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Support processes for stroke survivors and their spouses: a realistic evaluation

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Bangor University

**SUPPORT PROCESSES FOR STROKE
SURVIVORS AND THEIR SPOUSES: A
REALIST EVALUATION**

Peter Reece Jones

School of Healthcare Sciences

Bangor University

2017

Thesis submitted to Bangor University for the degree of

Doctor of Philosophy

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Abbreviations

CAB – Citizen Advice Bureau

CBT – Cognitive Behaviour Therapy

CCMO – Conjectured Context-Mechanism-Outcomes

CMOCs – Context-Mechanism-Outcome Configurations

CSD – Centre Stage Diagramming

Demi-regs – Demi Regularities

EBP – Evidence Based Practice

FAD – Family Assessment Device

GP – General Practitioner

HAD – Hospital Anxiety & Depression Scale

HCP – Health Care Practitioner

H&SCP – Health and Social Care Practitioner

HRQoL – Health Related Quality of Life scores

ICT – Information and Communication Technologies

LQI – Longitudinal Qualitative Interviews

MBSR – Mindfulness Based Stress Reduction

MeSH – Medical Subject Headings

MRC – Medical Research Council

PTG – Post Traumatic Growth

QLR – Qualitative Longitudinal Research

RCT – Randomised Controlled Trail

RAMESES - Realist And Meta-narrative Evidence Syntheses: Evolving Standards

RELATE – originally Marriage Guidance Council

SoC – Sense of Coherence

TIA – Transient Ischaemic Attack

UK – United Kingdom

USA – United States of America

WHO – World Health Organisation

Outputs

Jones, P.R., Burton, C., & Rycroft-Malone, J., (2013) The impact of stroke on couple family functioning. *Cardiovascular Diseases*. **35**; Supp 3; p216

Jones, P.R., Burton, C., & Rycroft-Malone, J., (2012) Supporting families affected by Stroke: A Realist Synthesis of the intervention literature. *International Journal of Stroke*. **7**; Supp 2; p42

Jones, P.R., Burton, C., & Rycroft-Malone, J., (2011) Dyadic approach to coping with a stroke: secondary analysis of qualitative dataset. *International Journal of Stroke*. **6**; Supp 2; p60

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Abstract

Study aim and objectives:

This thesis reports on a study that develops a novel explanatory theory around the family context of stroke recovery. This was developed from the perspectives of the evidence base for family interventions, the experiences of stroke couples over time, and the experiences of generalist and specialist staff. The thesis culminates in a realist (contingent) programme theory which melds these perspectives with extant theory to explain how health and social care professionals can better support couples through the aftermath of stroke.

Methods:

Realist principles are employed to generate a better understanding of the mechanisms and contexts that lead to outcomes (CMOs) for couples following a stroke. After a critical literature review, a realist synthesis was completed on eleven systematic reviews examining interventions supporting stroke survivors and their family carers. Coterminal with the synthesis, in-depth dyadic interviews were carried out with six stroke couples. Three stroke couples agreed to follow-up longitudinal interviews over a two-year period. Four stroke service provider focus groups were conducted (2 in Wales, and 2 in England), as well as a focus group with RELATE counsellors completed data collection.

Findings:

Four conjectured CMOs were developed and refined through the longitudinal couple interviews and service provider focus groups. The study has shown that interventions need to focus on the stroke survivor and the main family carer as a dyad whose interactions affect stroke outcomes, both physically and emotionally. Centring on the relationship between the stroke dyad is a key aspect of supporting longer-term stroke rehabilitation that limits the psychological damage for both stroke survivor and family carer. An attachment theoretical perspective on social support between spousal couples emerged from the findings to show how enhancing positive and reciprocal interactions develops resiliency that improves their quality of life. Use of technology can help maintain longer-term communication between the stroke family and professional support, enabling a partnership that tailors interventions to their needs.

Recommendations:

The theoretical propositions uncovered in this study could inform research, policy and practice through recognising and centralising the dyadic nature of stroke rehabilitation in the community. To date, interventions to help stroke families have been 'patient-centred' and have consistently shown limited efficacy in combatting psychological distress. Taking a relational perspective can enhance both stroke survivor and family carer coping skills throughout the stroke trajectory. Practitioners need organisational commitment to develop their skills in family assessment and given the time to foster a relational focus on care, prioritising relationship dynamics over functional therapy.

CHAPTER ONE: The Study in Context

1.1 Introduction

This research thesis endeavours to cast light on how health care professionals (HCP) and health policy commissioners can adopt support strategies that ameliorate the burden and stress experienced by stroke survivors and their families. This chapter will provide a rationale for the thesis and its contribution to knowledge about stroke support interventions within a United Kingdom (UK) context. The thesis is fashioned around a critical realist perspective particularly the realist evaluation formulation described by Pawson and Tilley (1997), and the detailed rationale for utilising such an approach will be outlined in chapter two. The initial impetus for employing a realist explanation is the limited evidence from randomised controlled trials (RCTs) over the past 30 years in establishing how family carers and stroke survivors can be helped in the aftermath of a stroke (Bakas et al., 2014; Cheng, Chair, & Chau, 2014). The dearth of validated intervention techniques for health and social care practitioners to use in practice, and for policy implementers to prescribe, has consequences for the effective and efficient use of resources. In this chapter, the policy and clinical importance of support offered to stroke family carers is discussed, focussing on problem-solving, psychosocial and psychoeducational provision, rather than pharmaceutical interventions. A framework for the study will be developed through a critical literature review (Grant & Booth, 2009), and will conclude with the study's main aims and objectives, and a brief summary of the content of each chapter.

The contribution to knowledge emanating from this thesis is around a realist or contingent programme theory that provides some explanation to health and social care practitioners as to how they could better support families through the aftermath of stroke.

1.2 Justification for this thesis

1.2.1 Personal motivations

This thesis came about through my interests in combining theory and practice. As a nurse caring for adults in hospital and community settings the main driver is to support and comfort the ill patient. This support is likely to involve direct hands-on care or 'doing something' to and with the 'patient'. This 'doing' to patients should be exposed through reflection-on-action so that decisions taken can be scrutinised through the prevailing 'evidence'. The ethos of nursing is individualised patient-care and the 'evidence' that is considered robust to support practice lies in the domain of the average, particularly the ubiquitous systematic review and meta-analysis. As a nurse academic teaching students it becomes increasingly difficult to apply the evidence from the general to the particular, to individualise patient-care. Through expertise within the School the 'delights' of realism and realist evaluation showed promise in squaring the circle of evidence and the practice context. A further influence in my pursuit of this thesis was my background as a health visitor, with its 'family' orientation towards practice, being fortunate not only advising young families, but the 'well-elderly' within general practice. Visiting the elderly on the practice list enabled me to acquire insight into their long-term needs for health and social care. This at the time was rare, as health visiting is substantially based around the young family. A fair proportion of the clients I visited were post-stroke and the issues they experienced as a family long after the acute stage stayed with me.

1.2.2 Clinical justification

This thesis uses a realist evaluation approach to garner data that will inform the research question 'how can stroke survivors and their families be helped to manage the long-term consequences of a stroke'. There is extensive literature that details the stress experienced by family carers and stroke survivors when recovering from a stroke (and other chronic conditions such as dementia). In an early study, Cohen (1978) found that in a three-year follow-up of 32 stroke survivors, 21 of them were relatively independent, being mobile and continent, living with their spouses, but from a psychosocial perspective they were found

to be depressed and withdrawn. Correspondingly Belcher, Clowers, and Cabanayan, (1978) interviewed 42 married, older, stroke survivors and their spouses about their current rehabilitation needs 12 months post-stroke. They found that social psychological needs were more important than physical rehabilitation. Results from these early studies about the psychosocial needs of stroke families have been replicated over the past 30 years. In a more recent cross-sectional study by Bergström, Eriksson, von Koch, and Tham, (2011) looking at life satisfaction of 54 stroke survivors and their spouses 12-months post-stroke, found that those couples who were generally satisfied with life reported significantly lower impact of the stroke than those reporting less satisfaction. These authors recommend that future research and clinical practice should evaluate family functioning and the shared relationship between the stroke survivor and spouse. In a critical review by Visser-Meily, van Heugten, Post, Schepers, and Lindeman (2005) of intervention studies for caregivers of stroke survivors concluded that “We could not identify sufficient evidence from the reviewed studies to confirm the efficacy of interventions on caregivers of stroke patients” (p.266). They speculated that some of the reasons for such a conclusion was the heterogeneous nature of the samples included in the studies, combining both spouses, partners, and children, not accounting for the gender or age within the sample, and limited focus on the family caregiver needs as part of the intervention. In two recent systematic reviews on family caregiving interventions in stroke, Cheng, Chair, and Chau (2014) and White, Cantu, and Trevino (2015) concluded that ‘simple’ interventions are unlikely to provide consistent impact on family carer burden and stress. White et al., (2015) state that it is the “...complexity of the caregiving situation” (p.96) that accounts for such limited support for family stroke interventions over the past 30 years.

1.3 Policy background for stroke family support

In 2010, the National Assembly for Wales, Health, Wellbeing and Local Government Committee produced a report into stroke services in Wales, which intended to throw some light on why Wales lagged England on most criteria audited by the Royal College of Physicians' sentinel audit (now the Sentinel

Stroke National Audit Programme [SSNAP]). An example from the 2010 audit showed that twenty-four hour access to thrombolysis was 57% for England but 0% for Wales, with 100% of hospitals in England and Northern Ireland having dedicated stroke units but standing at 93% in Wales, nonetheless this was recognised as a "major improvement for Wales" (p.51) (Royal College of Physicians (Clinical Effectiveness & Evaluation Unit on behalf of the Intercollegiate Stroke Working Group), 2011). The focus of action in the UK for stroke management is the hyper-acute, acute, and early rehabilitation phases (six-months post-stroke). Within the audits there is no data on longer term rehabilitation, or the effect of stroke on the survivor's immediate family. However, the Health, Wellbeing and Local Government CommitteeL (2010) did comment on the lack of longer term provision and recommended that the Welsh Government, "...increase the emphasis on community and longer-term rehabilitation and support" (p.53).

