldest 91. In terms of pre-existing health problems, at the time of the stroke, 12% had no other co-morbidities; 40% had one or two co-morbidities; 48% had three or more co-morbidities. Prior to the stroke, 65% of participants were not working; this rose to 86% of participants six months post stroke. Other than employment status, participant characteristics at three and six months were similar to the overall sample.

Table 4.1 Participant characteristics for Stage One

Variable	Respondent n (%)		
	Baseline	3 months	6 months
	n = 87	*n* = 76	*n* = 71
Gender			
Female	35(40.2)	32 (42.1)	31 (43.7)
Male	52 (59.8)	44 (57.9)	40 (56.3)
Age			
Mean (SD)	69.7 (14.1)	69.7 (14.0)	69.3 (14.1)
Range	18 – 91	18 – 91	18 – 91
Ethnic group			
Asian	10 (11.5)	9 (11.8)	9 (12.7)
Black	6 (6.9)	5 (6.6)	5 (7.0)
White British	65 (74.7)	57 (75)	52 (73.2)
White non-British	6 (6.9)	5 (6.6)	5 (7.0)
Marital status			
Married/ has partner	45 (51.7)	40 (52.6)	38 (53.5)
Single, divorced or widowed	42 (52.2)	36 (47.4)	33 (46.5)

Living arrangements			
Living alone/ in an institution	38 (43.7)	33 (43.4)	31 (43.7)
Living with someone	48 (55.2)	42 (55.3)	40 (56.3)
Employment status			
Full-time paid work	19 (21.8)	4 (5.3)	6 (8.6)
Part-time or voluntary work	11 (12.6)	8 (10.7)	4 (5.7)
Not working	57 (65.5)	63 (84.0)	60 (85.7)
Co-morbid conditions			
None	10 (11.5)	8 (10.5)	8 (11.3)
One	14(16.1)	13 (17.1)	12 (16.9)
Two	21 (24.1)	19 (25.0)	18 (25.4)
Three	18 (20.7)	17 (22.4)	16 (22.5)
Four +	24 (27.6)	19 (25.0)	17 (23.9)

4.2 Participants characteristics: Stage Two

32 participants were selected to take part: 29 consented, two were no longer contactable, and one declined. Participants ranged in age from 18 to 90 years old, 12 were ≤ 65 and 13 were working prior to the stroke; 12 participants were women; and roughly half (15) were white British. Stroke severity (NIHSS) scores ranged from two (mild) to 21 (severe), mean (S.D.) 9 (5.5). In terms of social factors, they ranged from having no friends to having 20 close friends; 17 lived with family members, nine lived alone, two lived in sheltered housing and one lived in a nursing home; 14 were married; and 21 had grown up children. 10 participants had aphasia. In terms of their FAST scores at the baseline interview (two weeks post stroke) seven had severe expressive aphasia (expression scores on the FAST 0-3 out of 10), of which two also had severe receptive aphasia (auditory comprehension scores on the FAST 0-3 out of 10). By the time of the qualitative interview, clinical judgement indicated two participants persisted with severe expressive aphasia, and a further five participants had moderate expressive aphasia of which two also had mild

receptive aphasia. Figure 4.2 shows how the participants fit into the sampling matrix, while Table 4.2 gives further information on participant characteristics for Stage Two.

Figure 4.2: Distribution of participants in the sampling matrix

	Moderate-Severe stroke (NIHSS 11+)		**Moderate stroke** (NIHSS 6-10)		**Mild stroke (**NIHSS 0-5)	
Good social support*	≤ 65 years old	66+ years old	≤ 65 years old	66+ years old	≤ 65 years old	66+ years old
	♂; age: 63; **(aphasia)** Friends: 20 ♂; age: 58; Friends: 1	♀; age: 82; Friends: 1.5 Living alone	♀; age: 65; Friends: 20	♂; age: 74; Friends: 5	♂; age: 57; Friends: 4	♀; age: 76; Friends: 4; Living alone ♂; age: 75; Friends: 2
Moderate social support*	♂; age: 65; Friends: 9 ♂; age: 65; **(aphasia)** Friends: 0	♀; age: 68; **(aphasia)** Friends: 0 Living alone ♂; age: 66; Friends: 3	(n = 0)	♂; age: 76; Friends: 1 Living alone	♂; age: 65; Friends: 0	♀; age: 86; Friends: 3 Living alone ♂; age: 69; **(aphasia)** Friends: 7 ♂; age: 76; Friends: 5 ♀; age: 90; Friends: 2-3
Poor social support*	♂; age: 58; **(aphasia)** Friends: 0; Living alone ♂; age:48; **(aphasia)** Friends: 5; Living alone ♂; age: 63; **(aphasia)** Friends: 4-5	♀: age: 66; **(aphasia)** Friends: 0 Living in nursing home	♂; age: 18; Friends: 1	♀; age: 74; **(aphasia)** Friends: 4 Living alone ♀; age: 74; Friends: 2 Living alone ♀; age: 78; Friends: 4-5	♀; age: 62; **(aphasia)** Friends: 4	♀; age: 83; Friends: 3; Living alone ♂; age: 68; Friends: 3

Explanatory note: * **Social support** as measured by the MOS Social Support Survey six months post stroke (Sherbourne and Stewart, 1991): participants grouped according to whether they scored in the top, middle, or bottom third of the population; **Friends:** number of close friends reported at six months post stroke, defined as 'people you feel at ease with and can talk about what is on your mind'. **Domestic situation:** Participants living with family members unless otherwise stated.

Table 4.2: Participant characteristics for Stage Two

Characteristics		Participant numbers
Gender	Female	12
	Male	17
Age (in years)	Mean (S.D.): 68 (14); Range: 18 to 90	
Ethnic Group	Asian	2
	Black	6
	White (British)	15
	White (non-British)	6
Marital status	Married - Has partner	16
	Single	5
	Divorced - Widowed	8
Stroke Type	Ischaemic	21
	Haemorrhagic	8
Mobility	Walks independently, no limitations	9
	Walks independently, with limitations (e.g. reduced stamina, unsteadiness)	9
	Walks with assistance	5
	Non-ambulant	6
Communication disability	None	18
	Dysarthria	1
	Aphasia	10

4.3 Descriptive statistics for stroke-related and other variables

Table 4.3 provides descriptive statistics for the potential predictors of social support and social network used in multiple regression analysis in Chapter Five. Mean (SD) and range is provided for all scale variables. Where a variable has a skewed distribution (skewness greater than ±1), the median

and interquartile range are also provided. The histograms for all distributions are provided in Appendix 13.

Table 4.3 Stroke-related and other variables: descriptive statistics

Variable	**Baseline** ***n* = 87**	**3 months** ***n* = 76**	**6 months** ***n* = 71**
Categorical variables	**Participants, n (valid %)**		
Stroke type			
Ischaemic	75 (86.2)	67 (88.2)	62 (87.3)
Haemorrhagic	12 (13.8)	9 (11.8)	9 (12.7)
Stroke severity (categories)			
Mild (NIHSS 0 – 5)	50 (58.8)	68 (91.9)	63 (94.0)
Moderate (NIHSS 6 – 12)	28 (32.9)	6 (8.1)	4 (6.0)
Severe (NIHSS 13 +)	7 (8.2)	0	0
*n**	*n*= 85	*n* = 74	*n* = 67
Communication			
Aphasia			
Non-aphasic	55 (63.2)	62 (81.6)	60 (84.5)
Aphasic	32 (36.8)	14 (18.4)	11 (15.5)
Dysarthria			
Non-dysarthric	45 (51.7)	68 (89.5)	67 (97.1)
Mild-moderate dysarthria	33 (37.9)	8 (10.5)	2 (2.9)
Severe dysarthria	9 (10.3)	0	0
Scale variables			
Stroke severity (NIHSS)			
Mean (SD)	5.91 (4.40)	2.04 (2.72)	1.52 (2.12)
Median (IQR)	4 (3.0 – 8.0)	1 (0 – 3.0)	1 (0 – 2.0)
Range	0 – 21	0 – 12	0 – 10
n	*n* = 85	*n*= 74	*n* = 67
Activities of Daily Living (BI)			
Mean (SD)	65.89 (31.64)	89.60 (18.05)	91.23 (15.52)
Median (IQR)	70.00 (41.25–100)	100 (90–100)	100 (90–100)
Range	5 – 100	25 – 100	35 – 100
n	*n* = 84	*n* = 75	*n* = 69
Extended ADL (FAI)**			
Mean	27.94 (8.22)	17.87 (11.79)	19.11 (11.91)
Range	1 – 42	0 – 38	0 – 39
n	*n* = 86		
Other variables			
Psychological Distress (GHQ-12)			
Mean (SD)	4.95 (3.62)	4.20 (3.76)	3.48 (3.62)
Range	0 – 12	0 – 12	0 – 12
Aphasia (Short Frenchay			

Aphasia Screening Test, FAST)			
Mean (SD)	16.51 (3.60)	17.90 (2.90)	18.02 (3.10)
Median (IQR)	18.00 (25 – 29)	19.00 (27–30)	19.00 (27–30)
Range	5 – 20	8 – 20	7 – 20
n	*n* = 83	*n* = 69	*n* = 66

**n* given only when there is missing data
**Baseline FAI scores refer to one month prior to the stroke
NIHSS, National Institute for Health Stroke Scale[215]; SSS, Social Support Survey[48]; SSNS, Stroke Social Network Scale[222]; BI, Barthel Index[216]; FAI, Frenchay Activities Index[223]; GHQ -12, General Health Questionnaire-12[221]; FAST, Frenchay Aphasia Screening Test[218]

Variables with skewed distributions

As was anticipated some of the variables had skewed distributions. Thus the NIHSS, measuring stroke severity, was positively skewed as participants mostly had mild strokes (58.8% at baseline). Further, as participants recovered, NIHSS scores became more positively skewed. Thus by six months 94% scored ≤ 5 (skewness at baseline was 1.15, and by six months 2.07). The Barthel Index, measuring ADL, was not skewed at baseline, but again, as participants recovered they increasingly scored at ceiling, thus this scale became negatively skewed by six months. Finally, the short Frenchay Aphasia Screening Test (short FAST) was negatively skewed, again reflecting that most participants scored at ceiling. This was particularly pronounced pattern by six months, where only 16% of the sample had aphasia.

While some skewness may be expected, this is potentially problematic for carrying out parametric statistical tests which assume a normal distribution. One option is to transform data, for example, through log transforming it[154]. However, there is debate about whether transformation is really the best option.

Both Field (2000)[256] and Tabachnick and Fidell (2007)[154] recommend that in larger samples, the distribution is of less importance. This is due to the central limit theorem, which suggests that in big enough samples, the sampling distribution will be normal. It is suggested that the mean of a large sample will be a reasonable representation of the parent population regardless of the distribution[257]. A sample size of 30 is considered adequate for the sampling distribution to approximate normal[258]. The current sample size is well above this criterion.

Further, there are arguments against transformation. Firstly, in changing the units of measurement in one variable, it may change the differences between different variables, which is of concern for multiple regression[257]. An option is to then transform all the variables (using the same transformation): yet this may worsen the distribution in other variables. The other major concern is interpretability: transformed data is harder to interpret and relate back to the 'real world'[259].

In conclusion, although the distribution of the NIHSS, BI and FAST were skewed, the sample size was reasonably large, and a decision was taken to use non-transformed scores.

Stroke type, stroke severity, and disability

The majority of participants had an ischaemic stroke (86%), with 57% having a mild stroke, 31% having a moderately severe stroke, and 9% having a severe stroke. Stroke severity ranged from NIHSS score of 0 (very mild) to 21 (severe). The severity of participants' stroke symptoms significantly decreased over time: Wilks' Lambda = .41, $F(2, 65) = 45.87$, $p < .001$, $\eta = .58$. Similarly, there was significant improvement in Activities

of Daily Living (BI): Wilks' Lambda = .50, $F(2, 64) = 31.56$, $p < .001$, $\eta = .50$.

There was also significant change in extended ADL (FAI): Wilks' Lambda = .46, $F(2, 68) = 39.63$, $p < .001$, $\eta = .54$. Post hoc comparisons using Bonferoni correction indicated that baseline scores were significantly higher than at three or six months ($p < .001$). Baseline scores refer to the month prior to the stroke. Although six month scores were higher than three month scores, suggesting improvement, this trend did not reach significance. The FAI contained one item on gardening, which was non-applicable to participants without a garden. In this sample, this item was non-applicable to 39% of participants at baseline; 42.1% of participants at three months; and 43% at six months. Missing data was imputed for each case, using the case's mean. No participant had more than 13.3% missing data (ie two items).

Communication disability

Dysarthria was scored using the single item from the NIH Stroke Scale, which classifies people as 'normal', 'mild-moderate' or 'severe'. The proportion of participants with dysarthria fell from 48.2% at baseline to only 3% at six months, with no participants experiencing severe dysarthria at this stage.

Aphasia was assessed both with the FAST, and through a single item on the NIHSS. In fact, there was considerable missing data on the total FAST score, owing to the number of participants who did not complete the written portion of the test due to hemiparesis, other physical difficulties, poor literacy, and unwillingness (28%, 25% and 18% missing data at two weeks,

three months and six months respectively). A decision was made to use the short FAST for the purposes of multiple regression analyses. The short FAST differs from the total FAST in that it does not include the section of the test that assesses reading and writing. Missing data rates for the Short FAST were 5% (baseline), 9% (3 months) and 7% (6 months). Reasons for missing data on the Short FAST included two blind participants; one deaf participant; one participant who declined the verbal expression sections at baseline due to oral cancer and severe dysarthria; three participants with missing data at three months; and two participants with missing data at six months. Short FAST scores improved over the six months post stroke: Wilks' Lambda = .61, $F(2, 61) = 19.77$, $p < .001$, $\eta = .39$. Post hoc comparisons showed that there was significant change between baseline and the other two time points ($p < .001$), but not between three and six months. Presence/ absence of aphasia is also provided in Table 4.3 for interest. This was calculated from the FAST where possible, and otherwise from the NIHSS item. The proportion who had aphasia fell from 36.8% to 15.5% over the six months post stroke.

Psychological distress

Although psychological distress (GHQ-12) did significantly reduce from baseline to six months, distress levels remained high throughout the project (Wilks' Lambda = .86, $F(2, 69) = 5.71$, $p <.01$, $\eta = .14$; post hoc comparisons showed that the significant difference was between baseline and six months, $p <.01$). Hilari *et al.* (2010)[137], reporting on the same sample, observed that 66% of participants could be classified as suffering from high distress at baseline, with 58% still classified as feeling high distress three months post stroke, and 45% at six months.

4.4 Perceived social support following a stroke

Table 4.4 gives information about the participants' perceived social support following their stroke, both for the overall scale (MOS SSS), and also for the five subdomains. Histograms showing the distributions of the overall scale and subdomains are provided in Appendix 14. Median (IQR) is only provided where a scale or subdomain is skewed (where skewness > ±1).

Table 4.4 Perceived social support: descriptive statistics

Perceived social support (MOS Social Support Survey)			
Overall scale	**Baseline** ***n* = 87**	**3 months** ***n* = 76**	**6 months** ***n* = 71**
Perceived social support (SSS)			
Mean (SD)	3.82 (0.96)	4.00 (0.92)	3.83 (1.08)
Range	1.42 – 5.00	1.47 – 5.00	1.16 – 5.00
n	*n* = 86	*n* = 73	*n* = 70
Subdomains			
Emotional support			
Mean (SD)	3.89 (1.04)	4.07 (0.99)	3.90 (1.17)
Median (IQR)	4.00 (3.25–5.0)	4.42 (3.25–5.0)	4.25 (3.0 – 5.0)
Range	1 – 5	1 – 5	1 – 5
Informational support			
Mean (SD)	3.72 (1.01)	3.98 (0.96)	3.79 (1.14)
Range	1 – 5	1 – 5	1 – 5
Tangible support			
Mean (SD)	3.74 (1.16)	4.09 (1.14)	3.97 (1.19)
Median (IQR)	4.00 (3.0 – 4.75)	4.50 (3.25 – 5.0)	4.50 (3.25 – 4.75)
Range	1 – 5	1 – 5	1 – 5
Social companionship support			
Mean (SD)	3.78 (1.08)	3.85 (1.11)	3.63 (1.23)
Range	1 – 5	1 - 5	1 – 5
Affectionate support			
Mean (SD)	4.02 (1.14)	4.04 (1.15)	3.90 (1.25)
Median (IQR)	4.33(3.33–5.0)	4.67(3.33–5.0)	4.33 (3.0 – 5.0)
Range	1 – 5	1 – 5	1 – 5

These scores suggest that many in the sample felt reasonably well supported: at six months, 50% of participants perceived support to be available to them either most of the time or all of the time, scoring ≥ 4 (44.2% at baseline, and 57.5% at three months). Still, 25% of participants at both baseline and six months felt supported either not at all, or only some or little of the time, scoring ≤ 3 (19% at three months).

Perceived social support (SSS) did alter over the six month period: Wilks Lambda = .89, $F(2, 65) = 3.90$, $p < .05$, $\eta = .11$. In fact, post hoc tests showed that there was no significant change from prior to the stroke (baseline) to six months post stroke, and the only significant difference was between three months and six months. At three months, levels of perceived social support marginally increased ($p < .05$).

A similar pattern emerged in the five subdomains of the scale: the baseline scores did not significantly differ from the six month scores. As with the overall score, the subdomains' three month scores were higher on average than the baseline or six month scores: this, however, did not reach statistical significance.

In terms of skewness, the overall scale was somewhat negatively skewed (skewness at baseline = -.50; at three months = -.72; at six months = -.75). The three subdomains with the most skewed distribution were: at baseline the Affectionate subdomain (skewness = -1.12), and at three months the Affectionate subdomain (skewness = -.99), Emotional subdomain (skewness = -1.0) and Tangible subdomain (skewness = -1.22). As discussed above, it was decided that the sample was sufficiently large that it would be acceptable to use non-transformed data in parametric tests.

4.5 Social networks following a stroke

Table 4.5 provides descriptive statistics for the Stroke Social Network Scale, including its five subdomains. Again, histograms and normal probability plots for the overall scale and the subdomains at the three time points are provided in Appendix 15. As above, the median (IQR) is only provided where a subdomain is skewed (skewness > ± 1).

Table 4.5 Stroke Social Network Scale: descriptive statistics

Social Networks (Stroke Social Network Scale)			
Overall scale	**Baseline**	**3 months**	**6 months**
Social Network Mean (SD) Range *n*	 60.69 (15.22) 11.32 – 91.70 *n* = 87	 58.04 (16.74) 6.84 – 92.81 *n* = 75	 56.78 (15.44) 10.26 – 85.15 *n* = 71
Subdomains			
Satisfaction Mean (SD) Median (IQR) Range	 85.17 (15.61) 88.33 (78.33 – 96.67) 35.83 – 100	 84.60 (19.49) 88.33 (80.83–96.67) 3.33 – 100	 82.56 (19.23) 86.67 (80.0–93.33) 6.67 – 100
Children Mean (SD) Range	 57.60 (35.52) 0 – 100	 57.67 (35.74) 0 – 100	 58.78 (34.21) 0 – 100
Relatives Mean Range	 37.76 (28.55) 0 – 88.89	 39.07 (28.40) 0 – 100	 36.78 (29.17) 0 – 93.33
Friends Mean (SD) Range	 56.98 (24.95) 0 – 95	 48.77 (25.55) 0 – 100	 43.96 (28.08) 0 – 95
Groups Mean (SD) Range	 35.06 (37.10) 0 – 100	 27.78 (31.99) 0 – 100	 30.98 (34.19) 0 – 100

Having a stroke caused participants' social networks to become weaker: Wilks' Lambda = .82, $F(2, 68) = 7.35$, $p = .001$, $\eta = .18$. Post hoc comparisons showed that baseline social network scores were significantly higher than at six months ($p = .001$). Other differences were not significant.

In terms of the subdomains, only one subdomain showed significant change between baseline and six months: the Friends subdomain, Wilks' Lambda = .80, $F(2, 68) = 8.49$, $p = .001$, $\eta = .20$. Post hoc tests showed that there was a significant difference between baseline and six months ($p < .001$).

Although post stroke people became less satisfied with their social network, and had less group involvement, neither of these trends reached statistical significance. The Children factor and the Relatives factor appeared to be particularly stable elements of the network

Finally, in terms of skewness, the overall scale was somewhat negatively skewed (skewness at baseline: -.48; at three months = -.64; at six months = -.69). The domain with the most skewed distribution was the Satisfaction domain: it was negatively skewed as most participants felt satisfied with their social network.

4.6 Comparison of those with aphasia and those without aphasia on social support and social network scores six months post stroke

The mean scores of those with aphasia (n = 11) and those without (n = 60) on the social support and social network measures at six months post stroke are shown in Table 4.6. Independent t-tests were carried out to compare these.

Table 4.6 Social support and network at six months post stroke: comparing participants with aphasia to those without

Measure	Participants without aphasia, *n* = 60	Participants with aphasia, *n* = 11	p values	Effect size	
	Mean (SD)	Mean (SD)		Cohen's *d* value	eta squared
Perceived social support (MOS SSS)	3.83 (1.13)	3.83 (0.82) *n* = 10	p = 0.99, ns	<.001	<.001
Social network (SSNS)	58.62 (14.14)	46.75 (18.90)	p = 0.018	2.43	0.08
Satisfaction	83.59 (16.69)	76.89 (30.04)	p = 0.49, ns (equal variances not assumed)	0.72	0.01
Children	60.33 (35.12)	50.34 (38.67)	p = 0.38, ns	0.89	0.01
Relatives	37.93 (27.97)	30.50 (35.91)	p = 0.44, ns	0.77	<0.01
Friends	47.00 (24.90)	27.42 (38.77)	p = 0.13, ns (equal variances not assumed)	1.61	0.04
Groups	34.44 (34.43)	12.12 (26.97)	p = 0.028 (equal variances not assumed)	2.41	0.08

In terms of perceived social support, those with aphasia had comparable levels of support to those without: t (69) = .001, ns. However, in terms of social network, those with aphasia had significantly lower overall network scores: t (69) = 2.43, p = 0.018, Cohen's *d* = 2.43

To investigate which subdomains of the social network scale showed significant change, further t-tests were carried out. To ensure that the chances of a type I error remained below 0.05, despite the multiple analyses, the Bonferroni method was employed. Specifically, since there were five subdomains, the criterion for significance was adjusted to 0.01 (0.05 divided

by five). While those with aphasia had lower scores on all five subdomains, particularly the Groups subdomain, these trends were not significant.

There were no significant differences between those with and without aphasia on either social network or perceived social support pre-morbidly.

4.5 Summary

Perceived social support (SSS) remained relatively stable following a stroke: there was no significant change from prior to the stroke (baseline) to six months post stroke. This pattern was true for all five subdomains representing the different functions of support.

By contrast, pre-stroke social networks were significantly stronger than post stroke social networks. In the Friends factor participants scored significantly worse six months post stroke compared with their pre-stroke score. The most stable subdomains were those which related to family: the Children factor and the Relatives factor.

Those with aphasia had comparable levels of perceived social support, yet scored significantly less well on the social network scale.

Chapter Five. Predictors of social support and social network: methods and results

An aim of this project was to examine what factors predict perceived social support and social network six months post stroke. Concurrent factors were explored, as well as variables collected at baseline. The overall design of the project and the measures used were described in Chapter Three. Participant characteristics and how participants scored on the different variables was described in Chapter Four. This chapter focuses on what methods were used to analyse the data, and the results of that analysis.

The following research questions are addressed in this chapter:

RQ4: What concurrent factors predict perceived social support six months post stroke?

RQ5: What baseline factors predict perceived social support six months post stroke?

RQ6: What concurrent factors predict social network six months post stroke?

RQ7: What baseline factors predict social network six months post stroke?

5.1 Methods

Multiple regression was used to explore the four research questions stated above (RQ4-7).

Potential independent variables (IVs) were: demographics (marital status, age, gender, ethnicity, whether living alone, employment status); type of stroke (ischaemic or haemorrhagic); severity of stroke (NIHSS)[215]; aphasia (FAST)[218]; dysarthria; activities of daily living (BI)[216]; extended activities of daily living (FAI)[223]; and psychological distress (GHQ-12)[221].

The dependent variables (DVs) were: perceived social support, measured with the Medical Outcomes Study Social Support Survey (SSS)[48]; and social network, measured with the Stroke Social Network Scale (SSNS)[222].

5.1.1 Multiple regression

Multiple regression assesses the relationship between one continuous DV and several IVs. It is suitable for complex, real-life research questions, such as the present one[260]. Standard multiple regression was used. In this form of multiple regression all IVs are entered into the equation simultaneously. Each IV is evaluated in terms of how much unique variance in the DV it explains. How much of the variance in the DV is explained by the IVs as a block is also assessed. Standard multiple regression was chosen rather than hierarchical multiple regression (where the order in which the IVs are entered into the equation is determined by the researcher). This is because it

best suited the research question: the relative importance of potential predictors of social support after stroke has not been the subject of previous research, and thus a method which makes fewer assumptions about the relative importance of IVs is more appropriate[256]. Stepwise multiple regression (in which the order that IVs are entered into the model is based on mathematical criteria alone) was avoided due to methodological concerns.[256, 261]

In terms of deciding which IVs to enter, only those where there was justification based on the literature, (ie those variables shown to have a relationship with social support in previous research) and which correlated significantly with the DV in univariate analyses were considered.

5.1.2 Multiple regression assumptions

A variety of assumptions need to be met prior to carrying out multiple regression analysis, in order for the model to be considered reliable and generalizable to the population from which the sample was drawn[256]. The criteria for how these assumptions were met, including diagnostic tests, are listed below.

Ratio of cases to IVs: Too few cases in relation to the number of IVs may result in an unreliable regression model. Field (2000)[256] and Stevens (1992)[262] both suggest that social scientists should aim to have at least 15 subjects per predictor. The number of potential predictors in the project was large, compared to the sample size. In order to determine which IVs were significantly associated with the DV, Pearson correlation coefficients, t-tests and ANOVAs were carried out as appropriate. Only those variables which were significantly associated with the DV were entered into the equation.

Where there were too many IVs significantly associated with the DV, they were all entered into the equation, IVs which were not statistically significant were removed, and the equation re-run without them as recommended by Field (2000)[256]. This has the advantage of leaving fewer predictors in the final model.

Multicollinearity and singularity: Multicollinearity exists when the IVs are highly correlated with one another. When two variables are highly correlated it becomes difficult to assess the individual importance of a predictor; it also makes the model more unstable[256]. The correlation matrix of IVs was examined for high correlations ($r > 0.65$). Further, the variance inflation factor (VIF) was calculated: this indicates whether predictors have strong linear relationships with other variables. VIF should be below 10[263]. The tolerance statistic was also used, the inverse of the VIF (1/VIF): values below 0.2 are cause for concern, and values below 0.1 suggestive of serious problems[264]. Should potential IVs be found to be highly correlated, one should be removed from the equation. The rationale for which variable to include was based on: the variable most highly correlated with the DV; the variable with the strongest theoretical justification; the variable which was most reliable.

Singularity occurs when one IV is in fact a combination of other IVs. Careful examination of the IVs was employed to avoid this.

Normality, homoscedasticity, independence of residuals: This refers to the distribution of the scores, and the relationships between the variables. To check assumptions have been met, it is possible to examine the residuals scatterplots. Residuals are the differences between the obtained and the

predicted DV scores, and as such, show the errors of prediction. The assumption is that the residuals are normally distributed about the predicted DV scores (normality); that they have a straight-line relationship with the predicted DV scores (linearity); and that the variance of the residuals about predicted scores is the same for all predicted scores (homoscedasticity)[154].

In order to check these assumptions, the Normal Probability Plot of the Regression Standardised Residual and the Scatterplot were examined. In the Normal Probability Plot, the points should lie in a reasonably straight diagonal line, suggesting normality. In the Scatterplot, most of the residuals should be roughly rectangular in distribution, with most scores near the zero point. Deviations from this, such as a curvilinear distribution, suggest a violation of assumptions.

Independence of errors: Another assumption is that the errors of prediction should be independent of one another. This is testable through analysing the residuals. In this study, the Durbin-Watson statistic was used, which tests whether adjacent residuals are correlated. Values greater than 1 and less than 3 were considered acceptable[256].

Outliers: Tabachnick and Fidell define an outlier as ‘a case with such an extreme value… it distorts statistics’ (p72), and caution that it may lead to both Type I and Type II errors, and to results that only generalise to samples with similar outliers[154]. When carrying out multiple regression, extreme cases may have an undue influence on the regression solution, affecting the values of the estimation regression coefficients. This may impact on how well the model fits the data, and the extent to which it can be generalised to other samples[256].

Outliers may be univariate (an extreme value on one variable) or multivariate (an extreme combination of scores on two or more variables).

Prior to entry in the multiple regression analyses, univariate analyses were carried out. For continuous variables, outliers were defined as cases with large standardised scores. Tabachnick and Fidell (2008) suggest that cases with a *z* score in excess of ±3.29 are potential outliers[154]. For dichotomous variables, univariate outliers are likely to arise where the 'split' between categories is very uneven (90-10 or more). Rummell (1970) recommends deleting dichotomous variables with 90-10 or more extreme splits. The reasons are two-fold: the correlation between these variables and others are deflated; and the scores for the cases in the small category (the 'outliers') have more influence than those in the larger category[265].

In terms of multivariate outliers, Mahalnobis distances were calculated. Mahalanobis distances are the distances of cases from the means of the IVs. In order to identify whether any cases were outliers the critical chi-square value was determined, using the number of IVs as the degrees of freedom, and an alpha level of 0.001 (see Tabachnick and Fidell, 2008, Table C4, p 949)[154].

Diagnostic tests were conducted to check how much influence each case was having on the model as a whole, specifically whether any individual case was having undue influence, thereby negatively impacting on the model's ability to predict all the other cases. Two tests that provide this function are Cook's distance and leverage values. With Cook's distance, any case with influence scores larger than 1.00 may be cause for concern[266]. Leverage assesses the influence of the observed value of the DV over the

predicted value. Cases that are not unduly influential in the model should have leverage values close to the average, where the average leverage value is defined as (k + 1)/n (where k = number of IVs). Stevens (1992)[262] recommends that cases with leverage values over three times the average (3(k + 1)/n) are having an undue influence on the model, and should be investigated further.

A further measure to investigate whether any individual case is unduly influencing the variance of the regression parameters is the covariance ratio (CVR). Belsey *et al.* (1980)[267] recommend that if a case has a CVR value < 1 – [3(k + 1)/ n], then deleting this case will improve the precision of some of the model's parameters (where k = number of IVs). Conversely, deleting a case that has a CVR value > 1 + [3(k + 1)/ n will worsen the model's parameters.

Finally, outliers in the solution were investigated through examining standardised residuals. Residuals are the difference between the value of the outcome predicted by the model, and the actual observed outcome. Cases with large residuals are not well predicted by the model, and will lower the multiple correlation. In order to identify cases that are outliers, Field (2000)[256] recommends analysing the standardised residuals: cases with standardised residuals greater than ±3.29 are cause for concern. If more than 5% of cases had standardised residuals with an absolute value greater ±2, then the model would not be a good representation of the data.

When outliers were identified, the following approach was adopted. Firstly, the data was rechecked to ensure it had been correctly gathered and entered. Assuming the data was correct, potential options included deleting,

rescoring or transforming outliers. However, transformation of a variable (functions such as natural logarithms and square roots) should be cautiously approached: although reducing the impact of outliers they may also change the relationship between the original variable and other variables, as discussed above[257]. Stevens (1992)[262] recommends that so long as a case has a Cook's distance of <1, 'there is no real need to delete that point, since it does not have a large effect on the regression analysis' (p118). Nonetheless, he goes on to observe that outliers should still be investigated further to understand why they do not fit the model better. One option when in doubt is to report the model results both with and without the outliers[268]. Useful discoveries may be made through exploring unusual values; as such, it could be argued that deletion should be a last resort.

5.1.3 Multiple regression analyses

The following calculations were carried out. ANOVA was used to test the statistical significance of the result, specifically, whether the model is significantly better at predicting the outcome than the mean (or whether *R* for regression was significantly different from zero). R^2 was calculated to estimate the amount of variability in the DV explained by the model. The adjusted R^2 was also calculated in order to assess how much of the variance of the DV would be accounted for had the model been derived from the population from which it was drawn. The unstandardized regression coefficients (*B)* were inspected. These show the individual contribution of an IV in explaining variance in the DV; *t*-statistics were used to assess whether the contribution was significant. Standardised regression

coefficients (β) were also calculated in order to compare the relative contribution of the different IVs. The unique contribution of an IV was assessed through squared semipartial correlations (sri^2): these assess the amount by which R^2 would be reduced if that IV were to be removed from the equation. The difference between the total variance explained by the model (R^2) and the sum of the unique variances of the IVs (ie the amount of variance that is explained jointly by the IVs) was also calculated. Finally, 95% confidence intervals of the unstandardized regression coefficients were inspected. These are the boundaries within which the *B* values of 95% of samples will fall. Confidence intervals should not cross zero, as this would suggest in some samples the relationship between the IV and DV is positive and in others it is negative. Such an IV can be said to weaken the overall model.[256]

5.1.4 Summary of methods

Standard multiple regression analyses were used to explore the relationship between a set of IVs and social support/ social network following a stroke. IVs were only entered into an equation if they were significantly associated with the DV, and there was theoretical justification for inclusion. The assumptions of multiple regression were tested. All data analyses were performed using IBM SPSS 19.00 for Windows.

5.2 Results: What concurrent factors predict perceived social support six months post stroke (RQ4)?

In order to determine which concurrent variables were significantly associated with social support at six months, Pearson product-moment correlation coefficients, t-tests and ANOVAs were carried out as appropriate, and the results presented in 5.2.1 below. Diagnostic tests were then carried out to check assumptions were met (5.2.2). Finally, multiple regression analysis was carried out, and the results presented in 5.2.3.

5.2.1 Univariate analyses (RQ4)

Variables significantly associated with social support at six months post stroke

Demographic variables: marital status and whether someone was living alone were both significantly associated with perceived social support. To assess the relationship between marital status and perceived social support, an independent t-test was used. Those in a relationship (married/ has partner) had significantly higher social support levels (mean = 4.24; SD = 0.91) than those who were not in a relationship (single, widowed, divorced) (mean = 3.39; SD = 1.10); $t(68) = -3.52$, $p = 0.001$. An independent samples t-test also showed that those living with someone else had higher levels of support (mean = 4.11; SD = 1.02) than those who lived on their own (mean = 3.47; SD = 1.07); $t (68) = -.2.53$, $p < 0.05$.

Other variables: Pearson product-moment correlation coefficient was used to investigate the relationship between social network (SSNS) and perceived social support: a moderate correlation was found ($r = 0.46$, $p < 0.001$).

There was also a significant correlation between psychological distress (GHQ-12) and perceived social support ($r = -0.36$, $p < 0.01$): the more distressed a person felt, the less likely they were to feel well supported.

Variables not significantly associated with perceived social support at six months post stroke

Demographic variables: Age and social support were not significantly correlated($r = .03$, ns). Women had slightly higher levels of social support (mean = 3.96, SD = .87) than men (mean = 3.72, SD = 1.22), but this difference was not significant; $t (67.4) = 0.95$, ns, equal variances not assumed. The relationship between ethnicity and perceived social support was assessed using ANOVA. Participants were divided into four groups: White British; Asian; Black; White Other. There was no statistically significant difference between the groups: $F (3,63) = 0.72$, ns. Finally, employment status was also found not to be significantly related to perceived social support. Participants were grouped into those in work (full-time, part-time or voluntary) versus those not in work and an independent t-test carried out ($t(67) = -0.51$, ns).

Other variables: In terms of stroke variables, there was no significant difference in perceived social support scores between those who had had an ischaemic stroke (mean = 3.82; SD = 1.12) versus those who had had a haemorrhagic stroke (mean = 3.89; SD = 0.78), $t (68) = 0.80$, ns. Stroke severity was also not significantly associated with social support, either when considered as a continuous variable ($r = -0.06$, ns) or as a categorical variable where participants were divided into mild, moderate or severe strokes. In practice, at six months participants either fell into the mild or

moderate categories: there was no significant difference between these two groups, t(64) = 0.85, ns.

Pearson correlation coefficient was used to assess the relationship between perceived social support and the following IVs: number of co-morbidities (r = -0.19, ns); ADL (BI) (r = 0.07, ns); extended ADL (FAI) (r = 0.12, ns); and aphasia (short FAST) (r = 0.10, ns). None of these relationships were found to be significant. In terms of dysarthria, at six months all participants were categorised into either having no dysarthria, or mild dysarthria. No significant difference was found between the perceived social support of these two groups (t(66) = 1.69, ns).

Summary

Four variables were found to be significantly associated with perceived social support (SSS) at six months: social network (SSNS) ($p < 0.001$); marital status ($p < 0.001$); psychological distress (GHQ-12) ($p < 0.01$), and whether someone was living alone ($p < 0.05$). These four variables were therefore considered as potential IVs in the multiple regression equation.

5.2.2 Mutliple regression assumptions (RQ4)

Ratio of cases to IVs: for RQ4, there were 70 participants (missing data for one participant). Using the recommendation of Field (2000) and Stevens (1992) of 15 participants for each IV, there should be no more than four IVs, thus this assumption was met.

Multicollinearity and singularity: two IVs failed the multicollinearity assumption. Living arrangements and marital status were highly correlated

with one another ($r = 0.75$, $p < 0.001$): those in a relationship were more likely to be living with someone. Since marital status was more strongly associated with the DV this variable was included, and living arrangements excluded. The three remaining IVs did not correlate with one another higher than $r = -.22$, suggesting an absence of further multicolinearity. Tolerance values for the three IVs ranged from 0.93 to 0.98, well above the criterion 0.20. Similarly, VIF values were all below 10 (ranging from 1.0 to 1.1). There was also no singularity.

Normality, homoscedasticity, independence of residuals: Inspection of the Normal Probability Plot of the Regression Standardised Residuals suggests that the residuals were normally distributed as the points lie in a fairly straight diagonal line (see Appendix 16). The histogram of the standardised residuals also supports this (see Appendix 16). An examination of the scatterplot of the standardised residuals versus the standardised predicted values of the DV suggests that the assumptions of homoscedasticity and linearity were met (see Appendix 16).

Independence of errors: The errors of prediction were independent of one another, as shown by the Durbin Watson test, which had an acceptable value of 1.84.

Outliers: In terms of univariate outliers, each of the IVs and the DV were inspected prior to being entered into multiple regression analysis. There were no cases which had a standardised score in excess of ±3.29, suggesting no univariate outliers[154].

Multivariate outliers can be detected by Mahalnobis distances. Using a p <0.001 criteria, there were no multivariate outliers among the cases: the maximum Mahalanobis distance was 11.44, less than the critical X^2 for 3df at 16.27.

In order to detect if any cases were unduly influential in the solution, Cook's distances and leverage values were investigated. The maximum Cook's distance was 0.26, less than 1, and acceptable. The average leverage value ((k+1)/n) was 0.057. Stevens (1992) recommends that cases that have a value that is three times the average (ie 0.17) may be having an undue influence on the solution. In this equation, the maximum leverage value was 0.16, less than 0.17, and so acceptable.

A further measure to investigate whether a case is influencing the variance of the regression parameters is the covariance ratio (CVR). The criteria used was: CVR > 1 + [3(k + 1)/n] = 1.17; CVR < 1 – [3(k+1)/n] = 0.83. According to Belsey *et al*. (1980)[267] deleting cases with CVR < 0.83 will improve the precision of the model. In this model, case 62 (CVR = 0.75) deviated slightly from these boundaries. Case 38, however, has CVR value = 0.50, and deletion of this case could potentially improve the model.

In terms of outliers in the solution, case 38 had a standardised residual of -3.40, less than -3.29 and therefore cause for concern as the model did not appear to predict this case well[154]. Four further cases had standardised residuals exceeding ±2 (2.29, -2.06, -2.16, -2.45). However, 98% of residuals were within ±2.5, suggesting a reasonable representation of the data overall[256].

Overall, there were concerns about case 38, given that it had a standardised residual <-3.29, and a CVR value 0.33 lower than recommended: both these figures suggest the model would be improved without this case. Nonetheless, it was reassuring that other diagnostic tests were acceptable. In this situation, it was decided to run the regression equation both with and then without case 38, and report R^2 for both. As suggested by Stevens (1992) 'one should still be interested in studying such points [outliers] further to understand why they did not fit the model' (p118)[262]. Thus the potential reasons why case 38 did not conform to the model will be addressed in the discussion.

5.2.3 Standard multiple regression results (RQ4)

Table 5.1 is a summary of the regression model. It shows R, R^2 and adjusted R^2, as well as both the standardised (***B***) and unstandardized (***β***) regression coefficients. It also displays both the *t*-statistics and probability levels, as well as the squared semipartial correlations $(sri)^2$. Finally, it gives the correlation values between the DV and IVs.

Table 5.1 Concurrent predictors of perceived social support six months post stroke

Variables	Social Support Survey (SSS) (6 mths) (DV)	Social Network (SSNS) (6 mths)	Marital Status	Psycholo-gical distress (GHQ-12) (6 mths)	*B*	*β*	*t*	sri^2
Social Network (SSNS) 6 months	r = .46***				.02	.36	3.61**	.12
Marital Status	r = .39***	r = .13			.73	.34	3.51**	.11
GHQ-12 6 months	r = -.36**	r = -.22*	r = -.03		-.08	-.27	-2.81**	.07
Intercept = 2.25								
Mean (SD)	3.83 (1.08)	56.78 (15.44)	N/A	3.48 (3.62)				
n	70	71	71	71				
					R^2 = .40[a]			
					Adjusted R^2 = .37			
					R = .63***			

*** p < .001; ** p < .01; * p < .05

[a] Unique variability = .30; shared variability = .10

R for regression was significantly different from zero, with F(3, 66) = 14.56, p < .001. The overall model accounted for 40% of the variance in the SSS scores. Adjusted R^2 = .37 suggesting that 37% of the variance in perceived social support six months post stroke can be explained by a person's social network, marital status, and level of psychological distress. The *B* coefficients show that all three IVs were significant predictors (social network: t(69) = 3.61, p < .01; psychological distress: t(69) = -2.81, p < .01;

marital status: $t(69) = 3.51$, $p < .01$). 95% confidence limits were also calculated for the B coefficients. The confidence limits for social network were 0.01 to 0.04; those for marital status were 0.31 to 1.14; and for psychological distress they were -0.14 to -0.02: none of these confidence intervals included zero as a possible value, confirming their significance.

The IV with the largest β value was social network, suggesting this variable explained the most variance in the perceived social support scores. Inspecting the squared semi-partial correlations of the IVs shows how much unique variance each IV explained. Social network accounted for 12% unique variance, marital status accounted for another 11%, while psychological distress explained 7% unique variance. The three IVs in combination contributed another 10% of shared variability. The direction of the relationships suggest that those with stronger social networks felt better supported; those who were married or in a relationship felt better supported; while those who were experiencing psychological distress felt less well supported.

There were concerns that case 38 was not well predicted by the model, and may be distorting the regression parameters. The model was therefore rerun without this case. Without case 38, the overall model accounted for 46% (adjusted $R^2 = .44$) of the variance in perceived social support scores. Thus an extra 6% of the variance could be explained if this case was removed. The model expected case 38 to feel better supported than he did, given his low psychological distress score, and relatively high social network score. Possible reasons for this unusual result are given in the discussion.

5.3 Results: What baseline factors predict perceived social support six months post stroke (RQ5)?

5.3.1 Univariate analyses (RQ5)

Baseline variables significantly associated with perceived social support at six months post stroke

Pre-stroke perceived social support (SSS) ($r = .65$, $p < 0.001$), and pre-stroke social networks (SSNS) ($r = .38$, $p = 0.001$) were both significantly associated with perceived social support (SSS) six months post.

Marital status, as measured at baseline, was also significantly associated with perceived social support six months post stroke: those in a relationship prior to the stroke had significantly higher social support scores (mean = 4.16; SD = .97) than those not in a relationship (mean = 3.45; SD = 1.09); $t(68) = -2.87$, $p < .01$.

Baseline variables not significantly associated with social support at six months post stroke

The following demographic variables were found not to be significantly associated with perceived social support at six months: whether the participant was living alone prior to the stroke ($t(67) = 1.61$, ns); age ($r = 0.03$, ns); gender ($t(68) = 0.91$, ns); ethnicity ($F(3, 66) = 0.72$, ns); employment status prior to the stroke ($t(68) = 0.72$, ns).

The following variables were measured two weeks post stroke, and not found to be significantly associated with perceived social support six months post stroke. These were: stroke severity (NIHSS) ($r = 0.13$, ns);

number of co-morbidities (r = -0.19, ns); ADL (BI) (r = -0.09, ns); psychological distress (GHQ-12) (r = -0.09, ns); aphasia (short FAST) (r = 0.13, ns); and dysarthria (F(2, 67) = 0.86, ns). Finally, participants were asked to rate their extended ADL, using the FAI, in the month prior to the stroke. This also was not significantly associated with perceived social support six months post stroke (r = 0.01, ns).

Summary

Three baseline variables were found to be significantly associated with perceived social support at six months: social support; social network; and marital status (all p <.01). No other baseline variable was significantly associated with perceived social support at six months.

5.3.2 Mutliple regression assumptions (RQ5)

Ratio of cases to IVs: there were three IVs and 69 participants (missing data for SSS for one participant at baseline and one participant at six months). This ratio was good.

Multicollinearity and singularity: The IVs did not correlate with one another higher than r = .41. Tolerance values ranged from 0.73 to 0.86, above the criterion 0.20. Similarly, VIF values were all below 10 (ranging from 1.16 to 1.37).

Normality, homoscedasticity, independence of residuals: The residuals were normally distributed and the assumptions of homoscedasticity and linearity were met (see Appendix 16 for Normal Probability Plot of the Regression Standardised Residuals, the histogram of the standardised residuals, and the

scatterplot of the standardised residuals versus the standardised predicted values of the DV).

Independence of errors: the errors of prediction were independent of one another, as shown by the Durbin Watson test, which had an acceptable value of 2.08.

Outliers: there were no univariate outliers among either the IVs or the DV, as evidenced by their standardised scores, which all lay between ±3.29. In terms of multivariate outliers, the maximum Mahalanobis distance was 13.55, less than the critical X^2 for 3df at 16.27. Maximum Cook's distance was 0.19, less than 1. The average leverage value was (k + 1)/n = 0.06, with one case (case 12) having a leverage value of 0.20, which exceeded the recommended cut-off point [3(k + 1)/n = 0.17][262], suggesting this case should be investigated further to determine whether it is unduly influencing the equation. The covariance ratio (CVR) was also calculated. The boundaries were: CVR > 1 + [3(k + 1)/n] = 1.17; CVR < 1 – (3(k+1)/n = 0.83. Two cases fell below the lower boundary: case 5 (CVR = 0.55) and case 27 (CVR = 0.67) suggesting that these cases damaged the precision of the model's parameters. Finally, in terms of outliers in the solution, both case 5 and case 27 had standardised residuals greater than ±2.5 (case 5 = -3.18; case 27 = -2.73). All other residuals fell within ±2, (97.14% of cases), suggesting that overall the model was a good representation of the data.

In summary, it was reassuring that the maximum Cook's distance was acceptable, suggesting that no case was unduly influencing the equation. Although case 12 had a leverage value that slightly exceeded the recommended cut-off point, its Cook's distance (0.10) was acceptable.

Nonetheless, it appears that case 5 was an outlier on the solution, and should be investigated further. As with RQ4, the equation was run both with and without case 5, and R^2 reported both ways.

5.3.3 Standard multiple regression results(RQ5)

Table 5.2 Baseline predictors of perceived social support six months post stroke

Variables	Social Support (SSS) 6 months (DV)	Social support (SSS) pre-stroke	Social network (SSNS) pre-stroke	Marital status baseline	*B*	*β*	*t*	sri^2
Social support (SSS) pre-stroke	r = .65***				.64	.55	5.35***	.24
Social network (SSNS) pre-stroke	r = .38**	r = .41***			.01	.16	1.59	.02
Marital status baseline	r = .33**	r = .37***	r = .15		.25	.12	1.21	.01
Intercept = .52								
Mean (SD)	3.83 (1.08)	3.91 (0.94)	61.81 (15.57)	N/A				
n	70	70	71	71				
					R^2 = .46[a]			
					Adjusted R^2 = .43			
					R = .68***			

*** p < .001; ** p < .01; * p < .05

[a] Unique variability = .27; shared variability = .19

Table 5.2 is a summary of the regression model. *R* for regression was significantly different from zero, with F(3, 65) = 18.30, p < .001. The overall model accounted for 46% (adjusted R^2 = .43) of the variance in perceived social support scores at six months. The *B* coefficients show that

only one IV was a significant predictor: social support at baseline: $t(68) = 5.17$, $p < .001$. 95% confidence limits were calculated: for social support at baseline these were 0.40 to 0.88; for social network at baseline they were 0.00 to 0.02; and for marital status -0.16 to +0.67, suggesting that in some samples this variable has a positive relationship with the DV, and in other samples a negative relationship, potentially weakening the model.

Baseline social support accounted for 24% unique variance, baseline social network a further 2%, while the three IVs in combination contributed another 19% of shared variability. The direction of the relationships suggest that those who felt well supported prior to the stroke were likely to feel well supported six months post stroke. This result is in line with the ANOVA presented in Chapter Four (p200) which found no significant difference between baseline perceived social support and social support six months later.

Finally, there were concerns that the model did not predict case 5 well. When the model was rerun without case 5, it accounted for 52% (adjusted $R^2 = .50$) of the variance in perceived social support scores. Thus an extra 6% of the variance could be explained when case 5 was excluded from analysis. This case was not well predicted by the model in that his perceived social support scores reduced much more than expected following the stroke.

5.4 Results: What concurrent factors predict social network six months post stroke? (RQ6)

5.4.1 Univariate analyses (RQ6)

Concurrent variables significantly associated with social network at six months post stroke

Demographic variables: There was a significant association between gender and social networks. Women had higher social network scores (mean = 61.23; SD = 11.75) than men (mean = 53.33; SD = 17.14), t (68.09) = 2.30, $p < .05$, equal variances not assumed.