Neither the Sentinel audit or the Health, Wellbeing and Local Government Committee report express much opinion about the role of the family in supporting the stroke survivor, only noting that they are important. The National Clinical Guideline for Stroke, (2012) has a section that recommends health and social care staff (H&SC) involve the main informal carer in every aspect of stroke management, however, it does not comment on support needs for family carers in dealing with their relative following a stroke. The tenure of policy reports in the UK has focused on the services and support for the stroke survivor with the family carer needs being secondary, even though the National Clinical Guideline for Stroke (2012) recognised the importance of the family carer, as the following quote signifies. "Their role and their involvement with the person with a stroke is vital from the outset. However, the section on these carers is placed at the end because carers usually have the longest and the only constant and continuing relationship with the patient, long after most other services have stopped" (p.129).

Evidence has consistently shown that having a family carer to support the stroke survivor in the community is beneficial for the wellbeing of the patient

(Evans, Hendricks, Haselkorn, Bishop, & Baldwin, 1992; Greenwood & Mackenzie, 2010). In the latest 'American Heart and Stroke Association' scientific statement about the evidence for stroke family carer and dyad interventions for long-term stroke care showed that "...most studies measured only short-term outcomes (and)...it is important to be clear whether the interventions are targeted to the stroke survivor, the caregiver, or both" (Bakas et al., 2014 p.2849). Similarly, Heslin, Forster, Healey, and Patel (2016) in a systematic review of economic evidence for stroke family carer interventions showed there to be some clinical benefits that are cost-effective, but warn that a "...major challenge in any review is the heterogeneity and complexity of interventions" (p.131). In a meta-ethnographic review of qualitative data of family stroke carers, Greenwood and Mackenzie (2010) showed that family carer lives post-stroke was one of loss and adaptation to their previous roles and relationship with the stroke survivor. However, not all family carers responded negatively to this 'biographical disruption' (Bury, 1982), but some were able to accept and adjust to their changed circumstances. Again in one of the few longer-term analysis of stroke survivors and family carer needs by Godwin, Ostwald, Cron, and Wasserman (2013) showed that four years following a stroke, survivors and carers had lower Health Related Quality of Life Scores (HRQoL) compared to their first year post-stroke, recommending the need for long-term psychosocial support. The next few sections of this chapter will outline the effects of stroke on the family and stroke survivor, making the case that stroke support should be inclusive and based on biopsychosocial principles.

1.4 Mapping the literature

1.4.1 Developing a framework for the study

A detailed discussion of the realist approach will be given in chapter two, but the basic premise of realist evaluation is the development, refining and testing theories that underlie complex social programmes (Pawson, Greenhalgh, Harvey, & Walshe, 2005), in this thesis the long-term support of stroke families. Implementing support services for stroke families is a complex process, and for realist enquiry developing a framework to guide the study is a prerequisite and

involves a process of "...digging through" (p.7) the literature and drawing on experience to identify key terms, concepts and mid-range theories that provide some explanation about the subject of interest" (Rycroft-Malone et al., 2012). Developing an initial framework for the investigation incorporates the aims and purpose of the study and articulating what 'candidate theories' that may underlie long-term family support in stroke. This process of developing the theoretical framework within the realist approach can be exploratory and developmental involving an initial review of the literature.

1.4.2 Critical review of the literature

To develop the scope and framework for the study, an initial critical review of the literature was conducted. Grant and Booth, (2009) identified a critical review as one of 14 categories of reviews utilised in the health literature. The rationale behind a critical review in Grant and Booth's (2009) typology is to "...identify conceptual contribution to embody existing or derive new theory" (p.93). A critical review was apposite for this stage of the study as the purpose was to overview the wide-ranging literature already available on family cares and chronic illness with the intention of identifying significant contributions that support conceptual development. A critical review does not have to be formally structured as a systematic review, but embraces the literature pertaining to the topic then providing a narrative evaluation of this literature. A realist review described in chapter three, is a synthesis of the literature or secondary data using realist evaluation principles that looks for generative mechanisms and programme theories, building and testing these theories, underpinned with contributions from relevant stakeholders (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013a).

The critical review carried out in this in this chapter summarised literature, including research reports (qualitative, quantitative, and systematic reviews), guidelines, and books. Other resources were also searched including 'related article' searches in PubMed for all studies of interest to the review, scanning reference lists of relevant studies, and identified key references in a 'pearl-growing' technique (Barnett-Page & Thomas, 2009). The searches were

conducted on PubMed, Medline, CINAHL, PsychINFO and Google Scholar. Initial keywords and MeSH headings (incorporating US terminology) were 'stroke, carers, spouse, family, family functioning, randomised controlled trials (RCT), qualitative, intervention, chronic illness, long-term conditions, rehabilitation, primary or community care, psychosocial, social, cognitive, behavioural, problem-solving', Quality of Life, burden, stress and coping.

The aim was to obtain a comprehensive literature directed at family support for people with chronic or long-term illness, including stroke. Through the related searches, literature on dementia, Parkinson's disease, and chronic obstructive pulmonary disease (COPD), cancer and palliative support was also accessed if it included reference to family support. The review process was iterative in that seemingly relevant literature was reviewed and added to the conceptualisation of family support following a stroke. The results of the critical review are discussed in the remainder of the chapter.

1.5 Stroke and its effect on the stroke survivor

Stroke is defined by the World Health Organisation (WHO) (Wittenauer & Smith, 2012) as a clinical syndrome consisting of "...rapidly developing clinical signs of focal (at times global) disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin" (p.6). According to WHO (2012) nearly 15 million people each year are diagnosed with a stroke worldwide. In the UK, the number diagnosed is about 150,000 (National Audit Office, 2010), with 1.2 million survivors. In Wales, there are around 11,000 people diagnosed each year, with over 65,000 living with a stroke (Report of Inquiry into Stroke Services in Wales, 2010) Stroke is the third most common cause of death and the single most common cause of on-going disability in the UK, costing an estimated £9 billion per year (Stroke Association, 2017). Stroke presents in two forms, ischaemic stroke where there is a clot in the brain and accounts for 80% of strokes, with an initial treatment of thrombolysis. The second common form of stroke is haemorrhagic stroke (20%) with subarachnoid or intracerebral bleeding; in both types of stroke the resultant disability is related to location of the trauma and its magnitude (Rowat, 2011).

For the stroke sufferer, the effects of stroke can be life-threatening, as nearly 15% of those who experience a first time stroke die within the first three months, with a further 18% mortality during the first year (67,000 deaths), but has been falling in the UK due to better control of vascular risk factors (Brønnum-Hansen, Davidsen, & Thorvaldsen, 2001; Lee, Shafe, & Cowie, 2011). However, these results are region dependent, with Wales, Northern Ireland and Scotland fairing worse than England primarily due to the two highest key risk factors of hypertension and smoking rates (O'Donnell et al., 2010; Scarborough, Morgan, Webster, & Rayner, 2011). Nonetheless, even with better survival rates, Wolfe et al., (2011) estimated from a population-based cohort of stroke survivors in the UK that 20% to 30% had poor outcomes over ten-years follow-up. The poor outcomes relate to both functional and cognitive/emotional domains, and these difficulties remain relatively stable twelve-months post-stroke (Wolfe et al., 2011). Problems faced by stroke survivors include incontinence, both faecal 11% at 12 months (Harari, Coshall, Rudd, & Wolfe, 2003) and urinary 15% at 12 months (Patel, Coshall, Rudd, & Wolfe, 2001). At one year, depression affected 16.4% of stroke survivors, with 70% being untreated (Hackett & Pickles, 2014), and also cognitive impairment remained at 39% after 12 months (Coco, Lopez, & Corrao, 2016). Similar results were found by Baumann, Couffignal, Le Bihan, & Chau, (2012) two-years post-stroke that stroke survivors (n=94) still had impaired sensory (44.7%), memory (31.9%) and motor (35.1%) functioning. Given these statistics, Wolfe et al (2011) recommend that health and social services provide long-term, on-going assessment and rehabilitation for stroke survivors. Indeed the issues seen as important to perceived recovery from stroke are not always well-matched with those of health professionals, with stroke survivors identifying wider social and contextual needs that mean a return to meaningful life activities as being imperative, not simply physical functioning (Burton & Gibbon, 2005; Hartigan, O'Connell, Mccarthy, & Mahony, 2011).