ANOVA was used to assess the relationship between ethnicity and social network: there was a statistically significant difference in the social network scores: $F(3,67) = 3.19$, $p < .05$. Post hoc comparisons using the Tukey HSD test indicated that the mean score for Black participants (mean = 71.83; SD = 10.37), was significantly higher than for Asian participants (mean = 47.46; SD = 18.31). White British participants (mean = 56.40; SD = 14.95) and White Other participants (mean = 62.48; SD = 4.83) did not differ significantly from other groups. The ethnic variable is categorical, which means it is not possible to enter into a multiple regression equation. Therefore, a new dichotomous dummy variable was created: Black participants, non-Black participants. These two groups were statistically different: $t(69) = -2.33$, $p < 0.05$. A further dichotomous dummy variable (Asian participants, non-Asian participants) did not reach statistical significance: $t(69) = 1.98$, $p = .052$.

Other variables: The following six month variables were significantly associated with social network (SSNS) at six months: social support (SSS) ($r = .46$, $p < 0.001$); activities of daily living (BI) ($r = 0.36$, $p < 0.01$); extended activities of daily living (FAI) ($r = 0.33$, $p < 0.01$); aphasia (short FAST) ($r = .37$, $p < 0.01$).

Six month variables not significantly associated with social network at six months post stroke:

The following demographic variables were not associated with social network at six months: marital status ($t(69) = -1.03$, ns); whether living alone or with someone else ($t(69) = -1.22$, ns); employment status ($t(68) = -1.65$, ns); and age ($r = 0.6$, ns). In terms of other variables there was no significant association between social network (SSNS) and the following: psychological distress (GHQ-12) ($r = -0.22$, ns); stroke severity (NIHSS) ($r = -0.13$, ns); dysarthria ($t(67) = -0.22$, ns); number of co-morbid conditions ($r = -0.12$); type of stroke ($t(69) = -1.14$, ns).

Summary

Social network at six months was significantly associated with: perceived social support ($p < 0.001$), ADL ($p< 0.01$), extended ADL ($p < 0.01$), aphasia ($p < 0.01$), gender ($p < 0.05$) and ethnicity ($p < 0.05$), with women scoring more highly than men, and black participants scoring more highly than Asian participants. A dichotomous variable (black/ non-black) was created to enter into multiple regression.

5.4.2 Mutliple regression assumptions (RQ6)

Ratio of cases to IVs: There were six IVs that were significantly associated with the DV. However, extended ADL, and ADL were strongly correlated with one another (r = 0.66). Since both these variables were moderately correlated with the DV (r = 0.33; r = 0.36), and are measuring related concepts of equal theoretical interest, a decision was made to retain the IV that had the best distribution. ADL, as measured by the BI, had a highly skewed distribution (skewness = -2.02), as well as univariate outliers (maximum *z* score: -3.62), reflecting that by six months post stroke, most participants scored at ceiling and were ADL independent. There was also missing data for two participants. The FAI, by contrast, had a normal distribution (skewness = -0.14), no univariate outliers, and no missing data. A decision was made to retain the FAI and exclude the BI from further analysis.

This still meant there were too many IVs: with a ratio of 15 participants for each IV, this would suggest 75 participants would be needed. In fact there were 65 participants (missing data for five participants for the Short FAST; missing data for one participant for the SSS). Thus there were initially too many IVs. As set out in the methods section, the equation was initially run with five IVs. IVs which were not statistically significant were removed, and the equation re-run without them. In practice, this meant that gender was not included in the final equation, as it was not a significant predictor. The remaining assumptions were based on running the multiple regression model with the following four IVs: perceived social support (SSS); extended ADL (FAI); aphasia (short FAST); and ethnicity (black/ non-black).

Multicollinearity and singularity: From the remaining four IVs, there was no multicollinearity or singularity. The IVs did not correlate with one another higher than r = 0.46. Tolerance values ranged from 0.71 to 0.96, well above the criterion 0.20. Similarly, VIF values were all below 10 (ranging from 1.05 to 1.42).

Normality, homoscedasticity, independence of residuals: Inspection of the Normal Probability Plot of the Regression Standardised Residuals suggests that the residuals were normally distributed as the points lie in a fairly straight diagonal line (see Appendix 16). The histogram of the standardised residuals also supports this (see Appendix 16). An examination of the scatterplot of the standardised residuals versus the standardised predicted values of the DV suggests that the assumptions of homoscedasticity and linearity were met (see Appendix 16).

Independence of errors: The errors of prediction were independent of one another, as shown by the Durbin Watson test, which had an acceptable value of 2.30.

Outliers: Initially, the IVs and DV were analysed for univariate outliers. The DV (SSNS) and two IVs (SSS and FAI) had no points that exceeded ±3.29. The other two IVs, however, had outliers, as defined by this criterion. In the case of the Short FAST this reflected the skewed nature of the distribution: since most participants scored near ceiling six months post stroke, the participants who still had severe aphasia were outliers. In fact, only one case exceeded -3.29 for the Short FAST (case 19 = -3.57). It was considered that this was acceptable to proceed with. In the case of the final IV (Black/non-Black), the difficulty arose due to the small number of Black

participants (n = 5) compared to non-Black participants (n = 66). This uneven split could potentially cause its association with other variables to be deflated[154]. It was decided to retain this variable for further analysis for theoretical interest, while acknowledging this limitation.

In terms of multivariate outliers, using a p<.001 criterion for Mahalanobis distance, the critical X^2 for 4df was 18.47. In this equation, one case (case 19, the univariate outlier on the short FAST) exceeded this limit and had a Mahalanobis distance of 21.51. Maximum Cook's distance was 0.32, less than 1, suggesting that there were no cases having an undue influence on the equation. The average leverage value was (k + 1)/n = 0.077. Using the cut-off point recommended by Stevens [(3(k +1)/n = 0.23] to identify cases having an undue influence, three cases were identified (case 16 = 0.28; case 19 = 0.35; and case 21 = 0.27). The covariance ratio (CVR) was also calculated. Cases with a CVR value < 1 – (3(k+1)/n = 0.77 were identified. In this model, no case had a CVR value below this limit. Finally, in terms of outliers in the solution, no case had a standardised residual >3, suggesting no outliers, and only one case (case 7) had a standardised residual >2 (-2.21), thus over 98% of cases lie within ±2, suggesting that the model was a good representation of the data.

In summary, the fact that the maximum Cook's distance <1, and the standardised residuals all fall within ±2.5 suggesting a reasonable fit to the data, provided reassurance. Case 19 was clearly an extreme case as it was both an outlier on the Short FAST, and also a multivariate outlier, according to its Mahalanobis distance and leverage value. Nonetheless, the model appeared to predict it reasonably well, and its Cooks distance (0.03)

provided reassurance that it did not appear to be unduly influencing the equation. The equation was therefore run with all cases.

5.4.3 Standard multiple regression results (RQ6)

Table 5.3 Concurrent predictors of social network six months post stroke

Variables	Social Network (SSNS) 6 mths (DV)	Social support (SSS) 6 mths	Aphasia (short FAST) 6 mths	Extended ADL (FAI) 6 mths	Ethn-icity (Black/ other)	*B*	*β*	*t*	sri^2
SSS	r = .46***					5.40	.38	3.91***	.14
short FAST	r = .37**	r = .10				1.45	.29	2.57**	.06
FAI	r = .33**	r = .01	r = .51***			.32	.25	2.25*	.05
Ethnicity	r = .27*	r = .15	r = -.25*	-.20		20.18	.34	3.36**	.10
Intercept = -17.94									
Means (SD)	56.78 (15.44)	3.83 (1.08)	18.02 (3.09)	19.11 (11.91)	1.07 (.26)				
n	71	70	66	71	71				
						R^2 = .46 [a]			
						Adjusted R^2 = .42			
						R = .68***			

*** p < .001; ** p < .01; * p < .05

[a] Unique variability = .35; shared variability = .11

Table 5.3 is a summary of the regression model. *R* for regression was significantly different from zero, with F(4, 64) = 12.39, p < .001. The overall model accounted for 46% of the variance in the social network scores. Adjusted R^2 = .42, suggesting that 42% of the variance in social network six months post stroke can be explained by a person's social

support, aphasia, ethnicity and extended ADL. The *B* coefficients show that all four IVs were significant predictors. Inspection of the 95% confidence intervals shows that for none of these IVs did the confidence limits include zero, supporting their significance.

The IV with the largest β value was social support, suggesting this variable explained the most variance in the social network scores. Inspecting the squared semi-partial correlations of the IVs shows that social support accounted for 14% unique variance; ethnicity accounted for 10%; aphasia for a further 6%; and extended ADL for 5%. The four IVs in combination contributed another 11% of shared variability. The direction of the relationships suggested that the people with the strongest social networks were those who: felt better supported; had fewer language difficulties; performed more extended ADL; were of African or Caribbean ethnic background.

Finally, the equation was re-run, this time excluding Case 19. R^2 remained at 0.46 (adjusted R^2 = .43) providing reassurance that this one case was not having an undue influence on the regression model.

5.5 Results: What baseline factors predict social network six months post stroke? (RQ7)

5.5.1 Univariate analyses (RQ7)

Baseline variables significantly associated with social network at six months post stroke

Baseline demographic variables: gender and ethnicity did not vary from baseline to six months, and so the analysis of the previous question applied, and both variables were significantly associated with social network at six months.

Other baseline variables: aphasia measured two weeks post stroke (short FAST), was significantly associated with social network at six months ($r = .37$, $p < .01$). The following social variables measured at the time of the stroke were also significantly associated with social network six months post stroke: perceived social support (SSS) ($r = .36$, $p < .01$) and social network (SSNS) ($r = .75$, $p < .001$).

Baseline variables not significantly associated with social network at six months post stroke

The following baseline demographic variables were not associated: age ($r = 0.06$, ns); whether living alone ($t(68) = 0.06$, ns); marital status ($t(69) = -0.26$, ns); employment status ($t(69) = 0.85$, ns). Other baseline variables also not associated were: ADL (BI) ($r = 0.13$, ns); extended ADL (FAI) ($r = 0.19$, ns); dysarthria ($F(2, 68) = 0.91$, ns); stroke severity (NIHSS) ($r = 0.03$, ns); psychological distress (GHQ-12) ($r = -0.16$, ns); type of stroke ($t(69) = -1.14$, ns); number of co-morbidities ($r = -0.12$, ns).

Summary

The following baseline variables were significantly associated with Social Network six months post stroke: social network ($p < 0.001$), aphasia ($p < 0.01$), perceived social support ($p < 0.01$), gender ($p < 0.05$) and ethnicity ($p < 0.05$). These five variables were considered for entry in the multiple regression equation.

5.5.2 Multiple regression assumptions (RQ7)

Ratio of cases to IVs: There were five IVs that were significantly associated with the DV. This meant there were too many IVs, given that n = 68 (missing data for one participant on SSS; missing data for three participants on short FAST). Therefore, the equation was run, IVs which were not statistically significant were removed, and the equation re-run without them. In practice, this meant that perceived social support, ethnicity and gender were excluded from further analysis. The IVs included in the final equation were: social network at baseline; and aphasia at baseline. The remaining discussion of assumptions is based on running the multiple regression model with these two IVs.

Multicollinearity and singularity: The IVs did not correlate with one another higher than r = 0.23, suggesting an absence of multicollinearity. The tolerance value was 0.95, well above the criterion 0.20. Similarly, the VIF value was 1.05, below 10 and acceptable. There was also no singularity.

Normality, homoscedasticity, independence of residuals: Inspection of the Normal Probability Plot of the Regression Standardised Residuals suggests that the residuals were normally distributed as the points lie in a fairly straight diagonal line (see Appendix 16). The histogram of the standardised

residuals also supports this (see Appendix 16). An examination of the scatterplot of the standardised residuals versus the standardised predicted values of the DV suggests that the assumptions of homoscedasticity and linearity were met (see Appendix 16).

Independence of errors: The errors of prediction were independent of one another, as shown by the Durbin Watson test, which had an acceptable value of 2.44.

Outliers. Initially, univariate outliers were investigated among the IVs and DV. No case had a standardised score >±3.29, suggesting no outliers. In terms of multivariate outliers, the maximum Mahalanobis distance was 10.51, less than the critical X^2 for 2df at 13.82. Maximum Cook's distance was 0.74, less than one, and therefore acceptable. The average leverage value was (k + 1)/n = 0.044. Using the cut-off point recommended by Stevens [(3(k +1)/n = 0.13] to identify cases having an undue influence, two cases slightly exceeded this limit with values of 0.16 (case 11) and 0.14 (case16). The covariance ratio (CVR) was also calculated. The boundaries were: CVR > 1 + [3(k + 1)/n] = 1.13; CVR < 1 – (3(k+1)/n = 0.87. Two cases fell below the lower boundary: case 15 (CVR = 0.65) and case 54 (CVR = 0.78). Finally, in terms of outliers in the solution, case 15 had a standardised residual -3.25. All other residuals fell between ±2.5, suggesting a reasonable fit of the data.

In summary, the model appeared to be a reasonable representation of the data, with no outliers on the solution (no standardised residuals >±3.29). Maximum Mahalanobis distance, Cook's distance, and leverage values all provided reassurance that no one case is having an undue influence on the

model. Nonetheless, Case 15 had a low standardised residual (-3.25), and low CVR value. R^2 will be reported both with and without this case.

5.5.3 Standard multiple regression results (RQ7)

Multiple regression was run with two IVs: social network at baseline; and aphasia at baseline. The unstandardized regression coefficients *(B)*, standardised regression coefficients *(β)*, t values and the semipartial correlations *(sri2)* are presented below in Table 5.4.

Table 5.4 Baseline predictors of social network six months post stroke

Variables	Social Network (SSNS) 6 mths (DV)	Social network (SSNS) Baseline	Aphasia (short FAST) Baseline	*B*	*β*	*t*	sri^2
Social network (2 wks)	r = .75***			.70	.71	8.96***	.48
Aphasia (short FAST) 2 wks	r = .37**	r = .21*		.89	.22	2.80**	.05
Intercept: -1.24							
Means	56.78	61.81	16.49				
Standard Deviations	15.44	15.57	3.81				
n	71	71	68				
				R^2 = .61 [a]			
				Adjusted R^2 = .60			
				R = .78***			

*** p < .001; ** p < .01; * p < .05

[a] Unique variability = .53; shared variability = .08

R for regression was significantly different from zero, with F(2, 65) = 51.71, p < .001. The overall model accounted for 61% of the variance in the social network scores. Adjusted R^2 = .60, suggesting that 60% of the variance in social network six months post stroke can be explained by a person's social network prior to the stroke, and the severity of aphasia at baseline. The *B* coefficients show that both IVs were significant predictors: social network: t(68) = 8.96, p < 0.001; aphasia: t(68) = 2.80, p < 0 .01. Baseline social network accounted for 48% unique variance, aphasia accounted for 5%. The two IVs in combination contributed another 8% of shared variability. The direction of the relationships suggest that the people with the strongest social networks were those who: had strong social networks prior to the stroke; had fewer language difficulties just after the stroke.

As there were concerns that case 15 was having an undue influence on the equation, it was run once more without this case. R^2 = .63, and adjusted R^2 = .62, thus not substantially different from the model with case 15 included. Case 15 represented someone whose social network changed very substantially post stroke, which is why his baseline social network was not a good indicator of his network six months post stroke.

5.6. Summary

Four research questions were addressed in this chapter. The main results were as follows:

RQ4: what concurrent factors predict perceived social support six months post stroke?

Roughly 40% of the variance in perceived social support six months post stroke could be explained by three variables: a person's social network, their marital status, and their level of psychological distress. Specifically, those with strong social networks, who were in a relationship, and had low levels of psychological distress were likely to perceive themselves to be well supported six months after a stroke.

RQ5: what baseline factors predict perceived social support six months post stroke?

Only one baseline factor was a significant factor in predicting perceived social support six months post stroke: how well supported a person felt prior to the stroke. No other baseline factor was a significant predictor, thus severity of stroke, level of disability, aphasia, and psychological distress at time of stroke, did not influence patterns of perceived social support in the months following the stroke. It appeared that perceived social support was a relatively stable construct: those who felt well-supported prior to the stroke were likely to feel well supported post stroke, regardless of stroke severity. The model accounted for 43% of the variance in perceived social support.

RQ6: what concurrent factors predict social network six months post stroke?

Forty-two per cent of the variance in social networks could be explained by the following variables, all measured at six months post stroke: perceived social support, ethnic background, aphasia, and extended ADL. Thus the people who had the strongest social networks six months post stroke were

those who: felt well supported; were of African or Caribbean ethnic background; and had few language or activity limitations.

RQ7: what baseline factors predict social network six months post stroke?

Only two baseline variables were significant predictors of social network six months post stroke: a person's social network pre-stroke, and aphasia as measured at the time of the stroke. Together, they explained 60% of the variance in social networks. No other baseline variable was a significant predictor, for example, severity of stroke, level of disability, psychological distress, even social variables such as perceived social support and marital status. A person's social network pre stroke was the most significant predictor (accounting for 48% of unique variance). Aphasia was the only other predictor, suggesting that language difficulties impede a person's ability to maintain their social network, more so than any other stroke related factor.

5.6.1 Overall summary

Perceived social support appeared to be relatively robust after a stroke: those people who felt well supported prior to the stroke were likely to feel well-supported post stroke. Similarly, a person's social network prior to the stroke was the strongest predictor of their social network six months post stroke. Other factors, such as stroke severity, disability, and psychological distress, measured at the time of the stroke, did not predict either social support or social networks six months post stroke. The exception was aphasia: language disability was the only stroke-related factor measured at

the time of the stroke that impacted on a person's ability to maintain a strong social network over the following six months.

In terms of variables measured at six months post stroke, perceived social support predicted social network, and vice versa, confirming the close relationship between these two concepts. Additionally, perceived social support was predicted by marital status and psychological distress. Social network, by contrast, was predicted by ethnicity, aphasia and extended ADL.

Chapter Six. Friendship following a stroke

As shown in Chapter Four, the Friends factor of the Stroke Social Network Scale was the only domain that changed significantly post stroke. Thus friendships appear to be a vulnerable element of a person's network, replicating the findings from other research projects[2, 8, 104, 173]. However, although it is well-established that people appear to be at risk of losing friends post stroke, it is less well understood *why* people lose their friends, and how this process is perceived by the individual. Further, not everyone loses their friends, and even those who do are unlikely to lose all their friends. Yet it is unclear what factors protect some friendships and not others, and which people are particularly at risk of losing their friends.

In seeking to explore these issues, this chapter addresses the broad research question: what happens to friendships post stroke? (RQ6). This is further broken down into the following four components:

A) Is there a reduction in contact with friends following a stroke?
B) What are the perceived causes of friendship loss?
C) What factors help to protect friendships?
D) How is friendship loss and change perceived by the individual?

The term 'friend' in the qualitative analysis covered all social contacts who were neither family nor paid, including both close, confiding friendships as well as those more peripheral to the individual. Thus friendship in the context of group activity is also considered. For the quantitative data only information on 'close friends' was collected. A close friend was defined as

‘people you feel at ease with and/or can talk about what is on your mind’. Information was also collected on group membership.

In section 6.1 evidence is provided from Stage One of the project. The remainder of this chapter uses qualitative evidence, from Stage Two of the project, and is based on the following paper: Northcott and Hilari (2011)[7]. A copy of this paper is provided in Appendix 17.

6.1 Stage One: quantitative data on friendship and groups

6.1.1 Is there a reduction in contact with friendships post stroke?

As reported in 4.3, the Friends factor of the Stroke Social Network Scale was the only subdomain to show significant change: Wilks’ Lambda = .80, $F(2, 68) = 8.49$, $p = .001$, $\eta = .20$

In order to investigate which items of this subdomain were changing, and if any were remaining stable, each of the four individual items were analysed: F1 (number of close friends), F2 (how often they saw their close friends), F3 (how often in telephone, letter or email contact with close friends), and F4 (what proportion of their friends live close by). Descriptive statistics for these four items are presented in Table 6.1 below. Raw scores are provided, for ease of interpretation. The number of close friends is capped at seven, in order to reduce the effect of outliers, as justified in Chapter Three.

Table 6.1 Friends factor: descriptive statistics for baseline, three months and six months

Friends subdomain (taken from Stroke Social Network Scale)			
	Baseline (*n* = 87)	3 months (*n* = 76)	6 months (*n* = 71)
F1 Number of close friends*			
Mean (SD)	4.12 (2.29)	3.71 (2.23)	2.89 (2.31)
Range	0 – 7	0 – 7	0 – 7
		n = 75	*n* = 70
F2 Frequency of face to face contact**			
Mean (SD)	2.99 (1.65)	2.40 (1.59)	2.17 (1.68)
Range	0 – 5	0 – 5	0 – 5
		n = 75	
F3 Frequency of telephone, letter or email contact**			
Mean (SD)	3.08 (1.75)	2.71 (1.79)	2.57 (1.78)
Range	0 – 5	0 – 5	0 – 5
		n = 75	*n* = 70
F4 How many close friends live nearby***			
Mean (SD)	1.46 (1.02)	1.20 (1.01)	1.23 (1.12)
Range	0 – 3	0 – 3	0 – 3
	n = 85	*n* = 75	

*definition of 'close friend': people you feel at ease with and/or can talk about what is on your mind
**Response options: 0 = not at all; 1 = about once a month; 2 = 2 or 3 times a month; 3 = at least once a week; 4 = 2 or 3 times a week; 5 = every day
***Response options: 0 = none of them; 1 = some of them; 2 = most of them; 3 = all of them

In order to determine if significant change had taken place, one-way repeated measures ANOVAs were carried out for all four items. There was significant change in the following three items:

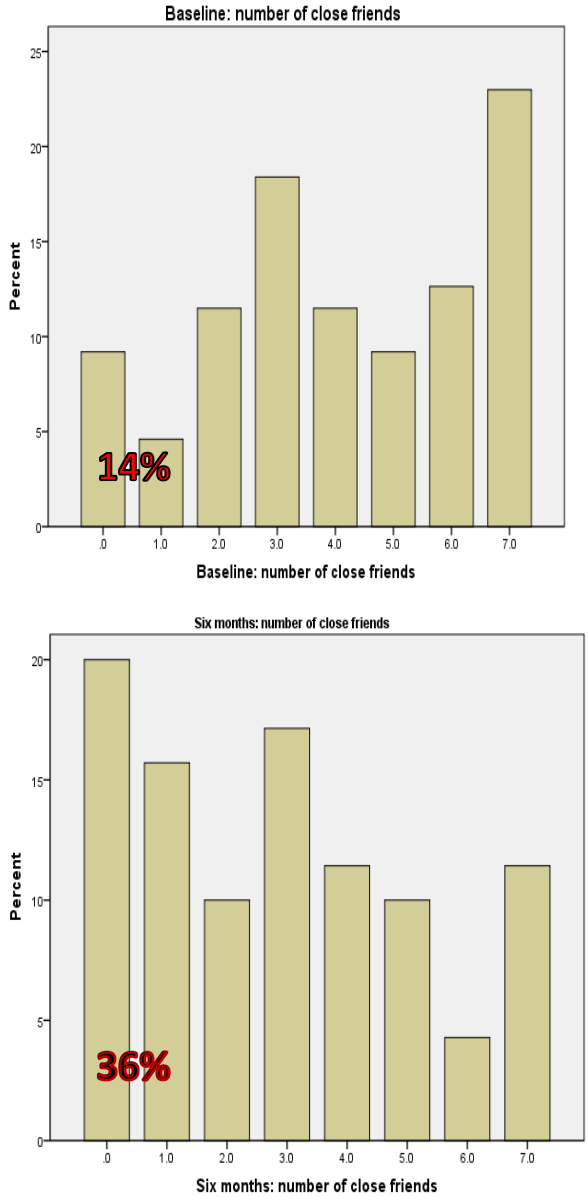
- F1, number of close friends Wilks' Lambda = .78, $F(2, 67) = 9.46$, $p < .001$;
- F2, frequency of face to face contact, Wilks' Lambda = .82, $F(2, 68) = 7.32$, $p = .001$;

- F3, frequency of telephone, letter and email contact, Wilks' Lambda = .90, $F(2, 67) = 3.80$, $p < .05$.

The only item where there was no significant change was the proximity item.

Figure 6.1 below provides information on how many friends participants had at baseline and six months post stroke. As can be seen, at baseline 14% of participants described themselves as having one or no friends (10% reported having no friends). By six months, this had risen to 36% having one or no friends (20% no friends). Conversely, at baseline 36% of participants reported they had six or more friends, while at six months only 16% reported having six or more friends.

Figure 6.1 The number of close friends, before and after a stroke



In summary, as anticipated by the literature, not only do people have fewer friends after a stroke, there is also a reduction in face to face, telephone, letter and email contact. Further, the proportion of people who no longer have any friends rises from 10% at baseline to 20% at six months post stroke.

6.1.2 Is there a reduction in group involvement post stroke?

As reported in Chapter 4, there is no significant reduction in the Group factor of the SSNS following a stroke. Table 6.2 provides information on the two items that make up this factor.

Table 6.2 Group factor: descriptive statistics for baseline, three months and six months

Groups subdomain (taken from Stroke Social Network Scale)			
	Baseline (*n* = 87)	3 months (*n* = 76)	6 months (*n* = 71)
WN2 Number of groups			
Mean (SD)	0.88 (1.00)	0.71 (0.94)	0.79 (1.00)
Median (IQR)	1.00 (0 – 2)	0 (0 – 1)	0 (0 – 1)
Range	0 – 3	0 – 3	0 – 3
	n = 85	*n* = 75	
WN3 How actively involved in groups*			
Mean (SD)	0.74 (0.89)	0.48 (0.77)	0.57 (0.85)
Range	0 – 2	0 – 2	0 – 2
	n = 85	*n* = 73	*n* = 69

* 0 = not active even if belong to a group; 1 = fairly active; 2 = very active

There is a trend towards participants having the least group involvement at three months post stroke, and the most involvement prior to the stroke. The dip at three months may reflect that many participants were still in rehabilitation units at this time point, or had only recently returned home. However, this pattern does not reach statistical significance.

Even prior to the stroke, 55% of participants were not actively involved in any group. This figure rises to 68% at three months post stroke, and 67% at six months.

6.2 Stage Two: qualitative data on friendship

Part of the qualitative interview probed friendships (see Topic Guide in Appendix Seven). The data on friendship change is presented here. Support provided by friends is explored in more detail in Chapter Nine. The sample for this dataset is described in Chapter Four (see 4.2); and the qualitative interviewing techniques used described in Chapter Three (see 3.7).

6.2.1 Perceived causes of friendship loss post stroke

There were a variety of reasons that people gave for why they had lost friends such as loss of shared activities, reduced energy levels, poor mobility, unhelpful responses of others, environmental barriers, aphasia, and the changing social desires of participants. In some cases, it was clear that a friend was 'lost' to a participant, for example, the friend had not contacted them since the stroke. In many cases, however, it was less clear cut: participants may have less or no contact with a person post stroke, but still consider them a 'friend'. Thus this section explores not only the reason why friends were 'lost', but also why participants could feel less close to friends, or saw them less frequently.

Loss of shared activities

A major change in how friendships functioned post stroke was the loss of shared activities. Although the purpose of some of these activities may not have been primarily sociable, in losing the activity participants also tended to lose the friends and social contacts that was a part of the experience. There was a wide range of lost activity described, including work, attending religious services, sport, cultural activities, organised groups and other social or semi-social events.

An example of a participant who had made good friends through an activity, lost post stroke, is Gerta. Gerta was 82 at the time of the stroke and lived alone. Prior to the stroke she attended a circle dance class, which she enjoyed: *'Well, one thing which I was very fond of doing was circle dance… the stimulation and the contact and relationships.'* After her stroke several members of the class came to visit her in hospital, sent her a plant, and were *'very concerned afterwards, and wanted me to come back.'* Due to vertigo and exhaustion she decided it was *'just too much, I can't do it, even though I enjoyed it very much.'* A year on, she no longer sees any of the contacts she knew through the class.

Reduced energy levels

People felt exhausted post stroke, even in this chronic phase, which impacted on their desire and ability to socialise. Even those with mild strokes described restricting social engagements and coming back early from social events. Exhaustion could also have a negative impact on socialising in the home. An example is Bridget, 74 years old and living on her own. Following the stroke, she was housebound and often exhausted. Although lonely and wanting company, she found herself pushing away potential guests, as the following excerpt illustrates:

> *'How can you invite somebody, and all of a sudden, you go to sleep, and you can't comprehend or have tea with them or something? It's not very nice you know. Somebody did ring me up one day, and say, you know, come and I'll bring the cakes. I said, oh, not today, I'm, you know, otherwise occupied, that's what I had to say. But when I put the phone down I cried because I had to go to bed.' (Bridget, p5)*

Exhaustion also made it harder for participants to initiate or arrange social events. An example is Patricia. Friendships which relied on her taking the lead on organisation had slipped away from her since the stroke, as she no longer had the energy to take on this role: '*I can't be bothered to phone them [a group of friends] and make arrangements and go out with them any more…I just don't have the energy level, it's really quite simple.'*

Poor mobility and other physical symptoms

For those who were housebound, they were only able to see friends who were prepared and physically well enough to come to them. Since friends are usually of the same age, for some of the older participants this could mean that face to face contact was no longer possible. Even those able to leave the house independently could report being fearful of having a fall, meaning they stayed at home more than they used to.

Other physical symptoms also impacted on people's social lives, both directly (for example, difficulty writing making correspondence with old friends no longer possible), or indirectly (visual field disturbance meaning they could no longer drive).

Unhelpful responses of others

The most extreme negative response was where the participant felt that a friend, or even an entire friendship circle, had abandoned them after the stroke ('*When I was still alright, I didn't have this stroke on one side, everybody likes me, once I got the stroke, no-one care about me any more.')* Other unhelpful responses reported included friends who ridiculed them; friends who told them how to feel; friends who pitied or patronized them. For example, one participant described how work colleagues' attitudes had

changed since he came back from the stroke: *'The young chaps at work tend to feel a bit more, how can I say, sorry for me to some degree, which I don't like really, they try to treat me as, you know, a little bit somebody who's, ah bless him, he's got something wrong with him.'*

Environmental barriers

Using public transport could become more difficult post stroke, and it was universal for participants to avoid lengthy or complicated travel. Similarly other factors like anxiety about 'difficult' buildings with steps or insufficient toilets, or a lack of suitable seating, could deter participants from going out.

Aphasia

Those with aphasia appeared to have the most negative experiences in terms of other people's responses. Several reported others laughing at them or mocking their speech, which could lead to a sense of shame or embarrassment, and an avoidance of talking. ('*They laugh at me if it mistake… That's why sometimes I just keep quiet [crying]').* There was no other physical symptom which was similarly mocked. The most extreme negative response of 'deserting' the participant or cutting off contact altogether was again only reported by those with aphasia. They were also more likely to experience difficulties keeping in contact with friends who lived abroad, as writing and speaking on the telephone could be difficult. Finally, those with aphasia were the most likely to say that even where they still saw friends, the substance of the friendship had been altered, for example, humour could be more difficult, conversations were less likely to be two way, it could be harder to join in or get their point across.

Although there were people with aphasia who had not lost friends, all the participants in this project who had lost their entire friendship networks had aphasia.

Changing social desires of participants: 'I seem to be closing in on myself'

Part of the reason why friendships changed post stroke appeared to stem from the changing social desires of the participant. In part, this was a response to the many factors described above: socialising with friends becomes a less attractive option if one is fatigued, walking is more effortful, communicating is a challenge, or the logistics of travelling to and attending an event become more onerous. However, there were also more internally driven reasons given by participants as to why they no longer had the same desire to see some or all of their friends and acquaintances. There was a sense that many participants were 'closing in' on themselves, and wanting to withdraw from the wider world. They gave a variety of reasons for this phenomenon.

Participants described how they felt less good company now: if previously they had felt themselves to be witty and fun, they might now feel boring. For example, one participant said he worried that he will seem dull, out of date, and less knowledgeable now that he spends so much more time at home and is not out and about working or at various cultural events.

There was also a reluctance to have others see them unwell or disabled: they worried that others would dismiss them, value them less, or pity them. Some spoke of feeling ashamed or self-conscious. Even those who did resume social activities could keep themselves semi-detached to avoid others

noticing the extent of their disability. An example of someone who resumed an activity but felt removed from social contact is 58-year old Edward. Before his stroke he had taken up archery, becoming *'quite good'*. He had only recently gone back and struggled with the coordination required: he felt he was now *'absolutely useless with the shooting'*. He described the impact this had on him:

> *'And you tend to feel a bit more vulnerable then, you think, Oh God, are people looking at me, you know, he's a total waster coming up here, and you got all these people round you thinking "Oh God", and I tried to stay back, away from people, so that I wasn't involved.' (Edward, p3)*

Many participants described feeling more introverted. An example is 74-year old Gordon. He knew many people locally, having lived in the same house for over 20 years. Before his stroke he said *'[I] used to go out so much before, I used to know everybody'*, and described himself as outgoing. Following the stroke, although physically able to walk, he commented, *'I just don't feel like going out now…just I seem to be closing in on myself'*. Others describe how going out to meet people could be a cause of anxiety and fear. In comparison, staying at home could make a person feel secure. The stroke could make them reassess their own vulnerability, and redraw the boundaries of where they felt comfortable. This is illustrated by the following quote:

> *'I felt quite safe inside the house and I didn't really feel a desire to go outside, I couldn't see any point in going outside. Um. You*

become quite introvert and frightened when you have [a stroke], because you realise you're rather vulnerable.' (Peter, p 8)

Feeling unwell, depressed, anxious, self-conscious, or the effort of concealing the stroke could all make social situations less enjoyable. Further, some of the functions of social activity were arguably lost. Social gatherings that had been fun, and taken the participant's mind off any worries, could now be stressful and heightened their awareness of their own difficulties. Activities where they had previously enjoyed 'expert' status, bolstering their self-esteem and status, could now have the opposite effect. Loss of reciprocity could also challenge their sense of social identity. A common refrain was that people could no longer be bothered with many social activities.

If in part participants were withdrawing from their wider social worlds out of a sense of vulnerability or the emotional discomfort of socialising post stroke, there was another strand of reasoning that also emerged from the data. There appeared to be a revamping of what was important, which was reflected in a new selectivity about social engagement. There was often a preference for seeing family and only close friends. Interactions with acquaintances or strangers appeared to be less valued post stroke. One participant said he used to find meeting new people exciting whereas now he feels it's a waste of time; another described how since his stroke he no longer has tolerance for *'aimless chatter'*. By contrast, several described the comfort they have found in talking *'the same old rubbish'* with long established friends.

It was also common for people to report that since the stroke they preferred meeting up with friends one to one or in small groups. Large crowds and noisy gatherings were often avoided. This phenomenon is illustrated by Gerta, 82 years old and living on her own.

> *'I have been invited to some meals out before Christmas, and it was often very noisy in some of the restaurants, you know, and in some places, that's the point where you feel you have changed, one is changed a bit. One is more inclined to talk to one person, and not to mix too much in a big crowd.' (Gerta, p10)*

The stroke could enable participants to re-evaluate what they were looking for in their social worlds. This is illustrated by 18-year old Pratik. He described how the stroke was a turning point, and a catalyst for change. Following the stroke he was no longer prepared to be in social situations which made him unhappy, and he consciously chose to lose touch with a group of friends who he felt undermined him.

Participants who reported a change in their desire to socialise lost many, sometimes all, of their friends and acquaintances. It appeared that these internally driven reasons were a major factor in understanding the reason why friendship loss is so frequently described post stroke.

6.2.2 What factors help to protect friendships?

Feeling 'close' to a friend

The greatest protection of all was the quality of the friendship prior to the stroke. Those who felt very close to someone generally succeeded in maintaining such a friendship, even where there were various other obstacles. The friends least likely to be lost were those who *'cared'*, *'showed concern'*, with whom they had shared history, and who knew them well enough that they didn't need to feel self-conscious, for example, about dropping off to sleep when together. Conversely, those on the periphery of their social network were more vulnerable to being lost.

Proximity

Living locally was a strong protective factor for the friendship. It meant there was no need to negotiate public transport and that visits could be more spontaneous.

Availability of the friend

Various factors affected how 'available' a friend would be, such as whether they were retired, were mobile, could drive, were in good physical and psychological health, and had few other commitments.

Not activity based prior to the stroke

Those friendships that were partially or wholly based around meeting up in each other's homes appeared to be more robust post stroke than those where the participant only saw the friend when out and about, for example, when going to an activity.

Regular, supportive groups

Several participants described going to a particular café, pub, club or group at least once a week, in some cases, almost every day. Thus there was an element of 'scaffolding', whereby the meeting place and time was regular, which made maintaining such friendships easier. Participants described talking to whichever of their friends happened to have come along that day. This method of meeting friends avoids the necessity of initiating or organising contact, and although pre-arranged was often relatively informal

It was possibly the most supportive type of group the participant could attend, since it was likely they would know all members, which could help if they were coming to terms with new disability. There may have been something protective, too, about the fact that the friends all knew each other in these set ups, thus could potentially support one other in supporting and accommodating the participant.

In a similar vein, friendships made through church or mosque also had a protective 'scaffolding': so long as the participant was physically able to attend religious services post stroke, they would be met by a supportive community on a regular basis.

Family friends

Where a friend knew the spouse, the participant could be enabled to remain in contact with them since it was the spouse who would be likely to be organising the contact, and, for example, inviting them to the house and hosting them.

Being open about having had a stroke

Those participants who were open about their stroke and its consequences succeeded in maintaining their most important friends in this project.

Having a 'friends-based' social network prior to the stroke

For these participants, friends, as opposed to family, occupied a central role in their social network prior to the stroke, and were likely to be the main source of emotional and companionship support. Almost all those with friends-based social networks pre-stroke reported maintaining their most important friends, if not all their friends, post stroke. This is discussed in more detail in Chapter Eight.

The case example below illustrates how these protective factors can help someone maintain their friendships, even where they have aphasia.

Retaining friends despite having aphasia

Andy was 69 when he had his stroke, leaving him with moderate aphasia. Despite his language difficulties, he felt the stroke had not changed his friendship patterns. He is an example of someone who had many of the 'protective' factors listed above: he had a long-established and supportive group of friends who lived locally, whom he saw at a nearby club on a regular basis; he had a 'friends-based' social network prior to the stroke; the stroke had not affected his mobility; he was open about his aphasia and strategies that helped; and he did not display any tendencies to 'close in' on himself: *'Don't afraid, keep talking, don't shut away, yes, yes. I don't do that. I wouldn't do any of that.'*

6.2.3 How is friendship loss and change perceived by the individual?

There was much variation in how people felt about their changing social situation: although some were devastated, not everyone lamented the changes.

The participants who were the most hurt by the changes were those who felt rejected or mocked by people they had thought were friends. The hurt could additionally be accompanied by bitterness, a lack of comprehension about why their friends had abandoned them, and anger or defensiveness.

More commonly, participants did not express bitterness or hurt, but did feel a sadness that they were no longer in such frequent contact with friends and acquaintances. They missed activities and social events that they had given up, such as dancing classes or going to football matches, or even their daily walk.

Sadness was often tempered by the hope that their situation would improve. Many participants still hoped that in the future they would be able to resume various activities. An example is Pablo, 63 years old with aphasia. He described friends he knew through fishing. Since his stroke, he had not been able to go fishing and no longer saw these friends. However, he still considered his fishing friends to be his 'friends'. He was hoping that one day he would go fishing again, and the friendships would be picked up at that point. Thus although he was sad that he could not go fishing, he did not feel he had 'lost' his friends. Indeed, a recurrent theme was that people didn't feel less close to friends and social contacts, just didn't see them so often. While they might wish they could see them more, it was not hurtful, did not challenge their concept of friendship.

Participants also expressed sadness about the ways in which even close friendships had needed to change post stroke. Particularly for those who were housebound, an element of reciprocity could be lost. This is illustrated by Adebomi, 68 years old with aphasia. She was now reliant on friends visiting her, and when they arrived, not only could she not offer them a meal (she had previously been a keen cook), she couldn't even make them a cup of tea, all of which she found upsetting. Many of those with aphasia described frustration and distress relating to the difficulties in having conversations with friends.

There were also those who were positive about losing friends and acquaintances: they no longer wanted to be out and about mixing with people, preferring to limit their social interactions.

Finally, a small subset of participants felt that their friendships had been strengthened by the stroke, which was a source of happiness to them.

6.2.4 Unpacking the relationship between depression and loss of friends

A theme emerging from the interviews was the prevalence of depressive type symptoms in this chronic phase post stroke such as feelings of sadness, despair and anxiety, having no energy, lack of interest or motivation to engage in activities, low self-esteem, and a sense of feeling stuck or 'lifeless'. Such depressive feelings could make a person disinclined to socialise: a wish to withdraw and retreat from others was common as described above. The lack of social contact, however, arguably intensified

the feelings of depression, such that a vicious cycle could be set up. This is illustrated by the following case example. Before the stroke, 62-year old Patricia was a journalist who prided herself on her fluency and humour. The stroke left her with mildly reduced fluency which in turn meant that in the months post stroke: *'I didn't feel that I had the right level of conversation to hold myself up in company…. I didn't feel that I could I suppose inflict myself. I didn't want to go to places and not be able to contribute in every way, I didn't feel I could.'* Prior to the stroke she had a busy social life, post stroke this was severely restricted. She also described her depression, where life seemed *'very dull and dim'*, where she couldn't see a way out, felt despair, no longer had any energy or interest in life. She described the relationship between reduced contact and depression: *'I didn't go [out] because I felt insecure and I felt insecure because I didn't go out. So it kind of built up to this [feeling depressed].'* Sitting at home, doing nothing, made her feel lonely: '*I hate loneliness. Loneliness frightens me more than anything at all.'*

6.2.5 New friendships and group activity post stroke

A subset of participants attended new facilitated groups following their stroke. These groups could be run by charitable organisations, and designed for a certain subset of the stroke population (for example, the younger stroke survivors, or those with aphasia). Others attended groups at rehabilitation hospitals, or run through the local council or social services.

Some participants spoke of liking the people they met through such groups and found it a positive experience. This, however, was not universal, and

others described not having much in common with the other group attendees. No-one in this project referred to people they had met through such groups as ‘friends’. When Chris, who had lost all his friends post stroke, was asked whether the people he met at stroke-related groups substituted for the lost friends, he said no, and started to cry.

6.3 Combining qualitative and quantitative data: complementary evidence?

Both the quantitative and qualitative evidence suggest people are at risk of losing friends post stroke. In fact, the quantitative data may underestimate the extent of friendship loss as it focuses on close friends rather than peripheral contacts. It is those on the periphery, however, who appear to be particularly vulnerable network members according to the qualitative data. Both data sources demonstrate not only that friends were lost, but also that there was reduced contact with retained friends. Further, both sources suggest that a proportion of participants lost their entire friendship network post stroke.

A common theme in the qualitative data, which was not apparent in the quantitative data, was the loss of friends through no longer being able to attend groups. Although there was a (non-significant) trend for people to be less active in groups post stroke, there was no significant change in the Groups factor. One explanation is that many participants were involved in stroke-related groups six months post stroke, which may have masked the loss of pre-stroke group activities.

6.4 A personal reflection on the process of gathering qualitative data

This chapter has presented the material that emerged from qualitative interviews in carefully organised themes. The process of revealing intimate experiences, however, is complex and untidy: themes were not generally succinctly described and summarised by participants but more often emerged through sensitive probing. As observed by Legard *et al.* (2003, p 142)[249], it is likely that a participant will have new insights, and travel with the interviewer 'down avenues of thought they have not explored before'. This next section presents a more personal reflection on the process of gathering qualitative data. In particular, it examines one particular interview as an example of how distressing realities may be buried beneath the stories which a person feels more comfortable with when talking about their life. The ethical considerations of potentially unravelling these protective layers is also discussed.

Tomasz was 66 years old and still working when he had a severe stroke. The interview began with mapping out his social network.

SN: So over the last week, can you remember who you've seen?

Tomasz: I tell you, I have seen my usual friends

SN: Who are your usual friends then?

Tomasz: Well, my wife's friends, my friends… If we feel like to see each other we phone, and they are coming or we go there

Twice more in the early stages of the interview he stressed how many friends he had, and how frequently he saw them *('But you see, I need itemise, difficult to tell you how many friends I've got… It won't be enough room on that list!'… 'so many!'*). It was apparent that Tomasz could not mobilise independently post stroke, which would seem likely to effect his friendships. Initially, a gentle probe asking about change was used:

SN: Do you think things have changed a bit with your friendships? After the stroke?

Tomasz: No because I have friends, they are good friends, I don't have ten per cent friends, they are 100 per cent friends.

The concept of strong friendship was clearly important to Tomasz, and I didn't want to probe the reality of 'no change to his friendships' at this relatively early stage in the interview. Instead, we discussed the role of the '100 per cent' friend more generally, and the conversation turned to how difficult he found it to be accepting help rather than providing help. This led to him to disclose the despair he felt having to rely on his family even to leave the flat. At this later stage in the interview, when trust had been more firmly established, and he was more comfortable revealing difficult emotions, I repeated the question about friends:

SN: So does that [the stroke] change what you do when you see friends?

Tomasz: Well, I see them rarely. Not so often, isn't it. Because it's hard for me to get down. I have to rely on public transport. I need my son to be free to take me there. So it's not frequent.

SN And do they tend to come here more?

Tomasz: Yes, if they come… Of course [I miss seeing them]

These excerpts suggest that there are possibly many 'truths' which we all tell ourselves and each other. The validity of the analysis necessarily relies on the sensitivity with which the stories were discovered during the interview process.

A further observation is the upsetting nature of some of the interview data. In enabling participants to reflect on their stories, it could feel that protective layers were being stripped from them. The following quote is from Pratik, an 18-year old stroke survivor: *'You're the only person who listens to me, really. …you're the only person I've talked to about this sort of stuff… how the situation is right now. The first person.'*

The accepting nature of the interview, and the chance to feel listened to, did appear to be a valued experience for many. For example, Chris, who had severe aphasia post stroke, indicated that nothing had helped after his stroke, other than the chance to talk about it in the interview. No interviewee elected to stop the interview, although in two cases the recording was temporarily suspended due to interviewee distress: in both cases they wanted to continue the interview. Further, no interviewee appeared distressed at the end of the interview, and all were given both my own contact details, and details of other useful organisations as described in

Chapter Three. Nonetheless, having previously worked as a clinician, I found it unsettling not to be able to build an ongoing therapeutic relationship. Further, it is possible that participants may have been left 'with feelings and thoughts stirred up by the interview long after the researcher has moved on' (Lewis, 2003, p 68)[255], which may be an area worthy of research in itself.

6.5 Summary of findings

This project provided both quantitative and qualitative evidence that friendships are vulnerable post stroke: loss of friendship was common, and participants had less face to face, telephone, letter or email contact. Various reasons were given for this reduction in contact with friends, such as: fatigue, poor mobility, loss of shared activities, unhelpful responses of others, and the changing social desires of participants. The subset of participants who experienced the most extensive loss of friends were those who described a sense that they were 'closing in' on themselves leading to a withdrawal from social contact and a new preference for meeting only close friends and family. Those with aphasia experienced the most hurtful negative responses from others and found it more difficult to retain their friends unless they had strong supportive friendship patterns prior to the stroke. The factors which helped to protect friendships included: having a shared history, friends who showed concern, who lived locally, where the friendship was not activity-based, and where the participant had a 'friends-based' social network prior to the stroke.

Chapter Seven. What happens to family relationships after a stroke?

The main story regarding family would seem to be one of stability: both the Children's factor and the Relative's factor remained constant post stroke, with no significant change (Chapter 4). This is not to say, however, that change did not take place within the family unit. This chapter looks at how relationships with spouses, partners, children and relatives have been affected by the stroke. The following research question is addressed:

RQ9: What happens to family relationships following a stroke?

The research question will be explored using data from both Stage One (quantitative) and Stage Two (qualitative) of the project. Participant characteristics for both datasets are provided in Chapter Four (see 4.1 and 4.2), and the methodology used to collect the data is described in Chapter Three.

7.1 Spouse/ partners

7.1.1. Marital stability: quantitative evidence

No participant in the project who completed the six month interview divorced or separated from their spouse following the stroke. One participant's wife died shortly after his stroke: this was the only reason for a person's marital status to change.

At baseline, 11 participants said they had a partner. Of these, three were lost to follow up; one participant split up with their partner; and seven remained with their partner.

In conclusion, in this sample marital/partner status was rarely affected by having a stroke.

7.1.2 Changes to the marital relationship: qualitative evidence

Although it was uncommon that the stroke resulted in relationships breaking up in this project, it was the cause of major change. The changes included: shifting roles; a cause of new conflict; and also potential positive changes.

Changing roles

The most common change following the stroke was that the spouse took on the role of caregiver. Where a participant was too disabled to take on practical tasks, this could mean the spouse needed to assume new responsibilities. For example, one participant could no longer access the stairs into the kitchen, so her 90-year old husband was having to cook for them both for the first time, which was a cause of worry to her.

The extent to which the spouse took on new caring roles depended on the level of disability of the participant, and how much paid carers were involved. In some instances, the spouse's life could be altered significantly, which could in turn lead to a change in the relationship with the participant. Previously independent equal partnerships could be altered, with the participant now suddenly dependent on their spouse, and feeling responsible for the spouse having their old freedoms curtailed.

An example of a relationship where the roles changed post stroke is Tomasz. He was 68 when he had the stroke and still working. The stroke left him virtually housebound and dependent on his wife. He explained, *'Well now I am problem for family… my wife have to look after me… She cannot go to see friend as often as before because she want to look after me… She make sacrifice. She's less happy.'* He reported that he couldn't do anything to change this situation, but just had to rely on her. All this made him *'very depressed,'* and the only thing that kept him going was the hope that things would change.

Participants described how they found it harder post stroke to take on the role of provider, or look after or 'treat' their spouse. Participants described their sadness that they could no longer provide financially for their spouse, were unable to take their spouse on holiday, or take their spouse out as they used to. This situation was exacerbated if their spouse then became ill. This is illustrated by Cormac's situation. Since the stroke his wife's Parkinson's Disease had deteriorated which meant she could no longer clean the house. He was attempting to help, but was finding it difficult: he was aware of his wife's high standards which he struggled to meet with his lack of experience and weakened right hand.

New conflict

In addition to the strains imposed by the shifting roles post stroke, participants described other new causes of conflict that had arisen as a result of the stroke.

Having a stroke could mean the participant was likely to be at home more. This could be a possible cause of conflict. Becomingly increasingly

housebound was a contributing factor in the rows described by Rose. Rose's spouse described how they *'just sit in front of each other all day long – it's not good'*.