Recent research has begun to examine the effect of a 'minor' or 'mild' stroke on the patient and family (Edwards, Hahn, Baum, & Dromerick, 2006.). A minor stroke has been defined "...as a non-disabling event resulting in minimal

neurological impairment, as measured on stroke severity and functional outcomes scales (e.g. Barthel Index >80-100)" (Green & King, 2011, p.15). Rothwell, (2007) maintains that mild strokes and transient ischaemic attack now account for 60% of all cases of stroke. In a United States (US) study Edwards et al., (2006) assessed 219 mild stroke patients six months after hospital admission. Eighty-seven percent of stroke survivors reported some changes in their day-to-day activities that impacted on their quality of life despite being assessed as fully independent. Deficits related to reduced employment activities (62%), reduced social activities (36%), concentration problems (30%) and irritable mood (22%). Carlsson, Forsberg-Wärleby, Möller, and Blomstrand, (2007) in a mixed-methods study of 56 stroke couples where a partner had a mild stroke one year previously, showed that life satisfaction was affected for both spouses with life as a whole, leisure and sex life being affected the most (70%). For the stroke survivor fatigue was the single most pressing problem (72%), with 50% experiencing decreased stress tolerance and memory problems, and 40% to 50% reporting irritability, emotionalism, concentration difficulties and lack of initiative. Green and King (2010) also looked at mild stroke couples one year post-discharge, and showed an increase in depression and a worsening of marital functioning in both spouses over the 12-month period. Further analysis of this cohort (Green & King, 2011) showed that while the stroke survivors' physical functioning improved the psychosocial measures remained static. Specifically, depression and subsequent effect on the marital relationship were problematic at 12-months post stroke. Green and King (2011) recommended that further longitudinal studies are required to examine the effects of minor strokes on the psychosocial recovery of both partners. Some researchers are disputing the validity of 'minor' stroke or 'transient ischaemic attack' (TIA) as a 'lesser' condition, commenting that this categorisation as 'mild' negates the importance of rehabilitation services for these families (Rothwell, 2007). With the physical, cognitive and psychological outcome of a stroke, there are therefore important concomitant effects for the attendant family of a stroke survivor once they have recovered enough to return to their community.

1.6 Effect of stroke on the informal carer and family

Since the 1970's there is increasing recognition of the effects that chronic conditions such as stroke place on the family carer (Nolan, Grant, & Keady, 1996). Studies have identified a range of difficulties experienced by stroke family carers. These problems include higher levels of strain, perceived burden, stress, depression, reduced quality of life, stroke survivor functioning and social relationships (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011; Cecil et al., 2011; Draper & Brocklehurst, 2007; Franzén-Dahlin, Larson, Murray, Wredling, & Billing, 2007; Gaugler, 2010; Godwin et al., 2013; Han & Haley, 1999; Rigby, Gubitz, & Phillips, 2009; Schulz & Sherwood, 2008; Visser-Meily et al., 2009).

In a systematic review of 24 studies describing stroke caregiver burden Rigby et al., (2009) differentiated between various contributing factors that influenced carers. Stroke survivor characteristics including degree of disability, cognitive and mental health parameters showed inconsistent effect on carer burden. Characteristics of the stroke family carer revealed consistent findings, that the extent of depression, anxiety and amount of caregiver input adversely affected perceived burden, although the timescale of caregiving did not have an effect. Rigby et al, (2009) concluded that the quality of studies was problematic, the lack of longitudinal data and the small heterogeneous sample sizes, but that the degree of depression and anxiety exhibited by the stroke survivor, with the amount of time committed to caregiving showed consistency. In a recent mixed-method systematic review of longitudinal studies looking at stroke family carer outcomes Gaugler, (2010) indicated that carer subjective health measures showed little change over the longer term. Gaugler (2010) speculated that this result demonstrated family carer resilience in coping with their perceived burden. Haley et al., (2009) conducted a prospective epidemiological study of stroke patients and their family carers. According to the authors' an epidemiological study has benefits over clinically-based cohorts in that it avoids an over-representation of severely impaired stroke survivors. Results from this study confirmed previous research that caregivers rated mood (depression and anxiety) and cognitive disturbances in the stroke survivor as their most burdensome problems, while dressing and incontinence issues were the most

stressful functional issues. In addition, Haley et al, (2009) showed that the sample (n=75) "...appeared to be coping quite well and better than reported previously" (p.2132), with many (over 90%) reporting benefits of the caregiving role, such as a greater appreciation of life, and recommended that health care professionals should reinforce identified benefits of caring, such as learning new skills, and increase self-efficacy.

Visser-Meily et al., (2009) analysed the psychosocial functioning of a cohort of stroke family carers (n=121 at year 3) over three years, and found that perceived caregiver burden moderately declined, but that social relationships deteriorated, with depression scores increasing in the third year after an initial fall during the first-year post-stroke. Baumann, Couffignal, Le Bihan, Chau, and Lu, (2012) looking at quality of life and life satisfaction scores of family carers (n=62) two-years post-stroke, identified carer life satisfaction was lower for those whose spouses had greater memory and emotional dysfunction. Improvement in life satisfaction of stroke family carers has indicated the role of social support (Grant, Elliott, Giger, & Bartolucci, 2001; Heuvel et al., 2002). In a three-year longitudinal study Adriaansen, van Leeuwen, Visser-Meily, van den Bos, and Post, (2011) showed that life satisfaction of stroke family carers (n=180) was positively related to social support, irrespective of caregiver strain scores, which showed an overall decline over the three years from 29.8 at two months post-stroke to 25.2 at three years. Before outlining the role of informal family caregiving in stroke, a brief review of the role of the family will be presented.

1.7 Family and kinship

This section outlines an examination of the role of family and kinship within western society. This discussion lays the basis for a better understanding of the roles played by family carers in stroke and chronic illness provision in general. Theories about the place of family in modern western societies can be described in terms of pre and post-industrial family groupings (Gillies, 2003). In pre-industrial agrarian societies, families were patriarchal, constituting of a community with little boundary distinction between the family, social and work

or economic functions. The family thus conceptualised, worked as a unit of different ages and kinship ties, where the extended family unit of grandparents, aunts and uncles as well as grandchildren lived in the same house and worked for the collective good (Gillies, 2003). The industrial revolution with its increased specialism of labour, leading to greater urbanisation was the termination of this romanticised view of the family (Giddens, 2009). However empirical work by Macfarlane, (1986) disputes this view of pre-industrial family structure, reviewing parish records, he concluded the nuclear family has been a consistent feature in the UK since the 16th Century.

Sociological accounts of post-industrial families begin with functionalist theory especially that of (Parsons, 1951/1991), where the family's main role is the socialisation of children and the appropriate place for the emotional outlet of adult needs, so that a couple-based relationship is better able to resist the stress of post-industrial society. Through this nuclear rather than extended family structure, stability and core values are transmitted within the wider society (Giddens, 2009). The functionalist account demarcated specific sex roles within the family, with the caring function of the wife/mother and the husband/father who is the provider. However, this vision of the nuclear family with little kinship contact was disputed by empirical studies such as Young and Willmott, (1973) description of East end London, and Townsend's, (1957) study of older people, showing that even with geographical limitations, women in particular were critical in maintaining generational ties.

Morgan, (1975) has critiqued the functionalist perception of the family maintaining that it idealises the reality and that it is based on American cultural norms and that 'the family' is seen as a separate institution within society, but in reality, it cannot function in isolation. A Marxist view of the family (Engles, 1986) saw the nuclear family and marriage as a way of ensuring ownership of the means of production. Property was owned by males, and needed greater control of women to pass on to their (male) heirs. Another Marxist, Zaretsky, (1976) sees the family as part of capitalist system in that household work performed by women allows the men to labour uninterrupted by fulfilling basic

needs. This theme is also taken by feminist writers (Delphy & Leonard, 1992) who see family life as disadvantaging women, but through the patriarchy of men rather than capitalism per se. Again Morgan (1975) critiques the Marxist and feminist perspectives of the family in that they take a stereotypical view of kinship relationships as a male/female couple with children.

Recently, Jamieson, Morgan, Crow, and Allan, (2006) view 'marriage' as being less important as an economic institution mainly due to less family businesses and more importantly men and women with independent salaries. Therefore, women have more 'power' and are less willing to accept paternal dominance due to their financial limitations. The family and couple-hood can now be viewed as relationship centred rather than a fiscal arrangement. Emphasis on individuality and choice in modernist society has resulted in people choosing their partner based on relationship compatibility, and as such there can be easier dissolution of the partnership exemplified by the increased divorce and re-marriage rates (Jamieson et al., 2006). This perspective on the family has been further developed by Finch, (2007) and moves away from viewing the family as a social institution to the family as a set of activities. Finch (2007) endorses the concept of 'display' in which families engage in every day practices with each other that make them a 'family' as Finch (2007) elucidates, "By 'displaying' I mean to emphasize the fundamentally social nature of family practices, where the meaning of one's actions has to be both conveyed to and understood by relevant others if those actions are to be effective as constituting 'family' practices" (p.66). This perception of the 'family' fits with the changing pattern of family life in western societies, the increasing diversity, due to same sex marriage, cohabitation, multiple family ties due to divorce and re-marriage, and multiplicity of cultural ties. Finch's (2007) concept of display has three components; families are not the same as a household, flexibility of family structures over time, and the connection between the person and family.

Greater freedom of action and de-stigmatisation of divorce, single mothers and cohabitation, family households increasingly do not reflect the wider network of earlier family associations (Jamieson et al., 2006). According to Finch (2007)

these 'previous' family ties need to be displayed to others, and cannot be inferred from current household residents. Tied-in with the previous point is the flexibility of family structures where relationship displays are needed to maintain the 'family' through changing household structures. The third component of why family practices are important is the maintenance of personal and family identity. A person's identity is linked to the wider social and family network, so as the members of the 'family' change then a person's identity is affected and so displaying family ties becomes important to the preservation of one's identity. Finch's (2007) proposition of 'displaying' family practises applies to all 'family' structures, the difference being the extent of display.