Another way in which the stroke could cause conflict is where the participant felt their personality had changed post stroke. For example, Edward described how he would swear and lose his cool in the months following the stroke, which his wife said was not like him, and which she found difficult to deal with. Edward loved his wife, and observed that this was why he behaved worse with her than anyone else: *'It's anyone who's nearest and dearest, nearest person is obviously going to take a lot of the force, the brunt.'*

Similarly, a spouse would be most likely to notice and feel the effects of depression. Hakim's marital difficulties with his wife coincided with severe depression post stroke. Depression was a common sequela after a stroke and several participants described the negative impact depression could have on their relationship with their partner or spouse.

The participants whose marriages/partnerships had been most adversely affected (splitting up or becoming estranged) both had aphasia as well as severe depressive symptoms. Although aphasia was not mentioned as a contributing factor, a reasonable inference might be that it did not facilitate resolution of these conflicts.

Positive changes

Despite the difficulties, participants mostly reported feeling close to their spouse. For some participants, the relationship appeared not only intact but

stronger. Coming so close to death could make both the participant and their spouse appreciate their life together more. It could also be a chance to re-negotiate aspects of the relationship: one participant said his wife let him play jazz which she didn't before; she also read him more poetry.

An example of the stroke functioning as a catalyst to make husband and wife closer is Brian. At 57, he worked long hours running his own successful business when he had a relatively mild stroke. Following the stroke, he made the decision to work part-time. This meant that he and his wife could spend more time together, going to cricket matches and travelling, which he described as positive. As he put it, *'I think maybe having a stroke with obviously the awareness that it could have been much more serious, um, I think you treasure the relationships that you have more…We probably value life a little bit more, and, you know, very grateful for what we've got.'* He described himself as *'very lucky'* to be married to his wife.

7.2 Children

The Children factor of the Stroke Social Network Scale remained stable post stroke, and most participants reported seeing their children with the same frequency as prior to the stroke. However, despite this apparent stability, various factors made it more likely that some participants would see their children *more* than prior to the stroke, while others would feel *less* close to their children. Furthermore, there were changes in the sorts of activities participants did with their children post stroke. Finally, a major change that

took place was shifting roles, where the parent was receiving rather than giving: this often represented a painful transition.

7.2.1 Contact with children: quantitative evidence

The Children factor, as presented in Chapter Four, remained stable: there was no significant change between the mean scores at Baseline; three months; and six months.

In terms of the participants at baseline, 65 out of 87 participants had children (75%); at three months 76% had children (58 participants); and at six months 79% had children (56 participants). Table 7.1 provides the statistics only for those participants who had children. Descriptive statistics for the following items are displayed: C2 (frequency of face to face contact), C3 (frequency of telephone, letter and email contact), and C4 (proximity).

Table 7.1 Children factor: descriptive statistics for baseline, three months and six months post stroke

Children subdomain (taken from Stroke Social Network Scale)			
Only participants with children included	Baseline (*n* = 65)	3 months (*n* = 58)	6 months (*n* = 56)
C2 Frequency of face to face contact*			
Mean (SD)	3.30 (1.78)	3.28 (1.74)	3.29 (1.66)
Median (IQR)[y]	4.00 (2 – 4)	4.00 (2.75 – 5)	4.00 (2 – 5)
Range	0 – 5	0 – 5	0 – 5
	n = 64		
C3 Frequency of telephone, letter or email contact*			
Mean (SD)	3.75 (1.55)	3.56 (1.85)	3.34 (1.77)
Range	0 – 5	0 – 5	0 – 5
	n = 64	*n* = 57	
C4 Proximity of nearest child or close relative **			
Mean (SD)	2.83 (1.56)	2.86 (1.54)	2.96 (1.48)
Median (IQR)[y]	4.00 (1.25 – 4)	4.00 (2 – 4)	4.00 (2 – 4)
Range	0 – 4	0 – 4	0 – 4
	n = 64	*n* = 57	

*Response options: 0 = not at all; 1 = about once a month; 2 = 2 or 3 times a month; 3 = at least once a week; 4 = 2 or 3 times a week; 5 = every day
**Response options: 0 = no child/ close relative; 1 = 50+ miles; 2 = 16-50 miles; 3 = 6-15 miles; 4 = 1-5 miles; 5 = within a mile/ same house
[y] Median (IQR) only given for skewed distribution

In terms of face to face contact, the proportion of participants who saw their children once a week or more was 70% both prior to the stroke and six months post stroke. It rose slightly to 76% at three months post stroke. In terms of telephone, letter or email contact with children, the proportion of participants who were in contact at least once a week remained high throughout (baseline: 84%; three and six months: 77%). Finally, over half the participants in this project lived within a mile, or in the same house, as a child or relative, both prior to the stroke (53% at baseline) and after (57% at

six months post stroke). There was no significant change in any of these items.

7.2.2 Contact with children: qualitative evidence

Change in frequency of contact and feelings of closeness

The majority of participants reported that they were in contact with their children with the same frequency as before the stroke, supporting the picture provided by the quantitative evidence. Nonetheless, a subset of participants reported seeing their children *more* than prior to the stroke. The factor that differentiated this group was the importance placed on the family unit by the participant prior to having the stroke: their spouse and children were central to their whole outlook. Typical words used to describe their family included: *'the most important unit is the family, without a shadow of a doubt', 'means everything to me', 'particularly close-knit family – I'm very proud'.* These participants would commonly report feeling 'closer' to their children post stroke, they would describe feeling *'blessed'*, or *'lucky'* to have such a good relationship and be touched by the level of concern shown to them.

Another factor that predisposed participants to see their children more would be if the rest of their network had either completely or mostly disappeared following the stroke, and the children were the only network members still left.

The subset of participants who felt less close to their children following the stroke had a poor relationship with their children prior to the stroke.

Although the amount of contact might not have changed, having a stroke could create expectations and hopes, and when these were not met post stroke, it could cause the relationship to further deteriorate. Thus, while it may have been distressing not to see a child pre-stroke, the fact that the estrangement continued even after they had had the stroke could make it particularly painful. Equally, a lack of concern prior to the stroke may have been a source of irritation, but post stroke it could be very hurtful.

Aphasia could also be a cause of change within the parent-child relationship. For those with more severe aphasia, there could be frustrations and difficulties when communicating with their children. These included: it was harder to have a conversation; that they didn't talk as much now; the child only sometimes understood what they were trying to say. Children, however, could also fill in the gaps left by friendship loss post aphasia, and some did describe that their children understood them as well or better than others. Nonetheless, all those feeling estranged from a child in this project had aphasia. Although they did not explicitly refer to their aphasia in discussing their relationship with their children, having aphasia arguably may have exacerbated poor communication.

Changes in how participants spent their time with their children

While there might be little change for many participants in how often they saw their child or how close they felt, almost every participant described changes in what they did together. The main changes described were: more likely to meet up in the participant's home; restrictions in the sort of outdoor activities they could do together; receipt of additional support. These trends are now described below.

Receiving visits

Following a stroke, participants were more likely to receive visits than meet up outside the house. Even in the house, participants described a change of activities: they might be less able to host, for example, less able to cook a meal. For those participants whose interactions with their children were primarily home-based before the stroke, this represented less of a change, particularly if they had a supportive spouse to facilitate contact.

Restrictions in shared outdoor activities

In terms of outdoor activities, many participants reported that they could no longer join their children in more active pursuits, such as playing golf or rallying, or even going food shopping. Even when they did an activity outside the house with a child, they described becoming tired, and needing to walk more slowly and take rests, or come home early. They also reported having to consider issues that would not have been in their mind before the stroke, such as not drinking or eating so much, or considering toileting needs. Even those with mild strokes described changes in how they experienced shared activities, for example, not being able to do an activity for so long, or needing to leave early to go to bed. Also described by those who had apparently made an almost full recovery is that they felt more aware of their own physical vulnerability, and so were less willing to do physically demanding activities such as white water rafting with their children.

Receiving additional support

Receiving additional instrumental support is another change described by many. This is explored in more detail in Chapter Nine.

Changing roles in the parent-child relationship

Having a stroke could challenge a person's ability to carry out the parental role. The stroke could mean the participant was accepting help from their children, rather than the other way round, for the first time. It could threaten their ability to provide financially for their family, mean they could no longer help their child care for grandchildren, make it harder to cook for their child, or mean handing over the family business. Often, this shift of roles was described as difficult. This was particularly so for those who were still working prior to the stroke, and who had no previous experience of disability. Such participants tended to go to great lengths to resume previous roles however difficult. Edward, for example, says the stroke *'hasn't stopped me'* in his fatherly role, despite his new exhaustion and difficulty driving. He is still determined to *'be there'* for his children: *'If they said, Dad, we'd like you to come down, I'd be down there, I'd get down there somehow, wherever… It's me who should be looking after them, you know, it's this parental thing.'*

Peter is an example of how the shift in child and parental roles could be a difficult experience. His wife and three children were central to his whole outlook, with everyone else dismissed as just *'social stick ons'*. Even after having a severe stroke, leaving him with lasting disability, he said*: 'I still see myself in the role of making sure the family's OK'*. However, no longer able to run the family business, he had to hand it over to his son: *'It's very hard to allow somebody to take over your position… traumatic.'* No longer able to *'make sure things are available'*, he concluded, *'I mean, I'm not so effective as I was'*, in his role as a father.

Also expressed was a new sense of frailty, and an awareness that they may not always be able to be there for their family. One participant described himself and his wife as the cement that held the whole family together: *'You feel if anything happened to [my wife] and I, what will happen to them?'*

Those least disabled were more able to continue in their parental role. For example, one participant was overseeing building work at his house so that his daughter could get married from there, and was relieved that he had recovered sufficiently to be able to give the father of the bride speech. Another still helped his son with practical gardening chores, even though he now found them exhausting. Other aspects of the parental role could still be continued despite new levels of disability. Examples included passing on business knowledge and experience, sharing family history and passing on knowledge about a shared cultural background. Finally, participants could still show interest and concern in their children's lives.

7.3 Relatives

This section refers to all family members who are neither spouse nor children. The quantitative evidence suggests that there is little change following a stroke: people tend to be in contact with the same number of relatives, and see their relatives the same amount.

The qualitative evidence suggests three main trends. Firstly, the stroke could act as a catalyst to encourage relatives to 'rally round', resolve disputes, and even create strong new bonds. Secondly, where the relative was in poor health themselves, the stroke could mean that face to face contact was no

longer possible. Finally, for a proportion of participants, the stroke made no difference to their relationship with their relatives.

7.3.1 Contact with relatives: quantitative evidence

The Relatives Factor, as presented in Chapter Four, remained stable over time.

The proportion of participants who reported not having any relatives varied. At baseline 27.6% (25 participants) reported having no close relatives; this fell to 16.1% (14 participants) at three months, before rising back up to 26.8% (19 participants) at six months. Certainly, there was fluidity in how many relatives a participant considered to be close. The data presented in Table 7.2 refers to all participants, including those who at some time point did not consider themselves to have any close relatives.

Table 7.2 Relatives factor: descriptive statistics for baseline, three months and six months post stroke

Relatives subdomain (taken from Stroke Social Network Scale)			
	Baseline (*n* = 87)	3 months (*n* = 76)	6 months (*n* = 71)
R1 Number of close relatives			
Mean (SD)	2.48 (2.21)	2.36 (1.90)	2.39 (2.13)
Range	0 – 6	0 – 6	0 – 6
		n = 75	
R2 Frequency of face to face contact*			
Mean (SD)	1.43 (1.78)	1.60 (1.65)	1.52 (1.73)
Range	0 – 5	0 – 5	0 – 5
	n = 86	*n* = 75	
R3 Frequency of telephone, letter or email contact*			
Mean (SD)	2.16 (1.82)	2.29 (1.81)	2.00 (1.78)
Range	0 – 5	0 – 5	0 – 5
		n = 75	

*Response options: 0 = not at all; 1 = about once a month; 2 = 2 or 3 times a month; 3 = at least once a week; 4 = 2 or 3 times a week; 5 = every day

In terms of the number of close relatives, or frequency of face to face contact, there was no significant change. There was, however, a significant difference in how much telephone, letter, or email contact they had with their relatives. The most contact was reported at three months post stroke (mean = 2.29; SD = 1.81). This was significantly higher than at six months post stroke (mean = 2.00; SD = 1.78). Wilks' Lambda = 0.91, $F(2, 68) = 3.37$, $p < 0.05$.

Participants were more likely to be in contact with relatives via letter, email or telephone, than to meet up face to face. Thus the proportion of participants who saw a relative at least once a week was roughly 30% at all time points (28% pre-stroke; 31% at three and six months). This compared to 50% who were in at least weekly contact via letter, telephone or email

before the stroke, remaining at 49% at three months, and dropping to 44% at six months.

7.3.2 Relatives: Qualitative evidence

Becoming closer since the stroke

Stroke a reason to 'rally round'

The most common narrative in this project was that the stroke had made people closer to their relatives. Commonly described was how relatives had *'drawn closer', 'rallied round'*, been in more frequent contact: in all cases this was described as a positive thing. This trend was particularly pronounced for those who were in 'family-based' social networks post stroke (ie family rather than friends were their primary source of support, described in more detail in Chapter Eight).

A catalyst for resolution of family disputes

Not only could the stroke mean that close relatives became closer, it could also bring together those who had fallen out. In one instance the stroke was a catalyst for the resolution of a family dispute. Another described his brothers being brought *'back into the fold'*. Both these participants suggested that this was because the stroke had brought home the frailty of life. As one participant remarked, *'Perhaps it always takes something like this to bring people round, to be nice'*. The stroke could also cause the participant to view their family in a more positive light. One describes becoming more accepting of his family's values, and less critical of their life choices, following the stroke.

New bonds formed due to stroke

Not only was the stroke a catalyst for more frequent contact within existing relationships, but it could cause previously distant relatives could become close friends. This is illustrated by John. John was 76 years old, lived alone, and did not have any children. Before the stroke he was reasonably close to his older brother, speaking on the phone once a week. He would also receive birthday cards and occasional visits from his nephews and nieces. His primary source of support were his friends, however. Following the stroke, he became increasingly close to his nephew, who visited him in hospital and helped him when he first came back home. One year on, he would speak to his nephew almost every day, they went out socially, and were even planning a holiday together. His nephew became one of his closest friends and his greatest source of support.

Contact becoming more difficult since the stroke

Following the stroke, some people did describe that it had become more difficult to be in contact with relatives. The main reasons were aphasia and the poor health of the relatives.

Relatives' poor health

Relatives, unlike children, were more likely to have health problems of their own, since they were often the same age or older than the participant. Thus a frequent reason why it had become harder to see a relative was not only the participants' disability, but their relatives' ill health. As such, although relatives could provide important support, it was a more vulnerable source than that of a child. Prior to the stroke, the participant may have been the 'healthy' one, who travelled to see their relative, and provided practical or

emotional support. Following the stroke, this may no longer have been possible. For several participants, a relative had become unwell after they'd had their stroke. Disabled by their stroke, they could find it hard to visit the relative in hospital, or provide any support once the relative had left hospital. The combination of both the relative and themselves being unwell could cause a massive change in the relationship. Where the relative was a primary source of support, this could cause considerable distress.

An example of someone whose relative became ill is Ivy. She had lived with her sister all her life, and had no children or other living relatives. She described how they were *'great friends'* and that *'we've always been together.'* When Ivy had the stroke, it was her sister who helped her: *'she's very kind, and she gave me courage… I owe it all to my sister.'* A few months later, her sister became ill, was admitted to hospital, and never became well enough to return home. Ivy described the impact this had on her life: *'I miss her terribly… At night sometimes I see something on there [the TV] and I turn round to say something to her, and then I realise she's not there, you know…it's very lonely.'*

Aphasia

Aphasia could make telephone contact in particular more problematic. One participant described how she no longer speaks as much to her relatives in the Philippines and the States because her talking is so difficult to understand, and she *'always mistakes'*.

No change to the relationship since the stroke

A proportion of participants described no change in their relationship with a relative. This included three main groups. Firstly, there were those who

were in telephone contact with relatives abroad: they were unlikely to see these relatives more often due to logistical reasons. The stroke, however, could make telephone contact more difficult for those with aphasia. Secondly, there were participants who had a relative living less than five minutes' walk away who they saw at least once a week both before and after the stroke. Finally, there were those participants who remained indifferent to their relatives, and saw them infrequently or not at all. Unlike with children, long-term estrangement from a relative was rarely a cause of distress.

7.4 Summary

Family were reliable network members after a stroke: both the qualitative and quantitative evidence suggests that participants saw their family as frequently as before the stroke. The stroke, nonetheless, was a cause of change within the family.

In this project, the stroke did not cause any marriages to break up. However, roles within the marriage were often challenged. It was common for the spouse to provide more support, and take on a caregiver role. Conversely, it became harder for participants to care for or 'treat' their spouse. This could be a cause of great distress. New conflicts were described. These could stem from increased time spent at home together, personality changes, and depression. Despite these difficulties, most participants reported feeling close to their spouse. In some cases, the stroke acted as a catalyst to bring them closer together and appreciate their spouse more.

Contact with children was stable post stroke. 70% of participants saw their children at least once a week both before and after their stroke. Those

participants whose children were central to their outlook before the stroke reported feeling closer to them post stroke. Conversely, in this project, those who had troubled relationships with their children prior to the stroke could feel let down and further estranged post stroke. There were changes in the types of activities participants did with their children post stroke (more likely to be home based, or receiving additional support; restrictions in shared outdoor activities). Participants also described a shift in parent/child roles: it was often a painful transition to be receiving rather than giving.

There was no significant change in the number of close relatives, or frequency of face to face contact (about 30% saw a relative at least once a week at all three time points). The qualitative data found that for many the stroke made little difference to patterns of interaction (for example, where relatives lived round the corner, or where relatives had been estranged for many years). However, for a subset of participants, the stroke caused them to become closer to relatives: the stroke could make relatives 'rally round' and resolve family disputes. Conversely, however, the stroke could also be the reason that contact became more difficult: where the relative was in poor health themselves, and the participant had previously been the 'healthy' or younger person, contact could become difficult. Aphasia could also make remote contact with relatives living abroad challenging.

In summary, family members were a robust element of the social network. Nonetheless, beneath the apparent stability of the quantitative data there were major changes in how family relationships functioned, including some distressing role shifts necessitated by receipt of additional support.

Chapter Eight. Drawing the elements together: a social network typology

This chapter will firstly define what a typology is in the social sciences. The rationale for creating a social network typology in the present study will then be discussed. The chapter will go on to outline the process by which a social network typology was established, with reference to relevant literature. The resulting typology will then be defined and described. Having established the typology, the chapter will examine how individuals from the different network types respond after having a stroke, whether there are patterns of change, and what is underlying those patterns. Finally, triangulatory evidence for the validity of the typology will be provided by cluster analysis.

The research question addressed in this chapter is RQ 10: What are the reasons why a person shifts from one social network type to another following a stroke?

8.1 What is a typology?

A typology is a way of grouping participants (or potentially features or phenomena) into categories, and has been used extensively in qualitative research. Typologies are usually multifactorial (ie which category a person is assigned to may be determined by several factors), and the categories are discrete and independent of one another, thus an individual may only belong to one category[253]. In sectoring the social world in this way, typologies potentially help to explain patterns, and 'aid systematic understanding'[269].

Typologies have also been used in quantitative research. In social network research cluster analysis has been used to group participants into different social network 'types'[72]. Cluster analysis is a family of statistical methods defined as a way of 'classifying multivariate data into subgroups. By organizing multivariate data into such subgoups, clustering can help reveal the characteristics of any structure or patterns present.'[270] Thus the process of taking two or more defining 'elements' and using these to determine which group an individual is assigned to is common to both cluster analysis and qualitative analytic processes.

8.2 Why create a social network typology?

The social web in which a person is embedded will display an array of attributes. As outlined in Chapter One, these may be structural, such as size or composition of members, interactional, such as frequency of contact, or more subjective assessments of meaning and satisfaction. One way of conceptualizing social networks is to distinguish major groupings and patterns, or network 'types' through examining key components[75]. Examples of network 'types' might be having a 'restricted network' (having few social ties) or a 'diverse network' (extensive social ties). Such network typologies have been shown to be predictive of various outcome variables in the elderly population, such as mental health[72] and morale [73]. The type of network a person belongs to has also been shown to be an important factor in how a person responds to aging and ill health, and the patterns of support they both seek and receive[271]. Thus the use of network typologies is argued to have salience for both research and in service delivery.

Social network typologies have been developed using general population samples, and have not been specifically applied to the stroke population or indeed to any other groups with chronic illness. In addition, a strength of the current study is that a typology has been used to provide understanding of how social networks may change over time. This means it is possible to examine which network types remain stable post stroke, and if not, who shifts from one network to another and why, and whether there are any protective factors that enable people to maintain their pre-stroke network type. The qualitative nature of this study means that the process by which these shifts do, or do not, occur can be analysed, and the meaning this may hold for individuals can be explored.

A further aim in developing a social network typology is to create a framework within which to place the qualitative findings of Chapter Six (friendship) and Chapter Seven (family relationships), as well as the quantitative findings of Chapter Four (descriptive statistics documenting a reduction of social network, with friendships being vulnerable).

8.3 Establishing a typology: methods

In creating a typology, the following considerations were taken into account. Firstly, to establish meaningful, easily recognizable categories, which both emerge from the data, and help to explain the data. Secondly, to create a typology that could be compared with findings from the existing literature on social network typologies. Finally, to develop a typology which

could be applied to both pre-stroke data and post stroke data, in order that shifts in network type could be analyzed.

8.3.1 Data used to assign participants to different categories in current project

Pre-stroke categorisation

For grouping participants into social network types prior to the stroke, two sources of information were used: firstly, reflections on their pre-morbid networks during the in-depth qualitative interview; secondly, items from the Stroke Social Network Scale[222] administered two weeks post stroke, and relating to pre-morbid social network. A decision was made not to rely solely on the qualitative interview since participants' memories about pre-stroke life appeared on some occasions to be coloured by their subsequent experiences. For example, if a friend had 'deserted' them post stroke, it could be difficult to acknowledge that the friend had ever been important to them. Nonetheless, the process of classification relied on qualitative analysis techniques rather than statistical techniques.

Post stroke categorisation

Participants were re-classified to reflect their situation a year post stroke. The primary source for this was the qualitative interview. The PhD candidate did, however, observe trends found in the Stroke Social Network Scale administered six months post stroke, particularly where this could shed light on how a participant had moved from their baseline situation to their social network one year on.

8.3.2 Relationship between existing social network typologies and the present study

There already exists a body of work analyzing social network 'types', both qualitative and quantitative. In order that results from the present study could be seen within the context of the wider literature, a decision was taken that existing typologies would inform the development of the typology in this research project. Although informed by the literature, the emerging categories nonetheless remained faithful to the data collected. Where the present typology diverged from existing typologies, this process was documented, with reasons given (see 8.4.4).

In conducting a literature search, studies were considered where they described the development of a social network typology, used with an adult population. Qualitative and quantitative methodologies were acceptable, however, only typologies derived from social network variables (such as structural or interactional elements of the network) were considered. Typologies that included non-social network variables in their construction, such as religiosity, were not included. There was no restriction in terms of geographical location or publication date. Only English language publications were considered.

In order to find relevant studies, the following search strategy was undertaken. Firstly, the following electronic databases were searched: Academic Search Complete; CINAHL Plus; E-journals; Health Policy Reference Centre; MEDLINE; PsycARTICLES; Psychology and Behavioral Science Collection; PsycINFO; and SocINDEX. These

databases were searched for peer-reviewed journal articles where the following terms appeared in the abstract:

1. “social network typ*” OR “support network typ*”

Search results were stored on EBSCOhost. Further articles and book chapters were considered from following up references, or through recommendation by expert advisors.

The articles retrieved through this process were then screened against the eligibility criteria. Having extracted relevant articles, the social network typologies have been briefly described (number and location of participants; appropriateness of methodology used; defining variables; resulting typology). The commonalities between the resulting typologies and the extent to which they can be applied to the current data is then discussed.

8.4 Establishing a typology: results of literature search

8.4.1 Studies included

The electronic database search took place in February 2013, and resulted in 35 references. A further eight references were found through consulting reference lists, and one through recommendation from an expert. Of these 44 references, 37 were excluded for the following reasons: replicating an existing social network typology (17, of which eight used Wenger’s support network typology[75], and nine were based on network typologies developed by Litwin[72, 272]); study not examining social network types (8); duplicates (5); typology derived from variables other than social network factors (4);

insufficient information given on social network typology variables (1); not in English (1); unavailable (1).

The remaining seven studies were included for further analysis. The table below (Table 8.1) provides information on: authors and date study published; participant information including numbers and location; methodology; variables used to define the typology; and the resulting typology.

The studies took place in five countries: the USA (2); Israel; Canada; Holland; and the UK (2). Diverse methodologies have been used: qualitative (two, both in the UK); *k*-means cluster analysis (four); and log-linear analysis with categorical latent variables (one). Only 1/7 studies included adults of all ages (Spencer and Pahl)[273], the other 6/7 studies focus on the elderly population.

Table 8.1 Summary of existing social network typologies

Authors	Participants and methodology	Defining variables	Resulting typology (% of sample for quantitative studies only)
Qualitative methodology			
Wenger (1994)[75]	*n* = 30; age 79+; rural North Wales. Visited 2-4 times a year for 4 years. Convenience sampling. Validity of typology strengthened as has been replicated in larger-scale projects, both in the UK[274] and abroad[275, 276].	1) Availability of local close kin; 2) Level of involvement of family, friends and neighbours; 3) Level of interaction with community and voluntary groups	1) *Local family dependent* (relies on close family ties; few friends and neighbours) 2) *Locally integrated* (large support network including family, friends, neighbours, community involvement) 3) *Local self-contained* (smaller support network, relying primarily on neighbours) 4) *Wider community focused* (primarily friendship-centered, high community involvement, absence of local kin) 5) *Private restricted* (few local family or friends). Can be subdivided into: *independent married couples*, and *dependent elderly*
Spencer and Pahl (2006)[273]	*n* = 70; people of *all* ages living in urban and rural England. Purposive sampling. Framework Analysis used.	1) Relative numbers of family, friends and neighbours 2) Importance and content of the relationships 3) Breadth of roles played by friends and family 4) Characteristics of the friendships	1) *Friends-based* (friends outnumber family, key support provided by friends. Subdivided into *friend-like* – friends primary; and *friend-enveloped* – family also important) 2) *Family-based* (family outnumber friends, family of central importance. Subdivided into *family-like* – do also have some friends; and *family-enveloped*, which lack any close friendships) 3) *Neighbour-based* (there are as many neighbours as family or friends, neighbours take on wide range of roles) 4) *Partner-based* (partner and possibly children focus of their social world, lack other close relationships) 5) *Professional-based* (a reliance on professionals; lack of close friends or family)

Quantitative methodology: *k*-means cluster analysis			
Stone and Rosenth-al (1996)[277]	*n* = 3,186 (data taken from 1990 General Social Survey conducted by Statistics Canada); age 65+; representative sample of Canadians. Overall frequency statistics not provided.	1) Marital status 2) Network size 3) Proportion of network who are children, siblings, friends, parents and spouse 4) Living arrangements 5) Frequency of face to face and telephone contact with network members	1) *Small: Friendship-poor and socially isolated* (few friends, below average contact with children) 2) *Small: child-focused* (small network where primary contact is with children) 3) *Small: extended-family and friends-focused* (small networks where primary contact is with friends and siblings) 4) *Medium: Balanced* (average amount of contact with both friends and children) 5) *Large: Balanced* (high rates of interaction with friends; also contact with children and siblings) 6) *Very large: balanced* (extensive network with high rates of interaction with all of network)
Litwin (2001)[72]	*n* = 2,079 (data taken from survey carried out by Israeli Central Bureau of Statistics in 1997); age 60+; representative sample of people living in Israel. Association between network types and mental health reported.	1) Marital status 2) Number of proximate children (ie living close by) 3) Frequency of contact with children, friends and neighbours 4) Frequency of attendance at a synagogue 5) Frequency of attendance at a social club	1) *Diverse* (mostly married; frequent contact with children, friends and neighbours; involved with community; most extensive network) 30% 2) *Friends* (frequent contact with friends and family, limited contact with neighbours) 24% 3) *Neighbours* (frequent contact with children and neighbours, but few friends) 17% 4) *Family* (very frequent contact with children; minimal ties with friends and neighbours) 9% 5) *Restricted* (fewest social ties; least contact with children, almost no contact with friends) 20%
Fiori *et al.* (2006)[73]	*n* = 1,669 (data taken from the Americans' Changing Lives study, collected in 1986); age 65+; living in United States. Association between network	1) Marital status 2) Number of children 3) Frequency of contact with children and friends 4) Attendance at	1) *Nonfamily-restricted* (limited social ties. Unlikely to be married. If have children, have least contact) 16% 2) *Nonfriends* (few friends, unlikely to attend meetings. Average family contact) 16% 3) *Family* (high scores on children variables and also religious attendance) 12%

	types and morale found.	religious services 5) Attendance at meetings	4) *Diverse* (most extensive network, high scores on all network variables) 32% 5) *Friends* (frequent contact with friends. Infrequent attendance at religious and other meetings. Fairly frequent contact with children.) 24%
Litwin *et al.* (2011)[272]	*n* = 1,462 (data taken from the National Social Life, Health, and Aging Project, in 2005-6); age 65+; representative sample of older Americans. Association between network types and subjective well-being found.	1) Marital status 2) Number of children 3) Number of close relatives 4) Number of friends 5) Frequency of getting together with neighbours 6) Attendance at religious services 7) Attendance at meetings	1) *Diverse* (largest network type, greatest sociability including with neighbours, frequent attenders of religious services) 19% 2) *Friend* (greatest number of friends, most frequent attendance at organized meetings) 27% 3) *Congregant* (frequent attendance at religious services; other aspects of network 'average') 16% 4) *Family* (high number of children, few extrafamilial ties) 15% 5) *Restricted* (low scores on all variables) 22%
Quantitative methodology: log-linear analysis with categorical latent variables			
Aartsen *et al.* (2004)[278]	*n* = 1,552 (data drawn from the Longitudinal Aging Study Amsterdam (LASA)); 55-85 years old living in the Netherlands. Methodology requires categorical variables. For variables 2, 4 and 5, this was achieved through assigning participants to dichotomous variables, either above or below the mean.	1) Size of network (3 categories: 1-5; 6-14; >14) 2) Proportion of network who are kin (<60%; ≥ 60%) 3) Whether they have a friend (dichotomous) 4) Proportion of network who are neighbours (<11%; ≥ 11%) 5) Number of family members and neighbours	1) *Type I* (largest network. Most likely to have a friend. More non-kin than kin.) 32% 2) *Type II* (small-medium sized network, with fewer than average number of family members and neighbours. Half have no friends.) 20% 3) *Type III* (small-medium sized network. More family members than average. No friends, few neighbours) 16% 4) *Type IV* (medium-large network. Unlike Type I, focus is on family.) 32%

Restricted = restricted social networks social networks

Friends = friends-based

Family = family-based social networks social networks

Diverse = diverse-based

8.4.2 What existing typologies have in common

The above studies are diverse in methodology, the variables they choose to determine their typology, and cultural context. Despite this, there were similarities in the resulting network typologies. In all the studies, there can be found the following four network types: diverse, friends-based, family-based, and restricted. The next section will discuss these four network types in more detail, before commenting on methodological issues, and limitations in the studies.

Diverse social networks

7/7 typologies describe a 'diverse' network, where the individual has contact with diverse sources of support, including family, friends and neighbours, and often also community involvement. These tend to be the largest networks. In 4/4 of the studies using cluster analysis, participants scored highly on all variables. Almost one third of the population appeared to belong to this network type in 3/4 studies (30%[72]; 32%[73]; 19%[272]; and 32%[278]).

Friends-based social networks

7/7 typologies also included a network type that was primarily distinguished by the emphasis on friendship. For most typologies (6/7), membership of the friends-based network was dependent on non-kin being more important in some way than kin either in number count (Litwin *et al.*[272]; Aartsen *et al.*)[278]; emotional significance (Spencer and Pahl)[273]; or frequency of contact

(Wenger[75]; Stone and Rosenthal[14] ; Fiori *et al.*[73]). However, for the Israeli study (Litwin[72]), all network types presupposed close family relations, thus what distinguished the 'friends' and 'diverse' networks was contact with neighbours (relatively little contact with neighbours in the 'friends' network) rather than the relative importance of friends versus family.

In terms of involvement in the wider community, 3/7 typologies did not include a community/ group involvement measure[273, 277, 278]. Of those that did, 3 /4[75, 272, 279] found that those in Friends-based networks were relatively frequent group attenders, although 1/4 (Fiori *et al.*)[73] found the reverse.

There was also variation in the size of this network: for 1/7 it was the largest network (Aartsen *et al.*)[278]; 1/7 it was one of the smallest (Stone and Rosenthal)[277]; and for 5/7 it was somewhere in between. About a quarter of the population appeared to live in 'friends-based' networks (ranging from 24%[72, 73] to 32%[278]).

Family-based networks

7/7 studies found a sub-group of their population lived in 'family-based' networks. These networks were characterised by close family relationships, but an absence of other close ties. These networks were typically small.

The proportion of people who belonged in a 'family-based' networks was lower than those in friends-based or diverse networks, ranging from 9%[72] to 16%[278].

Restricted social networks

Finally, 7/7 studies found a network type or types characterised by minimal social ties. In 4/7 studies, this was not subdivided. 3/7 studies, however, did further divide this category. Essentially, there were those with minimal ties, but who did have one close relationship, generally a spouse (Wenger's *private restricted – independent married couples*[75]; Fiori *et al.*'s *non-friends*[73]; Spencer and Pahl's *partner-based*[273]). Alternatively, there were those who were isolated, and were without close relationships with family, friends or neighbours (Wenger's *private restricted – isolated*[75]; Fiori *et al.*'s *non-family*[73]; Spencer and Pahl's *professional-based*[273]).

The proportion of people in restricted network types ranged from 20% to 32%.

Additional network-types found

3/7 studies found a 'neighbour-based' network type. These were networks which relied predominantly on neighbours, and had few close friends or family (Wenger[75]; Spencer and Pahl[273]); alternatively did include family, but few other non-kin contacts (Litwin[72]). 2/ 7 studies did not include variables measuring contact with neighbours (Fiori *et al.*[73], Stone and Rosenthal[277]); a further 2/7 studies did have a neighbours variable, but failed to find a network category defined by it (Litwin *et al.*[272], Aartsen *et al.*[278]).

The only additional category to be described was a 'congregant' category (Litwin *et al.*)[272]. Participants in this category had average contact with friends and family, and were distinguished by their very frequent attendance

at religious services. Although 4/7 studies included religious attendance as a variable, this network category was not replicated in any other study.

8.4.3 Methodological concerns in the included studies

4/7 of the studies used *k*-means cluster analysis in order to determine network types. This method (described in detail below, 8.8) requires the analyst to pre-determine the number of clusters. It then allocates cases to maximize the differences between clusters, while minimizing the intracluster differences. Clearly, the number of clusters requested will influence the solution offered. 0/4 studies reported on any statistical procedure carried out to provide reassurance as to the stability or robustness of their solution (for example, clusters are considered to be more robust if they are not destabilized by case order[270]). Only 1 /4 (Stone and Rosenthal)[277] acknowledged this as a potential weakness observing 'the groupings we discuss below are partly constructed as well as partly discovered typologies'. For 2/4 (Litwin[72]; Stone and Rosenthal[277]) the process by which the number of clusters was determined was consideration of the literature, and then experimentally trying out different cluster solutions. Litwin[72] settled for the 5 cluster solution as 'it was deemed the most robust and the most reflective of trends found in the literature'. No evidence was provided as to why it was considered 'robust'. 1 /4 studies (Fiori *et al.*[73]) requested a 5-cluster solution to replicate Litwin *et al.*, 2001[3]; 1 /4 studies (Litwin *et al.*)[272] did not discuss the rationale for selecting a 5 cluster solution. A similar issue applied to Aartsen *et al.*'s study[278] using log-linear analysis: they too were required to specify the number of network

types for this analytic technique, and based this number on Wenger's work[75].

In terms of variables used, only 1 /4 of the cluster analysis studies (Fiori *et al.*)[73] standardized the variables, thus eliminating the effects of scale differences. There were concerns, too, over the variables used in Aartsen *et al.*'s study[278]: since their methodology forced them to dichotomise variables, important variability may not have been detected.

A further limitation of the quantitative studies is that they constitute secondary analysis. Thus they were limited in the variables they could enter into cluster analysis. For example, the only measure Litwin *et al.*[272] used to assess the role of children in a network was the number of children a person has. There was no measure, for example, of frequency of contact with children.

Of reassurance is that the network types developed by Litwin (2001)[272], Litwin *et al.* (2011)[72] and Fiori *et al.*[73] have been found to be predictive of other variables, such as morale[73], happiness[272], depression[280], physical activity[281 282], alcohol abuse[283], loneliness and anxiety[272]. Those in diverse networks (and to a lesser extent, friends-based networks) tend to do better on all these measures than those in restricted networks. This arguably lends validity to the network types established.

A final note concerns the cultural context. All the studies analysed social network patterns in 'western' countries. There is some evidence that social networks in other cultures may vary. For example, Cheng *et al.*[284] found that the role of 'distant' family (all relatives who are not children, grandchildren,

spouse or parents) played a larger part in the social networks of Chinese families. Increased morale associated with belonging to a friends-based network rather than a family-based network was also not found either in Hong Kong[284] or Japan[285].

8.4.4 Relationship between literature and typology development

Initially, the researcher considered whether any of the existing typologies would fit the current dataset. Although the broad classifications developed in other typologies matched the current sample reasonably well, in fact, the purpose and composition of the current project meant that further refinement was needed. The ways in which existing typologies could not be applied to the current data set are given below.

One issue was the emphasis on local family ties in both Litwin[72] and Wenger[75]. Litwin only considered 'proximate' children, and whether children live nearby is a key determining factor for Wenger. However, this did not reflect the patterns found in the current project, where it was uncommon for children to live close to their parents. Wenger[75] also places emphasis on 'local' friends. Again, the emphasis on locality made it difficult to categorise many participants according to Wenger's criteria.

An additional issue was that 3/7 of the typologies included a 'neighbours' network type. There was no-one in the present project who could be fitted into a 'neighbour' category as defined by any of the pre-existing studies. Although there were participants who had close ties with their neighbours

these same participants also had close ties with family and often friends, or alternatively did not distinguish between friend and neighbour.

Further, cluster analysis and log-linear analysis require quantitative variables (for example, frequency counts), while the current project used qualitative variables, where the emphasis was more on meaning and the lived experience of feeling supported or alone.

The project most similar to the current project was that of Spencer and Pahl[273] : the methodology was similar (in-depth qualitative interviews analysed using Framework Analysis); the aims of the studies were similar, both being primarily interested in exploring the subjective experience of support and social ties; the cultural context was most similar (England and Wales); and proximity was not used as a delineating variable. However, there were three reasons why their typology did not fit the current data. Firstly, Spencer and Pahl examine only the closest and most meaningful ties, whereas the role of more peripheral contacts was examined in the present study. Secondly, the emphasis of Spencer and Pahl's work is friendship, thus key variables in determining their typology included patterns of friendship (for example, 'roles' played by friends) which were not given as much prominence in the current study. Finally, Spencer and Pahl's typology reflects the broader age range of their study participants, and some aspects of their typology were more relevant to a younger cohort. Indeed, they specifically excluded the frail elderly. On examination it became clear that a proportion of the participants in the present study did not fit into any of their categories. For example, an elderly widow who has only distal family and friend contacts that she rarely sees would arguably

belong in a ‘restricted’ category. However, in the Spencer and Pahl typology she cannot belong to either of the ‘restricted’ types (‘partner-based’ or ‘professional based’), since she neither has a partner nor close contact with any professional.

To conclude, none of the typologies described above could be used with the current data set. Nonetheless, the broad categories common to all the typologies were a starting point for creating the typology below. These categories were: diverse, friends-based, family-based, and restricted (with the possibility that two restricted network types might be found, as with Spencer and Pahl[10], Wenger[5], and Fiori *et al.*[6]).

8.5 Defining the typology in the current project

The key dimensions used to define the typology, and so classify participants into the different network ‘types’, were as follows:

- Frequency of contact (face to face, telephone or letter) with children, relatives and close friends, and the extent to which people were satisfied with this contact

- Composition of the network, including relative number of kin versus non-kin, and close friends versus more casual social contacts (for example, acquaintances made through attending groups)

- Which network members were most likely to provide different types of functional support (for example, emotional support or tangible support) and how this support was perceived

Using these variables five network categories were derived. These are as follows:

1. Diverse
2. Friends-based
3. Family-based
4. Restricted-supported
5. Restricted-unsupported

Each of these types is defined below.

1. Diverse

These participants had the most extensive social networks, comprising both kin and non-kin. They had close relationships with their immediate families, whom they saw frequently, generally at least once a week. They were often also in frequent contact with a variety of other relatives. They also had strong friendships, and saw their friends regularly (typically once a week, if not more often). In addition, they often had a wide circle of acquaintances.

2. Friends-based

For these participants, friends occupied a central role in their social network: they typically had several friends whom they saw often (typically at least once a week), and were very satisfied with this contact. Friends were also likely to be the main source of many types of functional support.

3. Family-based

Family were the main source of functional support for these participants. They were likely to have a close relationship with several family members. They may or may not have had a few friends additionally, but were unlikely

to see these friends frequently. Friends were not considered as important as family ties.

4. Restricted-supported

These participants had limited social ties. They had very few or no friends. Whether they were in contact with acquaintances depended on their age: older members had lost most peripheral ties, whereas younger members could have contact with a number of acquaintances through work or hobbies. Despite their apparently sparse intimate social ties, they felt well-loved and supported. This sense of real concern came from one or two family members.

5. Restricted-unsupported

As with the above category, these participants had limited social ties. They either had no children, or did not live near a child. They had very few or no close, intimate friends. They differed from all the other network types in that participants received very limited functional support from any source.

8.6 Pre-stroke categorization

Based on information about their pre-morbid life, all participants could be assigned to one category using the above typology. This next section looks at what factors were associated with membership of the different social network categories before participants had the stroke.

In terms of living arrangements, those in the ‘diverse’ network typically lived with family members (either spouse, children, or both). By contrast,

those in ‘friends-based’ or ‘restricted’ networks typically lived alone, although a subset did live with either a spouse or other relative. There was only one participant who was classified as having a ‘restricted-unsupported’ network type prior to the stroke, and this participant was also the only one to live in sheltered accommodation pre-morbidly.

Prior to the stroke, the most frail participants (for example, finding housework a struggle), were likely to have restricted networks. Indeed, the restricted networks were made up predominantly of those aged over 75. Nonetheless, all five network categories included participants across the age range. Indeed, the oldest participant in the project (aged 90) still had retained her ‘diverse’ network prior to the stroke.

Those in ‘friends-based’ and ‘diverse’ categories attended groups, work or other social gatherings. Group membership was least common for those in the ‘restricted’ and the ‘family-based’ networks.

All those in the ‘family-based’ network and ‘diverse’ network had children, and had a supportive relationship with their children. The only exception was the youngest participant in the project: at 18, his important family relationships were his parents, and siblings. By contrast, those in the ‘friends-based’ network either did not have children, or had a troubled relationship with their children. Those in the ‘restricted-supported’ category generally had a close relationship with their grown up children. The one participant in the ‘restricted-unsupported’ category prior to the stroke had children, but those children lived far away, and were not in close contact.

8.7 What happens to the different network types post stroke?

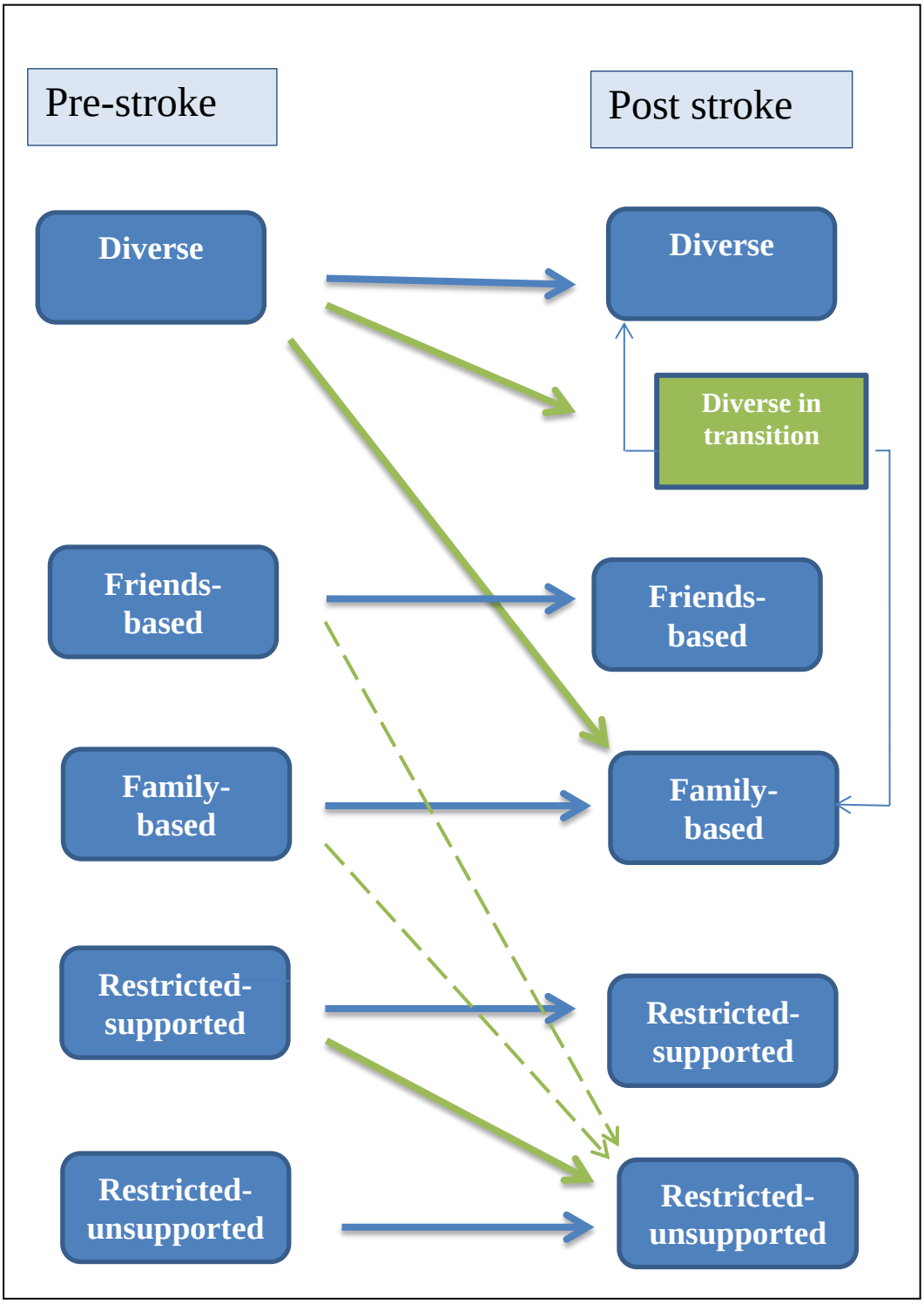
Figure 8.1 displays the patterns of change that occurred post stroke, with some network types more robust than others. The three network types found to be most stable were: friends-based, family-based, and restricted-unsupported. Participants who belonged to these types prior to the stroke were likely to belong to them post stroke. The most uncertainty rested with participants who had a 'diverse' network type prior to the stroke: they either became family-based; succeeded in maintaining their diverse network; or appeared to be in a state of transition. Those labelled 'diverse in transition' in Figure 8.1 appeared to be either in the process of regaining contacts and their former diverse status, or losing them, and becoming family-based. The other network category found to be unstable was restricted-supported. This was a vulnerable network type as the participant generally relied on only one network member for support. If their primary support person left the network, they became restricted-unsupported.

An alternative way of exploring the patterns is to consider which networks participants shifted into. The two network categories that became more numerous post stroke were the family-based network and the restricted-unsupported network. Indeed, only one participant was classified as restricted-unsupported prior to the stroke, whereas one year post stroke this network type became more common. Nobody moved out of the restricted network types into a more supportive category following a stroke.

These patterns are discussed in more detail below, with explanatory factors explored. Each of the main trends is illustrated by a detailed vignette. In

order to make the analytic process as transparent as possible, Figure 8.2 details the category membership of each participant, both before and after the stroke. How participants are distributed between the different categories can be seen from this figure. However, since the sample has been purposively selected to emphasise diversity, it is therefore not representative of the parent stroke population, and prevalence rates should be interpreted cautiously.

Figure 8.1 Patterns of change in social network type, before and after



Key

= social network type

= no change

= change

= less common pattern of change

Figure 8.2 Network type of all participants, before and after stroke

Pre-stroke				
Diverse	**Friends-based**	**Family-based**	**Restricted-supported**	**Restricted-unsup-ported**
Winnifred(65 yrs; spouse) Pablo (63yrs; family) Judy (76 yrs; alone) Brian (57 yrs; spouse) Cormac (75 yrs; spouse) *Daren (65 yrs; spouse)* *Rose (90 yrs; spouse)* *Tomasz (66 yrs; family)* *Raymond(63 yrs; spouse)* *Pratik (18 yrs; family)* *Martin (68 yrs; family)* *Gordon (74 yrs; spouse)* *Peter (65 yrs; spouse*	Steve (48 yrs; alone) Leonisa (74 yrs; alone) Patricia (62 yrs; son) John (76 yrs; alone) Gerta (83 yrs; alone) Andy (69 yrs; spouse) *Bridget (74 yrs; alone)*	Adebomi (68 yrs; alone) Edward (58 yrs; spouse) Dolores (66yrs; daughter) *Hakim (65; spouse)*	Susan (78 yrs; spouse) Dorothy (86 yrs; alone) *Ivy (82 yrs; sister)* *Chris (58 yrs; partner)*	Paul (76 yrs; alone; sheltered housing)

One year post stroke				
Diverse	**Friends-based**	**Family-based**	**Restricted-supported**	**Restricted-unsupported**
Winnifred Pablo **(aphasia)** Judy Brian Cormac ***Diverse in transition*** *Daren* *Rose* *Tomasz*	Steve **(aphasia)** Leonisa **(aphasia)** Patricia **(aphasia)** John Gerta Andy **(aphasia)**	Adebomi **(aphasia)** Edward Dolores **(aphasia)** *Raymond **(aphasia)*** *Pratik* *Martin* *Gordon* *Peter*	Susan Dorothy	Paul *Ivy* *Chris **(aphasia)*** *Bridget* *Hakim **(aphasia)***

Key *Italics:* participant shifts into family-based network type; *Italics:* participant shifts into 'diverse in transition'; *Italics:* participant shifts into restricted-unsupported network type
Alone/ family/ spouse: indicates who the participant lives with

8.7.1 Diverse

As described above, people who had diverse social networks prior to the stroke either became family-based post stroke, succeeded in retaining their diverse network, or appeared to be in a state of transition. No participant developed a diverse network after having a stroke.