1.8 Family care

Informal or family carers as defined in the Department of Health, (2014) Carer's Strategy are people who "spend a significant proportion of their life providing unpaid support to family or ... friends" (p.7). The provision of support to a family member by another is a normal and pervasive characteristic of human relationships, so what is it about the tasks of family life that merits the label of family carer? According to Schulz and Sherwood, (2008) it is assistance with personal care such as bathing or dressing that marks out family caregiving. In the UK the concept of 'informal or family care' has only been recognised in health and social policy terms since the 1970/80s (Beresford, 2008; Nolan, Grant, & Keady, 1996). Heaton, (1999) through a Foucauldian analysis of the policy discourse surrounding informal care in the UK, argues that the way 'care by the community' changed to 'care in the community' in the early 1970's, resulted in the expansion of the 'medical gaze' that re-defined the relationship between family members, "...the informal carer is the supervisor of the person they care for, in turn supervised by the statutory health and social care services." (p.771). This policy shift according to Beresford, (2008) is accounted for by interlinked events over this period:

1. Political and economic change: The economic recession of the 1980s, and the re-emergence of more right-wing governments across Europe and US triggered a review of the 'expensive' institutional forms of health and social care and the principle of less state intervention in people's

lives. Individuals and families should be given more control over their own decisions, rather than to accept just what the state provided. The above ideology of more individual accountability was coupled with the perceived 'cheaper' alternative of providing health and social care in the community rather than through centralised organisations. (p.4)

2. Feminist analysis of women's roles in society: Finch and Groves, (1983) argue how the 'new' community care policies impacted on women, who were the ones mainly left to deliver the practicalities of the policy for their family. The resultant effects of 'family' care were a lack of choice for women leading to increased health and social burden.
3. The scale and burden of unpaid family caring on society: Due to these policy changes and the improved longevity of the elderly who survive with increasing chronic illnesses; it was beginning to be recognised that the numbers of informal carers was burgeoning. Many family carers were providing long hours of care with little or no support from the health and social care services. The Carers Trust, (2015) estimates that carers save the Government between £67 billion and £87 billion a year. The same report found that the majority (55% of the whole sample of 639 participants) were caring for their spouse but increases to 87% in 70+ age group.
4. The shift to incorporating informal carer needs was explicitly contained in the The National Service Framework for Long-term Conditions, (2005) for England as the following quote recognises: "Quality requirement 10: Supporting family and carers: Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right".

However, the Welsh strategy for older people of which stroke was a key component National Service Framework for Older People in Wales, (2007) did not explicitly focus on carer needs in their framework. The Welsh Assembly Government Committee Report of Inquiry into Stroke Services in Wales (2010) heard evidence from a wide range of stakeholders in stroke care and one of its

recommendations was an increased focus on longer-term support for stroke survivors including an emphasis on their family carers.

Increasing recognition of the role of informal carers to society prompted the national census of 2001 to introduce a new question to estimate the number and workload on informal and family carers in the UK. The census defined 'informal carers' as 'people who provide care for family members, neighbours or others who are sick, disabled or elderly' (Office of National Statistics, 2006). The question showed that there were over six million carers, with half aged over 50 years (Carers Trust, 2015). In Wales the 2001 census revealed that there were 340,000 carers (11.9% of the population), with 13% aged over 65 years. Recent estimates by the Cares Strategies Wales (2012) report the numbers of informal carers has increased by an estimated 8% to 370,000. Of these unpaid carers, approximately 60% provide care between 1-19 hours a week with nearly 40% providing care well over 20 hours per week.

In a recent survey of 639 older carers by Carers Trust, (2015) showed the effects of caring on family members. The gender distribution showed a prevalence of women as carers up until about 70+ years of age when the gender balance shifts towards men as the majority (Dahlberg, Demack, & Bamba, 2007). Older carers supported their spouse or partner, with an average caring commitment spanning 11-15 years. Over 60% of the respondents acknowledged they themselves had multiple long-standing health problems, with the caring role impacting negatively on their physical health. In the Carers Trust (2015) survey it was the 60-69 year old carers who felt the most detrimental impact of caring on their emotional and mental state. The main concerns expressed were ability to cope, the constant worry, and tiredness. However, the survey, using a subscale of the Adult Carers Quality of Life Inventory showed that despite the burden of caring for a spouse, the carers did feel that their commitment was worthwhile and was beneficial to their spouse, but again the 60-69-year-old carers reported being the least satisfied. When asked about professional health and social care support to help them in their caring role, there was a statistically significant low score across the age range

of carers. Informal caregivers felt that professionals only rarely met their needs as carers.

1.8.1: Informal or family caregiving as a concept

The above issues highlight how the family carer is viewed by health and social care policy makers, and therefore the available professional support network. Twigg and Atkin, (1994) identified four ways this professional relationship is constituted:

- Carer as resource: perceiving carers a 'resource' to be utilised in the management of the patient or client. Carer health is sustained in so far as it promotes client wellbeing.
- Carers as co-workers: recognition that the carer needs some support to maintain the prime function of patient interests.
- Carers as co-clients: carers are recognised and supported in their own right.
- The superseded carer: health and social service support for the care-recipient is met by the community, and removes the requirement for informal care altogether.
- Carer as expert: this fifth approach was added by Arksey and Glendinning, (2007) carers are seen as equal partners with the professionals, working as a team to support the care-recipient. This approach was one of the key features of the Carers Strategy (2008) and the 2010 review (Recognised, valued and supported, 2010). The carer as 'key partner' was also seen as a vital aspect of the Welsh Government strategy for carers (Government, 2012).

Arksey and Glendinning (2007) concluded that the way carers are perceived by health and social care practitioners influences the pattern of support they receive. In the 'carer as resource', support is limited and carer needs subsumed into patient care with no choice for the informal carer. The 'superseded carer' approach transcends the caregiving relationship between carer and care-recipient, a model Twigg and Atkin (1994) perceive as useful for people with disabilities as it reduces dependency and increases choice to this group. There

has been some support for the possibility that relying on family carers does negatively affect the stroke survivor and their sense of perceived burden leading to a lower quality of life (McPherson, Wilson, Chyurlia, & Leclerc, 2011). However, with stroke care and other chronic illnesses, exclusion of the family carer may not be a justifiable approach as both carers and stroke survivors may feel the need to be involved in a reciprocal arrangement. The model of 'carer as expert' (Nolan, 2001) may have merit as it attempts to take the central role of the carer into professional decision-making about the management of their relative.

However, there may also be an issue with the term 'carer', family or informal; in the way relatives view their role with kin, which problematizes the above typology. In a review by Molyneaux, Butchard, Simpson, and Murray, (2010) discussing the political and historical roots of informal carers, conclude that the term 'carer' should be scrapped as it is not 'fit for purpose'. The authors' base this conclusion on the way families associate with each other, particularly long-term partnerships in that they are 'caring for' as part of the mutuality of the relationship, rather than 'being their carer' that implies an outsider perspective (Hughes, Locock, & Ziebland, 2013). Furthermore, a family carer carries the 'burden of care' refuting the positive aspects of the role, as is becoming increasingly recognised (Archbold, Stewart, Greenlick, & Harvath, 1990). Molyneaux et al., (2010) indicate that the focus of interventions for 'carers' should "...be on the relationship from which it arose" (p.422), implying that this would also make families more receptive to outside assistance. In a more nuanced approach Hughes et al., (2013), discussing research with family carers of relatives with multiple sclerosis (MS), developed four 'types' of family carer attitudes. These 'identities' either embraced, enforced, absorbed or rejected the 'carer' characteristics.

Embracing the carer role meant that the family member felt comfortable in accepting the role of carer with their other roles, and was more prevalent in family members who did not live with the care recipient. With 'enforced' identity, the family carer accepted their role but under duress as it diminished their other

identities as wife or husband. The 'absorbed' carer represented a 'fluid' identity that related to MS as a condition in which some days the patient felt better so needed less 'caring' activities and the spousal relationship came to the fore. The final identity that of rejecting the notion of 'carer', was not based on an absence or denial of caring activities, but on the clear rejection that a spouse should carry out these tasks as part of a relationship (Hughes et al., 2013). In this thesis, the term 'family, spousal or informal carer' will be used as it clarifies the discussion, separating the professional carer role and the stroke survivor, it is realised that the term 'family or spousal carer' is problematic in relation to a spouse's relationship as a husband or wife.

1.8.2: Gendered nature of family caregiving

Hirst, (2004) analysing informal caregiving trends between 1991 and 1998, showed a marked difference between the beginning and the end of the decade in carer gender, with a marked increase in male family carers, with as many men as female carers. The gendered nature of caregiving also extends to the types of caregiving tasks that are assumed. Male caregivers report being regularly involved in providing instrumental support such as aiding in the completion of household tasks. In addition to this instrumental support, female caregivers are more likely to provide emotional support, which includes listening, sharing feelings, showing warmth and problems (Walker & Luszcz, 2009). The provision of emotional support has been demonstrated to be more psychologically onerous on caregivers than assisting with physical tasks (Merz, Consedine, Schulze, & Schuengel, 2009; Zarit & Reamy, 2013).

In a meta-analysis of 229 studies looking at gender differences in caregivers, Pinqart and Sörensen, (2006) identified that carers' experienced greater stress and burden than non-carers. However, they asserted that the methodological problems with the studies selected including an underlying gender-role theory bias, female carers demonstrated higher level of psychological stress than male carers but there was only a weak association, primarily seen between sibling rather than spousal caregivers. Pinqart and Sörensen (2006) concluded that their analysis corresponded to two earlier

reviews by Miller and Cafasso, (1992) and Vitaliano, Zhang, and Scanlan, (2003) in demonstrating only a small gender difference, and recommended that the evidence points to different research questions as indicated by Miller and Cafasso, (1992) quote, "What is needed may be less documentation of specific gender differences in isolated components of caregiving and more attention to the role that gender-role explanations play in assigning meaning to the caregiving experience." (p.506). A qualitative study on gendered account differences between stroke survivors using Frank, (1995) typologies of illness narratives as a framework, also demonstrated little differences in the way male and female stroke survivors interpreted their situation, with illness related issues being more important than gender (France, Hunt, Dow, & Wyke, 2013).