Participants who retained their diverse network

What determined who lost their diverse network, and who retained it was the extent to which they were able to maintain the non-kin element of their network. The family element of the network remained constant (and supportive) for everyone who had a diverse network prior to the stroke. The factors associated with a person either losing or preserving their friendships and social acquaintances have already been explored in Chapter Six. In particular, those people who maintained their diverse network had in common that they could still leave the house and attend groups or go to church, and they did not describe feeling withdrawn or depressed. A further factor appeared to be the participant's pre-stroke experience of disability and illness. Those participants who had already experienced serious illness but had nonetheless retained a diverse network prior to the stroke succeeded in maintaining their diverse status post stroke.

Winnifred: retained her diverse network post stroke

Winnifred was a 65-year old woman who had a moderate stroke, affecting her energy levels and mobility. Despite the stroke, she managed to retain her diverse network. Her network consisted of: her husband, her four sons and numerous other relatives, the majority of whom lived locally and visited her several times a week. She also had a large number of friends, both locally and back in the Caribbean. She had a particularly close relationship with her

downstairs neighbour who she saw most days. She also went to church every week, where she *'know everybody'*. She received all types of functional support (for example, instrumental, emotional, companionship) from a diverse array of sources including kin and non-kin, and had visitors every day, commenting the house was always full.

Winnifred exhibits many of the protective factors described in Chapter Six, which may have enabled her to maintain her unusually large and supportive network. She had lived in the same house for 30 years, and was well embedded in her community. Her network was primarily local: almost all her family and friends lived within a mile of her house. Church contacts for her were particularly strong, supportive and locally based. Physically, she had recovered sufficiently to be able to leave the house (with help), for example, to attend church and to go for short walks. Further, she displayed a positive approach to her social contacts (*'you have a smile on your face, they too have a smile'*) with no tendency to withdraw into herself. Her friendships were also not activity based, but they tended to chat 'for hours' over a cup of tea.

A final part of the jigsaw was perhaps Winnifred's pre-stroke experience of disability. Winnifred had become blind about five years before the stroke. Before she went blind she described how she used to *'be on the move, buzzing there, buzzing there, buzzing there'*. Since becoming blind, she described how *'more people here. More people come here.'* Thus she had already had to adapt her lifestyle, including becoming used to accepting help (for example, in leaving the house). She described how the stroke had not really changed things for her: in that sense, things had already changed. It appeared that the social contacts and activities that would typically be vulnerable post stroke (more activity based, less supportive, more distal) had already been lost five years previously.

From diverse to family-based

Those who became family-based all reported changing social desires, such as a sense of withdrawal, depression, and a hesitancy about rejoining social activities or leaving the house to go for a walk, even when physically able. They were also all male.

Peter: shifted from a diverse network to a family-based network

Prior to having a stroke, Peter had a classic 'diverse' social network. He had an active social life, as well as a close relationship with his family. At the age of 65, when Peter was still working long hours as a successful businessman, he had a severe stroke. Although he made a good recovery, and was able to walk a year later, he still experienced extreme fatigue and was not able to drive.

Post stroke he saw only his family, and a close couple who persisted in visiting him and his wife once a fortnight, as they had done for many years previously. He rarely saw any of his other friends and avoided social gatherings. Post stroke he explained that he *'can't be bothered'* to socialize, which in part seemed related to his fear that others might perceive him as *'the weaker member of the pack'.* He described how the stroke had left him feeling vulnerable, introverted and disinclined to leave the house.

Diverse, in transition

Those participants assigned to the 'diverse, in transition' category had severely reduced social contacts, and yet still retained enough that they did not qualify as family-based. It is possible that had these 'borderline' participants been visited a year further on, they may have managed to resume more social activities, such that they became more typical 'diverse' network members. Certainly, several spoke of their hope or determination

that they would continue to make progress which would enable them to resume social activities. Alternatively, a year on, they may have further deteriorated, and given up the struggle to maintain friendships that were arguably compromised by the extent of their disability, and belong more conclusively to the family-based network type. A case could be made for introducing a new sub category, such as 'diverse- depleted'. The sense of change that came through the interviews, however, led the researcher to consider such participants as primarily 'in transition'. As described by Wenger (1994)[75] those in the process of shifting from one network type to another are particularly difficult to categorise.

Those 'in transition' differed from those who had shifted to the family-based category in a few key respects. At the time of the interview they could not leave their house without considerable assistance. This contrasts with those who became family-based (although many did have mobility difficulties post stroke, none had become housebound) and those who retained their diverse status. Despite this level of disability, those in the 'diverse in transition' category sought out friendship where it was possible, and did not speak of avoiding social contact or situations.

Tomasz: an example of a diverse network in a process of transition

Tomasz was 66 and still working when he had a severe stroke. Prior to the stroke he had many friends, and liked to feel helpful and busy. He also had a close family, living with his wife and two sons, as well as having family back in Lithuania. At the start of the interview he insisted his friendships had not been altered by the stroke (*'they are 100% friends'*). Indeed, friends had visited him in hospital, and still phoned to give him moral support: his good friends, as he insisted, had not abandoned him. However, it gradually emerged that he

couldn't leave his flat without his son giving him assistance, that he now *'rarely'* saw friends, and that friendships had been altered as he found it difficult to be in receipt of their goodwill rather than helping them. He conceptualized network changes as temporary, however, and spoke often about his 'hope' that things would improve (*'If I have hope that tomorrow might be better, then I manage to survive today'*).

He appears to be a case of someone in transition. It is, of course, possible that he will make further recovery, regain some mobility, and be able to resume some of his former social life. Alternatively, it is possible that he will seek to replace his lost social contact with other forms of socializing, such as attending stroke groups (he hoped to go to one, although this hadn't yet been possible at the time of the interview). The alternative, however, is that over the following year he will gradually adjust to belonging to a 'family-based' network.

8.7.2 Friends-based

Given that friendship loss is common post stroke, it was interesting to find that people who belonged to a 'friends-based' network pre-stroke tended to remain members post stroke. In some cases this was despite various risk factors for friendship loss, such as: feeling withdrawn post stroke; having severe aphasia; being very elderly; losing shared activities; experiencing exhaustion; and physical disability. In fact, most friends-based participants did experience some friendship loss and reduced social activity. Nonetheless, they retained their membership of this network type as they kept their most important friends, and friends were still the main source of support.

It may be that participants were able to maintain their friends-based network as their friendships were particularly well-developed, and so robust, prior to the stroke. Since they had fewer family resources to fall back on, they may also have had more reason to maintain friendships post stroke.

The main threat to membership of this category was severe disability. The only shift that took place was from a friends-based network to a restricted-unsupported network. The participant who made this shift differs from the others in the friends-based group in the following respects: prior to the stroke she was in less good health; she had a smaller friendship base, in part as many of her good friends had either moved away or died; she attended no groups and few social activities. Post stroke, crucially, she became housebound. She also experienced discourse difficulties associated with her right hemisphere stroke, unlike any other participant in the qualitative project, which may have hindered her ability to maintain friendships. Although she still saw one friend who lived locally and would pop by, her main confidante and source of support post stroke was her care-worker. The impact of this reduction in her network left her struggling with depression.

The contrasting picture, that of a person who retained their friends-based network, is given below.

Steve: retained his friends-based network post stroke

Steve was 48 when he had a stroke, and working as an actor and also artist. He lived alone, was not married, nor did he have any children. Instead, his primary support system was his close friends. The only relatives he was in contact with were his two brothers and a cousin, who he described as important to him, even though they had little in common and he rarely saw them.

Steve had a severe stroke leaving him with long-term mobility difficulties and severe expressive aphasia, causing him to move into sheltered housing. Despite this, he retained his friends-based network.

This is not to say there was not any change. Before the stroke he'd stay out all night, go to the theatre or out for a pint: at the time of the interview he had been to the theatre only twice and never stayed out late. He had also lost touch with many acquaintances, and also a few people he had thought of as good friends. Despite all these changes, however, he managed to maintain his most important friendships. This close circle of friends he still saw frequently and they still provided emotional and companionship support. There may have been changes in how the friendships operated (they came to him more, he got more frustrated in conversation due to his aphasia), however, he still felt close to them. Given the severity of his aphasia, this was some accomplishment, and may reflect both the quality of his friendships, and also his level of motivation. When asked why friends were important to him post stroke, it took him over six minutes to write: *'They are the only think [thing] I have.'* This was an emotional moment for Steve.

8.7.3 Family-based

For those who were members of this category prior to the stroke they typically became closer to their family post stroke, and relied on them for increased levels of support. There was no clear pattern as to what happened to their relatively sparse friendship ties: for some, they lost contact with friends completely, others retained their friendships.

As described above, a proportion of participants who previously had 'diverse' networks became family-based post stroke. No-one with a friends-

based network or a restricted network developed a family-based network following the stroke.

It was rare to move out of this group: family relationships were relatively robust, providing the relatives remained in good health themselves. The only shift that took place was a participant who became restricted-unsupported. His profile was unusual: he fell out with his spouse and the rest of his family, which may have been associated with severe depression and (resolving) aphasia.

A case example is now given of someone who had a family-based network both before and after her stroke.

Adebomi: retained her family-based network post stroke

Adebomi was 68 and retired when she had a severe stroke. This left her housebound and with lasting disability and mild aphasia. Nonetheless, many elements of her social network remained unchanged. Post stroke she saw her son slightly more frequently, and he provided more tangible support. She remained in close phone contact with her daughter, and although she could no longer travel to the States, her daughter had come across to see her. Her aunt and cousin remained important parts of her network, and providers of emotional support.

In terms of non-kin, her main contact was with people she knew from her Mosque. Post stroke, a small group of them used to come to her flat every other week, as she could no longer go to the Mosque. Friends, however, were not the primary focus of her social network, even though she appreciated their companionship.

Although there were certainly changes in the dynamics of her network, particularly that people came to her, the structure appeared

relatively unchanged. Adebomi described herself as satisfied with her social network, and credits their contact and support with helping her to feel positive.

8.7.4 Restricted-supported

Participants in the restricted-supported category experienced little change post stroke, providing the relative who made them feel loved prior to the stroke was still available. They had already lost all their peripheral social contacts and were rarely involved with social events or activities prior to the stroke.

However, as noted above, this was a potentially vulnerable network structure, as the participant is dependent on one person for all their functional support needs. The reasons for participants shifting out of this category to become 'restricted-unsupported' were ill-health of the relative, and a relationship break-up.

The contrasting picture, of a participant who retained her 'restricted-supported' category is Dorothy, described in the vignette below.

Dorothy: remained in a restricted-supported network

Dorothy was 86 and a widow when she had a mild stroke, which left her more fatigued and slightly more disabled, although she was still able to live independently on her own. The stroke had little impact on her patterns of social support or her social network. Prior to the stroke she already had a severely reduced network. She was no longer able to see her friends who had all moved out of London and were too disabled to travel to see her, although she did speak to them on the phone. Her elderly sister lived around the corner, and they saw each other regularly. The main reason why she fell into the restricted-supported category rather than restricted-unsupported

category is her daughter. Although her daughter did not live locally and had her own health problems, Dorothy felt well-loved and supported by her daughter. She repeatedly described herself as very lucky to have such a daughter.

8.7.5 Restricted-unsupported

This was most isolated category to belong to. There was only one participant who belonged to this category prior to the stroke, although as discussed above, various participants acquired such a severely reduced social network post stroke. Before the stroke, they had either belonged to restricted-supported, friends-based or family-based networks. All those who belonged to the restricted-unsupported category described symptoms of depression post stroke, and most also expressed feelings of loneliness.

Chris: moved from restricted-supported to restricted-unsupported

Although Chris did not have close friends, he was in contact with a number of acquaintances prior to his stroke, through work, cricket, karate, and football. A former search and rescue pilot, he was fit and active. He lived with his partner, and had two sons, whom he saw perhaps once a month. It was his partner who he relied on for emotional and companionship support.

At the age of 58 he had a very severe stroke, leaving him with severe aphasia and difficulty walking. His expressive output was particularly limited, as he could neither write nor say more than ‘yes’, ‘no’ and swear words. The impact on his social network was catastrophic. He lost all contact with friends and acquaintances, and his partner left him. A year post stroke he still saw his sons, and his ex-partner resumed limited contact. However, he was otherwise isolated. The combination of the severity of his aphasia and disability, and his friendship pattern prior to the stroke (acquaintance

based, activity-based), made him particularly at risk of losing his social network. Further, his social identity pre-stroke appeared to be linked to being both fit and having status (as a manager of several stores), and he appeared disinclined to initiate social contact post stroke. Chris described how lonely and sad he felt, how awful life was following the stroke, and how he felt he would never adjust.

8.7.6 Summary of the main shifts that take place post stroke

Following a stroke, the most stable networks appeared to be family-based, friends-based and restricted-unsupported. Those participants who belonged to these network types prior to the stroke were likely to remain in them post stroke. The main network shift was participants moving out of the diverse category into the family-based category. Further, the restricted-unsupported network became noticeably more populated post stroke, and those who were members of this network type reported symptoms of psychological distress.

The main reasons why people shifted network type reflects the findings in the Chapters Four, Six and Seven: friendships are more vulnerable post stroke than family relationships. Hence the tendency for participants to move into the family-based network, and where there was no close family available, to move into the restricted-unsupported network. The causes of friendship loss are discussed in detail in Chapter Six, and help to explain who is more likely to experience the kinds of friendship loss that would cause them to change network type. Specifically, those participants who described a sense of ‘closing in’ on themselves were likely to shift from diverse to family-dependent.

Given the prevalence of friendship loss, it is of interest that those who belonged to a friends-based network prior to the stroke generally succeeded in maintaining that network post stroke. In fact, most friends-based participants did experience some friendship loss, but significantly, they managed to retain their most important friends, and friends were still the main source of support. They may have been enabled to maintain these close friendships due to their high quality prior to the stroke. Further, as they had fewer family resources to turn to, they had more need of these friendships for support following the stroke. Aphasia, even severe aphasia, did not preclude membership of this network type post stroke.

8.8 Cluster analysis: triangulatory evidence

The 29 participants who took part in Stage Two of the project were assigned into network types through qualitative techniques. The validity of the typology would arguably be strengthened through triangulation. In the present project, this was possible through using cluster analysis with the quantitative data from Stage One of the project (thus with 87 participants). The aim, then, of carrying out cluster analysis was to see whether the same network types emerged. Should similar network types be found in the quantitative data, this would provide reassurance as to the validity of the qualitative network types.

8.8.1. Cluster analysis: methods

As described above, cluster analysis is an exploratory data analysis tool, which organises data (in this project, participants) into clusters or 'groups'[286]. The variables entered into cluster analysis were four of the five

factors that make up the Stroke Social Network Scale[222]: Children factor, Friends factor, Relatives factor, and Groups factor. The Satisfaction factor was not included, so that the clusters would be derived from structural and interactional aspects of the network only. In this way, it more closely replicated the criteria used to create the qualitative social network typology. It also made the findings more comparable with typologies in the existing social network literature reviewed above (section 8.4). The six month data set was used to match the timing of the qualitative interviews as closely as possible. A decision was taken not to include the measure of functional social support (MOS Social Support Survey)[48], as this measure does not differentiate which network members are providing the support. Functional support was only a delineating variable in the qualitative typology in so far as it helped differentiate the role of network members.

Hierarchical cluster analysis was initially used to determine the optimum number of clusters[286]. Having determined the number of clusters, *k*-means clustering was used. These techniques are now described in more detail.

Hierarchical cluster analysis makes no assumptions about the number of clusters that will be created. Each case (participant) starts as a separate cluster. They are then combined sequentially, thus at each step the number of clusters is reduced, until there is only one cluster left. The way in which the cases are combined is based on maximising the similarity between cases within each cluster, while minimising the similarity between groups. In terms of measuring the distance between cases, squared Euclidean distance was used. Euclidean distance is the geometric distance between two cases[287]: the smaller the Euclidean distance, the more similar the cases.

Euclidean distance is only suitable for continuous variables, which is the case in this study[288].

There are different ways of conducting hierarchical cluster analysis, which use different criteria for merging clusters. Thus different solutions may be produced for the same data, depending on which method has been chosen[287, 288]. In order to find the optimal number of groups for the current data set, three different methods were employed and results compared in order to improve the validity of the results. The methods were: Between Groups, Furthest Neighbour and Ward's method. In Furthest Neighbour, the initial cluster is between the two most similar cases. These are then fused with the case that has the highest similarity score to both the original two cases. With Between Groups, the initial cluster is the same as for the Furthest Neighbour. However, the next case to be fused will be the case that is most similar to the average similarity of the initial cluster. In Ward's method, cases are joined into clusters such that the variance within a cluster is minimised.

As the process of fusing cases proceeds, increasingly dissimilar cases will be joined. The process should be halted, therefore, at a point where the clusters are meaningful and participants have been grouped in a useful way. In this project, the optimal number of clusters was determined by examining the agglomeration schedule. This gives information on the similarity (or distance) statistic used to create a cluster. The optimal number of clusters was defined by where there was a sharp jump in the size of adjacent coefficients (ie the measure of similarity or dissimilarity), determined

through inspection of the plot of the agglomeration coefficients against the number of clusters formed[288]. This data is presented in the results.

Having determined the optimal number of groups, *k*-means cluster analysis was employed to allocate participants to clusters. *k*-means clustering produces the number of clusters requested which are 'of the greatest possible distinction.'[286] At the start of the process, SPSS finds *k* cases that are well-separated, to be used as initial cluster centres. Cases are then assigned to a cluster, determined by their distance from those means. Cluster means are recalculated, based on the assigned cases. Cases are then reclassified based on the new set of means. This process is repeated until the cluster means change little between successive steps. Finally, cases are assigned to their permanent cluster. Thus, the algorithm repeatedly assigns cases to clusters, and a case could move from cluster to cluster during the process[288].

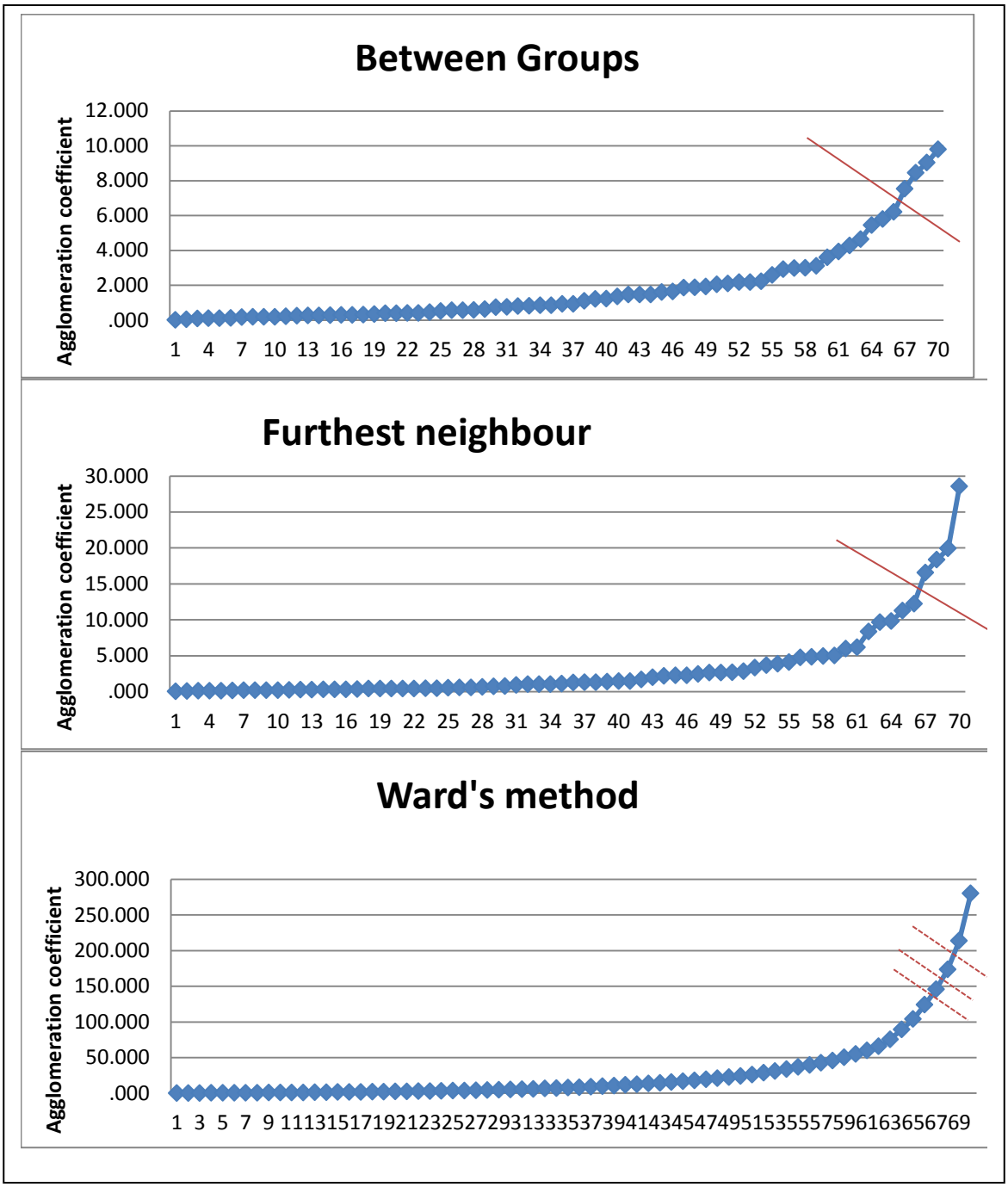
Since the variables used (social network factors) did not all have the same variance, they were standardised prior to entry into cluster analysis[287, 289]. In this way they all contributed equally to the distance or similarity between cases[288].

In terms of interpreting results, the characteristics of the clusters were reported. The means of each variable (ie social network factor) for the different clusters were presented. ANOVA was used to assess how distinct the clusters were: the size of the F value for each variable gives an indication as to how well it discriminates between clusters. Finally, the extent to which the cluster types match the qualitative network typology was discussed.

8.8.2 Cluster analysis: results

Initially hierarchical cluster analysis was carried out, using the following three techniques for combining clusters: Between Groups, Furthest Neighbour and Ward's method. Full agglomeration tables are provided in Appendix 18. The plots of the agglomeration coefficients against the number of clusters formed are presented below in Figure 8.3 for each method used. As can be seen from the plot, the first cluster formed in the clustering process contains cases very similar to one another (hence the low agglomeration coefficient). As the clustering process continues, cases that are more dissimilar start to be combined (hence the observed pattern that the agglomeration coefficients become larger). Where there is a sharp increase between adjacent coefficients, it suggests that to combine cases further would results in clusters made up of very dissimilar cases. With both Between Groups and Furthest Neighbour there is a relatively large increase in the coefficient values between the fourth and fifth steps, suggesting that a four cluster solution is preferable. For the Ward's method, the plot is more ambiguous, with potentially a two, three or four cluster solution all equally possible.

Figure 8.3 Plots of the agglomeration coefficients against the number of clusters formed: three methods of hierarchical cluster analysis



From this evidence, a four cluster solution appeared most valid, and therefore four clusters were requested, using *k*-means clustering. As discussed in the methods section, the social network factors were standardised prior to entry into cluster analysis, thus they have a mean of 0, and standard deviation of 1.

The final cluster centres are presented below in Table 8.2. Means approximately half a standard deviation above or below the overall mean for the sample are in bold: these potentially represent defining peaks of the clusters[73].

Table 8.2 Network types by delineating characteristics

	Delineating characteristics				
Network type	Children factor	Friends factor	Relatives factor	Groups factor	Frequency (%)
Diverse	.45	**.73**	.44	-.49	*n* = 21 (30%)
Friends-based	**-.62**	.48	-.08	**1.09**	*n* = 23 (32%)
Family-based	**.88**	**-1.26**	**1.12**	-.47	*n* = 9 (13%)
Restricted	-.18	**-.82**	**-.97**	**-.58**	*n* = 18 (25%)

All four delineating variables contributed to differentiating between the clusters, as indicated by their significant F values. ANOVAs are reported in full in Appendix 18.

The four clusters contained between 9 and 23 participants. The clusters that emerged could be matched to the social network typology developed from the qualitative data to some extent. Thus they may be characterised as follows:

1. **Diverse, Cluster One**: this cluster is relatively well endowed with both family and friends. It is unexpected, however, that it scores below average on the Groups factor.

2. **Friends-based, Cluster Two**: this cluster has above average non-kin (friends and groups) scores. Indeed, its Groups factor score is over 1 s.d. from the mean. By contrast, it has the lowest Children factor, and a slightly below average Relatives factor. This suggests that the primary source of support for those in this cluster is non-kin.

3. **Family-based, Cluster Three**: this cluster is strong in both the Children and Relatives factors. Indeed, it has the highest scores for both these domains. By contrast, non-kin contact is below average, with the Friends factor being over 1 s.d. below the mean.

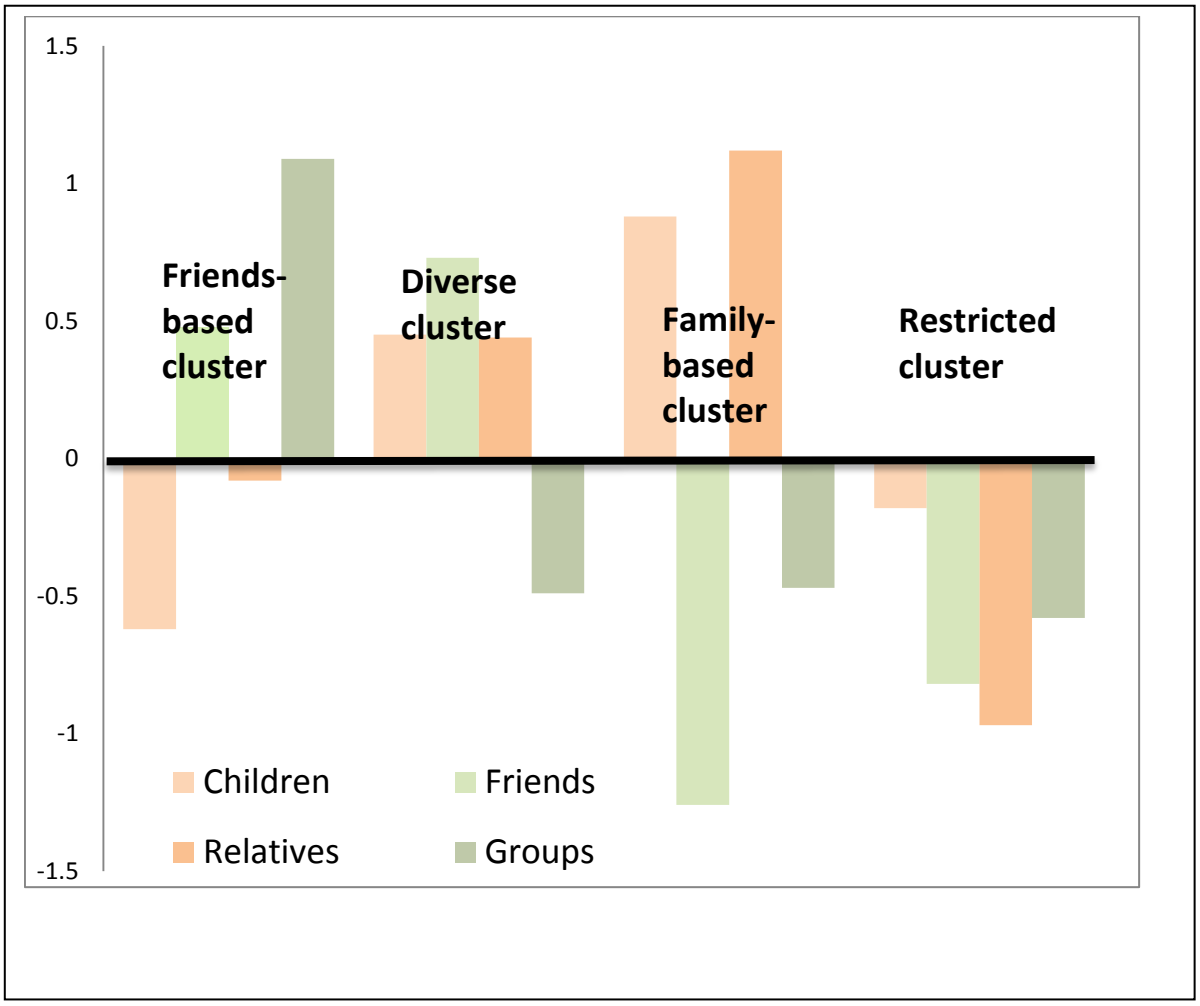
4. **Restricted, Cluster Four**: this cluster has low scores in all domains, indicating sparse social ties.

There is only one restricted network type, which would seem to subsume both of the restricted network types found in the qualitative typology. In fact, it would not have been possible to replicate the ‘restricted-

supported/unsupported' distinction, since functional support was not entered into cluster analysis.

The network types found through cluster analysis are represented graphically in Figure 8.4 below.

Figure 8.4 Mean scores of the social network factors by cluster type



8.8.3 Cluster analysis: summary

Cluster analysis was used to explore whether social network types could be found in the quantitative data, and if so, whether these matched the social network typology derived from qualitative analysis. In conclusion, cluster

analysis did provide triangulatory evidence for the qualitative social network typology. Firstly, a four cluster solution appeared to be the best match for the data (subsuming both restricted network types); further, when *k*-clustering techniques were applied the four clusters were characterised in a similar way to the qualitative network typology.

8.9 Social network typology: overall summary

A number of studies have developed social network typologies to help explain patterns of social support in the general population. Despite diverse cultural contexts and methodologies (qualitative, *k*-means cluster analysis, log linear analysis) this body of work has consistently found four network types: diverse (the most extensive network type with frequent contact with both kin and non-kin); friends-based (where friends occupy the central role in the network); family-based (few non-kin in network; family main source of support); restricted (network with the most limited ties). These network types were replicated in the present study using qualitative techniques, although like previous studies [5, 6, 10], two restricted network types were identified: restricted-supported, and restricted-unsupported. Defining dimensions were: frequency of contact with different members of the social network; composition of the network, including relative number of kin versus non-kin; which network members were most likely to provide different types of functional support. It was possible to assign all 29 participants to a network type both pre-stroke and post stroke.

A focus of the current study was to analyse who shifts network type post stroke and why. The network types that appeared to be most stable were friends-based and family-based. Participants who belonged to these network types prior to the stroke were likely still to belong to them post stroke. The main shift that took place was participants moving out of a diverse network into a family-based one. Less commonly, participants moved from restricted-supported, family-based and friends-based into restricted-unsupported. These shifts can be explained partly by the tendency for people to lose friends, but keep in contact with family (as reported in Chapters Six and Seven), hence the shift into the family-based network, and where no family was available, into the restricted-unsupported network. Against this background, it is interesting that the friends-based network appeared to be robust: this may reflect that those who belonged to this network prior to the stroke had unusually well-developed friendships. They also had fewer family resources to fall back on, so had increased motivated to maintain contact with their friends.

Triangulatory evidence for the validity of the typology was provided by *k*-means cluster analysis, using the factors of the Stroke Social Network Scale at six months as delineating variables. The four clusters produced had comparable characteristics to the network types derived from qualitative analysis.

Chapter Nine. Who provides what? The relationship between social support and social network

This chapter explores a further part of the social support jigsaw: what is the relationship between provision of functional social support and social networks? In Chapter Five, it was reported that the concepts of functional support and social network were moderately correlated at six months post stroke (r = 0.46). In Chapter Eight, the support provided by different network members helped to delineate the social network typology. This chapter unpicks in detail what functional support is provided by the different elements of the social network (such as spouse, children, and friends), what support is not provided, and how this is perceived. Evidence from both Stage One of the project (through correlation) and also Stage Two (qualitative evidence) are presented and results from these different strands of data compared.

The following research question is addressed in this chapter:

RQ11: Which network members provide what functional support following a stroke?

9.1 Assessing the relationship between social network and functional support: quantitative methods

The relationship between the different elements of a social network and the social support functions at both baseline and at six months were examined

through exploratory Pearson's product moment correlations. Social network elements consisted of the five factors used to create the Stroke Social Network Scale (SSNS)[222], and also marital status. In terms of functional support, the five functions of perceived support assessed by the MOS Social Support Survey[48] were examined. The definitions of these functions provided by Sherbourne and Stewart (1991)[48] are:

- Emotional (empathetic understanding, and the encouragement of expressions of feelings);
- Informational (the offering of advice, information, guidance or feedback);
- Tangible (the provision of material aid or practical assistance);
- Social companionship (the availability of other persons to do fun things with you);
- Affectionate (involving expressions of love and affection).

Further information on the psychometric properties of both the MOS SSS and the SSNS was provided in Chapter Three. Descriptive statistics of these variables were reported in Chapter Four. Copies of both the scales can be seen in Appendix Five.

The patterns of significant associations are discussed below. In terms of interpreting correlation values, r = .10 to .29 was considered small; r = .30 to .49 was considered medium; and r = .50 to 1.0 was considered large[290].

9.2 Assessing the relationship between social network and functional support: quantitative results

The results of these exploratory correlation analyses are presented in Table 9.1 (baseline) and Table 9.2 (six month data).

Table 9.1 Baseline: relationship between social network and functional support

Baseline (n=87)	**SSS overall**	**Emotional**	**Informational**	**Tangible**	**Social companionship**	**Affectionate**
SSNS overall	.41***	.30**	.33**	.47***	.33**	.37***
Satisfaction	.34**	.28**	.29**	.35**	.26*	.29**
Children	.29**	.19	.22*	.37***	.21	.30**
Relatives	.10	.04	.04	.19	.08	.04
Friends	.20	.19	.16	.20	.22*	.08
Groups	.24*	.15	.28*	.20	.18	.28**
Spouse	.37***	.26*	.33**	.31**	.37**	.39***

*** p < .001; ** p < .01; * p < .05

Table 9.2 Six months: relationship between social network and functional support

6 months (n=71)	**SSS overall**	**Emotional**	**Informational**	**Tangible**	**Social companionship**	**Affectionate**
SSNS overall	.46***	.43***	.45***	.42***	.41***	.36**
Satisfaction	.54***	.53***	.58***	.45***	.50***	.38**
Children	.26*	.25*	.16	.33**	.22	.22
Relatives	.24*	.24*	.30*	.17	.18	.22
Friends	.04	.02	.04	-.01	.06	.02
Groups	.18	.12	.21	.18	.13	.10
Spouse	.39**	.33**	.31**	.43***	.38**	.34**

*** p < .001; ** p < .01; * p < .05

The two elements of the social network that had the strongest association with functional support were: satisfaction with social network; and whether

or not the participant had a spouse. This was true both before and after the stroke.

The satisfaction factor of the SSNS was correlated with all functions of support. Prior to the stroke, correlations were small to medium ($r = .26$, $p < .05$ to $r = .35$, $p < .01$). Six months post stroke, the correlations were medium to large ($r = .38$, $p < .01$ to $r = .58$, $p < .001$), suggesting these two concepts were more closely linked post stroke.

Whether or not a participant had a spouse was moderately correlated with all functions of support, both before and after a stroke. As reported in Chapter Five, having a spouse was predictive of who felt well-supported six months post stroke. The findings from this chapter amplify this result: a spouse is a provider of *all* support functions, including, for example, social companionship and informational support, and remains a constant provider of support both before and after a stroke.

Prior to the stroke, the Children's factor was moderately correlated with Tangible support ($r = .37$, $p < .001$) and Affectionate support ($r = .30$, $p < .01$) and there was also a small association with Informational support ($r = .22$, $p < .05$). Post stroke, Tangible support remained significant ($r = .32$, $p < .01$), and in addition, Emotional support ($r = .24$, $p < .05$) was significantly associated.

The Relatives factor was not significantly associated with any of the support functions prior to the stroke. However, by six months post stroke there was a moderate correlation between the Relatives factor and Informational

support ($r = .33$, $p < .01$), and a small correlation with Emotional support ($r = .25$, $p < .05$).

By contrast the Groups factor was only associated with support functions prior to the stroke: Informational support ($r = .28$, $p < .05$) and Affectionate support ($r = .28$, $p < .01$). Six months post stroke it was not associated with any functional support. The Friends factor was modestly associated with Social Companionship prior to the stroke ($r = .22$, $p < .05$), but was not associated with any support function after the stroke.

In conclusion, the aspect of a person's network that was most strongly associated with functional support was how *satisfied* a person was with their network: this was especially true following a stroke. The network members who appeared to be most important in providing functional support both before and after a stroke were: spouse and, to a lesser extent, children. The Relatives factor was associated with Informational and Emotional support post stroke, but not prior to a stroke. Finally, while the Groups factor and Friends factor may have been modestly associated with functional support prior to a stroke, this was no longer the case post stroke.

9.3 The relationship between network members and functional support: qualitative evidence

This section discusses the different functions of support provided by various network members. The support functions are as defined by the MOS SSS, to assist in triangulation.

9.3.1 Functional support provided by spouse/ partner

The qualitative evidence supported the quantitative picture: the spouse was the network member who provided 'total' support, ie provider of all types of supportive functions. For all married participants, the spouse was considered the most important source of support. Compared to other network members, participants found it relatively easy to accept help from a spouse. For example, when Edward was asked if it was easier to accept support from his wife than others, he replied, *'Oh, Good Lord, yes'*. This contrasts with the frequently reported ambivalence on accepting help from other sources.

A common attitude appeared to be that 'support' was what was expected: the assumption was that it would be there. As one participant puts it: *'The wife's there [in hospital], but you sort of have to expect the wife to be worried about you.'* There were even those for whom receiving support was so much part of their relationship they hadn't consciously thought about it prior to the interview. As Peter put it, *'Well, you just don't think about it [support received from wife], because it's always there, isn't it, it's rather like water, there's always plenty of it about, you know.'*

Many participants became newly dependent on their spouse following the stroke. A proportion of participants speak of having to 'rely' on their spouse: they did not speak about having to rely on any other network member, and some described the negative impact this had on their relationship (explored in Chapter Seven).

The spouse was the main source of all support functions. Thus the spouse was the person who made them feel loved and valued, for example, by visiting them in hospital every day (Affectionate support). Since they would

be likely to be spending more time at home, the spouse's provision of Social companionship could become more important post stroke. The spouse was also the most likely person post stroke to advise a participant that they should seek medical care, or remind them to stay healthy in other ways (advising them to eat well, stop smoking, cross the road safely), constituting Informational Support. Further, the spouse was generally the main provider of Tangible support following a stroke. Participants would accept tangible help from a spouse that they would not accept from any other family member or friend. This was most apparent in accepting help with personal care (for example, help in the shower). Helping with therapy regimes, or daily reminders to take medication, was another type of support only provided by spouses in this project.

Finally, in terms of Emotional support many participants described how they would confide only in their spouse for personal, private or emotional matters (*'the only person I want to talk to is [my wife]'*). Discussing children, especially where there were concerns, was something participants preferred to do only with a spouse if they had one.

The only support function not provided by a spouse was expert advice provided instead by professionals. Further, for a subset of participants, personal care (subcategory of Tangible support) was given by paid carers rather than the spouse, for example, where the spouse had significant disability themselves.

The vignette below illustrates the central role of the spouse post stroke.

Case example: spouse as main provider of support

Pablo was 55 when he had a severe stroke. One year post stroke he still had moderate expressive aphasia, could not drive, and had impaired mobility. He lived with his wife and two sons. Although he said his relatives and sons were *'very good'*, and he had some close friends, it was *'My wife, number one. I got to shower, I got thing like that, everything from, for me.'* It was also his wife he talked to about personal things, or about his private worries. And it was his wife who visited him every day for three months when he was in hospital.

9.3.2 Functional support provided by children

Children did not provide 'total support', like a spouse. The qualitative data suggested that various functions of support were less likely to be provided by children (for example, personal care, confiding private worries). Further, it was common for participants to express conflicted feelings about accepting support and 'worrying' a child or being a burden. However, where a spouse was not available, participants generally preferred to ask their child for help rather than a friend or relative. Nonetheless, some support functions were accepted without reservation, including: Affectionate support, such as a child showing concern; and Social companionship, such as going on outings together and relaxing and having fun.

Unlike with spousal support, which was universally regarded as important, there was variation in the levels and perceived adequacy of support received from children. The primary reason for participants receiving what they

perceived as inadequate support was a degraded relationship with the child prior to the stroke: such participants either belonged to ‘restricted’ or ‘friends-based’ networks post stroke. Other reasons for a child providing limited support, even where the parent experienced increased support needs post stroke, were: a child living far away, for example, in a different country; the child’s ill health; and the child having other family commitments, work commitments or time consuming hobbies. Nonetheless, for a proportion of participants the contact they had with their children could be the most important support received. For example, an elderly widow described how her daughter’s calls were *‘the most important calls of all… just to speak to her and hear her voice.’*

Emotional support: participants mostly did not confide in their children about a private worry. A common reason for not confiding in children was that they did not want to worry their child, or impose on them, or make the child feel obligated. Frequently expressed was the sense that the child had their own life to lead, their own families to look after, and their own worries or health problems.

The subset who did confide in their children had in common that they did not have a partner and were female. They all expressed reservations about confiding in their children, and all said there were limits to what they could talk about (for example, *‘not intimate details’*) as well as periods when they would not talk about their own concerns (for example, when a daughter was undergoing chemotherapy). They described mixed feelings about confiding in a child. For example, one participant said that she felt *‘ashamed’* to be

revealing to her son that she couldn't cope. There was no-one in this project whose sole confidante was a child.

Informational support: Although there were examples of children giving their parents advice on, for example, eating less salt, or information on how to access music on the internet, this did not appear to be the most valued support function provided by children.

Tangible support: children provided many types of Tangible support, excepting personal care. Participants described how their children would help them in small ways, for example, buy small items, take letters to the post office, help to fill out forms or give them lifts. Unlike friends or relatives, it was not uncommon for children to help on a regular basis with tasks such as food shopping. Children also acted as advocates for their parents, for example, talking to medical personnel. This was particularly the case for more elderly participants.

In this project, no child provided personal care (other than one child who helped his father shave); nor did any child help with physical therapy or remind participants to take medication. This was equally as true for participants who lived with their children as those who did not.

Social companionship: Many participants spoke about 'being taken out' by their children following their stroke, for example, to a café, park, shops or cinema. As grown up children were likely to be fitter and more able than an elderly spouse, they were often better placed to take the individual out. Since many participants were either unable or reluctant to leave their house on their own, this sort of support could take on a different significance from

prior to the stroke, when they had been more independent. Being 'taken out' was universally described as a positive thing in the person's life, indeed, some participants with limited mobility described it as the highlight of their week. These companionable activities shared with a child could take on particular significance post stroke as other opportunities for social companionship reduced.

Affectionate support: children could be an important source of Affectionate support, and post stroke when a participant was potentially feeling vulnerable and low, feeling loved by a child could be significant to participants. This is illustrated by Daren. He was 65 at the time of the stroke, and prior to the stroke was still working and active. Ten months post stroke, he was still unable to walk outside the house. He described how he felt when his children came to visit him:

'Make you happy… brings some life back. Life, breath, strength. When they come, see, it wakes you up, make you feel you are wanted, you feel depressed before, you just forget it.' (Daren, p8)

9.3.3 Functional support provided by relatives

Emotional support: participants would typically confide in a spouse/partner rather than a relative. However, single female participants all had confiding relationships with relatives, mostly a sister, but also aunts and cousins. There was also a gay man who confided in his nephew.

Informational support: where participants had a relative with particular expertise, they would ask them for advice or information post stroke. For example, one participant sought advice from her nephew who was a physiotherapist. Advice from relatives, however, could also be a source of irritation. For example, one participant described how she disliked to be *'fussed'* by her sister. Another participant received unhelpful advice from relatives who *'don't have knowledge[about strokes]'*, and told him to *'rub chicken blood on my hand'*.

Tangible support: Relatives did not provide: personal care; liaise with medical staff or other professionals; or help the participant to comply with any medical or therapy regime. Further, it was unusual for a relative to help with housework, or to go shopping for them. As one participant puts it, *'I don't expect them (relations) to be around when I need shopping.'* The exceptions to this were two unmarried elderly women in the project who received some practical help from relatives. However, this was a vulnerable source of support in both cases: in one case, the relatives lived abroad, and only came over occasionally; in the other case, the elderly sister was herself admitted to hospital, and could no longer help the participant.

Social companionship: Many participants described how seeing their relatives cheered them up, made them laugh and relax. Given that often their social horizons had been limited by the stroke, this contact could take on a more central role in some of the participants' lives. This is illustrated by Martin. Before his stroke, he used to see his friends at the betting shop or out and about on his daily walks. Following the stroke, he rarely left his flat, and no longer had any social contacts. The only person he saw regularly

apart from his children was his sister-in-law, who lived in the same block of flats, and whom he met twice a week. When asked why this contact was important to him post stroke, he replied simply, *'I haven't many friends.'*

Affectionate support: knowing that a relative cared about them could be a source of support for participants. For example, Raymond described how his brother, who lived in America, phoned him at least once a week since the stroke, and sent him a weekly newspaper from the West Indies, where they grew up, to cheer him up. This level of concern and thoughtfulness made him feel *'good, good, yes, very good...it take some of the stress off you.'*

9.3.4 Functional support provided by friends

Post stroke the Friends factor was not associated with any support functions. The relative importance of family versus friends in providing functional support after a stroke was articulated by some participants in the qualitative data set as well. For example, Peter, 65, felt you couldn't expect to receive any support from friends: *'There's nobody else going to do anything for you, other than members of your family, nobody... you can't expect friends to do things, you know.'*

Nonetheless, for many participants, friends were an important source of some types of functional support. Indeed, for the subset of participants belonging to 'friends-based' social networks post stroke, they were the main source of functional support.

Emotional support: Friends could provide a valuable source of confiding emotional support. This is illustrated by Patricia (friends-based social

network). Patricia's main confidante was a friend. She rarely confided in her children, and had not told her new partner that she'd had a stroke. However, she derived much support from almost daily emails written to an old friend who lived abroad. She described what she gained from this contact:

> *'Back up. It's a back up to things that I think myself….I found it a tremendous comfort. There were times when I was absolutely despairing, I didn't know what to do with myself…But I would go in to sit on the computer [to email her friend], and that gave me a sort of soundness.' (Patricia, p 23)*

Confiding Emotional support was not a form of support that was universally either experienced or necessarily wanted from friends. Not everyone spoke of a need to work out their feelings in conversation. There was also the worry about burdening friends, particularly if emotional distress persisted long term. For example, Pratik did not confide in friends, and could not imagine doing so. He preferred to talk about less emotionally loaded things. For him, to confide in even his closest friends '*would be just weird, awkward for the both of us.'* Instead, he wanted to '*just talk to them about normal stuff, like a friendship should be, because you don't want to destroy that friendship, you don't want to burden them with more responsibilities about how you're feeling.'* Other participants said that they wouldn't feel it was right to confide in friends about private matters, particularly those relating to the family.

There may be a gender bias in who found this type of confiding support most useful amongst their friends. This is vocalised by Pablo. Although he had close male friends, who he felt understood and cared deeply for him, he

did not talk about emotional matters with them. He felt this was because he is a man:

> *'A woman, you can share, but the man, the talk, nothing, nothing to you….The man, is just, football, [inaudible], golf, er, nothing, go to fish, something like that.' (Pablo, p21)*

Pablo did, however, confide in his wife. Indeed, it was a pattern amongst the married men in this project that they were more likely to confide in their wives rather than in friends.

Informational support: Post stroke friends on occasion could provide information that was of value to the participant, such as that they were eligible to apply for benefits or a free gym membership, or the name of a 'good doctor'. When describing what was important in a friend, however, it was rare for a participant to talk of the provision of Informational support. Further, Informational support could sometimes be seen as unhelpful or unwelcome. For example, Pratik, aged 18, felt irritated on being told how to feel shortly after he'd had the stroke. Indeed, his dislike of this emotional advice was a catalyst for his ending contact with that group of friends.

> *'They were all telling me to be happy, which was, which when someone tells you how to feel it kind of makes you want to do the opposite of what they say.' (Pratik, p13)*

Tangible support: The Tangible support that was most commonly received was the buying of small inexpensive and non-essential items, typically a newspaper or food such as cake or fruit. Since many participants found it more difficult to go to the local shop following the stroke, these gifts were appreciated. Several participants also described how they would let friends

and neighbours help them with small practical matters, such as taking the top off the bleach. Being able to count on local friends and neighbours in the event of an emergency was also common. Since many participants worried about what would happen if they had another stroke, this was a valued type of support. An example is Gordon. Gordon knew many people on his street. He took comfort in knowing that he could call on neighbours in an emergency:

> *'If I went across to Mary now, and says I don't feel well, can Christie take me down in the car (to the hospital), she'd be across like a shot, she would… they'll do anything for you, you know. No problem.' (Gordon, p14)*

It was unusual to receive more substantial Tangible support. Where it was given it would typically be time-limited, which contrasts with the on-going nature of Tangible support provided by family. Thus, in the acute phase, particularly on first coming home from hospital, friends would sometimes fill in the gaps if no family was available, and help with the shopping or giving lifts. There was no-one who reported receiving personal care from a friend.

There was a reluctance to ask friends for practical help. People did not want to impose on friends, or be a burden to a friend. Even participants with significant unmet needs, and little family support, would be reluctant to ask friends for help, especially if the help they needed was perceived as time consuming, expensive or burdensome. This is illustrated by, Gerta, aged 82 and living on her own, categorised as having a 'friends-based' network. She described how difficult she would find it to go clothes shopping on her own

after the stroke. Although she felt her friends would be pleased to accompany her, she had not yet asked them. Over a year post stroke she had preferred not to buy clothes rather than impose on friends. She had no family to help.