In a recent quantitative longitudinal prospective study of post-stroke spousal carers (Alexander & Wilz, 2010) showed that female carers had initially reported (three-months post-stroke) greater stress and depression than corresponding male spouses. However, at 15-months there was a reversal of this result with male carers reporting greater depression and strain particularly if their partner had severe cognitive impairment, with improved adaptation by female carers. Alexander and Wilz (2010) invoke gender-role socialisation theory to explain their results, whereby the differential socialisation of girls and boys makes girls more 'sensitive' to others' emotional states than men, explaining the initial higher depression rates in female carers', whereas men need time to realise the difficulties and use denial as a coping response in the early stages of stroke rehabilitation.

Miller and Cafasso, (1992) distinguish between social-role hypotheses and gender-role socialisation in their analysis of gendered caregiving. Social-role hypothesis links the demands of the role, such as husband or wife, with stress or burden. These social roles are determined by cultural norms with individual variations; so a stereotypical view of a heterosexual marriage would be the male goes out to work and the female stays at home nurturing the children. Increasingly, due to cultural changes this stereotypical view is being eroded, with many different permutations coming to the fore (Sydie, 2007). With gender-

role socialisation, where attitudes and behaviours are related or assigned to each sex, where cultural norms direct the upbringing of the child as a girl or boy and is internalised into male (e.g., autonomous behaviours) and female (e.g., nurturing behaviours) stable personality patterns (Sydie, 2007). Miller and Cafasso (1992) argue that the social-role hypothesis explains their results best in relation to carer task behaviours, in that male and female spouses will adapt and undertake different roles such as personal care or financial management that previously was the jurisdiction of the care recipient before the disability. Likewise, the gender-role hypothesis fits best in understanding caregiver appraisal and response to the caregiving role. The hypothesis being that females more readily express their emotions, than men so report greater psychological burden (Sydie, 2007). However, Miller and Cafasso (1992) caution against simplistic, global (meta-theory) explanations and advise that more context specific questions need to be asked, such as: "...women might be expected to experience less burden because they are better prepared for the caregiving experience by their history of personal care and household management. Or, older men may have greater resilience because the loss of the work role may heighten their involvement in family caregiving as an outlet for growing domestic interests" (p.506). The questions posed by Miller and Cafasso (1992) move the debate forward to a more theoretical approach to research and policy-level analysis. In line with this process, it is now relevant to discuss the role of family and marriage in informal caregiving.

1.9 Family functioning

According to Rolland, (1994) most family functioning theorists view the family as a complex open system that needs to cope with three life-related domains: basic – provision of food and shelter, developmental – nurturing and progress, and hazardous task control – coping with unanticipated events such as severe illness, with each domain comprising of an instrumental and affective component. A frequently used family functioning assessment tool in stroke research is the McMaster Family Assessment Device (FAD) (Epstein-Lubow, 2012). This tool is based on extensive research and clinical practice with normal

and dysfunctional families and is based around the typology described above by Rolland (1994).

The McMaster Model has five precepts; the family is an interacting open system, one member of the family influences, and is influenced by the other members, family dynamics is the sum of the parts rather than individual behaviours, the way a family is structured and organised influences individual member behaviour, and the interactional communication styles influences each member's conduct (Miller, Ryan, Keitner, Bishop, & Epstein, 2000). Within the FAD scale there are six areas that are assessed, problem-solving, communication, roles, affective responsiveness, affective involvement, and behavioural control.

Problem-solving is the process family members use to solve issues that arise in life. The process can encompass instrumental problem-solving such as financial management, and affective problem-solving including the management of emotional control. Communication in the McMaster model is verbally orientated, as it is easier to measure than non-verbal communication, but again covers instrumental and affective practices (Miller et al., 2000). Roles are the positions family members adopt within the family for effective functioning, instrumental roles can include earning money to buy basic resources, to affective roles, such as the peace-maker within the family. These established roles can change radically with the imposition of a serious chronic illness such as a stroke (Rigby, Gubitz, & Phillips, 2009). Affective responsiveness is the emotional reactions family members give to the range of contextual stimuli that surround them, both qualitatively, in terms of expressive range and in proportion to stimulus experienced. So the range of response can be no response to over-reaction all of which affects family functioning (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Affective involvement is the degree of interest members of the family show in each other, not just instrumentally as in 'doing things' together but also in the degree of emotional involvement. The final area within the FAD assessment tool is behavioural control related to behaviours demonstrated by family members in relation to physical danger,

expressing psychological needs, such as love and sexual desire, and social interactions outside the family (Ryan et al., 2005).

Given the above descriptions and assessment criteria for family functioning, a stroke will disrupt the way a family operates that should be addressed by family members. The way a family adapts to an event is governed by the pre-incident family dynamics and relationships, as well as the family's life-cycle stage (Lawrence, 2012). The restructuring of family roles and behaviours after a chronic illness changes in respect of the timeline, as Rolland (1994) describes the crisis, chronic and terminal phases. An increasing influence on family adaptation in chronic illness is the relationships that exist between the family members, and in particular close partners or spouses (McPherson et al., 2011; Wilson, 2002).

1.10 Provisional framework

Figure 1.1 provides a map of the study area culled from the critical review of the literature. The three central boxes show the core framework with their influencing factors. Caregiver experiences of stress, burden or positive adaptation to an illness event such as a stroke or dementia is mediated by the perceived quality of the relationship between the caregiver and care-recipient. The premise being that if the caregiver and care-recipient can maintain a satisfactory relationship then this has a positive effect on their adaptation to the stroke leading to a satisfactory quality of life for both carer-giver and care-recipient.

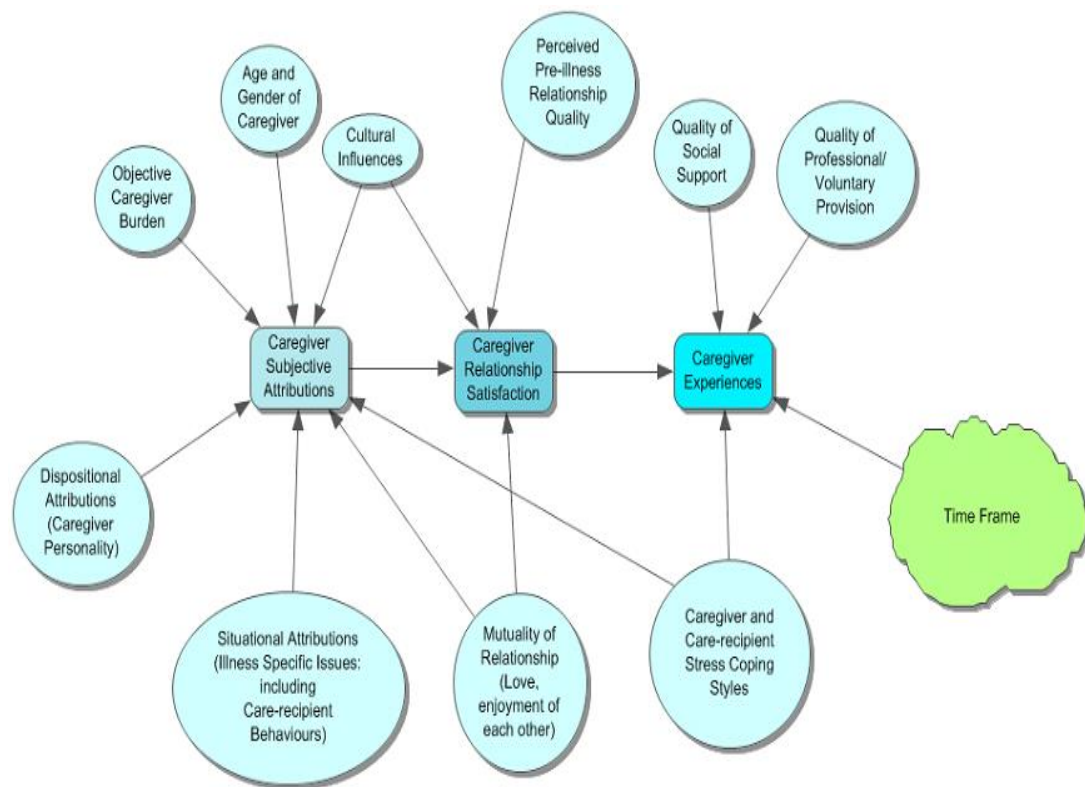


Figure 1.1: Theoretical framework following critical review of the literature

Subjective attributions are the personal causal hypotheses that people make to account for behaviours and actions of others (Bradbury & Fincham, 1990). These attributions can be positive or negative and are either attributed to the individual or to external/contextual events. If a partner brings his spouse a bunch of flowers, attribution can be filtered through the partner's knowledge of her spouse and the context of the act. So, if the couple had a quarrel the night before this may be viewed as an act of attrition. However, if there was no such context and the act of giving flowers outside anniversaries was not consistent behaviour then the spouse would view the gesture with suspicion as to some ulterior motive. Bradbury and Fincham, (1990) in their review link such attributional causes as an important aspect of marriage relationships. Influences that affect carer subjective attributions comprise two attributional factors, dispositional and situational. Dispositional attributional causes are related to the personality of the carer and care recipient, so in a 'happy' relationship the source of happiness is most likely to be attributable to the partner, and they focus on their partner's positive behaviour as part of the person's character whereas in a less happy relationship tended to see their

partner's negative behaviour as part of his or her character and downplay the partner's positive behaviour.

Linked to subjective attribution is the mutuality of the relationship. Mutuality is concerned with the degree of caring, affection, intimacy, mutual concern and overall relationship satisfaction experienced by those involved (Shim, Landerman, Davis, & Gardiner, 2011). Caregiving has a high interpersonal stress component, so the manner of interaction and use of interpersonal relationship strategies that build and sustain mutuality are suggested to be very important (Kramer, 1993). Kramer, (1993) describes positive carer relationship strategies as negotiation, compromise, considering the other person's limitations, empathy, and compassion. Negative relationship strategies involve criticising, ignoring, confronting, or minimising communication.

Another factor that has been shown to affect stroke family carer attributions is the degree of functional and psycho-cognitive issues experienced by the stroke survivor (Clarke & Black, 2005). Some studies have shown a link between objective and subjective stroke carer burden, worse patient physical functioning associated with higher levels of subjective caregiver burden (Blake, Lincoln, & Clarke, 2003; Schure et al., 2006). However, other studies have not demonstrated such a link, including an effect on carer health (McCullagh, Brigstocke, Donaldson, & Kalra, 2005). Nelson et al., (2008) showed that it was change in the stroke survivor's physical and particularly neurological functioning that affects subjective caregiver burden the most.

1.11 Aims of the thesis

This thesis is a theory-driven analysis through the application of a realist evaluation approach to the support of families affected by stroke (Pawson, 2013). The thesis will identify programme theories that help explain how interventions targeted at spousal carers of stroke survivors may work; to understand how and why interventions work in particular contexts, thereby leading to improved policy initiatives, research and clinical practice. A critical discussion of realist philosophy will be conducted in the following chapter,

suffice to relate here is that realist evaluation is about recognising possible 'generative mechanisms' (Bhaskar, 1978) that explain the relationship between the intervention, and how stakeholders, clinical staff, researchers, policy makers, and clients understand the set of circumstances presented to them, which then influences their actions. The mantra of realist evaluation is "...what is it about a programme that works for whom, in what circumstances, in what respects, over which duration, and why" (Pawson, 2013, p.15).

The thesis's significant and original contribution to knowledge is manifest in both theory and method. There have been numerous systematic reviews and meta-analyses of family carer interventions in chronic illness, including stroke but to date there has been no realist synthesis of this literature, comprising a realist review of traditional systematic reviews. The thesis also adopts a qualitative longitudinal approach to stroke survivor and spousal carer perspective, which has been lacking in much of the literature surveyed. This longitudinal approach is combined with dyadic or couple generated interviews that reinforce the family-based standpoint adopted in the thesis. Specifically, the questions addressed by this thesis are outlined below:

Research question 1:

How effective are interventions that promote improvements in stroke family carer stress and burden targeted and implemented?

Research question 2:

How do family carers and stroke survivors' experience the effects of stroke and the available services offered over the long term?

Research question 3:

What are the explanatory theories that help explain how interventions designed to improve stroke family quality of life?

The study is developed through three phases that mirror attributes of realist evaluation and is described in table 1.1:

Thesis Chapters	Method	Relationship to Realist Framework
Phase One: Chapters – 1,3,4,5 (chapter 2 – methodology)	<ul style="list-style-type: none"> • Critical Review • Realist synthesis of systematic reviews • Preliminary couple interviews 	Initial Programme Theory
Phase Two: Chapters – 6,7	<ul style="list-style-type: none"> • Longitudinal couple interviews • Professional stakeholder focus groups • RELATE focus group 	Developing, testing and refining programme theory Transferability and Stability
Phase Three: Chapter 8	Practice Framework Conclusions Recommendations	Middle range theory and demi-regularities

Table 1.1: Overview of thesis design

1.11.1 Overview of the thesis

Chapter 1 has set out the justification for the thesis and discussed findings from a critical review (Grant & Booth, 2009) of the literature concerning family carers and chronic illness, in particular stroke, with the intention of identifying significant contributions that support conceptual development. The study aims and research questions have been described.

Chapter 2 sets out the methodological approach employed for the study. A review of the main research paradigms are presented, namely positivism and interperativism. The epistemology and ontology underpinning these paradigms are discussed, as is that of realism. Justification for realist evaluation is presented and includes an in-depth explanation of its process.

Chapter 3 realist synthesis and systematic reviews are explained and compared. The meta-realist synthesis is presented detailing the realist review of eleven systematic reviews that have evaluated interventions targeting stroke family carers. The reviews are described in a logic model format with further

analysis of the most frequently cited RCTs within the systematic reviews. Intervention fidelity for the systematic reviews were extracted and fed into the initial programme theories.

Chapter 4 reports on the initial couple semi-structured interviews that included six couples (n=12). Pen-portraits of the couples are presented and issues surrounding the use of dyadic interviewing. Through a thematic analysis framework an overarching theme of 'reconstruction' emerged with two sub-themes of 'identity' and 'managing relationships'. This analysis fed into the initial programme theories.

Chapter 5 describes the development of the initial programme theory and the conjectured context-mechanism-outcome configurations developed from the critical literature review (chapter one), the realist synthesis (chapter three) and the initial couple interviews (chapter four). Validity and reliability issues are discussed in relation to realist evaluation.

Chapter 6 discusses the methods employed in refining the CMOs through an iterative approach that alternated between longitudinal couple qualitative interviews (LQI) and four focus group interviews consisting of health and social care professionals (H&SCP) from four different stroke units, together with one focus group with RELATE (originally the National Marriage Guidance Council) counsellors. The LQI incorporated centre stage diagramming as a technique to support the 'teacher-learner' style of qualitative interviewing recommended by Pawson and Tilly (1997), while the focus group interviews were analysed using template analysis.

Chapter 7 presents the findings from the couple LQI and focus group interviews that culminated in four refined programme theories.

Chapter 8 the final chapter concludes the thesis. It presents a discussion which considers the main findings of the study and its contribution to the field of stroke family carer support. Demi-regularities and the refined programme theory are

presented and related to relationship theory. The implications of the new findings for practice, research and policy are examined. Limitations and strengths of the study are described, as is a reflection of the whole PhD process.

Stage of Research	Months Carried Out	Purpose of each Stage	What was Learnt
Critical Review (Chapter 1)	Months 1-36 (36 month period)	To gain a broad perspective of the topic area and as part development of the initial programme theory	Identification of systematic reviews analysing interventions to support stroke survivors and their families
Realist Synthesis of Systematic Reviews (Chapter 3)	Months 18 - 36 (18 month period)	As part development of the initial programme theory	Insight into the limitations of systematic review analysis for realist synthesis
Preliminary Couple Interviews (Chapter 4)	Months 16 – 26 (10 month period)	As part development of the initial programme theory	Importance of stakeholder involvement in development of programme theory
Longitudinal couple Interviews (Chapter 7)	Months 36 – 50 (14 month period)	Programme theory testing and refinement	Importance of stakeholder involvement in development of programme theory
Focus Groups with Stroke Health Care Practitioners (Chapter 7)	Months 40 – 50 (10 month period)	Programme theory testing and refinement	Importance of stakeholder involvement in development of programme theory
Focus Group with RELATE Counsellors (Chapter 7)	Month 50 (1 month period)	Programme theory testing and refinement	Provided a relationship perspective for the programme theory

Table 1.2: Mapping the different stages of the inquiry

1.12: Conclusion

In summary, this chapter has set out the justification for the thesis through discussion of policy background to family stroke support in the United Kingdom (UK). The first phase of the realist evaluation approach was initiated with a critical literature review of the literature on support interventions for families who live with chronic illness, including stroke. From this review, an initial theoretical framework was developed that linked family experiences of

caregiving to their subjective perception of burden and stress, and caregivers' relationship satisfaction with the care-recipient. The study's rationale, aims and objectives have been presented, with an overview of the structure of the remaining chapters. The next chapter will give a detailed discussion of the realist approach underpinning the thesis.

CHAPTER TWO: The Methodological Approach

2.1: Introduction

Chapter one set the context and background framework for the research study, including stroke policies in relation to rehabilitation and informal family care. Stroke is a long-term condition that has both physical and psychological impacts, as the stroke survivor needs to adapt and cope with sometimes major functional disabilities. Psychologically, both stroke survivor and the main family carer even under minimal functional issues need to manage the psychological aftermath of the stroke, which can lead to depression, stress, and carer burden. Increasingly, there is a recognition that stroke impacts on the relationship between the stroke survivor and main family carer, particularly the spouse.

The next stage in the thesis is to identify and justify the selection of an appropriate methodology that is suited to the evaluation of complex social interventions such as the support needs of stroke family carers in the community. The core features of rehabilitation are that the process occurs within a framework encompassing all aspects of illness, and that the process depends upon co-ordinated, multidisciplinary team work who need to involve and educate the stroke survivor and family in the rehabilitation process. Interventions in this complex milieu are difficult to investigate and the Medical Research Council (MRC) has developed guidelines to address this complexity, which will be discussed in further detail later in this chapter (Craig et al., 2013). Methodology will be discussed through the invocation of ontology and epistemology. According to Scotland, (2012), ontology “asks what constitutes reality, in other words what is reality” (p.9). Epistemology is concerned with the nature and forms of knowledge, or “what it means to know”, while methodology is the process of acquiring knowledge. To further the discussion around the two main methodological approaches, positivism (empiricism), and interpretivism (constructivism) the debate will centre around three questions:

- Is social science the 'same' as the natural sciences, and so should utilize similar approaches to knowledge construction?
- Are the artefacts studied by the social sciences, such as society, relationships, or the self, 'real' in the same sense as objects in the material world?
- Can the ideals of the natural sciences, to generate law like relations between objects that are applied universally be transferred to the analysis of social life?

2.2: Scientific and Social Knowledge

2.2.1: Natural Science and knowledge

Scientific knowledge as it is recognised today dates to the Enlightenment period at the beginning of the 18th Century and remained dominant until the end of that century (Smith, 1998). The Enlightenment is so called because it opened the way to question the established knowledge base of Western Europe. Up until that time, knowledge about the world and human behaviour was sourced within religious doctrine, and was incontestable; but the Age of Enlightenment held that human progress is founded on rational moral principles supported by science and universal values (Porter, 1997). The conception of science and knowledge at this time was predicated on the idea that humans were seen as the originators of knowledge and therefore open to question through critical inquiry (Smith, 1998). Humans could 'know' about the world not just through reasoned thinking (rationalism), but also through empiricism, the idea that knowledge must be verified through the senses. Therefore, everything that can be known can be measured. Measurement of the natural world was achieved through the 'scientific method' and careful recording of observations that resulted in the delineation of causal events (Pedyowski, 2003).