> *Gerta: I want to go in weeks and weeks to John Lewis to buy [clothes and shoes], I have avoided it, thinking of busy Oxford Street and so on…but I mean I can find somebody, to say, have you got time [to accompany me]. It's a question of asking sometimes.*
>
> *SN: And are there people that you feel you can ask?*
>
> *Gerta: Yes, about two or three I think I could ask, yes. But I always think of their life, how much time they can spare.*

Not only was asking for help perceived as difficult, participants also reported turning down offers of help. Reasons included wanting to feel independent, not wanting to feel obligated, and not believing that the offers were really meant *('it's all half-hearted isn't it [offers of help]? They've got other things to do… you cannot impinge yourself on people'*). Worries about not being able to reciprocate also made participants less likely to accept offers of help. This is articulated by Peter. No longer able to drive post stroke, friends had offered to give him lifts, or come to him, which he had declined. He gave the following rationalisation: *'You've got to, it's a two way street, isn't it? You want to see, you can't expect people to come all the time.'*

In this project, those without family did not accept more Tangible support from friends than those with family in the long term, nor did those in a 'friends-based' social network.

Social companionship: Many participants spoke of how much they enjoyed chatting, joking, relaxing and having fun with friends. These conversations were not confiding or emotionally laden (hence Social companionship support rather than Emotional support). Participants would describe such conversations as having a *'right old chinwag'*, or *'a good old natter.'*

Given the newly restricted lifestyle of many participants, and the depression that often accompanied this, the value of friends coming over and making them laugh could be great. Bridget, for example, stated that the thing that helped her recover from post stroke depression was *'just a friend coming and having a laugh and a joke.'* Similarly, when Paul was asked how people had helped him after the stroke, he stated simply: *'Being able to joke'*.

It was not uncommon for those living on their own to describe the value of having frequent, even daily, chats with friends. An example is Dorothy. At 86, she rarely saw her friends, as not only was she less mobile, but so were her friends. She described what she gained from regular telephone conversations with her old friend Nancy.

> *'What they've been doing, and what I've been doing, and what I've not been doing. [laugh]. Nancy and I generally explain all our aches and pains…. it's nice to speak to somebody, somebody you know and like, and you can imagine, yes. Especially if I haven't spoken to anybody, you know, all day, and then I have a phone call, it's rather nice, you know, just have a chat.' (Dorothy, p16)*

However, even those who lived with family members described the particular value of a friend visiting them. The less mobile participants described sitting all day long with their partner, talking about the same

things, watching the same television. A visit from a friend could cheer them up, make them feel more positive, take their mind off their problems. As Susan said of a neighbour who called in and chatted to her: *'You feel better, you feel better… Gives you an uplift, if you might say.'* Similarly, Daren, who described himself as *'very very close'* to his family, still valued the chats he had with friends. He could not leave his home without assistance following the stroke, and described how he felt when friends visited:

> *'Yes sometimes when you sit down here on your own, depressed, somebody ring the bell, you get a 'whoa whoa yeah!' 'How are you?' 'Fine! Come in!' And at that time you regain some element of happiness. That's all. Then you sit down and chat, talk of past times.' (Daren, p14)*

In contrast to children, friends rarely took a participant out. Friends would be more likely either to meet the individual out and about, or where the participant was too disabled, they would come to the person's house.

Affectionate support: when asked what made someone a good friend participants described how a good friend cared about them, was concerned, thought about them. Following a stroke, people wanted their friends to be in touch, to find out how they were, either by visiting or phoning or sending a card or message via a third party. Indeed, there was the expectation that this *should* happen, that friends should be in touch on hearing bad news, and where this did not occur it could be a cause of some distress or difficulty within the friendship. Feeling a friend cared and was concerned was universally welcomed.

9.3.5 Functional support provided by groups

As discussed in Chapter Six, participants were involved in fewer group activities post stroke, thus there would be fewer opportunities for participants to receive support from groups. Even those who did return to a group could remain semi-detached, such that the activity had less of a supportive function for them. An example was Patricia, aged 62. She described how her lack of verbal fluency following the stroke impacted on the social experience of going to a ceramics group. As such, going to this group no longer provided Social companionship as it did prior to the stroke:

> *'I was always the talker, and um, I'm much more silent these days. I suppose that is an insecurity… it's less of a social activity now. It used to be a great social activity as well… I quite enjoy making pieces, but the fact that it was a great social group, I enjoyed it, very much. I still enjoy it, but I enjoy it less now, because it isn't as much of a social group. I really don't talk very much at all.' (Patricia, p11)*

Another change post stroke was that some participants attended new facilitated groups, as discussed in Chapter Six. The main type of support that participants mentioned receiving at these post stroke groups was Social companionship: being able to chat, compare experiences, have a laugh and a joke. Some of the groups also provided information and advice. No participant mentioned receiving Emotional, Tangible or Affectionate support through such facilitated groups, however. Further, for some participants, the groups were not enjoyable, and provided no supportive function. An example is 91-year old Rose, an artist:

> *'When I go to the hospital tomorrow, I mean, it's not much fun, you see all these old dears sitting around the tables, having, you know, I'm not, I'm not really in their scene at all really… I sit at the table*

sometimes but I don't have anything much to say to them.' (Rose, p9)

By contrast, Rose experienced real care and concern from her on-going fortnightly Women's Discussion group. In order to enable Rose to continue to attend post stroke, the group went to her house (*'used to meet in other people's flats, but of course, I can't get up and down the flats. So we have it here, instead'*). Indeed, as discussed in Chapter Five, those participants who were able to attend regular, supportive groups formed prior to the stroke, such as going to church, or meeting at the British Legion, could find valuable support from this source.

9.4 Summary of the support functions reported as most valuable post stroke: qualitative evidence

The support functions which appeared to be most valued, as perceived by the stroke survivors, are briefly described below.

9.4.1 Feeling that someone cares and is concerned

This sense of needing to feel connected to someone who cared was universal, unlike any other type of support. When asked what had really helped after their strokes, these were some typical responses:

'I'd have to go back to concern… my constant word, concern, yes.' (John, male, 76 years old, living alone, mild stroke, friends-based social network)

'I've got somebody there, someone cares… That's the main thing, the best thing, knowing that they're there… I'm not on my own.' (Gordon, 74, male, living with wife, moderate stroke, family-based social network)

'It's knowing that someone cares about you.' (Ivy, 82, living on own, severe stroke, restricted social network)

Perhaps the importance of this type of support following a stroke is demonstrated by those who did not feel they received it. Patricia, who was 62 when she had the stroke, described how her daughter did not visit her in hospital, and never asked how she was. Having always felt young for her age, and that illness was a state of mind, the stroke came as a major shock. As Patricia struggled with feeling unwell, suddenly 'old' and vulnerable, she wanted to feel connected to her daughter:

> *'The one thing that I needed, the only thing I needed from her, was a little bit of concern now and again, and I haven't had that.' (Patricia, p28)*

And when asked how her daughter could have given her this sense of concern, she said all it would have taken is, *'Just a telephone call now and again would have been the most important thing, yes.'* The impact on her relationship with her daughter was that she was, *'furious, very hurt'.*

9.4.2 'Responsive' tangible support

As discussed in Chapter One, receipt of tangible support can come with some psychological costs. The literature suggested that one way of mitigating those costs might be the concept of 'responsive' provision of support (defined as support that makes the recipient feel loved and

esteemed[105]). This appeared to be the case in the current dataset. It was striking that the provision of tangible support often appeared to be primarily appreciated for the extent to which it communicated care and concern. For example, the gift of a small radio when in hospital was appreciated because it made the recipient feel his daughter cared, that even in hospital he wasn't really on his own. Another example is Dorothy. Dorothy was 86, lived alone and had one daughter. Her daughter was the primary provider of all support, including tangible support.

> *'She does little helpful things. She knew, this is just an example, she knew I wanted a new ironing board, but there was nothing really the matter with the actual board, it was the stuff, you know, under the board, broken away. I'd made new covers. And she went to one of these big do it yourself places I think, and you could buy, like, a new piece to put on, about that thick.' (Dorothy, p5)*

The fact that her daughter had not only noticed her mother's ironing board, but had the sensitivity to buy new 'stuff' rather than a complete new board, so as not to waste her mother's newly made covers, is arguably an example of responsive tangible support. Dorothy commented her daughter was *'so concerned about me'* and described how very happy, very grateful she was to have such a daughter.

Conversely, some intensive tangible support (for example, cooking someone their meals every day) did not necessarily lead to a sense that the other person cared about them, which could leave the stroke survivor feeling isolated and detached from their supporters. Further, tangible support that was provided insensitively could have negative psychological

consequences, as one participant put it '*overdoing*' the help could make a person '*feel an invalid… absolutely worthless.*'

9.4.3 Acceptance

Another theme that was recurrent throughout the dataset was the sense that participants wanted others to accept them as they were post stroke. Thus they wanted people to have patience: patience in conversations, especially for those with aphasia; patience that they could no longer do things so quickly, but would still like to attempt to do them on their own; and have patience that they would need time to recover from the stroke. They wanted others to be tolerant: tolerant of their despair, of their post stroke temper outbursts, of their frustration and bad behaviour. Although participants varied in how open they wanted to be about the stroke, many spoke of wanting others to acknowledge what had happened, to have an awareness of what it meant and how slow recovery would be, and acknowledge their attempts to make changes to their lifestyle as a result of the stroke.

9.4.4 Social companionship

As discussed above, every day social 'chit chat' could lift a person's mood, and make a person feel connected to others. This form of 'support' was near universal, although could be threatened by severe aphasia. There also seemed to be much value placed on being taken out, and having a change of scene, particularly for those with limited mobility (*'Just to give me some fresh air instead of staying in the house… Make you happy'*). And for some joking and laughing was considered the most valuable support another could give.

9.4.5 Other support functions

Emotional ‘confiding’ support was another support function described as valued by some participants, as described above, although this was not universal.

Encouragement was also described as helpful by some when recovering from a stroke. Participants described how a supporter would give them ‘*encouragement*’, ‘*confidence*’, ‘*courage*’, ‘*strength*’ or ‘*hope*’. However, encouragement to do things the participant did not feel ready for could make them feel the other person was not aware of what they were going through. Being told to ‘keep your spirits up’ could also engender mixed feelings. Thus encouragement, as with tangible support, was arguably most valuable when ‘responsive’.

Finally, the provision of information is frequently hypothesised to play an important role following the onset of illness[45]. In this project, participants spoke about wanting to know what had happened to them, and what to expect; to be given an explanation for symptoms, and feedback on how they were doing. They also wanted to be given advice on how to manage some of the consequences of having a stroke, such as persistent tiredness. Being given information about their illness from someone knowledgeable, such as a healthcare professional, was valued. However, it could be problematic if given by someone who they felt didn’t understand or had only limited knowledge, such as well-meaning relatives.

9.5 Accounting for the discrepancies between the qualitative and quantitative findings

Some discrepancy between the qualitative and quantitative findings would be expected: they analyse data from different time points (six months compared to one year post stroke), and although the qualitative sample is drawn from the quantitative sample, purposive sampling techniques were employed rather than representative (discussed and justified in Chapter Three). It might, therefore be expected that the samples would display different characteristics. Furthermore, the quantitative data reflects perceived availability of support, whereas concepts such as quality, value and subjective meaning of support were probed in the qualitative interviews.

Nonetheless, in terms of the broad picture, the qualitative and quantitative data complemented one another. Thus for both, the spouse was the main source of support. Children were the next most likely network member to provide support. The Relatives factor was more strongly associated with support functions post stroke, although not with Tangible support. Groups provided little functional support for most participants post stroke in the qualitative project, which matches the quantitative data. In terms of the support provided by friends, both data sources suggest they were unlikely to provide Tangible support. Indeed, the quantitative data found only a modest correlation between the Friends subdomain and Social companionship prior to the stroke, and no significant associations with any support functions post stroke. This could be explained by the reduced contact with friends post stroke. However, the qualitative data suggested that for a subset of participants, even after a stroke, friends were a significant source of

Emotional, Affectionate and Social companionship support. This was particularly true for those in a ‘friends-based’ social network.

When examining the different social support functions in more detail, the main discrepancy between the qualitative and quantitative findings relates to two specific domains: Affectionate support and Social companionship support. These were not significantly correlated with the Children, Relatives or Friends domains. The qualitative project, however, found these network members did provide these support functions.

Turning first to Social companionship, there were different patterns found in the qualitative data. Thus, for a subset of participants, their child, relative or friend was perceived as an important source of Social companionship. However, many others either had no children, close relatives or friends, or were in contact with them only infrequently, impacting on how much Social companionship support they could receive from these sources. This contrasts with a spouse, who they saw every day.

The discrepancy regarding Affectionate support may be explained by the fact that there were differences in emphasis when assessing this support function in the qualitative and quantitative data. The authors of the MOS SSS define Affectionate support as ‘involving expressions of love and affection’. They assessed this concept through three items:

‘If you needed it, how often would someone be available to: 1) show you love and affection; 2) hug you; 3) love and make you feel wanted.’

The item on ‘being hugged’ was arguably culturally specific to the US: several participants found this item unacceptable or bizarre during

interviews. No participant in this project spoke of being hugged by a friend. Similarly, while participants may have felt close to friends and relatives, they did not speak of 'loving' a friend or relative. Thus the provider of physical and verbal expressions of love, as elicited by these questions, was the spouse or partner, as reflected in the quantitative findings.

In the qualitative analysis, the MOS SSS definition was taken as a starting point to assist triangulation ('expressions of love and affection'), and conceptualised to mean support that made the participant feel loved, feel wanted, but also by extension, that someone cared, was concerned: care and concern were words participants used to describe this concept rather than love. The emphasis in the MOS SSS on physical manifestations of love meant that it may not have adequately captured the diversity of sources who provided this support function in the UK. From the qualitative data, this sense that 'someone cares, someone is concerned/ loves me' was one of the support functions provided by friends, relatives and children that appeared to be most valued following a stroke.

9.5 Summary of main findings

It was found that *satisfaction* with the social network was strongly correlated with all functions of support and this was particularly the case post stroke.

The spouse was the most important source of functional support, both before and after the stroke. People found it easier to accept support from a

spouse than any other source. They were the only members of the support network to provide personal care and help with therapy regimes, and the most likely source of Emotional support.

Although children also provided support, it was common for participants to express reservations about worrying or imposing on their child. Some functions of support were easier to accept than others, such as a child making their parent feel loved and wanted, or taking their parents out. Children could also be a source of on-going Tangible support, for example, helping with the weekly food shop. Unlike with a spouse, where substantial support was almost always received, there was variation in how much support children provided.

Relatives appeared to provide more support post stroke than prior to the stroke, which could reflect the ‘rallying around’ phenomenon described in Chapter Seven. A subset of participants had particularly close relationships with relatives, and would confide in them. A common role was provision of Social companionship: someone to ‘take them out of themselves’, take their mind off their worries. It was rare that a relative provided Tangible support.

The quantitative data found that the Friends factor was associated with Social companionship prior to the stroke; and that post stroke it was not associated with any support function. This is likely to reflect the loss of friends described in Chapter Six. Nonetheless, for participants with a ‘friends-based’ social network, friends continued to be a major source of functional support, even after the stroke. No participant described receiving substantial Tangible support from a friend, however.

Finally, group membership appeared not to be associated with the provision of functional support following a stroke.

In terms of the support functions most valued, these were: feeling others cared and were concerned; responsive tangible support (ie tangible support that made the recipient feel loved and esteemed); acceptance; and social companionship. In addition, some participants described the value of confiding emotional support; informational support when given by an expert; and encouragement.

Chapter Ten. Discussion

This chapter will firstly examine and interpret the main results from this thesis, both with reference to the relevant literature, and also in terms of theoretical constructs of social support and models of loss. It will then discuss the strengths and limitations of the study. Finally, it will explore the clinical implications and relevance of the results, and discuss areas of future research.

10.1 Social support and social networks: descriptives and predictive models

10.1.1 Functional social support

RQ1: How do pre-morbid levels of perceived social support change over time following a stroke?

The literature review (Chapter Two) reported that post stroke functional social support was stable over time in 5/5 studies (4/4 perceived social support[10, 79, 196]; 1/1 received social support[17]). However, none of these studies included a pre-morbid assessment of functional support, thus they may have been measuring new patterns of social support formed since having the stroke. In the present study participants were asked about their pre-morbid perceived functional social support at two weeks post stroke (baseline). There was no significant change between the baseline and the three and six month assessments.

This stability is predicted by the social support literature. It has been argued that the perception of feeling supported is based on countless ‘invisible’ and

reciprocal everyday support exchanges[53]. It has also been suggested (for example, by Sarason *et al.*, 1990)[52] that perceived support in fact reflects attachment style (high perceived support related to secure attachment; low perceived support related to anxious or avoidant attachment). To support this, there is evidence that perceived support has been found to be a relatively stable construct in the general population[52]. Nonetheless, it was unclear whether this would apply to the stroke population for two reasons discussed below.

Firstly, having a stroke often necessitates receipt of considerable additional support[6, 104]. While this project did not quantify levels of received support, the chronic illness literature provides evidence that increased disability is associated with increases in received support[291, 292]. Further, the qualitative data suggested that a major change within the family post stroke was the receipt of additional support (see Chapter Seven). Thus there appears to be a dissociation between stable levels of perceived support and increased levels of received support. In fact, as noted in Chapter One, the association between received and perceived social support is only modest, estimated at r = .35 in a recent systematic review[54].

Secondly, while perceived social support may be relatively stable in everyday life, in fact there is some evidence that those who become disabled[291] or unwell[293, 294] may perceive themselves to be less well supported. Further, as noted in Chapters One and Two, there is a close relationship between perceived social support and mental health, both in the general population [82] and the stroke population[9-11]. Given the high levels of psychological distress in the current sample (66% classified as ‘high

distress' at two weeks; 58% at three months; 45% at six months)[137], it may have been anticipated that this would influence how well supported participants felt themselves to be.

The only change was that levels at three months were slightly higher than at six months. This may reflect the concern shown to participants in the early stages post stroke (for example, hospital visits, cards received, help on coming home).

In summary, this construct appeared to be relatively stable, despite the high levels of distress and additional support needs experienced by the sample.

RQ4&5: What baseline and concurrent factors predict perceived social support six months post stroke?

There was only one significant baseline predictor of perceived support at six months: perceived social support prior to the stroke. It is of interest that no other baseline factors were predictive. Thus severity of stroke, level of disability, aphasia and psychological distress at the time of the stroke did not impact on levels of perceived social support six months later. Those who felt well-supported prior to the stroke were likely to feel well-supported post stroke.

At six months, significant concurrent predictors were: social network, marital status and psychological distress. Since a social network is the structure through which functional support is provided[61] (see Chapter One), it is not surprising that those with a more robust social network had higher levels of perceived support. Psychological distress and perceived social

support have been found to be significantly associated in the stroke population[10, 11, 198, 205] thus it was anticipated that psychological distress might predict lower levels of perceived support in the current study. Finally, marital status was found to be a significant predictor. Correlational analysis in Chapter Nine demonstrated that the spouse/partner was the network member most highly associated with all support functions. There was also qualitative evidence for the vital role of the spouse. Nonetheless, post stroke the marital relationship was reported to be under strain, with new tensions and conflicts reported (see Chapter Seven). Further, carer stress is reported to be high in the stroke population[295]. Thus it is of interest that despite this strain, stroke survivors who were married still perceived themselves to be better supported than those who were not.

Although many other stroke studies have included a measure of functional social support as an independent variable in predictive models, none have explored what factors predict perceived social support. Thus in order to place these results in a broader context, it is necessary to look to the chronic illness literature. In fact, only two studies were found that examined predictors of perceived social support for people with chronic illness.

Sirri, Magelli & Grandi (2011)[296] examined predictors of perceived social support in 66 long-term survivors of cardiac transplant (on average, 10 years post transplant). They considered a broad range of possible predictor variables (for example, demographics, HRQL, co-morbidities, and clinical measures such as number of acute rejection episodes). There was only one significant predictor: depression (those who were more depressed had lower

perceived social support). Overall, their model explained around 28% of the variance (R^2 = .38; adjusted R^2 = .28).

McColl and Friedland (1995)[213] explored predictors of perceived social support in a mixed population: stroke (n = 90) and spinal cord injury (n = 120), results analysed together. Three models were generated as tangible, emotional and informational support were considered separately. Possible predictors included functional independence, demographics (for example, age, gender, marital status), time post onset, and illness type (stroke or spinal cord injury). For both the tangible support and the emotional support models there was only one significant predictor: illness type (spinal cord injury participants had higher levels of perceived support). For informational support, as well as illness type marital status was a significant predictor. It is striking how little variance these models explained, only between 3 – 6% (tangible support: R^2 = .035; informational support: R^2 = .06; emotional support: R^2 = .04. Adjusted R^2 not provided; number of variables entered into the model not stated).

Like the current study, Sirri *et al.* (2011)[296] found depressive symptoms to be associated with perceived social support. McColl and Friedland (1995)[213] did not measure psychological distress or depression which may in part explain the small amount of variance accounted for in their models. Both Sirri *et al.* and McColl and Friedland found marital status to be significantly associated with perceived social support (and predictive of informational support). Like the present study, McColl and Friedland did not find functional independence to be predictive. Thus while functional social support (particularly received emotional support) has been found to

facilitate recovery post stroke[17, 109], physical disability did not predict levels of perceived support in either the current study nor McColl and Friedland.

10.1.2 Social networks

RQ2: How does a person's pre-morbid social network change over time following a stroke?

Social network was measured using a new scale developed specifically for this project: the Stroke Social Network Scale (SSNS)[222], validated on both those with and without aphasia following a stroke.

The SSNS was administered at two weeks post stroke (where participants reflected on their social network in the month prior to the stroke), giving a baseline score. It was then re-administered at three months and six months. Overall SSNS scores significantly reduced over the six month period from baseline levels. Although other studies have reported that overall size of network reduces[8], or is less than controls[3], this is the first study to follow participants prospectively from a pre-morbid assessment, and report on a complex measure of social network rather than a single indicator such as size of network.

In terms of the subdomain scores, only one subdomain showed significant change: the Friends subdomain. This confirms the finding of many other studies, both quantitative[170, 173] and qualitative[5, 143], that contact with friends is vulnerable post stroke. By contrast, contact with the family subdomains (Children; Relatives) appeared to be stable. This again matches the trends found in the pre-existing literature[2, 180].

While participants had lower scores on the Group factor at six months, this trend did not reach significance. This may reflect that even prior to the stroke group membership was low. Thus pre-morbidly the mean number of groups (SD) attended was 0.88 (1.03), and roughly 50% of participants did not belong to any group. By six months post stroke the mean number (SD) of groups had reduced only a little to 0.79 (1.0), with roughly 52% not belonging to any group. Further, these figures give no insight into whether the 'type' of group had changed: ie whether recreational/leisure activities had been replaced by therapy groups or day centre attendance, as described by Davidson *et al.* (2008)[162]. The qualitative data (Chapter Nine) suggests this may indeed have been the case.

Perhaps not surprisingly, given the reduction in the overall social network score, the Satisfaction factor also reduced post stroke (ie participants felt less satisfied with their social networks post stroke), although again this trend did not reach significance.

RQ6&7: What concurrent and baseline factors predict social network six months post stroke?

Four variables were found to be significant concurrent predictors of social network at six months post stroke. These were: perceived social support, aphasia, extended ADL, and ethnic background.

Perceived social support was found to be the strongest predictor: those that felt well-supported had stronger social networks. Again, this confirms the close relationship between these two constructs, both measuring different aspects of social relationships. In fact, as reported in Chapter One, the correlation between functional and structural support is normally between .2

and .3[45]. In this project, the correlation was higher (r = .46 at six months). This may be due to the Satisfaction factor, a domain not always included in social network scales. It may be likely that one factor that makes a social network satisfying is perceiving oneself to be supported.

Aphasia was also found to be a significant predictor. Code *et al.* (2003)[145] was the only other study to look at predictors of an aspect of social network post stroke (hours spent out of the house). They also found that severity of aphasia was a significant predictor[145]. However, their study only recruited those with aphasia. Thus our study strengthens their conclusions: aphasia is a significant predictor of overall social network in a general stroke population. It may be that other studies looking at predictors of related concepts post stroke (for example, social dysfunction[297]; participation[134]) have underestimated the impact of aphasia, as they excluded people with language difficulties.

Extended ADL was also found to be a significant predictor. Thus those more able to perform extended ADL had stronger social networks. Other studies have also found that ADL/ level of disability post stroke are associated with aspects of the social network [4, 188], as well as participation[134].

Finally, those who were of African or Caribbean background had stronger social networks. The finding that ethnicity is a significant predictor is based on a small sample of black participants (n = 5), which may mean this result should be interpreted cautiously. Ethnicity has not been found to be a predictive factor in recent reviews of quality of life after aphasia[141], quality of life after stroke[298], or depression after stroke[150]. In terms of social

networks, the literature is mixed. In the stroke literature, two studies reported on this area. Boden-Albala *et al.* (2005)[179] recruited 655 stroke survivors in Manhatten, New York, USA, of whom 27% were African American, 54% Hispanic and 18% white. They found African Americans to be more isolated than whites or Hispanics at the time of the stroke, which they suggested may in part reflect the greater poverty of the African American population in the study area. Haun *et al.* (2004)[165] recruited 77 male stroke survivors, of whom 23% were black, 41% hispanic and 39% white. Unlike Boden-Albala *et al.* they did not find ethnicity to be a factor when exploring social isolation post stroke. 40% of whites were classified as 'isolated' or 'moderately isolated', compared to 45% of blacks and 48% of Hispanics (classified according to a qualitative typology). Similarly, mixed results can be found in the literature for the general elderly population[299 300].

Certainly, how a social network functions is very likely to be culturally specific[75, 284], and the interaction between social network and ethnicity may be influenced by larger societal issues, such as poverty and social exclusion[39]. Thus findings from more disaffected or excluded minorities (for example, Boden-Albala *et al.*[179]) may not translate to the present study. Pawson *et al.* (2005)[301] make the further point that the social network of a person of ethnic minority will reflect how well-established and numerous that minority is in the person's neighbourhood. The present project took place in West London, home to the Notting Hill Carnival, the largest carnival in Europe celebrating the traditions and the culture of the Caribbean community[302]. As such, it could be said to be an area where Afro-Caribbean people have a strong and proud ethnic identity.

Further insight into this finding is perhaps provided by the qualitative data. Those of Afro-Caribbean ethnicity were found to have strong family ties, high expectations of support from children, and often strong local church/mosque connections. Indeed, they were the only participants who reported receiving visits from congregant members in the event of becoming housebound.

This study also looked to see what baseline factors predicted social network at six months post stroke. Pre-morbid social network was the strongest predictor. This may suggest that social networks represent 'life-long adaptations'[75], and as such many elements remain stable even after a stroke, for example, the family domains.

There was only one other baseline factor that was a significant predictor: aphasia. Thus aphasia was found to be the only stroke-related factor that impeded a person's ability to maintain a strong social network in the months following a stroke, more so than stroke severity, level of disability, perceived social support or psychological distress.

10.2 The impact of stoke on family relationships

RQ9&11: What happens to family relationships following a stroke? What functional support do family network members provide?

10.2.1 Spouse

Replicating results reported in the meta-ethnographic review of Chapter Two, this project found that a stroke could cause tensions within a marriage, in particular, through lost roles and increased dependency[6, 104, 111]. Further, strong emotions post stroke such as depression and anger could be a cause of conflict[104], as could spending long hours together at home.[163]

A new theme reported by participants in the current project was that the stroke could also bring about *positive* changes in their marriage. A subset of participants described how coming so close to death could make them appreciate their relationship and their time together more. This could be seen as a form of 'sense-making' or 'benefit-finding' which has been described in the bereavement literature as associated with positive psychological adjustment[117].

In terms of the support provided by the spouse, this project again replicated previous studies that found that the spouse was the main provider of all support functions, including tangible, emotional and companionship support [104, 111, 164, 165]. This study strengthens these findings through providing evidence from mixed methods (for example, correlation; regression; qualitative analysis).

Participants described how it was easier to receive support from a spouse than any other network member, in part because support was what was

expected. As suggested by Wenger (1994)[75] 'total support' is the normative expectation from a spouse. Indeed, the spouse was the *only* source of personal care in the informal social network in this project. Thus where a person had no spouse (or a disabled spouse) they relied on formal services. Helping with therapy regimes, or reminders to take medicine, was another form of support only provided by a spouse in this project. Many also chose only to confide in their spouse about worries or concerns, particularly men.

Although conflict and tensions were certainly present in the current project, participants did not report that their spouse was overly controlling or taking over, which was a theme in other qualitative studies[5, 104, 165]. Although participants did speak of their irritation of others 'overdoing' their help or 'fussing', in this project this generally applied not to their spouse, but to other relatives (for example, sister, sister-in-law; grandchild). Norris *et al.* (1990)[192] also found that the most likely source of negative interactions (for example, unwanted advice or unwanted tangible support) was in fact siblings. For some of the interviews the spouse was present which may have inhibited participants from criticising their relationship.

10.2.2 Children

Like previous studies[2, 173], contact with children remained relatively stable following a stroke (70% saw their children at least once a week both before and after). Nonetheless, beneath this apparent stability, the qualitative data suggested that a proportion of participants felt less close to their children post stroke, while another subset felt closer. The normative expectation of a child is that in times of need, a child will be in contact, and be supportive[75,

[303, 304]. In fact, what was most wanted in this project was concern. Those who reported feeling their child was concerned expressed how 'lucky' or 'blessed' they felt. Where this failed to materialise, it could be a source of great distress, and cause the parent-child relationship to deteriorate. What differentiated these two patterns appeared to be primarily the quality of the relationship prior to the stroke. Other studies have also found that how adult children support their elderly parents can be predicted by patterns set up earlier in life: those who have invested more in their children have been found to receive more help[305]; those with a more reciprocal relationship tend to receive more[306]; and early family environment has been found to affect frequency of contact[304].

In terms of factors which limit frequency of contact, this project replicated the findings from the general population[303, 304]. Face to face contact could be limited by poor quality relationships (as discussed above), by children having other time consuming demands (small children, work), having health issues themselves, or living far away. In fact, Belanger *et al.* (1988)[180] found that proximity accounted for 28% of the variance in frequency of contact with children post stroke. Nonetheless, where the *quality* of the relationship was high, and the child maintained contact in other ways (for example, frequent phone calls), participants could still feel close and perceive themselves to be supported. This supported the finding in the meta-analysis conducted by Pinquart and Sorensen (2000)[59] that it is quality of contact with children rather than quantity which is most strongly associated with subjective well-being[59]. Hospital visits and concern at the time of the stroke were particularly appreciated, conforming to the normative expectation of 'emergency help', described by Wenger, 1994[75].

A major theme that emerged was the distress caused by shifts in the parent-child roles: this has also been described in the stroke literature[6, 104]. Participants described enormous efforts to continue in the role of 'parent' however exhausting. It has been suggested that one of the things that an older person most fears is becoming a burden to their children[307]. In fact, there is some evidence that receiving tangible support from a child is associated with depression and that this is true even when measures of need (for example, health status) are controlled for[308]. In this project, it was common for participants to express conflicted feelings about receiving support from a child: they did not wish to be a burden or for their child to feel obligated. In fact, as discussed above, no participant relied on a child for provision of personal care. This contrasts with findings from countries with less well-developed formal care, where grown up children, particularly daughters, are more likely to provide intensive support[303, 309].

Nonetheless, participants preferred to ask their child to help with tangible support needs rather than relatives or friends (for example, giving a lift to the hospital, help negotiating benefit forms). Unlike other network members, many children could be relied upon to give help in an on-going way (for example, help with the weekly shop). This conforms to the general literature that suggests that where a spouse cannot help, elderly people turn first to their children before other network members[309], and can expect regular help[75]. Children also appeared to be a major source of social companionship for participants: as they were younger and fitter than a spouse, they were often better placed to take their parents out.

10.2.3 Relatives

The stroke literature has painted a confused picture in terms of contact with relatives. Contact with relatives was analysed with friends in 2/3 studies, and found to reduce[2, 8]. However, since relatives and friends are thought to take on different roles in the network, it is unsatisfactory to analyse them together[75]. Hilari and Northcott (2006)[173] was the only study to analyse contact with relatives separately. Of the 83 participants with chronic aphasia, 42% reported they saw their relatives with the same frequency as before their stroke; 24% saw them less; 33% saw them more. In the present study, there was no significant change in contact with relatives overall. However, the qualitative evidence suggests that there were indeed three separate trends, as suggested by Hilari and Northcott[173]. Firstly, the stroke could be a catalyst for bringing relatives closer together. Parr *et al.* (1997) also documented how the stroke could cause relatives to 'rally round', and even be the catalyst for the ending of long-standing feuds.

A second pattern was where the stroke caused contact to become less frequent, which has been little explored in the literature. There appeared to be two main reasons: the relatives' poor health, and aphasia. Aphasia could make remote contact particularly challenging: several spoke of their difficulty making long-distance phone calls, or attempting to write. Since contact with relatives is more likely to be via telephone or letter than face to face (see Chapter Seven), aphasia could make it harder to have satisfying long-distance relationships.

Finally, the third pattern was of stability: participants described seeing their relatives with the same frequency as before the stroke. This included both

those who lived close by and saw each other frequently; and also those who were estranged and never, or hardly ever, were in contact. Unlike with children, such estrangement was rarely a cause of distress.

In terms of the support provided by relatives, this was in line with the 'normative expectations' suggested by Wenger[75]: relatives primarily provided emotional and companionship support. Tangible support was either not part of the relationship, or provided on a limited basis only. In this study informational 'support' from relatives was rarely sought or valued, and was more likely to be considered a source of irritation and tolerated only in so far as it stemmed from concern. The potential for advice to be perceived negatively is highlighted by the Norris *et al.* (1990)[192] study, who found that unwanted advice was the most frequent negative interaction post stroke. The qualitative analysis potentially calls into question the meaning and usefulness of the quantitative finding that the Relatives factor was associated with Informational support ($r = .30$, $p < .05$).

A further finding is that the Relatives factor was not associated with functional support prior to the stroke, but that this changes post stroke. It may be that even where contact remained stable, the significance of this contact changed post stroke: as people lost touch with friends and acquaintances, relationships with relatives could become more important. Parr *et al.* (1997)[104] also note that relatives could take the place of lost friends.

10.3 The impact of stroke on friendships and the wider network

RQ8&11: What happens to friendships following a stroke? What functional support do friends and the wider network provide?

This project adds to the accumulating evidence that people are likely to lose contact with friends following a stroke[3, 5, 8, 104, 143, 170]. In the current project this trend was found in both the quantitative and qualitative data sets.

One area identified as a gap in the literature review was a thorough analysis of what factors help to *protect* pre-stroke friendships. The current project suggested that there were several factors. The quality of the friendship prior to the stroke was perhaps the single most important factor, also identified by Dalemans *et al.* (2008)[5]. Proximity was another protective factor replicating Belanger *et al.* (1988)[180]. Where a friendship was based around an activity it would be more likely to be lost: post stroke people typically take part in fewer social activities[3, 4]. Thus friendships based around meeting up in each other's homes prior to the stroke would be more likely to be maintained. Friends of the family were less likely to be lost, as family members would take on the organising role: other projects have also found that the spouse in particular could facilitate social contact[5, 163]. Further, supportive regular groups, such as the British Legion or going to church, could help to facilitate continued contact, as could the availability of the friend. Another factor, not identified in the previous literature, relates to the network 'type' a person belonged to prior to the stroke. Those who had a 'friends-based'

social network prior to the stroke would be more likely to maintain at least their most important friends post stroke.

The qualitative literature provides rich analysis as to the causes of reduced participation post stroke, as described in Chapter Two. This project sought to explore the reasons for loss of friendship, specifically. As may be anticipated, many of the reported reasons for friendship loss replicated previously reported barriers to participation (poor mobility and other physical disability[5, 6, 143], loss of activities[5, 6, 104], aphasia[5, 104, 143], unhelpful responses of others[5, 167, 168], environmental barriers[6, 167]). Thus the causes of friendship loss were multifaceted. As also found by Labi *et al.* (1980)[4], not all of those who made a 'good' physical recovery resumed social activities .

One theme to emerge not previously discussed was that of fatigue, which impacted on participants' desire and ability to socialise both in and out of the house, and could make participants less inclined to initiate social activity. Since friendships tend to rely on reciprocity[273], this could undermine the continuance of contact. A systematic review found that the prevalence of post-stroke fatigue is between 23% to 75%, depending on how fatigue is defined[310]. A recent qualitative study interviewing people up to two years post stroke concluded that post-stroke fatigue was 'a significant problem in the stroke survivors' struggle to regain a new normalcy.'[311]

There was in fact much variation in how many friends people lost: not everyone lost friends. However, the subset who experienced the most extensive loss of friends were those who described a sense that they were

‘closing in’ on themselves, leading to a withdrawal from social contact. The finding that some of the barriers to social contact were internal has also been found in other studies[5, 6, 104, 163]. It is of interest, however, that the only other study to explore friendship specifically did not replicate this finding (Brown *et al.*, 2013)[143]. This may reflect the timing of the two projects: the participants in Brown *et al.*’s study were on average over six years post stroke. It may also reflect the differing research questions: Brown *et al.* focused on what constitutes ‘successful living’; the current project sought to explore the lived experience. Finally, it may also reflect the different recruitment strategies. The Brown *et al.* project recruited through stroke and aphasia groups, and the university aphasia research community. It is possible that more withdrawn and socially avoidant stroke survivors would be unlikely to attend such groups.

Support received from friends

In terms of the support received, the literature suggests that friends have an important role[273]. They typically belong to the same age group, and thus often have shared history and life perspectives which may bolster a sense of identity. Further, friends, unlike family, are chosen, and as such friendships tend to be reciprocal and based on shared values, interests and activities[312], which in turn has been said to be a boost to self-esteem[313]. Indeed, in the general elderly population, contact with friends is associated with higher subjective well-being[59] and longevity[314]. For the elderly person, it has been found that friends are an important source of emotional and companionship support[75]. Prior to the stroke the Friends factor was modestly associated

with Social companionship support. Post stroke, however, it was not correlated with any support function.

This may reflect that after a stroke in fact it is family who are the primary providers of support. Several participants described the relative importance of family compared to friends post stroke. Further, given the trend for people to lose contact with friends following a stroke, it may follow that they increasingly rely on family for emotional and companionship support. However, this result would seem to mask that for a subset of participants, in particular, those belonging to a 'friends-based' social network, friends were their *main* source of functional support, even after the stroke. Further, participants did describe a range of support functions that they received from friends, and found valuable, even if overall contact with friends was reduced.

One support function commonly described was companionship. Both those who lived alone and those who lived with family described the value of chatting, joking, *'having a right old chinwag'* with a friend. Davidson *et al.* (2008)[162] observed that 'chit-chat and gossip… joking, humorous interchanges and light-hearted conversations' were a key function of everyday communication with friends for older people, and could serve the function of 'relationship building and social affiliation.' (p334) Brown *et al.* (2013) also observed the value of 'laughter and engaging in positive interactions with friends.'(p170)

Affectionate support, in the sense of feeling others were concerned, was universally valued from friends. However, not everyone wished to confide in a friend. Further, few described any value in Informational support from a friend.

Wenger (1994)[75] suggests friends are unlikely to provide on-going tangible support. This was also found in the current project: tangible support tended to be small scale (for example, taking the top off the bleach). Participants described a reluctance to accept Tangible support particularly where they were unlikely to be able to reciprocate. This was as true for those in Friends-based networks as those in other network types. Reciprocity has been argued to be an important dynamic in a friendship[315], which may explain participants' reluctance to feel 'indebted' to a friend.

The value of post stroke groups

Thoits (2011)[53] suggests there is likely to be benefit from meeting 'experientially similar' others, who can validate the normalcy of the person's experiences, and can act as a role model (see Chapter One). The qualitative stroke literature supported this: the value of peer groups post stroke, both for those with and without aphasia was a strong theme in several studies such as Brown *et al.* (2013)[143] and Ch'ng *et al.* (2008)[111], and was a way of making new friends. It was not replicated in the current study, however. While several participants did attend new groups following their stroke, none described the people they met through them as 'friends'. Further, in some cases, participants explicitly described not enjoying them, in part because they felt they had nothing in common with other people

there or did not wish to be in a group, a finding also reported elsewhere[163, 316].

The most likely reasons for the current project not replicating the findings of Brown *et al.* and Ch'ng *et al.* may be two-fold. Firstly, the timing of the current project may not have allowed long enough for the formation of new 'post stroke' friends through going to groups. Secondly, the recruitment strategy may have been a factor. As discussed in Chapter Two, studies that recruited primarily or exclusively through stroke groups presented a more positive picture of the role of groups and their value in adjusting to post stroke life[111, 161, 168].

10.4 Social support and aphasia

RQ3: Are stroke survivors with aphasia different from those without aphasia on measures of social support and social network?

Parr *et al.* (1997)[104] state that 'language is the currency of relationships… aphasia reduces of the influence of one person it what was once a two-way process'. This group then faces particular challenges in maintaining social networks and the result can be isolation and loneliness [104]. This project documented similar trends. However, it was often the case that the themes for those with aphasia were the same as for those without aphasia. Thus both those with and without aphasia described similar shifts in family relationships and reduced contact with friends (see Chapters Six and Seven). Aphasia did not predict levels of perceived support; nor did those with

aphasia perceive their support to be lower than those without (Chapters Four and Five). Further, having aphasia was not a bar to belonging to a diverse or friends-based social network (Chapter Eight).

However, in other respects, aphasia did present particular challenges. Those with aphasia had significantly smaller social networks than those without. Further, it was striking that aphasia was the only stroke-related baseline factor that predicted social networks at six months post stroke. This result underlines the particular difficulty those with aphasia have in maintaining a strong and diverse social network.

The qualitative data provided further insight into the particular difficulties those with aphasia face in maintaining friendships. One theme was that those with aphasia experienced more stigma (for example, people mocking them). This replicates the pattern found in the meta-ethnographic synthesis in Chapter Two: aphasia studies also reported that participants felt stigmatised (for example, people thinking they were crazy, stupid, simple minded[5, 104, 143, 168]). This was much less frequently reported in the stroke studies. The consequence of such hurtful negative interactions was that people could avoid contact with both friends and the wider community, a finding replicated in other studies[5]. The stigma described may relate to the fact that aphasia is poorly understood, or even known about, in the general population. Studies have found that public awareness of aphasia is significantly lower than other neurological conditions with a similar prevalence such as Parkinson's Disease[317]. A recent review of international English-language national and regional newspapers found that Parkinson's

Disease was mentioned 27 times more often than aphasia, and often the references to aphasia were confusing [318].

Another difference lies in the direction of loss: is it the friends who are deserting the stroke survivor, or is it the stroke survivor who no longer wants to see the friend? For those without aphasia it was in fact rarely reported that a friend had 'abandoned' a participant. Rather they described friends who they no longer saw so frequently, or at all, but who they still liked. There was an acceptance that in giving up activities, whether this be an organised group, going to the pub or a party, or just walking to the local corner shop, they would no longer see certain people. People with aphasia, however, did describe feeling rejected or deserted by friends. This was also reported in the aphasia qualitative studies[143]. Feeling abandoned could make the loss of a friendship more hurtful.

Those without aphasia would often stress that the substance of important relationships had not altered, even if many external aspects had been forced to change (for example, meeting a friend for a cup of tea in the participant's house, rather than going for long walks down the river). This was not true for those with aphasia, who often would describe how the substance of the relationship *had* changed, both with friends and family (for example, conversations could be less two way, it could be less easy to discuss what was on their mind). Further, humour could be affected, and those with severe aphasia were less likely to describe the value of 'easy' chit chat, linking to Davidson *et al.* (2008)[162]'s study which found that light-hearted exchanges were less likely to happen or were less successful when a person had aphasia.

10.5 Social network typology post stroke

RQ10: What are the reasons why a person shifts from one social network type to another following a stroke?

The social network typology in the current study classified participants into five network types: diverse, friends-based, family-based, restricted-supported, and restricted-unsupported. These network types broadly match the literature[72, 73, 75, 273]. Where people shifted network, they typically became either family-based or, where no family was available, they became restricted-unsupported. Both these shifts reflect the loss of the wider network, thus the reasons why a person shifts network type largely reflects the causes of friendship loss described in Chapter Six (for example, changing social desires, fatigue, physical disability, aphasia). Of interest was that those who belonged to a friends-based network prior to the stroke were able to maintain their most important friendships post stroke, even where they had aphasia. This may reflect that they had well-developed friendships and fewer family resources to fall back on. A related finding comes from Labi *et al.* (1980)[4] who reported that those who named a friend rather than a spouse as their significant other, and those who lived alone, were less likely to reduce out of house socialising. Again, there is the suggestion that stroke survivors with fewer family resources, and/or better developed friendships are more likely to keep at least some out of house social contact.

The only other network typology study to follow participants longitudinally is Wenger (1994)[75]. She also found that participants tended to shift into the 'private-restricted' or 'family-dependent' network types, commenting that the shifts that she observed were 'predictable and patterned', commonly occurring as a result of increasing frailty and old age. Cross-sectional network studies have also found that older more disabled people are more likely to have family-based or restricted networks[72, 73]. Like the present study, Wenger also observed that loss of close kin network members could cause a person to shift network types: in the present study, participants who belonged to the restricted-supported network type prior to the stroke were vulnerable to becoming restricted-unsupported as they relied on only one close-kin network member for their support needs.

Wenger stresses that 'most network types remain stable'[75] (p26), and only a small percentage shift each year. Her study focused on the general elderly population, whereas the current typology was based on the year post stroke. Thus, unlike Wenger, over one third of the current sample shifted network types. While the sampling was purposive, and prevalence rates need to be interpreted cautiously, still, it is likely that following a stroke network shifts are relatively common. Further, while Wenger explores how increased physical needs can bring about network shifts, the current study suggests that in understanding network shifts it may also be useful to consider the psychological consequences of illness.

10.6 Social support and psychological distress

The link between psychological distress and social support has been a common thread running through this thesis. Thus psychological distress was one of only three significant predictors of perceived social support at six months; feeling anxious, vulnerable and depressed were cited as common reasons for losing contact with friends; and increased strain and role shifts in the family were also associated with distress.

Several authors have commented that the direction of causality is unclear [73, 312 68]. As this project was longitudinal it was possible to explore this area further. In a paper stemming from the larger project this study was part of, predictors and prevalence of psychological distress were explored[137]. It was found that pre-morbid loneliness and satisfaction with one's social network were predictive of psychological distress at six months. Further, loneliness and satisfaction with social network were the only concurrent predictors. This would seem to support the stress buffering hypothesis described earlier: those who felt connected to others at the time of the stroke appeared to have been 'protected' from the negative psychological consequences of having a stroke. It may be that in times of acute stress, as predicted by Cohen and Wills (1985)[45], a person has particular need to have supportive relationships.

The qualitative evidence in this project suggested that in fact often a vicious cycle could be set up: changes in social relationships caused by dependency/lost roles could lower mood, which in turn led to increased

tension in the family unit. Similarly, depressive feelings could make a person disinclined to socialise, and the resulting isolation could in turn lead to feeling more depressed.

A final comment relates to the finding that psychological distress was not associated with social network. However, *satisfaction* with social network was a significant predictor of distress in the larger project[173]. It may be that people vary widely in what they find satisfying in a social network, as suggested by Code *et al.* (2003)[319]. Therefore, it is plausible that it is being dissatisfied with one's network that leads to depression, rather than frequency of contact or size of network per se.

10.7 Theoretical models

10.7.1 Dual Process Model of bereavement (DPM)

Conceptualising support as helping with 'loss-oriented tasks', 'restoration-oriented tasks' and 'time out' may have some value. The support functions found in the qualitative interviews to be particularly valued post stroke could arguably be 'matched' to these tasks. Thus care/concern and acceptance may facilitate loss-oriented tasks, such as expressions of anger and despair. Further, feeling others care about them and accept them may make their losses more bearable through bolstering self-worth. Restoration-oriented tasks could arguably be facilitated by the care and concern of the wider community, as well as social companionship. Further, the value of

joking, laughing, and being distracted were well described, and correspond to the 'time out' of the DPM model.

Bereavement models tend to presume the need to talk through emotions, especially talking about the deceased in order to make sense of what has happened. For the stroke survivor there is the parallel journey of 'being able to adapt and cope with the changed self' (p12), which, as Brumfitt (2010)[320] notes, can be a painful process. Parr (1997)[104] refers to this as the "inside work" in which 'the aphasic person [is] actively making an account of what has happened which makes sense to them …. [is] constructing a new sense of self'. [p136] While undoubtedly helpful to many, it was not clear in the current project that confiding or talking support was valued by all participants. However, it may be that the understanding of others, and the sense that others cared and were concerned, helped to facilitate acceptance of the 'changed self'.

Finally, it is instructive that tangible support was most acceptable when 'responsive'. This links to the meta-ethnographic synthesis of Chapter Two which also found that tangible support that fostered independence was particularly appreciated. It could be argued that responsive tangible support that encourages independence is most likely to facilitate 'restoration'. Tangible support that is '*overdone*' can, as put by one participant, make a person feel '*absolutely worthless*', and may be hypothesised to hinder restoration.

10.7.2 Do any of the theoretical models explain the loss of friends and the wider network?

Both the DPM model and the stress-buffering hypothesis suggest that emotional support is likely to be beneficial when a person is experiencing acute stress (buffering hypothesis) or doing the 'grief work' (DPM). Since emotional support is most likely to be provided by the innermost circle (Chapter Nine) during this early phase family and intimates will be most important. Cohen and Wills (1985)[45] suggest that the wider network is most beneficial when not experiencing acute stress. Certainly, correlational analysis found that functional support was more strongly associated with satisfaction with social network after a stroke. Prior to the stroke, it may be that factors other than provision of functional support were more salient.

The Cohen and Wills model lists the benefits of having a strong social network in 'every day' life: 'provide(s) persons with regular positive experiences and a set of stable, socially rewarded roles in the community… provide(s) positive affect, a sense of predictability and stability in one's life situation, and a recognition of self-worth.' In fact, post stroke some social situations could have the reverse effect. Certainly, in the present study participants described how some social situations such as parties or sporting activities, instead of bolstering their self-esteem and identity as had been the case prior to the stroke, could have the reverse effect, leaving them feeling *'the weaker member of the pack'*. The stroke could make it hard to carry out 'socially rewarded roles'. Norm-referencing, instead of increasing self-worth, could do the reverse (for example, the black belt karate participant, pre-morbidly esteemed for his physical skills, who could no longer walk post stroke). And going into the community, instead of fostering

‘predictability and stability’ could underline how unstable their world had become through highlighting how much they could no longer do.