The empiricist tradition and the scientific method are not only used to understand and control the natural world, but was also the main method adopted in explaining (and controlling) the social world. During the Enlightenment period 'truth' about the world was transferred from the Divine to the rational, and in the process influenced the way society was organised,

challenging the rights of absolute rulers, arguing that the state should protect its citizens. Enlightenment ideas permeated all aspects of human life forming an intellectual, economic and political transformation that emphasised the role human enterprise had on changing the physical and social world (Zafirovski, 2011). Smith, (1998) identified this transformation as the 'scientific circuit of knowledge' (p.64) in which the scientific paradigm (method) leads to reason, humanity, progress and truth, both in the natural and social world. This scientific paradigm and its discourse about reality and knowledge exerted a powerful grip on Western thought and practices. In summary, empiricism and the 'scientific method' dictate that there can be no knowledge unless it is gained through experience and the senses. This approach may be acceptable in the natural sciences such as physics and chemistry, but it is highly contested in the social sciences (Pedynowski, 2003).

2.2.2: Social science and knowledge

A significant problem that persists in social science research is the question of what constitutes 'knowledge about the world'. Further, it is not just about 'knowledge' but about 'perceived truth', and the two paradigms for dealing with the 'perceived truth' have emerged as competitors (Smith, 1998). These are the scientific paradigm (quantitative research), based on a logical and positivist epistemology, and the naturalistic or interpretive paradigm (qualitative research) based on a phenomenological epistemology (Smith, 1998). These two paradigms differ on several fundamental assumptions, of which Smith (1998) considers three as noteworthy: the nature of reality, the subject-object problem, and the 'scope of findings' (Table 2.1).

	Positivist Paradigm Quantitative	Interpretivist Paradigm Qualitative
Role of Research	Preparatory	Means of exploration of Actor's interpretations
Relationship between researcher and subject	Distant	Close
Researcher's stance in relation to subject	Outsider and independent	Insider and inter-related

(subject-object relationship)		
Relationship between theory/concepts and research	Confirmation	Emergent
Research strategy	Structured	Unstructured
Scope of findings	Generalisations: Nomothetic statements that focus on similarities	Working hypothesis: Idiographic statements that focus on differences
Image of social reality	Static and external to social actor	Processual and socially constructed by actor
Nature of the data	Hard, reliable	Rich, deep

Table 2.1: Differences between the positivist and interpretivist paradigms (Bryman, 1988, p.94)

2.2.2.3: Nature of reality

For the positivist paradigm, there is a knowable world outside a person's thoughts and feelings (Guba & Lincoln, 2005). For the positivist scientist, such a world can be accessed if a person's subjective interpretation of events is minimised through the rigorous application of method. The research method that best encapsulates and symbolizes the positivist tradition is the experiment, in which the researcher attempts to eliminate as much external influences as possible stripping away irrelevant variables that are not under investigation. In this way, the social scientist attempts to ensure that the 'new' intervention has caused the change in outcome. Many of the intervention research within stroke and family caregiving has followed the positivist paradigm using RCTs and standardised assessment tools. This in part is inevitable due to the dominance of the biomedical over rehabilitation services (Wade & Halligan, 2017). A problem with an over-reliance on the biomedical approach is the mereological fallacy (Harré, 2012) in which there is a categorization of how the affected part can be segregated from the whole body for treatment purposes. So, if the stroke survivor has aphasia, the tendency is to concentrate on mechanical speech recovery, without regard to the wider psychological and social trauma that results from this communication deficit.

For the interpretivist researcher, reality is only knowable through a person's interpretation of the external world. 'Reality' is a subjective mental construction that guides our actions in the external world. Should our actions not fulfil this task, we have to change or enlarge our mental perceptions. Through communication between people, individual inter-subjective mental constructions become social constructions of 'reality' (Sterling-Folker, 2002). As such, people of similar cultural identity, communicating through the same language can come to see elements of the world as similar. However, people from different cultures (and sub-cultures) have a differing world view, giving rise to multiple realities. To access these diverse world views there is a requirement for alternative research approaches to elicit the meaning behind the perceived realities. Qualitative research attempts to gain the perspective of the people involved through observing and talking to participants in their environment with all its inherent complexity (Biggerstaff, 2011).

2.2.3: Subject-object dualism

The second assumption that of subject-object dualism, concerns the role of the investigator in the research process. In the positivist paradigm, the assumption is that the investigator will have no effect on the phenomenon under study and, equally important, that the phenomenon will have no effect on the researcher (Guba & Lincoln, 2005). For the social sciences, this assumption is difficult to sustain unconditionally, since the investigator and volunteer must interact at some basic level. Even in a postal survey where the researcher and respondent do not meet in person, the questions asked are filtered through the participant's perceptions, and just as significantly the researcher may misconstrue the answers given (Guba & Lincoln, 2005). For the interpretivist paradigm, this dichotomy of subject versus object is not an issue, as the disparity is overtly acknowledged and accounted for in their analysis.

If the subject-object assumption is problematic for the positivist paradigm, then the 'scope of findings' is difficult for the interpretivist paradigm to defend. The essence of research is to be able to transfer its outcomes from the particular to the general, for the good of society as a whole (Smith, 1998). The conclusions

from a positivist paradigm are that of 'generalisability' from the sample to the larger population. The limitation on generalisability is the exactitude of the research process, and this is determined through convention (Biggerstaff, 2011). So, the results from a well conducted survey or experiment, encompassing good sampling and randomisation can be confidently linked with the appropriate population. This is supported by Lipscomb, (2012) who argues that qualitative researchers should be very mindful of their responsibilities in inferring generalisability to their findings. This assertion may be too strong, in that qualitative research can inform clinical practice if the context surrounding data collection and analysis is made explicit, so that the reader can gauge the relevance of the findings to their own clinical situation.

A further perspective on objective/subjective dichotomy is provided by Sayer, (2000). He classifies three types of objective/subjective dyads:

- O1: means being value-free or value-neutral, with subjectivity (1) being value-laden. This is the every-day or common-sense understanding of the dichotomy.
- O2: is the 'search for objective knowledge or true knowledge' (Sayer, 2000, p.58), and is the definition discussed in the positivist view of science. For O2, subjectivity (2) implies a biased, human representation that cannot be regarded as 'the truth'.
- O3: for Sayer (2000, p.59) objective (3) is the 'thing' that 'pertains to objects', and have qualities that exist independently of our consciousness of them. So, for example, in the United Kingdom (UK), the National Health Service [NHS] as a social institution exists regardless of our feelings or beliefs about it, it is intransitive. Whereas, subjective (3) 'pertains to subjects' and does concern our beliefs and thoughts about the object, so we have a subjective experience of the NHS if we have ever visited a hospital in the UK.

The importance of the distinction according to Sayer (2000) is that O1 and O2 are conflated by the science community, in that subjectivity does not have a

place in truth telling. However, Sayer (2000) argues that what people think or believe about an object does have veracity, and should be a part of science to achieve as full an explanation as possible, so O1 and O2 can be subsumed into O3. As an example, we may think the NHS is a marvellous institution or we may think it is not very effective and provides poor service, based on experience. As such they are subjective, but they are capable of having an impact on the object, in this example policies that shape the NHS. For Objective 2, the de-subjectivity of science negates valuable information or data as not objective and should therefore be discounted. If Objective 3 is accepted then what people think or value can also be used as data to unpack and shape the social world.

2.2.4: Scope of findings

The basis of the positivist paradigm is the elimination of individual differences with its aggregation into a mean or average score that represents the population of interest. This nomothetic approach to the social sciences, such as psychology, contradicts the core of the discipline, to understand individual differences in behaviour (Willing, 2013). In addition, McCrae, Kurtz, Yamagata, and Terracciano, (2011) infer that generalisations from empirical studies 'decay' over time and exhibit a half-life, similar to radioactive substances. Generalisations in the social sciences will sooner or later, be consigned to history, so questioning the long-term validity of quantitative research results. By contrast, the naturalistic paradigm cannot establish generalisability from its results as easily as the scientific paradigm, since it does not provide sufficient numbers of people for aggregation. Indeed, those who support the interpretive paradigm argue that qualitative research is about richness of data rather than quantity of data (Willing, 2013). It is this ideographic approach, taking account of participant context and experiences that provides the naturalistic paradigm with its strength. The quantitative research approach in its pursuit of generalisability, requires the environment to be stripped of its context so that the subject and the variables of interest can ascertain causal or correlational links (Hammersley, 2007).

The debates between positivist and interpretivist paradigms often underpin an individual researcher's posture towards a particular research design and method that is independent of practicality. In general, it is the experimental and survey research designs that correspond to the positivist or scientific paradigm, while ethnography, grounded theory and phenomenology are research approaches that mirror the more interactionist or naturalistic stance of some social science researchers. Researchers today recognise the strengths and weaknesses of both sets of philosophical arguments and attempt to mix various research methods within the overall research design (Willing, 2013).