Social support theory also suggests that reciprocity is a key component of satisfying relationships. Gouldner (1960)[321]’s exchange theory proposes that reciprocity is ‘one of the universal “principle components” of moral codes’, thus on receiving support a person feels duty bound to reciprocate. He proposed that people prefer to be in relationships where there is a balanced exchange of support. In the current project loss of reciprocity was described as painful within the family. Family relationships, however, have the ‘scaffolding of habit’ (Parr, 1997)[104], and at least mostly survived this imbalance. Being unable to reciprocate potentially had a large impact on friendships. Some participants explicitly stated that they preferred not to see a friend than feel indebted. In many other cases it may have been an implicit reason and a cause for gradual erosion of the friendship dynamic (for example, needing to receive visits rather than make them; feeling too tired to initiate contact). It has been argued that some of the benefits of friendship, such as enhanced self-esteem and well-being, may be lost in situations where reciprocity is compromised[315].

Another strand that ran through the data was that many participants expressed changing social preferences. Some participants seemed to have made a positive choice to reduce the number of social activities they took part in. Many expressed less interest in superficial, larger gatherings, and preferred to meet with family and close friends. A new selectivity is also described in Dowswell *et al.*(2000)[6] and Hinckley (2006)[164]: participants preferred to ‘conserve energy’ and only surround themselves with people

who would be supportive. An alternative theoretical framework to describe this might be Carstensen's socioemotional selectivity theory[322].

Socioemotional selectivity theory suggests that when time in life is perceived as unlimited, people tend to prioritise goals that optimise the future, such as seeking out novel social partners who may provide information or expand horizons. However, when time is perceived to be limited social motivations change, and present-oriented goals that relate to emotional meaning are prioritised. Thus older people[323], and those with terminal illness[324] have been shown to prefer contact with immediate family and close friends. Arguably this could be extended to apply to those participants in the present project who described feeling newly vulnerable and aware of their own mortality. According to this theory, selectively reducing social contact in such circumstances is adaptive, and results in greater emotional well-being.

The reasons for friendship loss appeared to be multifactorial, and some spoke of a balancing act, between pushing themselves to engage with others, and recognising new limits, for example, as a result of exhaustion. Nonetheless, although some reduction in social contact could be argued to be adaptive, for many there persisted the link between social withdrawal and depressive symptoms. Further, there is evidence that this association between loss of friends and depression persists into the long-term. Astrom *et al.* (1993)[9] tracked stroke survivors for three years. At three months 31% were classified as depressed, at three years 29% were depressed, thus rates of depression persisted into the long-term. At three years there were only two significant predictors of depression: few social contacts and corticol

atrophy. Only 7% of the depressed participants had met a friend or relative in the previous week, compared with 66% of the non-depressed participants (comparable to pre-morbid levels). King *et al.* (2002)[10] also found that at two years post stroke only social factors predicted depression. Further, qualitative studies have described social withdrawal many years post stroke[5, 104].

In fact, both the DPM model and the Cohen and Wills model suggest that in the longer-term the role of the wider network, including friends, could be hypothesised to take on more importance as the person begins to adjust to their new stroke life (DPM) or experiences life as less acutely stressful (Cohen and Wills). The problem is that many participants appeared to be 'stuck' in a state of social withdrawal. The DPM model might suggest that such individuals are experiencing chronic grief, losing social contacts as a result. Alternatively, having lost the social contacts as possibly an adaptive response to the acute stress of having a stroke, it may become difficult to rebuild and re-engage once more, potentially leading to the vicious cycle of isolation and depression described above.

10.8 Strengths

10.8.1 Inclusion of people with aphasia

As documented in Chapter Two, stroke studies exploring social support have either excluded people with aphasia, relied on proxies, or only inadequately included them (for example, given no information as to how

their responses were facilitated). Further, while some aphasia studies have included healthy controls[3, 162, 174], none have included 'stroke' controls. The sensitive inclusion of people with aphasia in the current project has allowed their experiences to be directly compared with those who do not have aphasia following a stroke.

For Stage One (repeated measures cohort study) only those with severe receptive aphasia were unable to complete the measures used. The questionnaires were administered in interview format and all modalities of communication were used to facilitate both the comprehension and expression of participants. Further, the questionnaires were modified to make them accessible to people with language difficulties, as recommended by Rose *et al.*[325].

For Stage Two (qualitative interviews), even those who had scored <7/15 on the receptive domains of the FAST at baseline, but had remained involved with the project through their proxies, were potentially eligible to take part. Indeed, three of the ten people with aphasia in the qualitative project were recruited from the 'proxy' stream of the larger project. Further, people with aphasia were preferentially included in the qualitative sample to facilitate comparison of their experiences: roughly one third of the sample had aphasia.

Still, a limitation of the project was the small number (n = 11) of people with aphasia at six months in Stage One of the project. Further, the proxy responses of those with severe receptive aphasia in Stage One were not analysed in the current thesis. This may mean that this thesis has underestimated the negative impact of aphasia on social network. Yet

despite having a relatively small sample of people with aphasia, and not including those with severe receptive difficulties, aphasia was still a significant predictor of social network.

10.8.2 Study design

In 2003, Code *et al.*[145] called for research which took into account a person's pre-morbid social preferences, and which could also compare patterns in the acute and chronic stages following a stroke. In a similar vein, Cruice *et al.* (2006)[3] urged for longitudinal study designs to track the social changes that occur post stroke, including a qualitative component 'to study the breakdown of relationships, particularly those between people with aphasia and their friends' (p1222). They also called for research that assessed both quality as well as quantity of social contact; predictors of support; and the 'aphasic person's perception of support'.

The current project addresses all these concerns. The longitudinal design allowed study of the change that took place over the first year following a stroke. It also made it possible to consider which measures administered around the time of the stroke would be predictive of social support/network six months later. The choice of measures was careful, using those that had good psychometric properties, and would be appropriate to the population. As recommended by Counsell and Dennis (2001)[149], stroke severity and age were both included as potential predictors. The regression models were able to explain a reasonable proportion of the variance (between 37% and 60%). The timing of the qualitative interview (around one year) allowed further exploration of people's perceptions about social support in the chronic stage.

The design also included measurement of people's pre-morbid social support systems, assessed two weeks post stroke. A potential limitation is that this assessment of pre-morbid social support may have been coloured by the participants' early hospital experiences. Perhaps the only realistic alternative way of capturing pre-morbid social data is via a population-based sample, as carried out by Colantonio *et al.* (1993)[15] and Wilcox *et al.* (1994)[326]. There are limitations in this method as well, however: the social support data in these two studies was collected up to three years (Wilcox)/ six years (Colantonio *et al.*) prior to the stroke. Furthermore, the items used were generally restrictive (for example, measuring perceived social support through single items rather than validated scales). Through interviewing shortly after the stroke, detailed and rich data was collected about pre-morbid social network and support. As anticipated by Code *et al.*[145], understanding a person's pre-morbid social network and support helped to make sense of how they responded post stroke.

The mixed methodology was another strength of the study design. The qualitative interview could provide insight into trends found in the quantitative data (for example, the apparent stability of family); and explore why phenomena were occurring (for example, why people were losing contact with friends); and also provide a form of triangulation which arguably strengthened the validity of results, for example, use of cluster analysis to identify a similar sectoring of the population as developed in the qualitative social network typology.

A limitation was that the qualitative and quantitative data was not collected at the same time point. Had the quantitative data been collected at one year,

it would have been easier to tease apart whether diverging results were as a consequence of methodology or timing.

On a related point, it was anticipated that during the qualitative interview it would be possible to probe social support experiences and needs over the preceding year, including discussion of how they evolved. In fact, although most participants could remember the stroke incident and hospital experience in clear detail, the chronology of subtly changing need over the subsequent twelve months was often difficult to recall. To capture this, longitudinal qualitative data may have been illuminating.

Nonetheless, given the resource constraints, a rich, diverse data set was collected which could be employed to answer the research questions.

10.8.3 Sample

In terms of the sample for Stage One, the participants' characteristics were similar to the stroke population of the United Kingdom. The majority were male (60%), and over 65 years old (76%)[20]. Further, including those with aphasia reduced the chance of positively biased results. Nonetheless, there were limitations to the sample, which are discussed below (see Chapter 10.9.1).

The robust sampling procedure for the qualitative interviews ensured that a diversity of experience was captured. In particular, it was helpful to have a pool of potential participants about whom considerable information was already known, in order that sampling criteria could be relatively complex

(for example, many versus few friends; living alone versus living with family; high perceived support versus low perceived support).

A potential source of bias is low participation rates. In the present study, 76% agreed to take part in Stage One of the study. While there is no agreed minimum acceptable level for response rates, Singleton and Straits (1999)[153] suggest that interview surveys should achieve at least a 70% response rate. Thus the response rate for the present study is above this level. The proportion of participants who were followed up was 87% (three months) and 82% (six months). This compares favourably to many other stroke studies exploring social support. From Table 2.2, Chapter Two, it can be seen that for studies following to three months, the average follow up rate was 78.7%[11, 14, 15]; and for studies following up to six months, the average follow up rate was 81%[17, 182, 183, 207]. The reasonable response rate in the present project was facilitated through the researcher being flexible about both timing and location of follow up interviews; taking time to establish a rapport with interviewees and engage in their concerns, for example, through putting them in touch with external agencies as described in Chapter Three; and through ensuring participants felt appreciated for their time, for example, through sending Christmas cards thanking participants for their contribution to the project.

The participation rate was even higher for Stage Two: 29 (91%) agreed to take part; two (6%) were no longer contactable; and one person (3%) declined due to severe housing and financial difficulties. After discussion with the researcher (and provision of contact details for the Citizen's Advice

Bureau), it was not felt appropriate that an in-depth interview should take place.

10.8.4 Trustworthiness of results

When conducting multiple regression analyses, a number of measures were undertaken to ensure the trustworthiness of results. There was a rigorous process of testing regression assumptions to ensure that the models generated were valid. Initially univariate analyses were undertaken to identify significant variables. The ratio of cases to IVs was good for all four regression models. Multicollinearity was avoided, such that the predictor equation could be considered stable. The normality, linearity, homoscedasticity and independence of residuals meant that the model was both accurate and could be expected to generalise to the population under study. Finally, the choice of standard multiple regression was justified on the basis of the current knowledge about predictors of social support post stroke[154, 256].

With qualitative research, it is preferable if more than one analyst is involved in all stages of analysis, in order to minimise potential bias[159]. In the present project the analysis, although discussed with a senior researcher, was conducted by the present author only. Further, due to timescale practicalities, in the end respondent validation was not feasible. Still, measures were taken to improve the trustworthiness of findings. Firstly, a clear audit trail was maintained through all stages in the research process. Further, a reflective journal was kept, where the researcher considered her own biases. This journal was also used to record reflections after each interview and may have helped the researcher to maintain a naive approach

when probing interviewees (for example, taking care not to pre-judge how a person would feel on losing contact with a friend). Finally, the validity of the results was arguably strengthened through triangulation of methods.

10.9 Limitations

10.9.1 Choice of measures/ areas not covered

One limitation relates to the MOS Social Support Survey. The scale presupposes that people need/want the different support functions. ('If you needed companionship or assistance, how often would it be available to you?' Responses range from none of the time to all of the time). In fact, participants would sometimes say that they found it difficult to answer the question as they couldn't think of a time they would want/need the item in question. This particularly related to informational support ('I wouldn't ask anyone for advice…'). To a lesser extent it applied to the emotional support domain ('I wouldn't tell anyone my worries…') and to the affectionate support domain, specifically the item on being hugged. While participants were gently asked to consider a hypothetical situation when they might want such support, the validity of such responses is doubtful. Indeed, the outlier reported in Chapter Five for RQ4 arose through this issue. The participant in question valued his independence and stated that while close to others he did not 'need' any support. He therefore answered 'none of the time' for most items. As a result the regression model predicted he would feel better supported than suggested by the answers he actually gave. Nonetheless, the MOS SSS is a measure that is relatively brief, has sound psychometric properties, and has been validated on those with chronic illnesses. Further,

unlike many other social support scales, it includes a domain on Social Companionship, which they hypothesised to be of importance in the chronically ill population, and was found to be a valued support function in the qualitative analysis of the present project.

Other factors that were not assessed may also have played a role in predicting social support and social network. One such factor is cognition. Exploring a related concept, social dysfunction, Hommel *et al.* (2009)[297] found that cognition, particularly working memory, was a significant predictor. Glymour *et al.* (2008)[182] also found that (received) social support, particularly emotional support, could facilitate cognitive recovery.

The concepts of self-esteem, self-efficacy and personality traits such as extraversion/introversion have been found to be associated with social support[53, 117, 175, 327]: none of these were assessed in the current project. It is likely that had these concepts been included, a more finely-tuned understanding of social support may have been possible. Still, in choosing measures an aim was to keep respondent burden to a minimum, given that this population was vulnerable and often fatigued.

An area not explored in Stage One of the project was negative social interactions. Yet studies that have assessed negative social interactions have found that they explain more of the variance in personal adjustment (in the stroke population)[192] and depression (in the general population)[82] than positive support.

Another area not explored was social media. Holt-Lunstad & Smith (2012)[66] suggest that there is as yet little research comparing the benefits of online

social networks to face-to-face interaction. In this project, no participant mentioned online social contacts when asked about their social network in the qualitative interview. Indeed, it was rare even for participants to refer to email. This may suggest that for this particular cohort social media was not the most meaningful aspect of social interaction. Still, this may well be different for future cohorts.

10.9.2 Sample limitations

The results from this thesis can only generalise to those who have been admitted to a stroke unit, thus representing a more biased sample than had the recruitment been population-based[149]. Still, it is increasingly the case in England that people are admitted to stroke units[30].

Further, the exclusion criteria meant that various groups were not included in the project. In particular, those with second stroke, and those living in nursing homes prior to the stroke were excluded. It is likely that these participants would be older, have more pre-existing disabilities and be more socially isolated: lack of support is associated with admission to a nursing home[328, 329]. A further group who were excluded were those with a history of depression, who might be anticipated to have more mental health problems and so social support difficulties post stroke. Finally, as discussed above, the proxy responses of those with severe aphasia were not analysed in this thesis. Thus the current findings may present an overly optimistic view of social support post stroke.

In the qualitative project, there were only two participants under the age of 50, limiting the extent to which conclusions can be drawn about the younger stroke population. Further, only one participant in a nursing home took part in the qualitative interviews. She experienced extreme loss of social network. Nonetheless, it was not possible to compare systematically the experiences of those living in nursing homes with those living in the community. Finally, there was no participant in the qualitative project who had young children, thus all findings relate to contact with grown up children.

10.10 Clinical implications

One of the findings from this thesis was that psychological distress at six months post stroke predicted perceived social support. Further, the larger project also reported that perceived social support was predictive of psychological distress at three months, and low satisfaction with one's social network was predictive of psychological distress at six months [137].

To date, there has been more focus on increasing social support in order to improve psychological outcomes than vice versa. A recent systematic review examined the impact of social support interventions on depression/mood post stroke[330]. They included ten randomised controlled trials in their review, the majority of which were home-based support and care co-ordination (7/10) provided by nurses, social workers or other outreach workers. The results were disappointing: only one trial reported significant results (Claiborne, 2006)[331], which may have related to

additional provision of counselling (the only trial to provide more than two sessions of counselling, if needed).

So why were the schemes so unsuccessful, given the close link between social support and depression? It may in part lie in the mechanisms through which a person perceives themselves to be supported. As described in this thesis, perceived social support appears to be provided primarily through the innermost circle, particularly the spouse and to a lesser extent children. As such, it may be more successful to work with the existing social network. In reviewing the mixed social intervention literature in the general population, Holt-Lunstaad & Smith (2012)[66] similarly concluded that 'facilitating patient use of naturally occurring social relations may be more successful than provision of social support through personnel hired for that purpose.'

One such trial that explicitly sought to change the functioning of participants' natural social networks post stroke was Friedland and McColl (1992)[332]. Stroke survivors and their families were invited to attend between six to 12 sessions. These sessions were described as psycho-educational: participants learnt about the value of social support and networks; worked to improve their social support and establish new supports. Again, there was no difference between the intervention group and control group on either quality or quantity of social support, or on the measure of depression.

As pointed out by Wenger (1994)[75] a person's social network represents a 'life-long adaptation': she suggests that it is difficult to supplement or change the dynamics of a network, and almost impossible to create one. Perceived social support, this thesis would suggest, is also a relatively stable

construct for most, possibly based on a life-time of interpersonal relationships. As such, it may not be easy to alter a person's perception of feeling supported. This may in part explain Friedland and McColl's negative results.

An alternative, more promising, approach may be to support the supporters. As suggested above, the spouse appears to be the most important source of all types of support. Yet the marital relationship is also reported to be under strain. In fact, the evidence from couple-oriented interventions in chronic illness is promising. In a recent meta-analysis[333], couple interventions had significant effects on both patient mood, and also marital functioning. Perceived social support was not assessed. The majority of interventions included in the review were a combination of education of the patient and partner about the chronic illness, how to manage the illness, and improving communication or support within the couple. The studies focused on cancer, arthritis, HIV, chronic pain, diabetes and cardiovascular disease: none recruited stroke survivors. In terms of the stroke population, Evans *et al.* (1998)[334] showed that education combined with counselling for the care giver resulted in improved family functioning and resulted in better patient adjustment (as rated by care giver) than education alone or normal treatment.

Another area of concern highlighted by the current research was the disintegration of the wider network that commonly took place post stroke. One reason for reduced contact with friends was the loss of shared activities. There is mixed evidence for intervention targeting leisure pursuits: Jongbloed and Morgan (1991)[335] found no significant difference, when

leisure visits took place at home shortly after discharge; Drummond and Walker (1995)[336] reported significantly improved leisure participation for an intervention delivered in the chronic phase post stroke. An alternative/complementary approach, as suggested by the National Stroke Strategy[1], is to make work, education and leisure pursuits more accessible. Physical barriers such as difficulty using public transport, inaccessible toilets, lack of seating, and steps were identified by participants as reasons for losing touch with friends and giving up social activities. Making public spaces more 'stroke-friendly' may facilitate taking up new leisure pursuits, or resuming previous social activities, which in turn is likely reduce isolation. However, given the vulnerability and anxiety expressed by many participants, it is possible that such new activities would only become truly accessible if people were given psychological as well as practical support in accessing them.

While dismantling barriers in the physical environment is clearly welcome, the barriers to maintaining friendships in the current project were as likely to be internal as external. Given the close relationship between depression and social isolation, possibly leading to a 'vicious cycle' of withdrawal, interventions targeting this cycle may be effective. Some social approaches to therapy, particularly in the chronic phase, have been shown to be effective, in particular, for those with aphasia. Attending group-based therapy in a community-based aphasia therapy centre (Connect) was shown to improve quality of life for those with chronic aphasia[316]. At the centre, participants could choose from a 'menu' of services and activities, including discussion groups, self-advocacy, and counselling. The service was also evaluated qualitatively. Participants reported 'an increased desired to

participate' including going out more, talking to strangers in shops, and 'wanting more social contact with friends and family'. There was 'a desire to engage more in everyday social encounters'. Thus it seems that the holistic environment of Connect succeeded in enabling participants to move from social withdrawal to a desire to re-engage once more. Vickers (2010)[8] also found that those who attended groups perceived themselves to be significantly less isolated and more connected, and participated in more social activities.

Still, it was reported that a subset of participants at Connect reported no change in their quality of life. What differentiated these participants was that they 'did not like having therapy in a group, and did not feel comfortable being with other people with aphasia.'[316] Thus group therapy is not a panacea for everyone post stroke. For many participants in the current project, it appeared unlikely that they would attend groups. Some simply did not appear to like going to groups. Others were too socially withdrawn, or physically unable to travel to a group.

For those too withdrawn, depressed or anxious to attend groups, or for those whose grief has become 'blocked or distorted'[107], an appropriate intervention aimed at 'unblocking' grief might be psychotherapy, as discussed by Brumfitt (1995)[337]. White and Johnstone (2000)[121] make the case that rehabilitation counselling can help a person with emotional adjustment and grieving. Without such help, they argue that many 'are unable to incorporate "their" stroke disability into "their" future lives', in turn impacting on social engagement. They make the argument that rehabilitation counselling is often included in coronary care, oncology and

pain clinics, and call for its routine use for stroke care. Given the prevalence of depression post stroke in the current sample, and the anecdotal reported difficulty accessing psychological support reported by participants, it seems likely that there was indeed a need for more psychological support.

There is some evidence for the benefits of psychotherapeutic intervention post stroke. A systematic review[338] concluded that 'a significant improvement in mood and the prevention of depression was evident for psychotherapy' although the treatment effects were small. Most of the studies used problem focused or cognitive behavioural approaches. For those with aphasia, Thomas *et al.* (2012)[339] carried out behaviour therapy as a treatment for low mood in an RCT, and also reported significant results. These studies did not seek to modify social support or social networks. As such, there is a lack of available evidence as to whether becoming less depressed through such interventions facilitates a person in re-engaging socially.

For those unable or unwilling to leave their home, an alternative approach may be befriending. Lyon *et al.* (1997)[340] have pioneered the concept of communication partners, producing research showing statistically significant gains in the aphasic adult's well-being and communication. Possibly, the volunteer communication partner acts to artificially inflate a person's network, crucially adding a 'friend' with whom the person with aphasia can engage in social activities, and feel connected into the wider community. Peer befriending is recommended in National Stroke Strategy[1], and has been increasingly adopted by a number of localities in the last few

months (for example, in Gloucestershire and Sussex), although it has yet to be formally evaluated.

Finally, another way of changing the social experience of stroke survivors might be in increasing public awareness and shifting public attitudes. As mentioned above, public awareness of aphasia in particular appears to be low. Elman (2000)[341] suggests limited public awareness results in less empathy and understanding for re-integrating into the community, or, as Cruice and Bunning term it (2004)[342], difficulty gaining 'psychological' access. In order to increase public awareness, Elman suggests finding eloquent spokespersons, and using publicity and the media more shrewdly. She also discusses the role of judicial action in which far-reaching precedents can be set. Others have suggested targeting training and resources to community members (for example, doctors, lawyers)[343].

To turn to the macro level, there are societal issues about how to encourage strong social networks and social relationships since it is the social support patterns established *prior* to the stroke that predict subsequent depression. Holt-Lunstaad & Smith (2012)[66] suggest there should be public health campaigns about the health-giving benefits of social networks to encourage people to invest more in their social relationships, although there exists no evidence that social networks would be amenable to such intervention. They also suggest that public policies should be scrutinised for their effect on social support and networks. It may indeed be the case that were the social consequences of government policies made a priority, then reforms which resulted in people being forced or incentivised to relocate away from their existing social networks and extended family might be reconsidered.

In the health service, a way of leveraging change may be via patient reported outcome measures (PROMs) and patient reported experience measures (PREMs). Their purpose is to 'drive the changes in how healthcare is organised and delivered'[344]. Were PREMs to establish patient satisfaction was closely linked, for example, with rehabilitation counselling post stroke, this may provide justification for more widespread adoption of such a service.

10.11 Future research

One future area of research would be to develop a screening tool that could be used in the acute stroke period to predict who is at risk of social isolation in the longer term post stroke: currently no such tool exists. Indeed, although best practice is that every patient should be screened for depression using a valid screening test, such as the GHQ-12[345], the routine screening of social support using a validated scale is not part of current guidelines[1, 345]. Yet, research from the current project suggests that social support factors measured two weeks post stroke can be predictive not only of who will have poor social support six months post stroke, but also, who will experience psychological distress[137]. Psychological distress, by contrast, did not predict perceived social support or social network at six months.

At present, although there are many social support measures, none have been developed for this purpose. Thus there is no scale measuring satisfaction with social relationships that has been developed with stroke survivors (for example, through in-depth interviews or focus groups), piloted with stroke survivors, and then validated on a stroke population

including those with aphasia. Such a measure could explore components shown to be of value when recovering from a stroke (feeling others care and are concerned; acceptance; social companionship; 'responsive' tangible support). In order to target resources effectively at those most at risk of adverse psychosocial outcomes, a brief screening tool with good face validity and psychometric properties, validated both for those with and without aphasia, could be useful.

Another future direction is evaluating psychotherapeutic interventions in terms of social gains. There is little evidence in the stroke literature. However, a large RCT reported good results post myocardial infarction (the ENRICHD trial)[346]. Those with low levels of perceived social support received a form of cognitive behavioural therapy tailored to social support needs. The aim was to strengthen social network ties so they became 'more functional, supportive and satisfying.' Those in the intervention group had significantly higher levels of perceived social support than those in the control group. It was not reported whether levels of depression also reduced for these patients. Establishing whether a similar programme could work with stroke survivors might be useful.

Another approach which could potentially address both social and psychological needs simultaneously, is solution-focused brief therapy (SFBT)[14]. SFBT focuses on building up a picture of a preferred future, or the 'solution', and then exploring current resources in order to achieve that solution[15]. A recent systematic review of the effectiveness of SFBT reviewed 43 controlled outcome studies and found that 74% reported significant positive results, while 23% reported positive trends[16]. The

strongest evidence of its effectiveness was in treating adults with depression, where it was comparable yet briefer and therefore less costly than alternative approaches. Although its use has been described with those with aphasia[347], it has not yet been systematically evaluated in an intervention trial for this population.

For those more profoundly depressed, an intervention programme has been developed around the Dual Process Model of bereavement, and found to be an effective way for helping people coping with bereavement who are perceived to have 'complicated grief'[348]. It may be that principles from this therapy programme could be applied to those most 'stuck' following a stroke, to help them with both the 'grief work' and the 'restoration work'.

Another intriguing avenue is the concept of 'friendship enrichment programmes'[349]: a series of group lessons which aimed to 'empower' participants through improving existing friendships or developing new ones. These have been trialled with elderly women in the Netherlands, and have been found to improve the quality and quantity of the women's friendships. The intervention also showed a modest althought significant reduction in loneliness.

In terms of future observational studies, further investigation could explore friendship change and loss from the perspective of the friend. It could also be investigated whether the network 'type' a person belongs to is an influencing factor in how they respond to intervention, as has been suggested by Wenger (1994)[75]. Furthermore, following participants over a longer timespan may help to identify whether those who shifted into family-

based or restricted network types following the stroke were able to reverse the shift over time, and, for example, regain their former diverse networks.

10.12 Conclusion

This thesis has provided rich data describing what happens to a person's social support system following a stroke. The main findings were that perceived social support remained relatively stable post stroke, while a person's social network was likely to shrink. In particular, participants were likely to lose contact with friends and acquaintances. Aphasia appeared to exacerbate this situation: aphasia was the only stroke-related baseline measure that predicted social networks at six months. Thus aphasia, rather than stroke severity or psychological distress, made it difficult for a person to maintain a strong social network in the months following the stroke.

The close relationship between psychological distress and social support was evident throughout this thesis. The literature review documented how closely intertwined the two concepts were. Psychological distress was a significant predictor of perceived social support at six months. Distress was associated with shifts within the family unit. Further, feeling withdrawn and inward looking was cited as a reason for losing contact with friends. The thesis discussed possible therapeutic options for breaking this potentially vicious cycle.

If the ultimate aim of rehabilitation is quality of life[1], then attention needs to be paid to the considerable social costs of having a stroke. Those in health

care settings and social services are most likely to be in the front line as a person comes to terms with this life changing event. They are therefore likely to be well-placed to guide and support the family and stroke survivor through the early stages. In the longer term health, social care, voluntary services, and indeed the wider society all have a role in encouraging both physical and psychological access to social engagement. And for those stuck in a vicious cycle of despair and isolation, appropriate support should be given to enable them to re-engage. Finally, researchers have a role in establishing the most effective way to lessen the negative social and psychological consequences of having a stroke.

To quote Baumeister and Leary (1995)[103], 'the need to belong is a fundamental human motivation', a need which they observe is at its strongest in times of illness, vulnerability and distress. Following a stroke this thesis suggests a person does indeed need the buffer of people who are concerned, who can make them feel that they are not alone. To quote a participant from the project:

'That's the main thing, the best thing, knowing that they're there... I'm not on my own.'

References

1. Department of Health. National Stroke Strategy. Accessed in, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081062. 2007.

2. Astrom M, Adolfsson R, Asplund K and Astrom T. Life before and after stroke. Living conditions and life satisfaction in relation to a general elderly population. *Cerebrovasc Dis*. 1992; 2: 28-34.

3. Cruice M, Worrall L and Hickson L. Quantifying aphasic people's social lives in the context of non-aphasic peers. *Aphasiology*. 2006; 17: 333-53.

4. Labi ML, Phillips TF and Greshman GE. Psychosocial disability in physically restored long-term stroke survivors. *Archives of physical medicine and rehabilitation*. 1980; 61: 561-5.

5. Dalemans RJ, de Witte L, Wade D and van den Heuvel W. Social participation through the eyes of people with aphasia. *International journal of language & communication disorders / Royal College of Speech & Language Therapists*. 2010; 45: 537-50.

6. Dowswell G, Lawler J, Dowswell T, Young J, Forster A and Hearn J. Investigating recovery from stroke: a qualitative study. *Journal of clinical nursing*. 2000; 9: 507-15.

7. Northcott S and Hilari K. Why do people lose their friends after a stroke? *International journal of language & communication disorders / Royal College of Speech & Language Therapists*. 2011; 46: 524-34.

8. Vickers C. Social networks after the onset of aphasia: the impact of aphasia group attendance. *Aphasiology*. 2010; 24: 902-13.

9. Astrom M, Adolfsson R and Asplund K. Major depression in stroke patients. A 3-year longitudinal study. *Stroke; a journal of cerebral circulation*. 1993; 24: 976-82.

10. King RB, Shade-Zeldow Y, Carlson CE, Feldman JL and Philip M. Adaptation to stroke: a longitudinal study of depressive symptoms, physical health, and coping process. *Topics in stroke rehabilitation*. 2002; 9: 46-66.

11. Townend BS, Whyte S, Desborough T, et al. Longitudinal prevalence and determinants of early mood disorder post-stroke. *Journal of clinical neuroscience : official journal of the Neurosurgical Society of Australasia*. 2007; 14: 429-34.

12. King RB. Quality of life after stroke. *Stroke; a journal of cerebral circulation*. 1996; 27: 1467-72.

13. Perry L and McLaren S. An exploration of nutrition and eating disabilities in relation to quality of life at 6 months post-stroke. *Health & social care in the community*. 2004; 12: 288-97.

14. Mackenzie AE and Chang AM. Predictors of quality of life following stroke. *Disability and rehabilitation*. 2002; 24: 259-65.

15. Colantonio A, Kasl SV, Ostfeld AM and Berkman LF. Psychosocial predictors of stroke outcomes in an elderly population. *Journal of gerontology*. 1993; 48: S261-8.

16. Glass TA, Matchar DB, Belyea M and Feussner JR. Impact of social support on outcome in first stroke. *Stroke; a journal of cerebral circulation*. 1993; 24: 64-70.

17. Tsouna-Hadjis E, Vemmos KN, Zakopoulos N and Stamatelopoulos S. First-stroke recovery process: the role of family social support. *Archives of physical medicine and rehabilitation*. 2000; 81: 881-7.

18. Department of Health. The National Service Framework for Long-term Conditions. London: Department of Health, 2005.

19. Wade DT, Wood VA and Hewer RL. Use of hospital resources by acute stroke patients. *Journal of the Royal College of Physicians of London*. 1985; 19: 48-52.

20. National Audit Office. Reducing brain damage: faster access to better stroke care. London: National Audit Office, 2005.

21. Leal J, Luengo-Fernandez R, Gray A, Petersen S and Rayner M. Economic burden of cardiovascular diseases in the enlarged European Union. *European heart journal*. 2006; 27: 1610-9.

22. Stephen A and Rafferty J. *Health Care Needs Assessment*. Oxford: Radcliffe Medical Press, 1994.

23. Office of National Statistics. Mortality statistics causes, England and Wales, 1997. Office of National Statistics, 1998.

24. Engelter ST, Gostynski M, Papa S, et al. Epidemiology of aphasia attributable to first ischemic stroke: incidence, severity, fluency, etiology, and thrombolysis. *Stroke; a journal of cerebral circulation*. 2006; 37: 1379-84.

25. Wade DT. *Stroke (acute cerebrovascular disease)*. Oxford UK: Radcliffe Medical Press, 1994.

26. Connect. Accessed in, http://www.ukconnect.org/about-aphasia.aspx. 2013.

27. Hackett ML, Yapa C, Parag V and Anderson CS. Frequency of depression after stroke: a systematic review of observational studies. *Stroke; a journal of cerebral circulation*. 2005; 36: 1330-40.

28. Kauhanen ML, Korpelainen JT, Hiltunen P, et al. Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovasc Dis*. 2000; 10: 455-61.

29. Baldwin R. Depressive illness. In: Jacoby R and Oppenheimer C, (eds.). *Psychiatry in the elderly*. 2nd ed. Oxford: Oxford University Press, 1996.

30. National Audit Office. Progress in improving stroke care. London: National Audit Office, 2010.

31. Berzon R, Hays RD and Shumaker SA. International use, application and performance of health-related quality of life instruments. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 1993; 2: 367-8.

32. World Health Organisation. Accessed in, http://www.who.int/suggestions/faq/en/. 2013.

33. Intercollegiate Stroke Working Party. National clinical guideline for stroke. London: Royal College of Physicians, 2012.

34. NHS Executive. Clinical Governance in the NHS. London: NHS Executive Quality Management Branch, 1999.

35. Donne J. *The complete poetry and selected prose of John Donne*. New York: Random House, 2001.

36. Cooper JM. Aristotle on friendship. In: Rorty A, (ed.). *Essays on Aristotle's ethics*. Berkeley CA: University of California Press, 1980.

37. Durkheim E. *Suicide: a study in sociology*. London: Routledge, 1987, translated (1952).

38. Calhoun C. *Critical sociological theory*. New Jersey: Wiley-Blackwell, 2002.

39. Berkman LF, Glass T, Brissette I and Seeman TE. From social integration to health: Durkheim in the new millennium. *Soc Sci Med*. 2000; 51: 843-57.

40. Bowlby J. *Attachment and loss*. London: Hogarth Press, 1969.

41. Holmes J. *John Bowlby and the attachment theory*. London: Routledge, 1993.

42. Weiss R. The provisions of social relationships. In: Rubin Z, (ed.). *Doing unto others*. Englewood Cliffs, NJ: Prentice Hall, 1974.

43. Cobb S. Presidential Address-1976. Social support as a moderator of life stress. *Psychosomatic medicine*. 1976; 38: 300-14.

44. House JS. *Work, stress and social support*. Reading MA: Addison-Wesly, 1981.

45. Cohen S and Wills TA. Stress, social support, and the buffering hypothesis. *Psychological bulletin*. 1985; 98: 310-57.

46. Thoits PA. Stress, coping, and social support processes: where are we? What next? *Journal of health and social behavior*. 1995; Spec No: 53-79.

47. Barrera M. Social support in the adjustment of pregnant adolescent assessment issues. In: Gottlieb BH, (ed.). *Social networks and social support*. Beverly Hills, California: Sage publications, 1981.

48. Sherbourne CD and Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991; 32: 705-14.

49. Bowling A. *Measuring health. A review of quality of life measurement scales.* Buckingham UK: Open University Press, 1997.

50. Schwarzer R and Leppin A. Social support and health: a theoretical and empirical overview. *Journal of Social and Personal Relationships*. 1991; 8: 99-127.

51. Ditzen B and Heinrichs M. Psychobiology of social support: The social dimension of stress buffering. *Restorative neurology and neuroscience*. 2013.

52. Sarason BR, Sarason IG and Shearin EN. Social support as an individual difference variable: its stability, origins, and relational aspects. *Journal of personality and social psychology*. 1986; 50: 845-55.

53. Thoits PA. Mechanisms linking social ties and support to physical and mental health. *Journal of health and social behavior*. 2011; 52: 145-61.

54. Haber MG, Cohen JL, Lucas T and Baltes BB. The relationship between self-reported received and perceived social support: a meta-analytic review. *American journal of community psychology*. 2007; 39: 133-44.

55. Due P, Holstein B, Lund R, Modvig J and Avlund K. Social relations: network, support and relational strain. *Soc Sci Med*. 1999; 48: 661-73.

56. Bott E. *Family and social network*. London: Tavistock Press, 1957.

57. Barnes JA. Class and communities in a Norwegian island parish. *Human Relations*. 1954; 7: 39-58.

58. House J. Social support and social structure. *Sociological Forum*. 1987; 2: 135-46.

59. Pinquart M and Sorensen S. Influences of socioeconomic status, social network, and competence on subjective well-being in later life: a meta-analysis. *Psychology and aging*. 2000; 15: 187-224.

60. McDowell I and Newell C. *Measuring health: a guide to rating scales and questionnaires*. Oxford: Oxford University Press, 1996.

61. Lin N, Dean A and Ensel WM. Social support scales: a methodological note. *Schizophrenia bulletin*. 1981; 7: 73-89.

62. O'Reilly P. Methodological issues in social support and social network research. *Soc Sci Med*. 1988; 26: 863-73.

63. Seeman TE and Berkman LF. Structural characteristics of social networks and their relationship with social support in the elderly: who provides support. *Soc Sci Med*. 1988; 26: 737-49.

64. Berkman LF and Syme SL. Social networks, host resistance, and mortality: a nine-year follow-up study of Alameda County residents. *American journal of epidemiology*. 1979; 109: 186-204.

65. House JS, Robbins C and Metzner HL. The association of social relationships and activities with mortality: prospective evidence from the Tecumseh Community Health Study. *American journal of epidemiology*. 1982; 116: 123-40.

66. Holt-Lunstad J and Smith T. Social relationships and mortality. *Social and personality psychology*. 2012; 6: 41-53.

67. Seeman TE. Health promoting effects of friends and family on health outcomes in older adults. *American journal of health promotion : AJHP*. 2000; 14: 362-70.

68. Uchino BN, Bowen K, Carlisle M and Birmingham W. Psychological pathways linking social support to health outcomes: a visit with the "ghosts" of research past, present, and future. *Soc Sci Med*. 2012; 74: 949-57.

69. Vogt TM, Mullooly JP, Ernst D, Pope CR and Hollis JF. Social networks as predictors of ischemic heart disease, cancer, stroke and hypertension: incidence, survival and mortality. *Journal of clinical epidemiology*. 1992; 45: 659-66.

70. Ruberman W, Weinblatt E, Goldberg JD and Chaudhary BS. Psychosocial influences on mortality after myocardial infarction. *The New England journal of medicine*. 1984; 311: 552-9.

71. Waxler-Morrison N, Hislop TG, Mears B and Kan L. Effects of social relationships on survival for women with breast cancer: a prospective study. *Soc Sci Med*. 1991; 33: 177-83.

72. Litwin H. Social network type and morale in old age. *The Gerontologist*. 2001; 41: 516-24.

73. Fiori KL, Antonucci TC and Cortina KS. Social network typologies and mental health among older adults. *The journals of gerontology Series B, Psychological sciences and social sciences*. 2006; 61: P25-32.

74. Antonucci TC, Akiyama H and Takahashi K. Attachment and close relationships across the life span. *Attachment & human development*. 2004; 6: 353-70.

75. Wenger GC. *Support networks of older people: A guide for practitioners*. Bangor: Centre for Social Policy Research and Development, University of Wales, 1994.

76. Kawachi I and Berkman LF. Social ties and mental health. *Journal of urban health : bulletin of the New York Academy of Medicine*. 2001; 78: 458-67.

77. Gandy M, Sharpe L and Perry KN. Psychosocial predictors of depression and anxiety in patients with epilepsy: a systematic review. *Journal of affective disorders*. 2012; 140: 222-32.

78. Post MW and van Leeuwen CM. Psychosocial issues in spinal cord injury: a review. *Spinal cord*. 2012; 50: 382-9.

79. Teoh V, Sims J and Milgrom J. Psychosocial predictors of quality of life in a sample of community-dwelling stroke survivors: a longitudinal study. *Topics in stroke rehabilitation*. 2009; 16: 157-66.

80. Carpenter KM, Fowler JM, Maxwell GL and Andersen BL. Direct and buffering effects of social support among gynecologic cancer survivors. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*. 2010; 39: 79-90.

81. Mitchell I, Evans L, Rees T and Hardy L. Stressors, social support, and tests of the buffering hypothesis: Effects on psychological responses of injured athletes. *British journal of health psychology*. 2013.

82. Teo AR, Choi H and Valenstein M. Social relationships and depression: ten-year follow-up from a nationally representative study. *PloS one*. 2013; 8: e62396.

83. House JS, Landis KR and Umberson D. Social relationships and health. *Science*. 1988; 241: 540-5.

84. Cohen S. Psychosocial models of the role of social support in the etiology of physical disease. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. 1988; 7: 269-97.

85. Uchino B. *Social support and physical health: understanding the health consequences of relationships*. New Haven CT: Yale University Press, 2004.

86. Taylor J and Turner RJ. A longitudinal study of the role and significance of mattering to others for depressive symptoms. *Journal of health and social behavior*. 2001; 42: 310-25.

87. Baumeister R, Campbell J, Kreuger J and Vohs K. Does high self-esteem cause better performance, interpersonal success, happiness or healthier lifestyle? *Pyschological Science in the Public Interest*. 2003; 4: 1-44.

88. Taylor SE and Stanton AL. Coping resources, coping processes, and mental health. *Annual review of clinical psychology*. 2007; 3: 377-401.

89. Krause N. Life stress, social support, and self-esteem in an elderly population. *Psychology and aging*. 1987; 2: 349-56.

90. Symister P and Friend R. The influence of social support and problematic support on optimism and depression in chronic illness: a prospective study evaluating self-esteem as a mediator. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. 2003; 22: 123-9.

91. Atienza AA, Collins R and King AC. The mediating effects of situational control on social support and mood following a stressor: a prospective study of dementia caregivers in their natural environments. *The journals of gerontology Series B, Psychological sciences and social sciences*. 2001; 56: S129-39.

92. Rook K. Social relationships as a source of companionship: implications for older adults psychological well-being. In: Sarason BR, Sarason TG and Pierce GR, (eds.). *Social support: an interactional view*. New York: Wiley, 1990, p. 221-50.

93. Kamarck TW, Manuck SB and Jennings JR. Social support reduces cardiovascular reactivity to psychological challenge: a laboratory model. *Psychosomatic medicine*. 1990; 52: 42-58.

94. Uno D, Uchino BN and Smith TW. Relationship quality moderates the effect of social support given by close friends on cardiovascular reactivity in women. *International journal of behavioral medicine*. 2002; 9: 243-62.

95. Lepore SJ. Cynicism, social support, and cardiovascular reactivity. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. 1995; 14: 210-6.

96. Holt-Lunstad J, Uchino BN, Smith TW, Olson-Cerny C and Nealey-Moore JB. Social relationships and ambulatory blood pressure: structural and qualitative predictors of cardiovascular function during everyday social interactions. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. 2003; 22: 388-97.

97. Seeman T, Berkman LF and Rowe BDJ. Social ties and support and neuroendocrine function. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*. 1994; 16: 95-106.

98. DeVries AC, Craft TK, Glasper ER, Neigh GN and Alexander JK. 2006 Curt P. Richter award winner: Social influences on stress responses and health. *Psychoneuroendocrinology*. 2007; 32: 587-603.

99. Berkman LF. The changing and heterogeneous nature of aging and longevity: a social and biomedical perspective. *Annual review of gerontology & geriatrics*. 1988; 8: 37-68.

100. Uchino BN, Kiecolt-Glaser JK and Cacioppo JT. Age-related changes in cardiovascular response as a function of a chronic stressor and social support. *Journal of personality and social psychology*. 1992; 63: 839-46.

101. Uchino BN, Holt-Lunstad J, Uno D, Betancourt R and Garvey TS. Social support and age-related differences in cardiovascular function: an examination of potential mediators. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*. 1999; 21: 135-42.

102. Baron RS, Cutrona CE, Hicklin D, Russell DW and Lubaroff DM. Social support and immune function among spouses of cancer patients. *Journal of personality and social psychology*. 1990; 59: 344-52.

103. Baumeister RF and Leary MR. The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychological bulletin*. 1995; 117: 497-529.

104. Parr S, Byng S and Gilpin S. *Talking about aphasia*. Buckingham UK: Open University Press, 1997.

105. Maisel NC and Gable SL. The paradox of received social support: the importance of responsiveness. *Psychological science*. 2009; 20: 928-32.

106. Astrom M. Generalized anxiety disorder in stroke patients. A 3-year longitudinal study. *Stroke; a journal of cerebral circulation*. 1996; 27: 270-5.

107. Parkes CM. Psycho-social transitions: a field for study. *Soc Sci Med*. 1971; 5: 101-15.

108. Stroebe M and Schut H. The dual process model of coping with bereavement: a decade on. *Omega*. 2010; 61: 273-89.

109. Glass TA and Maddox GL. The quality and quantity of social support: stroke recovery as psycho-social transition. *Soc Sci Med*. 1992; 34: 1249-61.

110. Bowlby J. *Attachment and loss: vol 3. Loss: sadness and depression*. London: Hogarth, 1980.

111. Ch'ng AM, French D and McLean N. Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members. *Journal of health psychology*. 2008; 13: 1136-46.

112. Stroebe M and Schut H. The dual process model of coping with bereavement: rationale and description. *Death studies*. 1999; 23: 197-224.

113. Parkes C. *Bereavement: studies in grief in adult life*. 6th ed. Harmondsworth: Penguin Books, 1996.

114. Worden J. *Grief counselling and grief therapy: a handbook for the mental health practitioner*. New York: Springer, 1991.

115. Lazarus R and Folkman S. *Stress, appraisal, and coping*. New York: Springer, 1984.

116. Nolen-Hoeksama S, Parker L and Larson J. Ruminative coping with depressed mood following loss. *Journal of Personality and Social Pyschology*. 1994; 67: 92-104.

117. Boyraz G, Horne S and Sayger T. Finding meaning in loss: the mediating role of social support between personality and two construals of meaning. *Death studies*. 2012; 36: 519-40.

118. Tedeschi R and Calhoun L. *Trauma and transfiguration: growing in the aftermath of suffering*. Thousand Oaks, CA: Sage Publications, 1995.

119. Hogan NS and Schmidt LA. Testing the grief to personal growth model using structural equation modeling. *Death studies*. 2002; 26: 615-34.

120. Breen L and O'Connor MA. Family and social networks after bereavement: experiences of support, change and isolation. *Journal of Family Therapy*. 2011; 33: 98-120.

121. White MA and Johnstone AS. Recovery from stroke: does rehabilitation counselling have a role to play? *Disability and rehabilitation*. 2000; 22: 140-3.

122. Ritchie J. The applications of qualitative methods to social research. In: Ritchie J and Lewis J, (eds.). *Qualitative research practice: a guide for social science students and researchers*. London: Sage, 2003.

123. Pope C, Mays N and Poppay J. *Synthesizing qualitative and quantitative health evidence: a guide to methods.* Maidenhead: Open University Press, 2007.

124. Centre for Reviews and Dissemination. Systematic reviews: CRD's guidance for undertaking reviews in healthcare. Centre for Reviews and Dissemination: University of York, 2009.

125. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *Annals of internal medicine*. 2009; 151: W65-94.

126. Dixon-Woods M, Fitzpatrick R and Roberts K. Including qualitative research in systematic reviews: opportunities and problems. *Journal of evaluation in clinical practice*. 2001; 7: 125-33.

127. Thomas J and Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*. 2008; 8: 45.

128. Sandelowski M and J B. *Handbook for synthesising qualitative research*. New York: Springer, 2007.

129. Noyes J and Popay J. Directly observed therapy and tuberculosis: how can a systematic review of qualitative research contribute to improving services? A qualitative meta-synthesis. *Journal of advanced nursing*. 2007; 57: 227-43.

130. Campbell R, Pound P, Pope C, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med*. 2003; 56: 671-84.

131. Dixon-Woods M and Fitzpatrick R. Qualitative research in systematic reviews. Has established a place for itself. *BMJ*. 2001; 323: 765-6.

132. Moher D, Liberati A, Tetzlaff J and Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*. 2009; 151: 264-9, W64.

133. Robinson RG, Murata Y and Shimoda K. Dimensions of social impairment and their effect on depression and recovery following stroke. *International psychogeriatrics / IPA*. 1999; 11: 375-84.

134. Desrosiers J, Noreau L, Rochette A, Bourbonnais D, Bravo G and Bourget A. Predictors of long-term participation after stroke. *Disability and rehabilitation*. 2006; 28: 221-30.

135. Unit SE. Preventing social exclusion. London: Cabinet Office, 2001.

136. Vandenbroucke JP, von Elm E, Altman DG, et al. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): explanation and elaboration. *Epidemiology*. 2007; 18: 805-35.

137. Hilari K, Northcott S, Roy P, et al. Psychological distress after stroke and aphasia: the first six months. *Clinical rehabilitation*. 2010; 24: 181-90.

138. Hilari K. The impact of stroke: are people with aphasia different to those without? *Disability and rehabilitation*. 2011; 33: 211-8.

139. Doyle L. Synthesis through meta-ethnography: paradoxes, enhancements, and possibilities. *Qualitative Research*. 2003; 3: 321-44.

140. Dixon-Woods M, Agarwal S, Jones D, Young B and Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of health services research & policy*. 2005; 10: 45-53.

141. Hilari K, Needle JJ and Harrison KL. What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of physical medicine and rehabilitation*. 2012; 93: S86-95.

142. Cruice M, Worrall L and Hickson L. Perspectives of quality of life by people with aphasia and their family: suggestions for successful living. *Topics in stroke rehabilitation*. 2006; 13: 14-24.

143. Brown K, Davidson B, Worrall LE and Howe T. "Making a good time": the role of friendship in living successfully with aphasia. *International journal of speech-language pathology*. 2013; 15: 165-75.

144. Streiner DL and Norman GR. *Health measurement scales: a practical guide to their development and use*. Fourth Edition ed. Oxford UK: Oxford University Press, 2008.

145. Code C. The quantity of life for people with chronic aphasia. *Neuropsychological rehabilitation*. 2003; 13: 379-90.

146. Dixon-Woods M, Booth A and Sutton A. Synthesising qualitative research: a review of published reports. *Qualitative Research*. 2007; 7: 375-422.

147. Public Health Resource Unit. 10 questions to help you make sense of qualitative research. Oxford: Public Health Resource Unit, 2006.

148. Public Health Resource Unit. 12 questions to help you make sense of cohort study. Oxford: Publich Health Resource Unit, 2004.

149. Counsell C and Dennis M. Systematic review of prognostic models in patients with acute stroke. *Cerebrovasc Dis*. 2001; 12: 159-70.

150. Hackett ML and Anderson CS. Predictors of depression after stroke: a systematic review of observational studies. *Stroke; a journal of cerebral circulation*. 2005; 36: 2296-301.

151. Bowling A. Data collection methods in quantitative research: questionnaires, interviews and their response rates. *Research methods in health: investigating health and health services*. Maidenhead: Open University Press, 2004, p. 257-72.

152. Cook JV, Dickinson HO and Eccles MP. Response rates in postal surveys of healthcare professionals between 1996 and 2005: an observational study. *BMC health services research*. 2009; 9: 160.

153. Singleton R and Straits B. *Approaches to social research*. 3rd ed. Oxford: Oxford University Press, 1999.

154. Tabachnick BG and Fidell LS. *Using multivariate statistics*. 5th ed. Boston USA: Pearson Education, 2007.

155. Noblitt G and RD H. *Meta-ethnography, synthesising qualitative studies*. London: Sage publications, 1988.

156. Aveyard H. *Doing a literature review in health and social care*. Maidenhead: Open University press, 2010.

157. Brown K, Worrall LE, Davidson B and Howe T. Living successfully with aphasia: a qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *International journal of speech-language pathology*. 2012; 14: 141-55.

158. Mays N, Pope C and Popay J. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of health services research & policy*. 2005; 10 Suppl 1: 6-20.

159. Bryman A. *Social research methods*. 2 ed. Oxford: Oxford University Press, 2004.

160. Thomas J, Harden A, Oakley A, et al. Integrating qualitative research with trials in systematic reviews. *BMJ*. 2004; 328: 1010-2.

161. Brown K, Worrall L, Davidson B and Howe T. Snapshots of success: an insider perspective on living successfully with aphasia. *Aphasiology*. 2010; 24: 1267-95.

162. Davidson B, Howe T, Worrall L, Hickson L and Togher L. Social participation for older people with aphasia: the impact of communication disability on friendships. *Topics in stroke rehabilitation*. 2008; 15: 325-40.

163. Parr S. Living with severe aphasia: tracking social exclusion. *Aphasiology*. 2007; 21: 98-123.

164. Hinckley JJ. Finding messages in bottles: living successfully with stroke and aphasia. *Topics in stroke rehabilitation*. 2006; 13: 25-36.

165. Haun J, Rittman MR and Sberna M. The continnum of connectedness and social isolation during post stroke recovery. *Journal of Aging Studies*. 2008; 22: 54-64.

166. Pound P, Gompertz P and Ebrahim S. Social and practical strategies described by people living at home with stroke. *Health & social care in the community*. 1999; 7: 120-8.

167. Sumathipala K, Radcliffe E, Sadler E, Wolfe CD and McKevitt C. Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health. *Chronic illness*. 2012; 8: 31-44.

168. LeDorze G and Brassard C. A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases. *Aphasiology*. 1995; 9: 239-55.

169. Grohn B, Worrall LE, Simmons-Mackie N and Brown K. The first 3-months post-stroke: what facilitates successfully living with aphasia? *International journal of speech-language pathology*. 2012; 14: 390-400.

170. Astrom M, Asplund K and Astrom T. Psychosocial function and life satisfaction after stroke. *Stroke; a journal of cerebral circulation*. 1992; 23: 527-31.

171. Astrom M, Olsson T and Asplund K. Different linkage of depression to hypercortisolism early versus late after stroke. A 3-year longitudinal study. *Stroke; a journal of cerebral circulation*. 1993; 24: 52-7.

172. Hilari K, Wiggins RD and Roy P. Predictors of health-related quality of life (HRQL) in people with chronic aphasia. *Aphasiology*. 2003; 17: 365-81.

173. Hilari K and Northcott S. Social support in people with chronic aphasia. *Aphasiology*. 2006; 20: 17-36.

174. Ross K and Wertz R. Quality of life with and without aphasia. *Aphasiology*. 2003; 17: 355-64.

175. Chang A, Mackenzie AE, Yip M and R D. The psychosocial impact of stroke. *Journal of clinical nursing*. 1999; 8: 477-81.

176. Wyller TB, Holmen J, Laake P and Laake K. Correlates of subjective well-being in stroke patients. *Stroke; a journal of cerebral circulation*. 1998; 29: 363-7.

177. Adeniyi A, Idowu O, Ogwumike O and Adeniyi C. Comparative influence of self-efficacy, social support and perceived barriers on low physical activity development in patients with type 2 diabetes, hypertension or stroke. *Ethiopian journal of health sciences*. 2012; 22: 113-9.

178. Friedland J and McColl M. Social support and psychosocial dysfunction after stroke: buffering effects in a community sample. *Archives of physical medicine and rehabilitation*. 1987; 68: 475-80.

179. Boden-Albala B, Litwak E, Elkind MS, Rundek T and Sacco RL. Social isolation and outcomes post stroke. *Neurology*. 2005; 64: 1888-92.

180. Belanger L, Bolduc M and Noel M. Relative importance of after-effects, environment and socio-economic factors on the social integration of stroke victims. *International journal of rehabilitation research Internationale Zeitschrift fur Rehabilitationsforschung Revue internationale de recherches de readaptation*. 1988; 11: 251-60.

181. Feibel JH and Springer CJ. Depression and failure to resume social activities after stroke. *Archives of physical medicine and rehabilitation*. 1982; 63: 276-7.

182. Glymour MM, Weuve J, Fay ME, Glass T and Berkman LF. Social ties and cognitive recovery after stroke: does social integration promote cognitive resilience? *Neuroepidemiology*. 2008; 31: 10-20.

183. Sit JW, Wong TK, Clinton M and Li LS. Associated factors of post-stroke depression among Hong Kong Chinese: a longitudinal study. *Psychology, health & medicine*. 2007; 12: 117-25.

184. Knapp P and Hewison J. The protective effects of social support against mood disorder after stroke. *Pyschology, Health and Medicine*. 1998; 3: 275-83.

185. Ritchie J, Lewis J and Elam G. Designing and selecting samples. In: Ritchie J and Lewis J, (eds.). *Qualitative research practice: a guide for social science students and researchers*. London: Sage, 2003.

186. Kishi Y, Robinson RG and Kosier JT. Suicidal plans in patients with stroke: comparison between acute-onset and delayed-onset suicidal plans. *International psychogeriatrics / IPA*. 1996; 8: 623-34.

187. Sharpe M, Hawton K, Seagroatt V, et al. Depressive disorders in long-term survivors of stroke. Associations with demographic and social factors, functional status, and brain lesion volume. *The British journal of psychiatry : the journal of mental science*. 1994; 164: 380-6.

188. Osberg JS, DeJong G, Haley SM, Seward ML, McGinnis GE and Germaine J. Predicting long-term outcome among post-rehabilitation stroke patients. *American journal of physical medicine & rehabilitation / Association of Academic Physiatrists*. 1988; 67: 94-103.

189. Cruice M, Worrall L, Hickson L and Murison R. Finding a focus for quality of life with aphasia: social and emotional health and psychological well-being. *Aphasiology*. 2003; 17: 333-53.

190. Clark MS and Smith DS. Changes in family functioning for stroke rehabilitation patients and their families. *International journal of rehabilitation research Internationale Zeitschrift fur Rehabilitationsforschung Revue internationale de recherches de readaptation*. 1999; 22: 171-9.

191. Michael KM, Allen JK and Macko RF. Fatigue after stroke: relationship to mobility, fitness, ambulatory activity, social support, and falls efficacy. *Rehabilitation nursing : the official journal of the Association of Rehabilitation Nurses*. 2006; 31: 210-7.

192. Norris VK, Stephens MA and Kinney JM. The impact of family interactions on recovery from stroke: help or hindrance? *The Gerontologist*. 1990; 30: 535-42.

193. Owolabi MO. What are the consistent predictors of generic and specific post-stroke health-related quality of life? *Cerebrovasc Dis*. 2010; 29: 105-10.

194. Robinson RG, Starr LB, Kubos KL and Price TR. A two-year longitudinal study of post-stroke mood disorders: findings during the initial evaluation. *Stroke; a journal of cerebral circulation*. 1983; 14: 736-41.

195. Townend E, Brady M and McLaughlan K. A systematic evaluation of the adaptation of depression diagnostic methods for stroke survivors who have aphasia. *Stroke; a journal of cerebral circulation*. 2007; 38: 3076-83.

196. White JH, Alston MK, Marquez JL, et al. Community-dwelling stroke survivors: function is not the whole story with quality of life. *Archives of physical medicine and rehabilitation*. 2007; 88: 1140-6.

197. Beckley M. The influence of quality and quantity of social support in the promotion of community participation following stroke. *Australian Occupational Therapy Journal*. 2007; 54: 215-20.

198. Chau JP, Thompson DR, Chang AM, et al. Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital. *Journal of clinical nursing*. 2010; 19: 3042-50.

199. Dayapoglu N and Tan M. Quality of life in stroke patients. *Neurology India*. 2010; 58: 697-701.

200. Boynton De Sepulveda LI and Chang B. Effective coping with stroke disability in a community setting: the development of a causal model. *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses*. 1994; 26: 193-203.

201. Griffen JA, Rapport LJ, Bryer RC and Scott CA. Driving status and community integration after stroke. *Topics in stroke rehabilitation*. 2009; 16: 212-21.

202. Huang CY, Hsu MC, Hsu SP, Cheng PC, Lin SF and Chuang CH. Mediating roles of social support on poststroke depression and quality of life in patients with ischemic stroke. *Journal of clinical nursing*. 2010; 19: 2752-62.

203. Kim P, Warren S, Madill H and Hadley M. Quality of life of stroke survivors. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 1999; 8: 293-301.

204. Lam SC, Lee LY and To KW. Depressive symptoms among community-dwelling, post-stroke elders in Hong Kong. *International nursing review*. 2010; 57: 269-73.

205. Li SC, Wang KY and Lin JC. Depression and related factors in elderly patients with occlusion stroke. *The journal of nursing research : JNR*. 2003; 11: 9-18.

206. Morris PL, Robinson RG, Raphael B and Bishop D. The relationship between the perception of social support and post-stroke depression in hospitalized patients. *Psychiatry*. 1991; 54: 306-16.

207. Spencer K, Tompkings C, Schulz R and Rau M. The psychosocial outcomes of stroke: a longitudinal study of depression risk. *Clinical Aphasiology*. 1995; 23: 9-23.

208. Stephens MA, Kinney JM, Norris VK and Ritchie SW. Social networks as assets and liabilities in recovery from stroke by geriatric patients. *Psychology and aging*. 1987; 2: 125-9.

209. Ueki H, Washino K, Fukao T, Inoue M, Ogawa N and Takai A. Mental health problems after stroke. *Psychiatry and clinical neurosciences*. 1999; 53: 621-7.

210. Hilari K, Owen S and Farrelly SJ. Proxy and self-report agreement on the Stroke and Aphasia Quality of Life Scale-39. *Journal of neurology, neurosurgery, and psychiatry*. 2007; 78: 1072-5.

211. Cruice M, Worrall L, Hickson L and Murison R. Measuring quality of life: comparing family members' and friends' ratings with those of their aphasic partners. *Aphasiology*. 2005; 17: 333-53.

212. Hommel M, Miguel ST, Naegele B, Gonnet N and Jaillard A. Cognitive determinants of social functioning after a first ever mild to moderate stroke at vocational age. *Journal of neurology, neurosurgery, and psychiatry*. 2009; 80: 876-80.

213. McColl MA and Friedland J. The effects of age and disability on social support. *International journal of rehabilitation research Internationale Zeitschrift fur Rehabilitationsforschung Revue internationale de recherches de readaptation*. 1995; 18: 325-40.

214. Hilari K, Lamping DL, Smith SC, Northcott S, Lamb A and Marshall J. Psychometric properties of the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in a generic stroke population. *Clinical rehabilitation*. 2009; 23: 544-57.

215. Brott T, Adams HP, Jr., Olinger CP, et al. Measurements of acute cerebral infarction: a clinical examination scale. *Stroke; a journal of cerebral circulation*. 1989; 20: 864-70.

216. Mahoney FI, Wood OH and Barthel DW. Rehabilitation of chronically ill patients: the influence of complications on the final goal. *Southern medical journal*. 1958; 51: 605-9.

217. Collin C, Wade DT, Davies S and Horne V. The Barthel ADL Index: a reliability study. *International disability studies*. 1988; 10: 61-3.

218. Enderby P, Wood V and Wade D. *Frenchay Aphasia Screening Test*. Windsor UK: NFEW-Nelson, 1987.

219. Hilari K and Byng S. Measuring quality of life in people with aphasia: the Stroke Specific Quality of Life Scale. *International journal of language & communication disorders / Royal College of Speech & Language Therapists*. 2001; 36 Suppl: 86-91.

220. Hilari K, Byng S, Lamping DL and Smith SC. Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39): evaluation of acceptability, reliability, and validity. *Stroke; a journal of cerebral circulation*. 2003; 34: 1944-50.

221. Goldberg D. *The Detection of Psychiatric Illness by Questionnaire*. London, UK: Oxford University Press, 1972.

222. Northcott S and Hilari K. Stroke Social Network Scale: development and psychometric evaluation of a new patient-reported measure. *Clinical rehabilitation*. in press.

223. Wade DT, Legh-Smith J and Langton Hewer R. Social activities after stroke: measurement and natural history using the Frenchay Activities Index. *International rehabilitation medicine*. 1985; 7: 176-81.

224. Hilari K. Assessing health-related quality of life in people with aphasia. London: City University, 2002.

225. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med*. 1998; 46: 1569-85.

226. Goldberg D and Hillier V. A scaled version of the General Health Questionnaire. *Pyschological Medicine*. 1979; 9: 139-45.

227. Zigmond AS and Snaith RP. The hospital anxiety and depression scale. *Acta psychiatrica Scandinavica*. 1983; 67: 361-70.

228. Johnson G, Burvill PW, Anderson CS, Jamrozik K, Stewart-Wynne EG and Chakera TM. Screening instruments for depression and anxiety following stroke: experience in the Perth community stroke study. *Acta psychiatrica Scandinavica*. 1995; 91: 252-7.

229. Wade DT and Collin C. The Barthel ADL Index: a standard measure of physical disability? *International disability studies*. 1988; 10: 64-7.

230. Wylie CM. Measuring end results of rehabilitation of patients with stroke. *Public health reports*. 1967; 82: 893-8.

231. Wylie CM. Gauging the response of stroke patients to rehabilitation. *Journal of the American Geriatrics Society*. 1967; 15: 797-805.

232. Schuling J, de Haan R, Limburg M and Groenier KH. The Frenchay Activities Index. Assessment of functional status in stroke patients. *Stroke; a journal of cerebral circulation*. 1993; 24: 1173-7.

233. Turnbull JC, Kersten P, Habib M, McLellan L, Mullee MA and George S. Validation of the Frenchay Activities Index in a general population aged 16 years and older. *Archives of physical medicine and rehabilitation*. 2000; 81: 1034-8.

234. Enderby PM, Wood VA, Wade DT and Hewer RL. The Frenchay Aphasia Screening Test: a short, simple test for aphasia appropriate for non-specialists. *International rehabilitation medicine*. 1987; 8: 166-70.

235. Philp I, Lowles RV, Armstrong GK and Whitehead C. Repeatability of standardized tests of functional impairment and well-being in older people in a rehabilitation setting. *Disability and rehabilitation*. 2002; 24: 243-9.

236. Sarno JE and Sarno MT. The diagnosis of speech disorders in brain damaged adults. *The Medical clinics of North America*. 1969; 53: 561-73.

237. Enderby P and Crow E. Frenchay Aphasia Screening Test: validity and comparability. *Disability and rehabilitation*. 1996; 18: 238-40.

238. Syder D, Body R, Parker M and Boddy M. *Sheffield Screening Test for Acquired Language Disorders*. Windsor: NFER-NELSON, 1993.

239. Al-Khawaja I, Wade DT and Collin CF. Bedside screening for aphasia: a comparison of two methods. *J Neurol*. 1996; 243: 201-4.

240. Gibson L, MacLennan WJ, Gray C and Pentland B. Evaluation of a comprehensive assessment battery for stroke patients. *International journal of rehabilitation research Internationale Zeitschrift fur Rehabilitationsforschung Revue internationale de recherches de readaptation*. 1991; 14: 93-100.

241. Lyden P, Lu M, Jackson C, et al. Underlying structure of the National Institutes of Health Stroke Scale: results of a factor analysis. NINDS tPA Stroke Trial Investigators. *Stroke; a journal of cerebral circulation*. 1999; 30: 2347-54.

242. Rundek T, Mast H, Hartmann A, et al. Predictors of resource use after acute hospitalization: the Northern Manhattan Stroke Study. *Neurology*. 2000; 55: 1180-7.

243. Schlegel D, Kolb SJ, Luciano JM, et al. Utility of the NIH Stroke Scale as a predictor of hospital disposition. *Stroke; a journal of cerebral circulation*. 2003; 34: 134-7.

244. Meyer BC, Hemmen TM, Jackson CM and Lyden PD. Modified National Institutes of Health Stroke Scale for use in stroke clinical trials: prospective reliability and validity. *Stroke; a journal of cerebral circulation*. 2002; 33: 1261-6.

245. Schmulling S, Grond M, Rudolf J and Kiencke P. Training as a prerequisite for reliable use of NIH Stroke Scale. *Stroke; a journal of cerebral circulation*. 1998; 29: 1258-9.

246. Kasner SE, Chalela JA, Luciano JM, et al. Reliability and validity of estimating the NIH stroke scale score from medical records. *Stroke; a journal of cerebral circulation*. 1999; 30: 1534-7.

247. Lyden P, Raman R, Liu L, et al. NIHSS training and certification using a new digital video disk is reliable. *Stroke; a journal of cerebral circulation*. 2005; 36: 2446-9.

248. Muir KW, Weir CJ, Murray GD, Povey C and Lees KR. Comparison of neurological scales and scoring systems for acute stroke prognosis. *Stroke; a journal of cerebral circulation*. 1996; 27: 1817-20.

249. Legard R, Keegan J and Ward K. In-depth interviews. In: Ritchie J and Lewis J, (eds.). *Qualitative research practice: a guide for social science students and researchers*. London: Sage, 2003.

250. Robson C. *Real World Research*. 2nd edition ed. Oxford: Blackwell, 2002.

251. Rubin HJ and Rubin IS. *Qualitative interviewing: the art of hearing data*. Thousand Oaks, CA: Sage, 1995.

252. Ritchie J and Spencer L. Qualitative data analysis for applied policy research. In: Bryman A and Burgess R, (eds.). *Analysing qualitative data*. London: Routledge, 1994.

253. Ritchie J, Spencer L and O'Connor W. Carrying out qualitative analysis. In: Ritchie J and Lewis J, (eds.). *Qualitative research practice: a guide for social science students and researchers*. London: Sage, 2003.

254. Worrall L, T R, T H, et al. Access to written information for people with aphasia. *Aphasiology*. 2005; 19: 923-9.

255. Lewis J. Design Issues. In: Ritchie J and Lewis J, (eds.). *Qualitative research practice: a guide for social science students and researchers*. London: Sage, 2003.

256. Field A. *Discovering statistics using SPSS for Windows*. London: Sage, 2000.

257. Field A, Miles J and Field Z. *Discovering statistics using R*. London: Sage, 2012.

258. Field A. *Discovering statistics using IBM SPSS Statistics*. 4th ed. London: Sage, 2013.

259. Gelman A and Hill J. *Data analysis using regression and multilevel/hierachical models*. Cambridge: Cambridge University Press, 2007.

260. Pallant J. *SPSS Survival Manual*. 3rd ed. Berkshire: Open University Press, 2007.

261. Wright DB. *Understanding statistics: an introduction for the social sciences*. London: Sage, 1997.

262. Stevens J. *Applied multivariate statistics for the social sciences*. 2nd ed. Hillsdale, New Jersey: Erlbaum, 1992.

263. Myers R. *Classical and modern regression with applications*. 2nd ed. Boston, MA: Duxbury, 1990.

264. Menard S. Applied logistic regression analysis. *Sage university paper series on quantitative applications in the social sciences*. Thousand Oaks, CA: Sage, 1995, p. 07-106.

265. Rummel RJ. *Applied factor analysis*. Evanston, IL: Northwestern University Press, 1970.

266. Cook RD and Weisberg S. *Residuals and influence in regression*. New York: Chapman and Hall, 1982.

267. Belsey DA, Kuh E and Welsch R. *Regression diagnostics: identifying influential data and sources of collinearity*. New York: Wiley, 1980.

268. Barnett V and Lewis T. *Outliers in statistical data*. 2nd ed. New York: Wiley, 1994.

269. Lofland J and Lofland LH. *Analyzing social settings*. 3rd ed. Belmont, CA: Wadsworth, 1995.

270. Everitt B, Landau S, Leese M and Stahl D. *Cluster Analysis*. 5th ed. Chichester: John Wiley & Sons, 2011.

271. Wenger GC and Shahtahmasebi S. Variations in support networks: some social policy implications. In: J M, (ed.). *Aiding and aging: the coming crisis*. Westport, CT: Greenwood Press, 1990, p. 255-77.

272. Litwin H and Shiovitz-Ezra S. Social network type and subjective well-being in a national sample of older Americans. *The Gerontologist*. 2011; 51: 379-88.

273. Spencer L and Pahl R. *Rethinking friendship: hidden solidarities today*. New Jersery: Princeton University Press, 2006.

274. Wenger GC. Support network measurement and typology development in England and Wales. In: Litwin H, (ed.). *The social networks of older people: a cross-national analysis*. Westport, CT: Greenwood, 1996, p. 117-42.

275. Scharf T. Informal support for older people in post-unification East Germany: stability and change. *Journal of cross-cultural gerontology*. 1997; 12: 61-72.

276. Burholt V, Wenger C, Scott A, Yahya B and Roy S. Bangladeshi immigration to the United Kingdom: Older people's support networks in the sending and receiving countries. *Quality in Ageing and Older Adults*. 2000; 1: 18-30.

277. Stone L and Rosenthal C. Profiles of the social networks of Canada's elderly: an analysis of the 1990 General Social Survey data. In: Litwin H, (ed.). *The social networks of older people: a cross-national analysis*. Westport, Conneticut: Praeger, 1996.

278. Aartsen M, van Tilburg T and Smits CHM. A longitudinal study of the impact of physical and cognitive decline on the personal network in old age. *Journal of Social and Personal Relationships*. 2004; 21: 249-66.

279. Landau R and Litwin H. Subjective well-being among the old-old: the role of health, personality and social support. *International journal of aging & human development*. 2001; 52: 265-80.

280. Litwin H. The association between social network relationships and depressive symptoms among older Americans: what matters most? *International psychogeriatrics / IPA*. 2011: 1-11.

281. Litwin H. Physical activity, social network type, and depressive symptoms in late life: an analysis of data from the National Social Life, Health and Aging Project. *Aging & mental health*. 2012; 16: 608-16.

282. Litwin H. Social predictors of physical activity in later life: the contribution of social-network type. *Journal of Aging and Physical Activity*. 2003; 11: 389-406.

283. Shiovitz-Ezra S and Litwin H. Social network type and health-related behaviors: evidence from an American national survey. *Soc Sci Med*. 2012; 75: 901-4.

284. Cheng ST, Lee CK, Chan AC, Leung EM and Lee JJ. Social network types and subjective well-being in Chinese older adults. *The journals of gerontology Series B, Psychological sciences and social sciences*. 2009; 64: 713-22.

285. Fiori KL, Antonucci TC and Akiyama H. Profiles of social relations among older adults: a cross sectional approach. *Ageing and Society*. 2008; 28: 203-31.

286. Burns RP and Burns R. *Business Research Methods and Statistics Using SPSS*. London: Sage, 2008.

287. Field A. Postgraduate Statistics: Cluster Analysis. Accessed in, http://www.statisticshell.com/docs/cluster.pdf2000. 2013

288. Norušis MJ. *SPSS 16.0 Statistical Procedures Companion*. Upper Saddle River, NJ: Prentice Hall, 2008.

289. Hair JH and Black WC. Cluster analysis. In: Grimm LG and Yarnold PR, (eds.). *Reading and understanding more multivariate statistics*. Washington, DC: American Pyschological Association, 2000, p. 147-205.

290. Cohen JW. *Statistical power analysis for the behavioural sciences*. 2nd ed. Hillsdale, NJ: Lawrence Erlbaum Associates, 1988.

291. Taylor MG and Lynch SM. Trajectories of impairment, social support, and depressive symptoms in later life. *The journals of gerontology Series B, Psychological sciences and social sciences*. 2004; 59: S238-46.

292. Bolger N, Foster M, Vinokur AD and Ng R. Close relationships and adjustment to a life crisis: the case of breast cancer. *Journal of personality and social psychology*. 1996; 70: 283-94.

293. Lee MK, Park S, Lee ES, et al. Social support and depressive mood 1 year after diagnosis of breast cancer compared with the general female population: a prospective cohort study. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. 2011; 19: 1379-92.

294. Moyer A and Salovey P. Predictors of social support and psychological distress in women with breast cancer. *Journal of health psychology*. 1999; 4: 177-91.

295. Ostwald SK, Bernal MP, Cron SG and Godwin KM. Stress experienced by stroke survivors and spousal caregivers during the first year

after discharge from inpatient rehabilitation. *Topics in stroke rehabilitation*. 2009; 16: 93-104.

296. Sirri L, Magelli C and Grandi S. Predictors of perceived social support in long-term survivors of cardiac transplant: the role of psychological distress, quality of life, demographic characteristics and clinical course. *Psychology & health*. 2011; 26: 77-94.

297. Hommel M, Trabucco-Miguel S, Joray S, Naegele B, Gonnet N and Jaillard A. Social dysfunctioning after mild to moderate first-ever stroke at vocational age. *Journal of neurology, neurosurgery, and psychiatry*. 2009; 80: 371-5.

298. Carod-Artal FJ and Egido JA. Quality of life after stroke: the importance of a good recovery. *Cerebrovasc Dis*. 2009; 27 Suppl 1: 204-14.

299. Thomas Arcury, Chen H, Savoca MR, et al. Ethnic variation in oral health and social integration among older rural adults. *Journal of Applied Gerontology*. 2011; 32: 302-23.

300. Leon CFMd, Gold DT, Glass TA, L. K and George LK. Disability as a function of social networks and support in elderly African Americans and Whites: The Duke EPESE 1986-1992. *Journal of Gerontology: Social Sciences*. 2001; 56B S179-S90.

301. Pawson N, Rahgavan R and Small N. Social inclusion, social networks and ethnicity: the development of the Social Inclusion Interview Schedule for young people with learning disabilities. *British Journal of Learning Disabilities*. 2005; 33: 15-22.

302. The Notting Hill Carnival. Accessed in, www.thenottinghillcarnival.com 2013.

303. Tomassini C, Glaser K and Stuchbury R. Family disruption and support in later life: a comparative study between the United Kingdom and Italy. *Journal of Social Issues*. 2007; 63: 845-63.

304. Régnier-Loilier A. How often do adult children see their parents? *Population and Societies*. 2006; 427: 2-5.

305. Spitze G and Logan J. Sons, daughters, and intergenerational social support. *Journal of Marriage and the Family*. 1990; 52: 420-30.

306. Ikkink K, van Tilburg T and Knipscheer K. Perceived instrumental support exchanges in relationships between elderly parents and their adult children: normative and structural explanations. *Journal of marriage and the family*. 1999; 61: 831-44.

307. Bengston V and Kuypers J. The family support cycle: psychosocial issues in the aging family. In: Munnichs J, Museen P, Olbrich E and Coleman P, (eds.). *Life-span and change in a a gerontological perspective*. Orlando, FL: Academic Press, 1985, p. 257-73.

308. Lee G, Netzer J and Coward R. Depression among older parents: the role of intergenerational exchange. *Journal of Marriage and the Family*. 1995; 57: 823-33.

309. Schmid T, Brandt M and Haberkern K. Gendered support to older parents: do welfare states matter? *Eur J Ageing*. 2012; 9: 39-50.

310. Choi-Kwon S and Kim JS. Poststroke fatigue: an emerging, critical issue in stroke medicine. *International journal of stroke : official journal of the International Stroke Society*. 2011; 6: 328-36.

311. Kirkevold M, Christensen D, Andersen G, Johansen SP and Harder I. Fatigue after stroke: manifestations and strategies. *Disability and rehabilitation*. 2012; 34: 665-70.

312. Hartup W and Stevens N. Friendships and adaptation across the life span. *Current Directions in Pyschological Science*. 1999; 8: 76-9.

313. Lee GR and Shehan CL. Social relations and the self-esteem of older persons. *Research on aging*. 1989; 11: 427-42.

314. Giles LC, Glonek GF, Luszcz MA and Andrews GR. Effect of social networks on 10 year survival in very old Australians: the Australian longitudinal study of aging. *Journal of epidemiology and community health*. 2005; 59: 574-9.

315. DuPertuis LL, Aldwin CM and Bosse R. Does the source of support matter for different health outcomes? Findings from the Normative Aging Study. *Journal of aging and health*. 2001; 13: 494-510.

316. van der Gaag A, Smith L, Davis S, et al. Therapy and support services for people with long-term stroke and aphasia and their relatives: a six-month follow-up study. *Clinical rehabilitation*. 2005; 19: 372-80.

317. Flynn L, Cumberland A and Marshall J. Public knowledge about aphasia: A survey with comparative data. *Aphasiology*. 2009; 23: 393-401.

318. Sherratt S. Written media coverage of aphasia: a review. *Aphasiology*. 2011; 25: 1132-52.

319. Code C and Heron C. Services for aphasia, other acquired adult neurogenic communication and swallowing disorders in the United Kingdom, 2000. *Disability and rehabilitation*. 2003; 25: 1231-7.

320. Brumfitt S. Introduction. In: Brumfitt S, (ed.). *Psychological well-being and acquired communication impairments*. Chichester, UK: Wiley-Blackwell, 2010.

321. Gouldner A. The norm of reciprocity: a preliminary statement. *American Sociological Review*. 1960; 25: 161-78.

322. Carstensen LL, Isaacowitz DM and Charles ST. Taking time seriously. A theory of socioemotional selectivity. *The American psychologist*. 1999; 54: 165-81.

323. Fredrickson BL and Carstensen LL. Choosing social partners: how old age and anticipated endings make people more selective. *Psychology and aging*. 1990; 5: 335-47.

324. Carstensen LL and Fredrickson BL. Influence of HIV status and age on cognitive representations of others. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. 1998; 17: 494-503.

325. Rose TA, Worrall LE, Hickson LM and Hoffmann TC. Aphasia friendly written health information: content and design characteristics. *International journal of speech-language pathology*. 2011; 13: 335-47.

326. Wilcox VL, Kasl SV and Berkman LF. Social support and physical disability in older people after hospitalization: a prospective study. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. 1994; 13: 170-9.

327. Li L, Young D and Hu Z. Longitudinal study of quality of life following stroke. *Hong Kong J Psychiatry*. 2001; 11: 17-22.

328. Brosseau L, Potvin L, Philippe P and Boulanger YL. Post-stroke inpatient rehabilitation. II. Predicting discharge disposition. *American journal of physical medicine & rehabilitation / Association of Academic Physiatrists*. 1996; 75: 431-6.

329. Meijer R, van Limbeek J, Kriek B, Ihnenfeldt D, Vermeulen M and de Haan R. Prognostic social factors in the subacute phase after a stroke for the discharge destination from the hospital stroke-unit. A systematic review of the literature. *Disability and rehabilitation*. 2004; 26: 191-7.

330. Salter K, Foley N and Teasell R. Social support interventions and mood status post stroke: a review. *International journal of nursing studies*. 2010; 47: 616-25.

331. Claiborne N. Effectiveness of a care coordination model for stroke survivors: a randomized study. *Health & social work*. 2006; 31: 87-96.

332. Friedland JF and McColl M. Social support intervention after stroke: results of a randomized trial. *Archives of physical medicine and rehabilitation*. 1992; 73: 573-81.

333. Martire LM, Schulz R, Helgeson VS, Small BJ and Saghafi EM. Review and meta-analysis of couple-oriented interventions for chronic illness. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*. 2010; 40: 325-42.

334. Evans RL, Matlock AL, Bishop DS, Stranahan S and Pederson C. Family intervention after stroke: does counseling or education help? *Stroke; a journal of cerebral circulation*. 1988; 19: 1243-9.

335. Jongbloed L and Morgan D. An investigation of involvement in leisure activities after a stroke. *The American journal of occupational*

therapy : official publication of the American Occupational Therapy Association. 1991; 45: 420-7.

336. Drummond A and Walker M. Generalization of the effects of leisure rehabilitation for stroke patients. *British Journal of Occupational Therapy*. 1996; 59: 330-4.

337. Brumfitt S. Psychotherapy in aphasia. In: Code C and Muller DJ, (eds.). *Treatment of aphasia: From theory to practice*. London: Whurr, 1995.

338. Hackett ML, Anderson CS, House A and Xia J. Interventions for treating depression after stroke. *Cochrane Database Syst Rev*. 2008: CD003437.

339. Thomas SA, Walker MF, Macniven JA, Haworth H and Lincoln NB. Communication and Low Mood (CALM): a randomized controlled trial of behavioural therapy for stroke patients with aphasia. *Clinical rehabilitation*. 2013; 27: 398-408.

340. Lyon J, Cariski D, Keisler L, et al. Communication partners: enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology*. 1997; 11: 693-708.

341. Elman R, Ogar J and Elman S. Aphasia: Awareness, advocacy, and activism. *Aphasiology*. 2000; 14: 455-9.

342. Cruice M and Bunning K. An introduction – striving for access and inclusive communities: what does it all mean for the person and the profession? . *Presentation at the 11th International Aphasia Rehabilitation Conference* Milos, Greece. 2004.

343. Kagan A, Black SE, Duchan FJ, Simmons-Mackie N and Square P. Training volunteers as conversation partners using "Supported Conversation for Adults with Aphasia" (SCA): a controlled trial. *Journal of speech, language, and hearing research : JSLHR*. 2001; 44: 624-38.

344. Black N. Patient reported outcome measures could help transform healthcare. *BMJ*. 2013; 346: f167.

345. Intercollegiate Stroke Working Party. National Clinical Guidelines for Stroke. 3rd ed. London, UK2008.

346. Berkman LF, Blumenthal J, Burg M, et al. Effects of treating depression and low perceived social support on clinical events after myocardial infarction: the Enhancing Recovery in Coronary Heart Disease Patients (ENRICHD) Randomized Trial. *JAMA : the journal of the American Medical Association*. 2003; 289: 3106-16.

347. Burns K. Solution-focused brief therapy for people with acquired communication impairments. In: Brumfitt S, (ed.). *Psychological well-being and acquired communication impairment*. Wiley-Blackwell, 2010.

348. Shear K, Frank E, Houck PR and Reynolds CF, 3rd. Treatment of complicated grief: a randomized controlled trial. *JAMA : the journal of the American Medical Association*. 2005; 293: 2601-8.

349. Martina CM and Stevens NL. Breaking the cycle of loneliness? Psychological effects of a friendship enrichment program for older women. *Aging & mental health*. 2006; 10: 467-75.

Bibliography

AARTSEN, M., VAN TILBURG, T. & SMITS, C. H. M. 2004. A longitudinal study of the impact of physical and cognitive decline on the personal network in old age. *Journal of Social and Personal Relationships,* 21**,** 249-266.

ADENIYI, A., IDOWU, O., OGWUMIKE, O. & ADENIYI, C. 2012. Comparative influence of self-efficacy, social support and perceived barriers on low physical activity development in patients with type 2 diabetes, hypertension or stroke. *Ethiop J Health Sci,* 22**,** 113-9.

AL-KHAWAJA, I., WADE, D. T. & COLLIN, C. F. 1996. Bedside screening for aphasia: a comparison of two methods. *J Neurol,* 243**,** 201-4.

ANTONUCCI, T. C., AKIYAMA, H. & TAKAHASHI, K. 2004. Attachment and close relationships across the life span. *Attach Hum Dev,* 6**,** 353-70.

ASTROM, M. 1996. Generalized anxiety disorder in stroke patients. A 3-year longitudinal study. *Stroke,* 27**,** 270-5.

ASTROM, M., ADOLFSSON, R. & ASPLUND, K. 1993a. Major depression in stroke patients. A 3-year longitudinal study. *Stroke,* 24**,** 976-82.

ASTROM, M., ADOLFSSON, R., ASPLUND, K. & ASTROM, T. 1992a. Life before and after stroke. Living conditions and life satisfaction in relation to a general elderly population. *Cerebrovasc Dis,* 2**,** 28-34.

ASTROM, M., ASPLUND, K. & ASTROM, T. 1992b. Psychosocial function and life satisfaction after stroke. *Stroke,* 23**,** 527-31.

ASTROM, M., OLSSON, T. & ASPLUND, K. 1993b. Different linkage of depression to hypercortisolism early versus late after stroke. A 3-year longitudinal study. *Stroke,* 24**,** 52-7.

ATIENZA, A. A., COLLINS, R. & KING, A. C. 2001. The mediating effects of situational control on social support and mood following a stressor: a prospective study of dementia caregivers in their natural environments. *J Gerontol B Psychol Sci Soc Sci,* 56**,** S129-39.

AVEYARD, H. 2010. *Doing a literature review in health and social care,* Maidenhead, Open University Press.

BALDWIN, R. 1996. Depressive illness. *In:* JACOBY, R. & OPPENHEIMER, C. (eds.) *Psychiatry in the elderly.* 2nd ed. Oxford: Oxford University Press.

BARNES, J. A. 1954. Class and communities in a Norwegian island parish. *Human Relations,* 7**,** 39-58.

BARNETT, V. & LEWIS, T. 1994. *Outliers in statistical data,* New York, Wiley.

BARON, R. S., CUTRONA, C. E., HICKLIN, D., RUSSELL, D. W. & LUBAROFF, D. M. 1990. Social support and immune function among spouses of cancer patients. *J Pers Soc Psychol,* 59**,** 344-52.

BARRERA, M. 1981. Social support in the adjustment of pregnant adolescent assessment issues. *In:* GOTTLIEB, B. H. (ed.) *Social networks and social support.* Beverly Hills, California: Sage publications.

BAUMEISTER, R., CAMPBELL, J., KREUGER, J. & VOHS, K. 2003. Does high self-esteem cause better performance, interpersonal success, happiness or healthier lifestyle? *Pyschological Science in the Public Interest,* 4**,** 1-44.

BAUMEISTER, R. F. & LEARY, M. R. 1995. The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychol Bull,* 117**,** 497-529.

BECKLEY, M. 2007. The influence of quality and quantity of social support in the promotion of community participation following stroke. *Australian Occupational Therapy Journal,* 54**,** 215-220.

BELANGER, L., BOLDUC, M. & NOEL, M. 1988. Relative importance of after-effects, environment and socio-economic factors on the social integration of stroke victims. *Int J Rehabil Res,* 11**,** 251-60.

BELSEY, D. A., KUH, E. & WELSCH, R. 1980. *Regression diagnostics: identifying influential data and sources of collinearity,* New York, Wiley.

BENGSTON, V. & KUYPERS, J. 1985. The family support cycle: psychosocial issues in the aging family. *In:* MUNNICHS, J., MUSEEN, P., OLBRICH, E. & COLEMAN, P. (eds.) *Life-span and change in a a gerontological perspective.* Orlando, FL: Academic Press.

BERKMAN, L. F. 1988. The changing and heterogeneous nature of aging and longevity: a social and biomedical perspective. *Annu Rev Gerontol Geriatr,* 8**,** 37-68.

BERKMAN, L. F., BLUMENTHAL, J., BURG, M., CARNEY, R. M., CATELLIER, D., COWAN, M. J., CZAJKOWSKI, S. M., DEBUSK, R., HOSKING, J., JAFFE, A., KAUFMANN, P. G., MITCHELL, P., NORMAN, J., POWELL, L. H., RACZYNSKI, J. M. & SCHNEIDERMAN, N. 2003. Effects of treating depression and low perceived social support on clinical events after myocardial infarction: the Enhancing Recovery in Coronary Heart Disease Patients (ENRICHD) Randomized Trial. *JAMA,* 289**,** 3106-16.

BERKMAN, L. F., GLASS, T., BRISSETTE, I. & SEEMAN, T. E. 2000. From social integration to health: Durkheim in the new millennium. *Soc Sci Med,* 51**,** 843-57.

BERKMAN, L. F. & SYME, S. L. 1979. Social networks, host resistance, and mortality: a nine-year follow-up study of Alameda County residents. *Am J Epidemiol,* 109**,** 186-204.

BERZON, R., HAYS, R. D. & SHUMAKER, S. A. 1993. International use, application and performance of health-related quality of life instruments. *Qual Life Res,* 2**,** 367-8.

BLACK, N. 2013. Patient reported outcome measures could help transform healthcare. *BMJ,* 346**,** f167.

BODEN-ALBALA, B., LITWAK, E., ELKIND, M. S., RUNDEK, T. & SACCO, R. L. 2005. Social isolation and outcomes post stroke. *Neurology,* 64**,** 1888-92.

BOLGER, N., FOSTER, M., VINOKUR, A. D. & NG, R. 1996. Close relationships and adjustment to a life crisis: the case of breast cancer. *J Pers Soc Psychol,* 70**,** 283-94.

BOTT, E. 1957. *Family and social network,* London, Tavistock Press.

BOWLBY, J. 1969. *Attachment and loss,* London, Hogarth Press.

BOWLBY, J. 1980. *Attachment and loss: vol 3. Loss: sadness and depression,* London, Hogarth.

BOWLING, A. 1997. *Measuring health. A review of quality of life measurement scales,* Buckingham UK, Open University Press.

BOWLING, A. 2004. Data collection methods in quantitative research: questionnaires, interviews and their response rates. *Research methods in health: investigating health and health services.* Maidenhead: Open University Press.

BOYNTON DE SEPULVEDA, L. I. & CHANG, B. 1994. Effective coping with stroke disability in a community setting: the development of a causal model. *J Neurosci Nurs,* 26**,** 193-203.

BOYRAZ, G., HORNE, S. & SAYGER, T. 2012. Finding meaning in loss: the mediating role of social support between personality and two construals of meaning. *Death Studies,* 36**,** 519-540.

BREEN, L. & O'CONNOR, M. A. 2011. Family and social networks after bereavement: experiences of support, change and isolation. *Journal of Family Therapy,* 33**,** 98-120.

BROSSEAU, L., POTVIN, L., PHILIPPE, P. & BOULANGER, Y. L. 1996. Post-stroke inpatient rehabilitation. II. Predicting discharge disposition. *Am J Phys Med Rehabil,* 75**,** 431-6.

BROTT, T., ADAMS, H. P., JR., OLINGER, C. P., MARLER, J. R., BARSAN, W. G., BILLER, J., SPILKER, J., HOLLERAN, R., EBERLE, R., HERTZBERG, V. & ET AL. 1989. Measurements of acute cerebral infarction: a clinical examination scale. *Stroke,* 20**,** 864-70.

BROWN, K., DAVIDSON, B., WORRALL, L. E. & HOWE, T. 2013. "Making a good time": the role of friendship in living successfully with aphasia. *Int J Speech Lang Pathol,* 15**,** 165-75.

BROWN, K., WORRALL, L., DAVIDSON, B. & HOWE, T. 2010. Snapshots of success: an insider perspective on living successfully with aphasia. *Aphasiology,* 24**,** 1267-1295.

BROWN, K., WORRALL, L. E., DAVIDSON, B. & HOWE, T. 2012. Living successfully with aphasia: a qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *Int J Speech Lang Pathol,* 14**,** 141-55.

BRUMFITT, S. 1995. Psychotherapy in aphasia. *In:* CODE, C. & MULLER, D. J. (eds.) *Treatment of aphasia: From theory to practice.* London: Whurr.

BRUMFITT, S. 2010. Introduction. *In:* BRUMFITT, S. (ed.) *Psychological well-being and acquired communication impairments.* Chichester, UK: Wiley-Blackwell.

BRYMAN, A. 2004. *Social research methods,* Oxford, Oxford University Press.

BURHOLT, V., WENGER, C., SCOTT, A., YAHYA, B. & ROY, S. 2000. Bangladeshi immigration to the United Kingdom: Older people's support networks in the sending and receiving countries. *Quality in Ageing and Older Adults,* 1**,** 18-30.

BURNS, K. 2010. Solution-focused brief therapy for people with acquired communication impairments. *In:* BRUMFITT, S. (ed.) *Psychological well-being and acquired communication impairment.* Chichester, UK, Wiley-Blackwell.

BURNS, R. P. & BURNS, R. 2008. *Business Research Methods and Statistics Using SPSS,* London, Sage.

CALHOUN, C. 2002. *Critical sociological theory,* New Jersey, Wiley-Blackwell.

CAMPBELL, R., POUND, P., POPE, C., BRITTEN, N., PILL, R., MORGAN, M. & DONOVAN, J. 2003. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med,* 56**,** 671-84.

CAROD-ARTAL, F. J. & EGIDO, J. A. 2009. Quality of life after stroke: the importance of a good recovery. *Cerebrovasc Dis,* 27 Suppl 1**,** 204-14.

CARPENTER, K. M., FOWLER, J. M., MAXWELL, G. L. & ANDERSEN, B. L. 2010. Direct and buffering effects of social support among gynecologic cancer survivors. *Ann Behav Med,* 39**,** 79-90.

CARSTENSEN, L. L. & FREDRICKSON, B. L. 1998. Influence of HIV status and age on cognitive representations of others. *Health Psychol,* 17**,** 494-503.

CARSTENSEN, L. L., ISAACOWITZ, D. M. & CHARLES, S. T. 1999. Taking time seriously. A theory of socioemotional selectivity. *Am Psychol,* 54**,** 165-81.

CENTRE FOR REVIEWS AND DISSEMINATION 2009. Systematic reviews: CRD's guidance for undertaking reviews in healthcare. Centre for Reviews and Dissemination: University of York.

CH'NG, A. M., FRENCH, D. & MCLEAN, N. 2008. Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members. *J Health Psychol,* 13**,** 1136-46.

CHANG, A., MACKENZIE, A. E., YIP, M. & R, D. 1999. The psychosocial impact of stroke. *Journal of Clinical Nursing,* 8**,** 477-481.

CHAU, J. P., THOMPSON, D. R., CHANG, A. M., WOO, J., TWINN, S., CHEUNG, S. K. & KWOK, T. 2010. Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital. *J Clin Nurs,* 19**,** 3042-50.

CHENG, S. T., LEE, C. K., CHAN, A. C., LEUNG, E. M. & LEE, J. J. 2009. Social network types and subjective well-being in Chinese older adults. *J Gerontol B Psychol Sci Soc Sci,* 64**,** 713-22.

CHOI-KWON, S. & KIM, J. S. 2011. Poststroke fatigue: an emerging, critical issue in stroke medicine. *Int J Stroke,* 6**,** 328-36.

CLAIBORNE, N. 2006. Effectiveness of a care coordination model for stroke survivors: a randomized study. *Health Soc Work,* 31**,** 87-96.

CLARK, M. S. & SMITH, D. S. 1999. Changes in family functioning for stroke rehabilitation patients and their families. *Int J Rehabil Res,* 22**,** 171-9.

COBB, S. 1976. Presidential Address-1976. Social support as a moderator of life stress. *Psychosom Med,* 38**,** 300-14.

CODE, C. 2003. The quantity of life for people with chronic aphasia. *Neuropsychol Rehabil,* 13**,** 379-90.

CODE, C. & HERON, C. 2003. Services for aphasia, other acquired adult neurogenic communication and swallowing disorders in the United Kingdom, 2000. *Disabil Rehabil,* 25**,** 1231-7.

COHEN, J. W. 1988a. *Statistical power analysis for the behavioural sciences,* Hillsdale, NJ, Lawrence Erlbaum Associates.

COHEN, S. 1988b. Psychosocial models of the role of social support in the etiology of physical disease. *Health Psychol,* 7**,** 269-97.

COHEN, S. & WILLS, T. A. 1985. Stress, social support, and the buffering hypothesis. *Psychol Bull,* 98**,** 310-57.

COLANTONIO, A., KASL, S. V., OSTFELD, A. M. & BERKMAN, L. F. 1993. Psychosocial predictors of stroke outcomes in an elderly population. *J Gerontol,* 48**,** S261-8.

COLLIN, C., WADE, D. T., DAVIES, S. & HORNE, V. 1988. The Barthel ADL Index: a reliability study. *Int Disabil Stud,* 10**,** 61-3.

CONNECT. 2013. *Accessed in, http://www.ukconnect.org/about-aphasia.aspx* [Online]. 2013].

COOK, J. V., DICKINSON, H. O. & ECCLES, M. P. 2009. Response rates in postal surveys of healthcare professionals between 1996 and 2005: an observational study. *BMC Health Serv Res,* 9**,** 160.

COOK, R. D. & WEISBERG, S. 1982. *Residuals and influence in regression,* New York, Chapman and Hall.

COOPER, J. M. 1980. Aristotle on friendship. *In:* RORTY, A. (ed.) *Essays on Aristotle's ethics.* Berkeley CA: University of California Press.

COUNSELL, C. & DENNIS, M. 2001. Systematic review of prognostic models in patients with acute stroke. *Cerebrovasc Dis,* 12**,** 159-70.

CRUICE, M. & BUNNING, K. 2004. An introduction – striving for access and inclusive communities: what does it all mean for the person and the profession? . *Presentation at the 11th International Aphasia Rehabilitation Conference.* . Milos, Greece. .

CRUICE, M., WORRALL, L. & HICKSON, L. 2006a. Perspectives of quality of life by people with aphasia and their family: suggestions for successful living. *Top Stroke Rehabil,* 13**,** 14-24.

CRUICE, M., WORRALL, L. & HICKSON, L. 2006b. Quantifying aphasic people's social lives in the context of non-aphasic peers. *Aphasiology,* 17**,** 333-353.

CRUICE, M., WORRALL, L., HICKSON, L. & MURISON, R. 2003. Finding a focus for quality of life with aphasia: social and emotional health and psychological well-being. *Aphasiology,* 17**,** 333-353.

CRUICE, M., WORRALL, L., HICKSON, L. & MURISON, R. 2005. Measuring quality of life: comparing family members' and friends' ratings with those of their aphasic partners. *Aphasiology,* 17**,** 333-353.

DALEMANS, R. J., DE WITTE, L., WADE, D. & VAN DEN HEUVEL, W. 2010. Social participation through the eyes of people with aphasia. *Int J Lang Commun Disord,* 45**,** 537-50.

DAVIDSON, B., HOWE, T., WORRALL, L., HICKSON, L. & TOGHER, L. 2008. Social participation for older people with aphasia: the impact of communication disability on friendships. *Top Stroke Rehabil,* 15**,** 325-40.

DAYAPOGLU, N. & TAN, M. 2010. Quality of life in stroke patients. *Neurol India,* 58**,** 697-701.

DEPARTMENT OF HEALTH 2005. The National Service Framework for Long-term Conditions. London: Department of Health.

DEPARTMENT OF HEALTH 2007. National Stroke Strategy. Accessed in, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081062.

DESROSIERS, J., NOREAU, L., ROCHETTE, A., BOURBONNAIS, D., BRAVO, G. & BOURGET, A. 2006. Predictors of long-term participation after stroke. *Disabil Rehabil,* 28**,** 221-30.

DEVRIES, A. C., CRAFT, T. K., GLASPER, E. R., NEIGH, G. N. & ALEXANDER, J. K. 2007. 2006 Curt P. Richter award winner: Social influences on stress responses and health. *Psychoneuroendocrinology,* 32**,** 587-603.

DITZEN, B. & HEINRICHS, M. 2013. Psychobiology of social support: The social dimension of stress buffering. *Restor Neurol Neurosci*.

DIXON-WOODS, M., AGARWAL, S., JONES, D., YOUNG, B. & SUTTON, A. 2005. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy,* 10**,** 45-53.

DIXON-WOODS, M., BOOTH, A. & SUTTON, A. 2007. Synthesising qualitative research: a review of published reports. *Qualitative Research,* 7**,** 375-422.

DIXON-WOODS, M. & FITZPATRICK, R. 2001. Qualitative research in systematic reviews. Has established a place for itself. *BMJ,* 323**,** 765-6.

DIXON-WOODS, M., FITZPATRICK, R. & ROBERTS, K. 2001. Including qualitative research in systematic reviews: opportunities and problems. *J Eval Clin Pract,* 7**,** 125-33.

DONNE, J. 2001. *The complete poetry and selected prose of John Donne,* New York, Random House.

DOWSWELL, G., LAWLER, J., DOWSWELL, T., YOUNG, J., FORSTER, A. & HEARN, J. 2000. Investigating recovery from stroke: a qualitative study. *J Clin Nurs,* 9**,** 507-15.

DOYLE, L. 2003. Synthesis through meta-ethnography: paradoxes, enhancements, and possibilities. *Qualitative Research,* 3**,** 321-344.

DRUMMOND, A. & WALKER, M. 1996. Generalization of the effects of leisure rehabilitation for stroke patients. *British Journal of Occupational Therapy,* 59**,** 330-334.

DUE, P., HOLSTEIN, B., LUND, R., MODVIG, J. & AVLUND, K. 1999. Social relations: network, support and relational strain. *Soc Sci Med,* 48**,** 661-73.

DUPERTUIS, L. L., ALDWIN, C. M. & BOSSE, R. 2001. Does the source of support matter for different health outcomes? Findings from the Normative Aging Study. *J Aging Health,* 13**,** 494-510.

DURKHEIM, E. 1987, translated (1952). *Suicide: a study in sociology,* London, Routledge.

ELMAN, R., OGAR, J. & ELMAN, S. 2000. Aphasia: Awareness, advocacy, and activism. *Aphasiology,* 14**,** 455-459.

ENDERBY, P. & CROW, E. 1996. Frenchay Aphasia Screening Test: validity and comparability. *Disabil Rehabil,* 18**,** 238-40.

ENDERBY, P., WOOD, V. & WADE, D. 1987a. *Frenchay Aphasia Screening Test,* Windsor UK, NFEW-Nelson.

ENDERBY, P. M., WOOD, V. A., WADE, D. T. & HEWER, R. L. 1987b. The Frenchay Aphasia Screening Test: a short, simple test for aphasia appropriate for non-specialists. *Int Rehabil Med,* 8**,** 166-70.

ENGELTER, S. T., GOSTYNSKI, M., PAPA, S., FREI, M., BORN, C., AJDACIC-GROSS, V., GUTZWILLER, F. & LYRER, P. A. 2006. Epidemiology of aphasia attributable to first ischemic stroke: incidence, severity, fluency, etiology, and thrombolysis. *Stroke,* 37**,** 1379-84.

EVANS, R. L., MATLOCK, A. L., BISHOP, D. S., STRANAHAN, S. & PEDERSON, C. 1988. Family intervention after stroke: does counseling or education help? *Stroke,* 19**,** 1243-9.

EVERITT, B., LANDAU, S., LEESE, M. & STAHL, D. 2011. *Cluster Analysis,* Chichester, John Wiley & Sons.

FEIBEL, J. H. & SPRINGER, C. J. 1982. Depression and failure to resume social activities after stroke. *Arch Phys Med Rehabil,* 63**,** 276-7.

FIELD, A. 2000a. *Discovering statistics using SPSS for Windows,* London, Sage.

FIELD, A. 2000b. *Postgraduate Statistics: Cluster Analysis* [Online]. Accessed in, http://www.statisticshell.com/docs/cluster.pdf. 2013

FIELD, A. 2013. *Discovering statistics using IBM SPSS Statistics,* London, Sage.

FIELD, A., MILES, J. & FIELD, Z. 2012. *Discovering statistics using R,* London, Sage.

FIORI, K. L., ANTONUCCI, T. C. & AKIYAMA, H. 2008. Profiles of social relations among older adults: a cross sectional approach. *Ageing and Society,* 28**,** 203-231.

FIORI, K. L., ANTONUCCI, T. C. & CORTINA, K. S. 2006. Social network typologies and mental health among older adults. *J Gerontol B Psychol Sci Soc Sci,* 61**,** P25-32.

FLYNN, L., CUMBERLAND, A. & MARSHALL, J. 2009. Public knowledge about aphasia: A survey with comparative data. *Aphasiology,* 23**,** 393-401.

FREDRICKSON, B. L. & CARSTENSEN, L. L. 1990. Choosing social partners: how old age and anticipated endings make people more selective. *Psychol Aging,* 5**,** 335-47.

FRIEDLAND, J. & MCCOLL, M. 1987. Social support and psychosocial dysfunction after stroke: buffering effects in a community sample. *Arch Phys Med Rehabil,* 68**,** 475-80.

FRIEDLAND, J. F. & MCCOLL, M. 1992. Social support intervention after stroke: results of a randomized trial. *Arch Phys Med Rehabil,* 73**,** 573-81.

GANDY, M., SHARPE, L. & PERRY, K. N. 2012. Psychosocial predictors of depression and anxiety in patients with epilepsy: a systematic review. *J Affect Disord,* 140**,** 222-32.

GELMAN, A. & HILL, J. 2007. *Data analysis using regression and multilevel/hierachical models,* Cambridge, Cambridge University Press.

GIBSON, L., MACLENNAN, W. J., GRAY, C. & PENTLAND, B. 1991. Evaluation of a comprehensive assessment battery for stroke patients. *Int J Rehabil Res,* 14**,** 93-100.

GILES, L. C., GLONEK, G. F., LUSZCZ, M. A. & ANDREWS, G. R. 2005. Effect of social networks on 10 year survival in very old Australians: the Australian longitudinal study of aging. *J Epidemiol Community Health,* 59**,** 574-9.

GLASS, T. A. & MADDOX, G. L. 1992. The quality and quantity of social support: stroke recovery as psycho-social transition. *Soc Sci Med,* 34**,** 1249-61.

GLASS, T. A., MATCHAR, D. B., BELYEA, M. & FEUSSNER, J. R. 1993. Impact of social support on outcome in first stroke. *Stroke,* 24**,** 64-70.

GLYMOUR, M. M., WEUVE, J., FAY, M. E., GLASS, T. & BERKMAN, L. F. 2008. Social ties and cognitive recovery after stroke: does social integration promote cognitive resilience? *Neuroepidemiology,* 31**,** 10-20.

GOLDBERG, D. 1972. *The Detection of Psychiatric Illness by Questionnaire.,* London, UK, Oxford University Press.

GOLDBERG, D. & HILLIER, V. 1979. A scaled version of the General Health Questionnaire. *Pyschological Medicine,* 9**,** 139-145.

GOULDNER, A. 1960. The norm of reciprocity: a preliminary statement. *American Sociological Review,* 25**,** 161-178.

GRIFFEN, J. A., RAPPORT, L. J., BRYER, R. C. & SCOTT, C. A. 2009. Driving status and community integration after stroke. *Top Stroke Rehabil,* 16**,** 212-21.

GROHN, B., WORRALL, L. E., SIMMONS-MACKIE, N. & BROWN, K. 2012. The first 3-months post-stroke: what facilitates successfully living with aphasia? *Int J Speech Lang Pathol,* 14**,** 390-400.

HABER, M. G., COHEN, J. L., LUCAS, T. & BALTES, B. B. 2007. The relationship between self-reported received and perceived social support: a meta-analytic review. *Am J Community Psychol,* 39**,** 133-44.

HACKETT, M. L. & ANDERSON, C. S. 2005. Predictors of depression after stroke: a systematic review of observational studies. *Stroke,* 36**,** 2296-301.

HACKETT, M. L., ANDERSON, C. S., HOUSE, A. & XIA, J. 2008. Interventions for treating depression after stroke. *Cochrane Database Syst Rev***,** CD003437.

HACKETT, M. L., YAPA, C., PARAG, V. & ANDERSON, C. S. 2005. Frequency of depression after stroke: a systematic review of observational studies. *Stroke,* 36**,** 1330-40.

HAIR, J. H. & BLACK, W. C. 2000. Cluster analysis. *In:* GRIMM, L. G. & YARNOLD, P. R. (eds.) *Reading and understanding more multivariate statistics.* Washington, DC: American Pyschological Association.

HARTUP, W. & STEVENS, N. 1999. Friendships and adaptation across the life span. *Current Directions in Pyschological Science,* 8**,** 76-79.

HAUN, J., RITTMAN, M. R. & SBERNA, M. 2008. The continnum of connectedness and social isolation during post stroke recovery. *Journal of Aging Studies,* 22**,** 54-64.

HILARI, K. 2002. *Assessing health-related quality of life in people with aphasia.* Unpublished PhD, City University.

HILARI, K. 2011. The impact of stroke: are people with aphasia different to those without? *Disabil Rehabil,* 33**,** 211-8.

HILARI, K. & BYNG, S. 2001. Measuring quality of life in people with aphasia: the Stroke Specific Quality of Life Scale. *Int J Lang Commun Disord,* 36 Suppl**,** 86-91.

HILARI, K., BYNG, S., LAMPING, D. L. & SMITH, S. C. 2003a. Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39): evaluation of acceptability, reliability, and validity. *Stroke,* 34**,** 1944-50.

HILARI, K., LAMPING, D. L., SMITH, S. C., NORTHCOTT, S., LAMB, A. & MARSHALL, J. 2009. Psychometric properties of the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in a generic stroke population. *Clin Rehabil,* 23**,** 544-57.

HILARI, K., NEEDLE, J. J. & HARRISON, K. L. 2012. What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Arch Phys Med Rehabil,* 93**,** S86-95.

HILARI, K. & NORTHCOTT, S. 2006. Social support in people with chronic aphasia. *Aphasiology,* 20**,** 17-36.

HILARI, K., NORTHCOTT, S., ROY, P., MARSHALL, J., WIGGINS, R. D., CHATAWAY, J. & AMES, D. 2010. Psychological distress after stroke and aphasia: the first six months. *Clin Rehabil,* 24**,** 181-90.

HILARI, K., OWEN, S. & FARRELLY, S. J. 2007. Proxy and self-report agreement on the Stroke and Aphasia Quality of Life Scale-39. *J Neurol Neurosurg Psychiatry,* 78**,** 1072-5.

HILARI, K., WIGGINS, R. D. & ROY, P. 2003b. Predictors of health-related quality of life (HRQL) in people with chronic aphasia. *Aphasiology,* 17**,** 365-381.

HINCKLEY, J. J. 2006. Finding messages in bottles: living successfully with stroke and aphasia. *Top Stroke Rehabil,* 13**,** 25-36.

HOGAN, N. S. & SCHMIDT, L. A. 2002. Testing the grief to personal growth model using structural equation modeling. *Death Stud,* 26**,** 615-34.

HOLMES, J. 1993. *John Bowlby and the attachment theory,* London, Routledge.

HOLT-LUNSTAD, J. & SMITH, T. 2012. Social relationships and mortality. *Social and personality psychology,* 6**,** 41-53.

HOLT-LUNSTAD, J., UCHINO, B. N., SMITH, T. W., OLSON-CERNY, C. & NEALEY-MOORE, J. B. 2003. Social relationships and ambulatory blood pressure: structural and qualitative predictors of cardiovascular function during everyday social interactions. *Health Psychol,* 22**,** 388-97.

HOMMEL, M., MIGUEL, S. T., NAEGELE, B., GONNET, N. & JAILLARD, A. 2009a. Cognitive determinants of social functioning after a first ever mild to moderate stroke at vocational age. *J Neurol Neurosurg Psychiatry,* 80**,** 876-80.

HOMMEL, M., TRABUCCO-MIGUEL, S., JORAY, S., NAEGELE, B., GONNET, N. & JAILLARD, A. 2009b. Social dysfunctioning after mild to moderate first-ever stroke at vocational age. *J Neurol Neurosurg Psychiatry,* 80**,** 371-5.

HOUSE, J. 1987. Social support and social structure. *Sociological Forum,* 2**,** 135-146.

HOUSE, J. S. 1981. *Work, stress and social support,* Reading MA, Addison-Wesly.

HOUSE, J. S., LANDIS, K. R. & UMBERSON, D. 1988. Social relationships and health. *Science,* 241**,** 540-5.

HOUSE, J. S., ROBBINS, C. & METZNER, H. L. 1982. The association of social relationships and activities with mortality: prospective evidence from the Tecumseh Community Health Study. *Am J Epidemiol,* 116**,** 123-40.

HUANG, C. Y., HSU, M. C., HSU, S. P., CHENG, P. C., LIN, S. F. & CHUANG, C. H. 2010. Mediating roles of social support on poststroke depression and quality of life in patients with ischemic stroke. *J Clin Nurs,* 19**,** 2752-62.

IKKINK, K., VAN TILBURG, T. & KNIPSCHEER, K. 1999. Perceived instrumental support exchanges in relationships between elderly parents and their adult children: normative and structural explanations. *Journal of marriage and the family,* 61**,** 831-844.

INTERCOLLEGIATE STROKE WORKING PARTY 2008. National Clinical Guidelines for Stroke. 3rd ed. London, UK.

INTERCOLLEGIATE STROKE WORKING PARTY 2012. National clinical guideline for stroke. London: Royal College of Physicians.

JOHNSON, G., BURVILL, P. W., ANDERSON, C. S., JAMROZIK, K., STEWART-WYNNE, E. G. & CHAKERA, T. M. 1995. Screening instruments for depression and anxiety following stroke: experience in the Perth community stroke study. *Acta Psychiatr Scand,* 91**,** 252-7.

JONGBLOED, L. & MORGAN, D. 1991. An investigation of involvement in leisure activities after a stroke. *Am J Occup Ther,* 45**,** 420-7.

KAGAN, A., BLACK, S. E., DUCHAN, F. J., SIMMONS-MACKIE, N. & SQUARE, P. 2001. Training volunteers as conversation partners using "Supported Conversation for Adults with Aphasia" (SCA): a controlled trial. *J Speech Lang Hear Res,* 44**,** 624-38.

KAMARCK, T. W., MANUCK, S. B. & JENNINGS, J. R. 1990. Social support reduces cardiovascular reactivity to psychological challenge: a laboratory model. *Psychosom Med,* 52**,** 42-58.

KASNER, S. E., CHALELA, J. A., LUCIANO, J. M., CUCCHIARA, B. L., RAPS, E. C., MCGARVEY, M. L., CONROY, M. B. & LOCALIO, A. R. 1999. Reliability and validity of estimating the NIH stroke scale score from medical records. *Stroke,* 30**,** 1534-7.

KAUHANEN, M. L., KORPELAINEN, J. T., HILTUNEN, P., MAATTA, R., MONONEN, H., BRUSIN, E., SOTANIEMI, K. A. & MYLLYLA, V. V. 2000. Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovasc Dis,* 10**,** 455-61.

KAWACHI, I. & BERKMAN, L. F. 2001. Social ties and mental health. *J Urban Health,* 78**,** 458-67.

KIM, P., WARREN, S., MADILL, H. & HADLEY, M. 1999. Quality of life of stroke survivors. *Qual Life Res,* 8**,** 293-301.

KING, R. B. 1996. Quality of life after stroke. *Stroke,* 27**,** 1467-72.

KING, R. B., SHADE-ZELDOW, Y., CARLSON, C. E., FELDMAN, J. L. & PHILIP, M. 2002. Adaptation to stroke: a longitudinal study of depressive symptoms, physical health, and coping process. *Top Stroke Rehabil,* 9**,** 46-66.

KIRKEVOLD, M., CHRISTENSEN, D., ANDERSEN, G., JOHANSEN, S. P. & HARDER, I. 2012. Fatigue after stroke: manifestations and strategies. *Disabil Rehabil,* 34**,** 665-70.

KISHI, Y., ROBINSON, R. G. & KOSIER, J. T. 1996. Suicidal plans in patients with stroke: comparison between acute-onset and delayed-onset suicidal plans. *Int Psychogeriatr,* 8**,** 623-34.

KNAPP, P. & HEWISON, J. 1998. The protective effects of social support against mood disorder after stroke. *Pyschology, Health and Medicine,* 3**,** 275-283.

KRAUSE, N. 1987. Life stress, social support, and self-esteem in an elderly population. *Psychol Aging,* 2**,** 349-56.

LABI, M. L., PHILLIPS, T. F. & GRESHMAN, G. E. 1980. Psychosocial disability in physically restored long-term stroke survivors. *Arch Phys Med Rehabil,* 61**,** 561-5.

LAM, S. C., LEE, L. Y. & TO, K. W. 2010. Depressive symptoms among community-dwelling, post-stroke elders in Hong Kong. *Int Nurs Rev,* 57**,** 269-73.

LANDAU, R. & LITWIN, H. 2001. Subjective well-being among the old-old: the role of health, personality and social support. *Int J Aging Hum Dev,* 52**,** 265-80.

LAZARUS, R. & FOLKMAN, S. 1984. *Stress, appraisal, and coping,* New York, Springer.

LEAL, J., LUENGO-FERNANDEZ, R., GRAY, A., PETERSEN, S. & RAYNER, M. 2006. Economic burden of cardiovascular diseases in the enlarged European Union. *Eur Heart J,* 27**,** 1610-9.

LEDORZE, G. & BRASSARD, C. 1995. A description of the consequences of aphasia on aphasic persons and their relatives and friends, based on the WHO model of chronic diseases. *Aphasiology,* 9**,** 239-255.

LEE, G., NETZER, J. & COWARD, R. 1995. Depression among older parents: the role of intergenerational exchange. *Journal of Marriage and the Family,* 57**,** 823-833.

LEE, G. R. & SHEHAN, C. L. 1989. Social relations and the self-esteem of older persons. *Res Aging,* 11**,** 427-42.

LEE, M. K., PARK, S., LEE, E. S., RO, J., KANG, H. S., SHIN, K. H., LEE, K. S., CHUNG, K. W., KIM, S. W. & YUN, Y. H. 2011. Social support and depressive mood 1 year after diagnosis of breast cancer compared with the general female population: a prospective cohort study. *Support Care Cancer,* 19**,** 1379-92.

LEGARD, R., KEEGAN, J. & WARD, K. 2003. In-depth interviews. *In:* RITCHIE, J. & LEWIS, J. (eds.) *Qualitative research practice: a guide for social science students and researchers.* London: Sage.

LEON, C. F. M. D., GOLD, D. T., GLASS, T. A., L., K. & GEORGE, L. K. 2001. Disability as a function of social networks and support in elderly African Americans and Whites: The Duke EPESE 1986-1992. *Journal of Gerontology: Social Sciences,* 56B S179-S190.

LEPORE, S. J. 1995. Cynicism, social support, and cardiovascular reactivity. *Health Psychol,* 14**,** 210-6.

LEWIS, J. 2003. Design Issues. *In:* RITCHIE, J. & LEWIS, J. (eds.) *Qualitative research practice: a guide for social science students and researchers.* London: Sage.

LI, L., YOUNG, D. & HU, Z. 2001. Longitudinal study of quality of life following stroke. *Hong Kong J Psychiatry,* 11**,** 17-22.

LI, S. C., WANG, K. Y. & LIN, J. C. 2003. Depression and related factors in elderly patients with occlusion stroke. *J Nurs Res,* 11**,** 9-18.

LIBERATI, A., ALTMAN, D. G., TETZLAFF, J., MULROW, C., GOTZSCHE, P. C., IOANNIDIS, J. P., CLARKE, M., DEVEREAUX, P. J., KLEIJNEN, J. & MOHER, D. 2009. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *Ann Intern Med,* 151**,** W65-94.

LIN, N., DEAN, A. & ENSEL, W. M. 1981. Social support scales: a methodological note. *Schizophr Bull,* 7**,** 73-89.

LITWIN, H. 2001. Social network type and morale in old age. *Gerontologist,* 41**,** 516-24.

LITWIN, H. 2003. Social predictors of physical activity in later life: the contribution of social-network type. *Journal of Aging and Physical Activity,* 11**,** 389-406.

LITWIN, H. 2011. The association between social network relationships and depressive symptoms among older Americans: what matters most? *Int Psychogeriatr***,** 1-11.

LITWIN, H. 2012. Physical activity, social network type, and depressive symptoms in late life: an analysis of data from the National Social Life, Health and Aging Project. *Aging Ment Health,* 16**,** 608-16.

LITWIN, H. & SHIOVITZ-EZRA, S. 2011. Social network type and subjective well-being in a national sample of older Americans. *Gerontologist,* 51**,** 379-88.

LOFLAND, J. & LOFLAND, L. H. 1995. *Analyzing social settings,* Belmont, CA, Wadsworth.

LYDEN, P., LU, M., JACKSON, C., MARLER, J., KOTHARI, R., BROTT, T. & ZIVIN, J. 1999. Underlying structure of the National Institutes of Health Stroke Scale: results of a factor analysis. NINDS tPA Stroke Trial Investigators. *Stroke,* 30**,** 2347-54.

LYDEN, P., RAMAN, R., LIU, L., GROTTA, J., BRODERICK, J., OLSON, S., SHAW, S., SPILKER, J., MEYER, B., EMR, M., WARREN, M. & MARLER, J. 2005. NIHSS training and certification using a new digital video disk is reliable. *Stroke,* 36**,** 2446-9.

LYON, J., CARISKI, D., KEISLER, L., ROSENBEK, J., LEVINE, R., KUMPULA, J., RYFF, C., COYNE, S. & BLANC, M. 1997. Communication partners: enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology,* 11**,** 693-708.

MACKENZIE, A. E. & CHANG, A. M. 2002. Predictors of quality of life following stroke. *Disabil Rehabil,* 24**,** 259-65.

MAHONEY, F. I., WOOD, O. H. & BARTHEL, D. W. 1958. Rehabilitation of chronically ill patients: the influence of complications on the final goal. *South Med J,* 51**,** 605-9.

MAISEL, N. C. & GABLE, S. L. 2009. The paradox of received social support: the importance of responsiveness. *Psychol Sci,* 20**,** 928-32.

MARTINA, C. M. & STEVENS, N. L. 2006. Breaking the cycle of loneliness? Psychological effects of a friendship enrichment program for older women. *Aging Ment Health,* 10**,** 467-75.

MARTIRE, L. M., SCHULZ, R., HELGESON, V. S., SMALL, B. J. & SAGHAFI, E. M. 2010. Review and meta-analysis of couple-oriented interventions for chronic illness. *Ann Behav Med,* 40**,** 325-42.

MAYS, N., POPE, C. & POPAY, J. 2005. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *J Health Serv Res Policy,* 10 Suppl 1**,** 6-20.

MCCOLL, M. A. & FRIEDLAND, J. 1995. The effects of age and disability on social support. *Int J Rehabil Res,* 18**,** 325-40.

MCDOWELL, I. & NEWELL, C. 1996. *Measuring health: a guide to rating scales and questionnaires,* Oxford, Oxford University Press.

MEIJER, R., VAN LIMBEEK, J., KRIEK, B., IHNENFELDT, D., VERMEULEN, M. & DE HAAN, R. 2004. Prognostic social factors in the subacute phase after a stroke for the discharge destination from the hospital stroke-unit. A systematic review of the literature. *Disabil Rehabil,* 26**,** 191-7.

MENARD, S. 1995. Applied logistic regression analysis. *Sage university paper series on quantitative applications in the social sciences.* Thousand Oaks, CA: Sage.

MEYER, B. C., HEMMEN, T. M., JACKSON, C. M. & LYDEN, P. D. 2002. Modified National Institutes of Health Stroke Scale for use in stroke clinical trials: prospective reliability and validity. *Stroke,* 33**,** 1261-6.

MICHAEL, K. M., ALLEN, J. K. & MACKO, R. F. 2006. Fatigue after stroke: relationship to mobility, fitness, ambulatory activity, social support, and falls efficacy. *Rehabil Nurs,* 31**,** 210-7.

MITCHELL, I., EVANS, L., REES, T. & HARDY, L. 2013. Stressors, social support, and tests of the buffering hypothesis: Effects on psychological responses of injured athletes. *Br J Health Psychol*.

MOHER, D., LIBERATI, A., TETZLAFF, J. & ALTMAN, D. G. 2009. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med,* 151**,** 264-9, W64.

MORRIS, P. L., ROBINSON, R. G., RAPHAEL, B. & BISHOP, D. 1991. The relationship between the perception of social support and post-stroke depression in hospitalized patients. *Psychiatry,* 54**,** 306-16.

MOYER, A. & SALOVEY, P. 1999. Predictors of social support and psychological distress in women with breast cancer. *J Health Psychol,* 4**,** 177-91.

MUIR, K. W., WEIR, C. J., MURRAY, G. D., POVEY, C. & LEES, K. R. 1996. Comparison of neurological scales and scoring systems for acute stroke prognosis. *Stroke,* 27**,** 1817-20.

MYERS, R. 1990. *Classical and modern regression with applications,* Boston, MA, Duxbury.

NATIONAL AUDIT OFFICE 2005. Reducing brain damage: faster access to better stroke care. London: National Audit Office.

NATIONAL AUDIT OFFICE 2010. Progress in improving stroke care. London: National Audit Office.

NHS EXECUTIVE 1999. Clinical Governance in the NHS. London: NHS Executive Quality Management Branch.

NOBLITT, G. & RD, H. 1988. *Meta-ethnography, synthesising qualitative studies,* London, Sage publications.

NOLEN-HOEKSAMA, S., PARKER, L. & LARSON, J. 1994. Ruminative coping with depressed mood following loss. *Journal of Personality and Social Pyschology,* 67**,** 92-104.

NORRIS, V. K., STEPHENS, M. A. & KINNEY, J. M. 1990. The impact of family interactions on recovery from stroke: help or hindrance? *Gerontologist,* 30**,** 535-42.

NORTHCOTT, S. & HILARI, K. 2011. Why do people lose their friends after a stroke? *Int J Lang Commun Disord,* 46**,** 524-34.

NORTHCOTT, S. & HILARI, K. in press. Stroke Social Network Scale: development and psychometric evaluation of a new patient-reported measure. *Clinical Rehabilitation*.

NORUŠIS, M. J. 2008. *SPSS 16.0 Statistical Procedures Companion,* Upper Saddle River, NJ, Prentice Hall.

NOYES, J. & POPAY, J. 2007. Directly observed therapy and tuberculosis: how can a systematic review of qualitative research contribute to improving services? A qualitative meta-synthesis. *J Adv Nurs,* 57**,** 227-43.

O'REILLY, P. 1988. Methodological issues in social support and social network research. *Soc Sci Med,* 26**,** 863-73.

OFFICE OF NATIONAL STATISTICS 1998. Mortality statistics causes, England and Wales, 1997. Office of National Statistics.

OSBERG, J. S., DEJONG, G., HALEY, S. M., SEWARD, M. L., MCGINNIS, G. E. & GERMAINE, J. 1988. Predicting long-term outcome among post-rehabilitation stroke patients. *Am J Phys Med Rehabil,* 67**,** 94-103.

OSTWALD, S. K., BERNAL, M. P., CRON, S. G. & GODWIN, K. M. 2009. Stress experienced by stroke survivors and spousal caregivers during the first year after discharge from inpatient rehabilitation. *Top Stroke Rehabil,* 16**,** 93-104.

OWOLABI, M. O. 2010. What are the consistent predictors of generic and specific post-stroke health-related quality of life? *Cerebrovasc Dis,* 29**,** 105-10.

PALLANT, J. 2007. *SPSS Survival Manual,* Berkshire, Open University Press.

PARKES, C. 1996. *Bereavement: studies in grief in adult life,* Harmondsworth, Penguin Books.

PARKES, C. M. 1971. Psycho-social transitions: a field for study. *Soc Sci Med,* 5**,** 101-15.

PARR, S. 2007. Living with severe aphasia: tracking social exclusion. *Aphasiology,* 21**,** 98-123.

PARR, S., BYNG, S. & GILPIN, S. 1997. *Talking about aphasia,* Buckingham UK, Open University Press.

PAWSON, N., RAHGAVAN, R. & SMALL, N. 2005. Social inclusion, social networks and ethnicity: the development of the Social Inclusion Interview Schedule for young people with learning disabilities. *British Journal of Learning Disabilities,* 33**,** 15-22.

PERRY, L. & MCLAREN, S. 2004. An exploration of nutrition and eating disabilities in relation to quality of life at 6 months post-stroke. *Health Soc Care Community,* 12**,** 288-97.

PHILP, I., LOWLES, R. V., ARMSTRONG, G. K. & WHITEHEAD, C. 2002. Repeatability of standardized tests of functional impairment and well-being in older people in a rehabilitation setting. *Disabil Rehabil,* 24**,** 243-9.

PINQUART, M. & SORENSEN, S. 2000. Influences of socioeconomic status, social network, and competence on subjective well-being in later life: a meta-analysis. *Psychol Aging,* 15**,** 187-224.

POPE, C., MAYS, N. & POPPAY, J. 2007. *Synthesizing qualitative and quantitative health evidence: a guide to methods.,* Maidenhead, Open University Press.

POST, M. W. & VAN LEEUWEN, C. M. 2012. Psychosocial issues in spinal cord injury: a review. *Spinal Cord,* 50**,** 382-9.

POUND, P., GOMPERTZ, P. & EBRAHIM, S. 1999. Social and practical strategies described by people living at home with stroke. *Health Soc Care Community,* 7**,** 120-128.

PUBLIC HEALTH RESOURCE UNIT 2004. 12 questions to help you make sense of cohort study. Oxford: Publich Health Resource Unit.

PUBLIC HEALTH RESOURCE UNIT 2006. 10 questions to help you make sense of qualitative research. Oxford: Public Health Resource Unit.

RÉGNIER-LOILIER, A. 2006. How often do adult children see their parents? *Population and Societies,* 427**,** 2-5.

RITCHIE, J. 2003. The applications of qualitative methods to social research. *In:* RITCHIE, J. & LEWIS, J. (eds.) *Qualitative research practice: a guide for social science students and researchers.* London: Sage.

RITCHIE, J., LEWIS, J. & ELAM, G. 2003a. Designing and selecting samples. *In:* RITCHIE, J. & LEWIS, J. (eds.) *Qualitative research practice: a guide for social science students and researchers.* London: Sage.

RITCHIE, J. & SPENCER, L. 1994. Qualitative data analysis for applied policy research. *In:* BRYMAN, A. & BURGESS, R. (eds.) *Analysing qualitative data.* London: Routledge.

RITCHIE, J., SPENCER, L. & O'CONNOR, W. 2003b. Carrying out qualitative analysis. *In:* RITCHIE, J. & LEWIS, J. (eds.) *Qualitative research practice: a guide for social science students and researchers.* London: Sage.

ROBINSON, R. G., MURATA, Y. & SHIMODA, K. 1999. Dimensions of social impairment and their effect on depression and recovery following stroke. *Int Psychogeriatr,* 11**,** 375-84.

ROBINSON, R. G., STARR, L. B., KUBOS, K. L. & PRICE, T. R. 1983. A two-year longitudinal study of post-stroke mood disorders: findings during the initial evaluation. *Stroke,* 14**,** 736-41.

ROBSON, C. 2002. *Real World Research,* Oxford, Blackwell.

ROOK, K. 1990. Social relationships as a source of companionship: implications for older adults psychological well-being. *In:* SARASON, B. R., SARASON, T. G. & PIERCE, G. R. (eds.) *Social support: an interactional view.* New York: Wiley.

ROSE, T. A., WORRALL, L. E., HICKSON, L. M. & HOFFMANN, T. C. 2011. Aphasia friendly written health information: content and design characteristics. *Int J Speech Lang Pathol,* 13**,** 335-47.

ROSS, K. & WERTZ, R. 2003. Quality of life with and without aphasia. *Aphasiology,* 17**,** 355-364.

RUBERMAN, W., WEINBLATT, E., GOLDBERG, J. D. & CHAUDHARY, B. S. 1984. Psychosocial influences on mortality after myocardial infarction. *N Engl J Med,* 311**,** 552-9.

RUBIN, H. J. & RUBIN, I. S. 1995. *Qualitative interviewing: the art of hearing data,* Thousand Oaks, CA, Sage.

RUMMEL, R. J. 1970. *Applied factor analysis,* Evanston, IL, Northwestern University Press.

RUNDEK, T., MAST, H., HARTMANN, A., BODEN-ALBALA, B., LENNIHAN, L., LIN, I. F., PAIK, M. C. & SACCO, R. L. 2000. Predictors of resource use after acute hospitalization: the Northern Manhattan Stroke Study. *Neurology,* 55**,** 1180-7.

SALTER, K., FOLEY, N. & TEASELL, R. 2010. Social support interventions and mood status post stroke: a review. *Int J Nurs Stud,* 47**,** 616-25.

SANDELOWSKI, M. & J, B. 2007. *Handbook for synthesising qualitative research,* New York, Springer.

SARASON, B. R., SARASON, I. G. & SHEARIN, E. N. 1986. Social support as an individual difference variable: its stability, origins, and relational aspects. *J Pers Soc Psychol,* 50**,** 845-855.

SARNO, J. E. & SARNO, M. T. 1969. The diagnosis of speech disorders in brain damaged adults. *Med Clin North Am,* 53**,** 561-73.

SCHARF, T. 1997. Informal support for older people in post-unification East Germany: stability and change. *J Cross Cult Gerontol,* 12**,** 61-72.

SCHLEGEL, D., KOLB, S. J., LUCIANO, J. M., TOVAR, J. M., CUCCHIARA, B. L., LIEBESKIND, D. S. & KASNER, S. E. 2003. Utility of the NIH Stroke Scale as a predictor of hospital disposition. *Stroke,* 34**,** 134-7.

SCHMID, T., BRANDT, M. & HABERKERN, K. 2012. Gendered support to older parents: do welfare states matter? *Eur J Ageing,* 9**,** 39-50.

SCHMULLING, S., GROND, M., RUDOLF, J. & KIENCKE, P. 1998. Training as a prerequisite for reliable use of NIH Stroke Scale. *Stroke,* 29**,** 1258-9.

SCHULING, J., DE HAAN, R., LIMBURG, M. & GROENIER, K. H. 1993. The Frenchay Activities Index. Assessment of functional status in stroke patients. *Stroke,* 24**,** 1173-7.

SCHWARZER, R. & LEPPIN, A. 1991. Social support and health: a theoretical and empirical overview. *Journal of Social and Personal Relationships,* 8**,** 99-127.

SEEMAN, T., BERKMAN, L. F. & ROWE, B. D. J. 1994. Social ties and support and neuroendocrine function. *Ann Behav Med,* 16**,** 95-106.

SEEMAN, T. E. 2000. Health promoting effects of friends and family on health outcomes in older adults. *Am J Health Promot,* 14**,** 362-70.

SEEMAN, T. E. & BERKMAN, L. F. 1988. Structural characteristics of social networks and their relationship with social support in the elderly: who provides support. *Soc Sci Med,* 26**,** 737-49.

SHARPE, M., HAWTON, K., SEAGROATT, V., BAMFORD, J., HOUSE, A., MOLYNEUX, A., SANDERCOCK, P. & WARLOW, C. 1994. Depressive disorders in long-term survivors of stroke. Associations with demographic and social factors, functional status, and brain lesion volume. *Br J Psychiatry,* 164**,** 380-6.

SHEAR, K., FRANK, E., HOUCK, P. R. & REYNOLDS, C. F., 3RD 2005. Treatment of complicated grief: a randomized controlled trial. *JAMA,* 293**,** 2601-8.

SHERBOURNE, C. D. & STEWART, A. L. 1991. The MOS social support survey. *Soc Sci Med,* 32**,** 705-14.

SHERRATT, S. 2011. Written media coverage of aphasia: a review. *Aphasiology,* 25**,** 1132-1152.

SHIOVITZ-EZRA, S. & LITWIN, H. 2012. Social network type and health-related behaviors: evidence from an American national survey. *Soc Sci Med,* 75**,** 901-4.

SINGLETON, R. & STRAITS, B. 1999. *Approaches to social research,* Oxford, Oxford University Press.

SIRRI, L., MAGELLI, C. & GRANDI, S. 2011. Predictors of perceived social support in long-term survivors of cardiac transplant: the role of psychological distress, quality of life, demographic characteristics and clinical course. *Psychol Health,* 26**,** 77-94.

SIT, J. W., WONG, T. K., CLINTON, M. & LI, L. S. 2007. Associated factors of post-stroke depression among Hong Kong Chinese: a longitudinal study. *Psychol Health Med,* 12**,** 117-25.

SPENCER, K., TOMPKINGS, C., SCHULZ, R. & RAU, M. 1995. The psychosocial outcomes of stroke: a longitudinal study of depression risk. *Clinical Aphasiology,* 23**,** 9-23.

SPENCER, L. & PAHL, R. 2006. *Rethinking friendship: hidden solidarities today.,* New Jersery, Princeton University Press.

SPITZE, G. & LOGAN, J. 1990. Sons, daughters, and intergenerational social support. *Journal of Marriage and the Family,* 52**,** 420-430.

STEPHEN, A. & RAFFERTY, J. 1994. *Health Care Needs Assessment,* Oxford, Radcliffe Medical Press.

STEPHENS, M. A., KINNEY, J. M., NORRIS, V. K. & RITCHIE, S. W. 1987. Social networks as assets and liabilities in recovery from stroke by geriatric patients. *Psychol Aging,* 2**,** 125-9.

STEVENS, J. 1992. *Applied multivariate statistics for the social sciences,* Hillsdale, New Jersey, Erlbaum.

STONE, L. & ROSENTHAL, C. 1996. Profiles of the social networks of Canada's elderly: an analysis of the 1990 General Social Survey data. *In:* LITWIN, H. (ed.) *The social networks of older people: a cross-national analysis.* Westport, Conneticut: Praeger.

STREINER, D. L. & NORMAN, G. R. 2008. *Health measurement scales: a practical guide to their development and use,* Oxford UK, Oxford University Press.

STROEBE, M. & SCHUT, H. 1999. The dual process model of coping with bereavement: rationale and description. *Death Stud,* 23**,** 197-224.

STROEBE, M. & SCHUT, H. 2010. The dual process model of coping with bereavement: a decade on. *Omega (Westport),* 61**,** 273-89.

SUMATHIPALA, K., RADCLIFFE, E., SADLER, E., WOLFE, C. D. & MCKEVITT, C. 2012. Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health. *Chronic Illn,* 8**,** 31-44.

SYDER, D., BODY, R., PARKER, M. & BODDY, M. 1993. *Sheffield Screening Test for Acquired Language Disorders,* Windsor, NFER-NELSON.

SYMISTER, P. & FRIEND, R. 2003. The influence of social support and problematic support on optimism and depression in chronic illness: a prospective study evaluating self-esteem as a mediator. *Health Psychol,* 22**,** 123-9.

TABACHNICK, B. G. & FIDELL, L. S. 2007. *Using multivariate statistics,* Boston USA, Pearson Education.

TAYLOR, J. & TURNER, R. J. 2001. A longitudinal study of the role and significance of mattering to others for depressive symptoms. *J Health Soc Behav,* 42**,** 310-25.

TAYLOR, M. G. & LYNCH, S. M. 2004. Trajectories of impairment, social support, and depressive symptoms in later life. *J Gerontol B Psychol Sci Soc Sci,* 59**,** S238-46.

TAYLOR, S. E. & STANTON, A. L. 2007. Coping resources, coping processes, and mental health. *Annu Rev Clin Psychol,* 3**,** 377-401.

TEDESCHI, R. & CALHOUN, L. 1995. *Trauma and transfiguration: growing in the aftermath of suffering,* Thousand Oaks, CA, Sage Publications.

TEO, A. R., CHOI, H. & VALENSTEIN, M. 2013. Social relationships and depression: ten-year follow-up from a nationally representative study. *PLoS One,* 8**,** e62396.

TEOH, V., SIMS, J. & MILGROM, J. 2009. Psychosocial predictors of quality of life in a sample of community-dwelling stroke survivors: a longitudinal study. *Top Stroke Rehabil,* 16**,** 157-66.

THE NOTTING HILL CARNIVAL. 2013 *Accessed in, www.thenottinghillcarnival.com* [Online]

THOITS, P. A. 1995. Stress, coping, and social support processes: where are we? What next? *J Health Soc Behav,* Spec No**,** 53-79.

THOITS, P. A. 2011. Mechanisms linking social ties and support to physical and mental health. *J Health Soc Behav,* 52**,** 145-61.

THOMAS ARCURY, CHEN, H., SAVOCA, M. R., ANDERSON, A. M., LENG, X., BELL, R. A. & QUANDT, S. A. 2011. Ethnic variation in oral health and social integration among older rural adults. *Journal of Applied Gerontology,* 32**,** 302-323.

THOMAS, J. & HARDEN, A. 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol,* 8**,** 45.

THOMAS, J., HARDEN, A., OAKLEY, A., OLIVER, S., SUTCLIFFE, K., REES, R., BRUNTON, G. & KAVANAGH, J. 2004. Integrating qualitative research with trials in systematic reviews. *BMJ,* 328**,** 1010-2.

THOMAS, S. A., WALKER, M. F., MACNIVEN, J. A., HAWORTH, H. & LINCOLN, N. B. 2013. Communication and Low Mood (CALM): a randomized controlled trial of behavioural therapy for stroke patients with aphasia. *Clin Rehabil,* 27**,** 398-408.

TOMASSINI, C., GLASER, K. & STUCHBURY, R. 2007. Family disruption and support in later life: a comparative study between the United Kingdom and Italy. *Journal of Social Issues,* 63**,** 845-863.

TOWNEND, B. S., WHYTE, S., DESBOROUGH, T., CRIMMINS, D., MARKUS, R., LEVI, C. & STURM, J. W. 2007a. Longitudinal prevalence and determinants of early mood disorder post-stroke. *J Clin Neurosci,* 14**,** 429-34.

TOWNEND, E., BRADY, M. & MCLAUGHLAN, K. 2007b. A systematic evaluation of the adaptation of depression diagnostic methods for stroke survivors who have aphasia. *Stroke,* 38**,** 3076-83.

TSOUNA-HADJIS, E., VEMMOS, K. N., ZAKOPOULOS, N. & STAMATELOPOULOS, S. 2000. First-stroke recovery process: the role of family social support. *Arch Phys Med Rehabil,* 81**,** 881-7.

TURNBULL, J. C., KERSTEN, P., HABIB, M., MCLELLAN, L., MULLEE, M. A. & GEORGE, S. 2000. Validation of the Frenchay Activities Index in a general population aged 16 years and older. *Arch Phys Med Rehabil,* 81**,** 1034-8.

UCHINO, B. 2004. *Social support and physical health: understanding the health consequences of relationships,* New Haven CT, Yale University Press.

UCHINO, B. N., BOWEN, K., CARLISLE, M. & BIRMINGHAM, W. 2012. Psychological pathways linking social support to health outcomes: a visit with the "ghosts" of research past, present, and future. *Soc Sci Med,* 74**,** 949-57.

UCHINO, B. N., HOLT-LUNSTAD, J., UNO, D., BETANCOURT, R. & GARVEY, T. S. 1999. Social support and age-related differences in cardiovascular function: an examination of potential mediators. *Ann Behav Med,* 21**,** 135-42.

UCHINO, B. N., KIECOLT-GLASER, J. K. & CACIOPPO, J. T. 1992. Age-related changes in cardiovascular response as a function of a chronic stressor and social support. *J Pers Soc Psychol,* 63**,** 839-46.

UEKI, H., WASHINO, K., FUKAO, T., INOUE, M., OGAWA, N. & TAKAI, A. 1999. Mental health problems after stroke. *Psychiatry Clin Neurosci,* 53**,** 621-7.

UNIT, S. E. 2001. Preventing social exclusion. London: Cabinet Office.

UNO, D., UCHINO, B. N. & SMITH, T. W. 2002. Relationship quality moderates the effect of social support given by close friends on cardiovascular reactivity in women. *Int J Behav Med,* 9**,** 243-62.

VAN DER GAAG, A., SMITH, L., DAVIS, S., MOSS, B., CORNELIUS, V., LAING, S. & MOWLES, C. 2005. Therapy and support services for people with long-term stroke and aphasia and their relatives: a six-month follow-up study. *Clin Rehabil,* 19**,** 372-80.

VANDENBROUCKE, J. P., VON ELM, E., ALTMAN, D. G., GOTZSCHE, P. C., MULROW, C. D., POCOCK, S. J., POOLE, C., SCHLESSELMAN, J. J. & EGGER, M. 2007. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): explanation and elaboration. *Epidemiology,* 18**,** 805-35.

VICKERS, C. 2010. Social networks after the onset of aphasia: the impact of aphasia group attendance. *Aphasiology,* 24**,** 902-913.

VOGT, T. M., MULLOOLY, J. P., ERNST, D., POPE, C. R. & HOLLIS, J. F. 1992. Social networks as predictors of ischemic heart disease, cancer, stroke and hypertension: incidence, survival and mortality. *J Clin Epidemiol,* 45**,** 659-66.

WADE, D. T. 1994. *Stroke (acute cerebrovascular disease),* Oxford UK, Radcliffe Medical Press.

WADE, D. T. & COLLIN, C. 1988. The Barthel ADL Index: a standard measure of physical disability? *Int Disabil Stud,* 10**,** 64-7.

WADE, D. T., LEGH-SMITH, J. & LANGTON HEWER, R. 1985a. Social activities after stroke: measurement and natural history using the Frenchay Activities Index. *Int Rehabil Med,* 7**,** 176-81.

WADE, D. T., WOOD, V. A. & HEWER, R. L. 1985b. Use of hospital resources by acute stroke patients. *J R Coll Physicians Lond,* 19**,** 48-52.

WAXLER-MORRISON, N., HISLOP, T. G., MEARS, B. & KAN, L. 1991. Effects of social relationships on survival for women with breast cancer: a prospective study. *Soc Sci Med,* 33**,** 177-83.

WEISS, R. 1974. The provisions of social relationships. *In:* RUBIN, Z. (ed.) *Doing unto others.* Englewood Cliffs, NJ: Prentice Hall.

WENGER, G. C. 1994. *Support networks of older people: A guide for practitioners,* Bangor, Centre for Social Policy Research and Development, University of Wales.

WENGER, G. C. 1996. Support network measurement and typology development in England and Wales. *In:* LITWIN, H. (ed.) *The social networks of older people: a cross-national analysis.* Westport, CT: Greenwood.

WENGER, G. C. & SHAHTAHMASEBI, S. 1990. Variations in support networks: some social policy implications. *In:* J, M. (ed.) *Aiding and aging: the coming crisis.* Westport, CT: Greenwood Press.

WHITE, J. H., ALSTON, M. K., MARQUEZ, J. L., SWEETAPPLE, A. L., POLLACK, M. R., ATTIA, J., LEVI, C. R., STURM, J. & WHYTE, S. 2007. Community-dwelling stroke survivors: function is not the whole story with quality of life. *Arch Phys Med Rehabil,* 88**,** 1140-6.

WHITE, M. A. & JOHNSTONE, A. S. 2000. Recovery from stroke: does rehabilitation counselling have a role to play? *Disabil Rehabil,* 22**,** 140-3.

WILCOX, V. L., KASL, S. V. & BERKMAN, L. F. 1994. Social support and physical disability in older people after hospitalization: a prospective study. *Health Psychol,* 13**,** 170-9.

WORDEN, J. 1991. *Grief counselling and grief therapy: a handbook for the mental health practitioner,* New York, Springer.

WORLD HEALTH ORGANISATION. 2013. *Accessed in, http://www.who.int/suggestions/faq/en/* [Online].

WORLD HEALTH ORGANISATION 1998. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med,* 46**,** 1569-85.

WORRALL, L., T, R., T, H., A, B., J, E., D, O. & K, M. 2005. Access to written information for people with aphasia. *Aphasiology,* 19**,** 923-929.

WRIGHT, D. B. 1997. *Understanding statistics: an introduction for the social sciences,* London, Sage.

WYLIE, C. M. 1967a. Gauging the response of stroke patients to rehabilitation. *J Am Geriatr Soc,* 15**,** 797-805.

WYLIE, C. M. 1967b. Measuring end results of rehabilitation of patients with stroke. *Public Health Rep,* 82**,** 893-8.

WYLLER, T. B., HOLMEN, J., LAAKE, P. & LAAKE, K. 1998. Correlates of subjective well-being in stroke patients. *Stroke,* 29**,** 363-7.

ZIGMOND, A. S. & SNAITH, R. P. 1983. The hospital anxiety and depression scale. *Acta Psychiatr Scand,* 67**,** 361-70.