From a methodological perspective the discussion about the attributes of various types of research falls into a debate between 'quantitative' and 'qualitative' data collection methods (Hammersley, 2007). As can be seen from table 2.1 above, Bryman (1988) outlined the distinct characteristics of both approaches to data collection, although many researchers today use a multi-method approach, or as Hammersley (2007) labels it 'methodological eclecticism'. For example, experimental and quasi-experimental designs attempt to measure the effects of manipulating one variable on another in a highly-controlled way. Survey designs tend to collect standardised information from samples to examine the nature, frequency, distribution, and relationships between variables in a population (nomothetic). Qualitative research as discussed previously is concerned with collecting detailed information that is not reduced to measurement, in order to generate in-depth accounts of experiences from participants (ideographic) in the study (Willing, 2013). It is important to recognise that the same data collection methods can be applied to either quantitative or qualitative paradigms. For example, observation and interviewing are used in experimental and survey designs in a highly-structured manner, while in ethnographic or grounded theory research they are much less structured; in other words, there is a continuum of structure imposed on the method. In conclusion, there is merit and utility in both perspectives, the positivist view of reality and the interpretive standpoint. The above discussion highlights difficulties for policy makers in that the research orientation adopted,

creates problems in the analysis, implementation and evaluation of various social and health policies that they initiate.

2.3: Connecting Positivism and Interpretivism:

There are two fundamental assumptions for critical realism that bind it to the positivist and interpretive approaches to science, as Wainwright and Forbes, (2000) state making a “realist third way” (p260). The first major assumption is that realists believe the natural and more importantly for this analysis, the social world has a 'reality' or existence independent of our (human) interpretation of it, this assumption is supportive of the positivist tradition (Bhaskar, 1978; Maccarrini, Morandi, & Prandini, 2011; Sayer, 2000). In this ontology, the social world is 'real' because it has an effect on other objects in the world.

The difference between critical realism and positivism in its formation of reality is that realists view society as an open system whereas positivists operate in a closed system (Cruickshank, 2012; Maccarrini et al., 2011). An open system is one that allows unfettered boundaries between objects that become part of multiple causal relations, which imparts a state of complexity. Whereas a closed system limits the number of measurable variables to identify predictive relationships between objects, in so doing a closed system has to set boundaries to screen out potentially confounding variables (Bhaskar, 1978; Pedykowski, 2003). As a result, within open systems any event has many causes, and as a consequence may have many effects.

According to Bhaskar, (1978) the open system he describes is a stratified structure, comprising of the empirical, actual and real strata (Smith, 1998; Williams, 2003) (Figure 2.1).

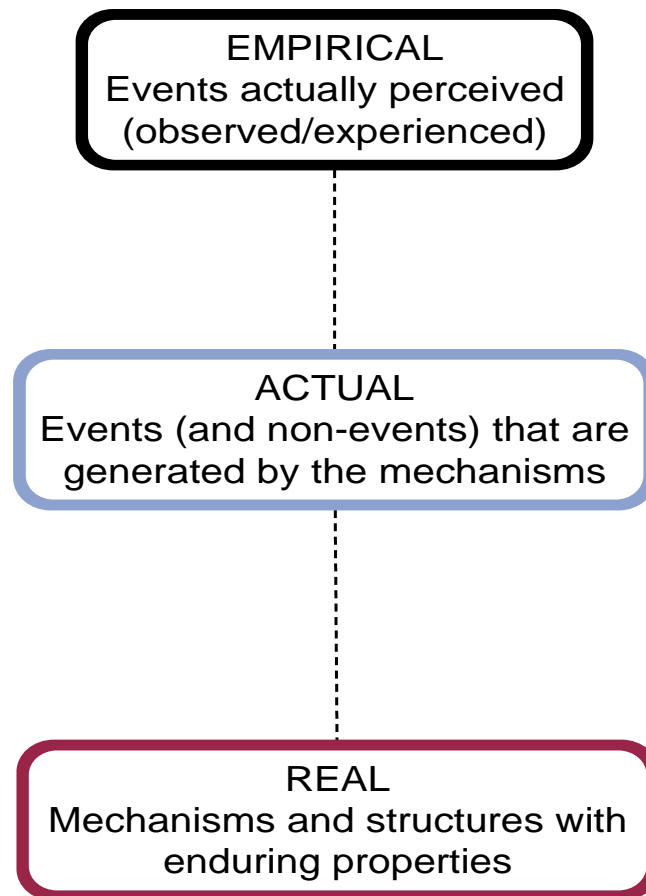


Figure 2.1: The three ontological levels of reality (after Mingers, 2004, p.23)

The empirical level is that which we all observe about the world and gives us our immediate experiences. In the actual domain, it is the manifestation of events caused by the real domain that for critical realists is the level where the perceptions, events and their unknown generative mechanisms co-occur. It is this third, real level of explanation that critical realists attempt to explain, as Williams (2003) remarks, “It is the third domain of the real, including the generative causal mechanisms it contains independent of our knowledge or sense of perception of them, that takes us to those realist parts that ' other approaches cannot reach'...” (p.52)

The supposition that connects critical realism to the interpretive paradigm is the acceptance that people construct mental schemas of the world they occupy, so becoming an inter-subjective cum socially created society (Williams, 2003). Realists do not go as far as constructivists and say that humans 'create' reality committing the 'epistemic fallacy' (Cruickshank, 2012; Sayer, 2000), which can develop into 'anarchistic relativism' (Wainwright & Forbes, 2000), but in realism, there is a recognition that the way the reality is 'described' (mainly through language) is not a direct representation, as Bhaskar (1978) observes on interpretive 'linguistic fallacy': "Science then, is the systematic attempt to express in thought the structures and ways of acting of things that exist and act independently of thought" (p.250). In addition, critical realists accept that there are underlying or generative mechanisms that operate beneath the observable, but are 'real' because they have an effect on the observable world (Moren & Blom, 2003).

One key area where realism protagonists' critique of the interpretivist paradigm helps in the analysis and understanding of complex social phenomena is the dismissal of interpretive over-reliance on participants' stories or narratives of their world (Wainwright & Forbes, 2000). The 'over-privileging of agency' (Williams, 2003), leads to an adherence by interpretive proponents to a participant's perspective of the world, at the expense of the wider contexts that are unknown to the agent concerned. A quote by Wainwright and Forbes, (2000) illustrates:

To not explore the impact on health inequalities of mechanisms within capitalism such as exploitation and alienation, for example, because they are not seen to exist in either a measurable way (positivism) or because they are not expressed by those who being researched (interpretivism) leads to huge gaps in any subsequent 'explanation' and ultimately to partiality and theoretical weakness. (p.271)

Since, in critical realism, there is an acceptance of certain, bounded tenets of both positivism and interpretivism, it therefore allows researchers to utilise the benefits of quantitative and qualitative methods in their empirical work (Sayer, 2000). Figure 2.2 below is a visual representation of the place of realism between positivism and interpretivism.

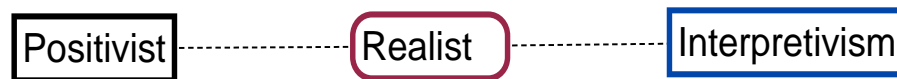


Figure 2.2: Place of critical realism in scientific ontology

2.4: Critical realism - a synopsis

Up to now there have been references to realist thinking, but in this section a brief synopsis of realist thought will be useful to reinforce the justification of this approach in the study. According to (Archer, 2010) critical realism is not just one philosophical approach but several, having family resemblances, but at their core “Critical realism is concerned with the nature of causation, agency, structure, and relations, and the implicit or explicit ontologies we are operating with. It asks what we mean by realism in the social world?” (p.1), in other words a meta-theory for the social sciences. Bhaskar (1975, 1978) developed contemporary critical realism as an ontologically-based philosophy of science that attempts to answer the question 'what must reality be like to make science possible?' (Bhaskar 1975: p.xxix). A key feature of critical realism is what Bhaskar (1975) refers to as the 'epistemic fallacy': the tendency to link ontology and epistemology to confuse that which exists, with the knowledge we have about it (what we believe). Critical realism as a term was not coined by Bhaskar (1975) who used 'Transcendental Realism' to argue that scientific theories were best understood as provisional statements about the characteristics of entities that exist in the natural world. Bhaskar, (1978) extended his philosophy into the social sciences using the term 'Critical Naturalism' which sought to show that social structures exist and that it is possible to study them in the same way as

natural ones. Thus Bhaskar (1978) describes a philosophy of social science that enables explanations of social structures impacting on people's health.

Sayer (2000) noted that "...one of the distinctive features of realism is its analysis of causation which rejects the standard Humean 'sucessionist' view that it involves regularities among sequences of events" (p.13). As discussed above the realist interpretation makes a distinction between the real and actual with 'generative' or causal powers that may, or may not, be activated depending upon other conditions notably the context, and other mechanisms. This is particularly important for this study where social processes are typically dependent upon the actions of stroke survivors, their family carers, and organisational structures that deliver stroke rehabilitation. Thus, for realists, causation is not a regular succession of events. "What causes something to happen has nothing to do with the number of times we observe it happening. Explanation depends instead on identifying causal mechanisms and how they work, and discovering if they have been activated and under what conditions" (Sayer 2000, p.14).

2.4.1: Stratification and emergence

For critical realists, reality is a "stratified, open system of emergent entities" (p.6) (Edwards, O'Mahoney, & Vincent, 2014). Stratification as discussed previously is the separation of the empirical, perceived experiences, the actual, the manifestation of events produced by the real, the mechanisms that generate the actual and the empirical. Following on from this stratification, entities or objects are said to have '*emergent powers*', that is, powers or propensities which cannot be reduced to those of their constituent parts. Central to the concept of emergence is the idea that there are both social structures and human agency which interact to produce emergent properties (Elder-Vass, 2010). These causal interactions are multiple in nature not one-to-one culmination but have 'multiple determination' (Bhaskar, 1975), that greatly increases the complexity of open systems. As an example of emergence, water or H₂O, has 'powers' that are distinct from its constituent parts, ability to extinguish a fire or the capacity to make someone wet, exists at a different level

from those of hydrogen or oxygen, and cannot be reduced to its constituent parts, which are highly flammable and are gaseous rather than liquid at room temperature.

2.4.2: Transitive and Intransitive domains

For Bhaskar (1975) knowledge has two domains, the transitive and the intransitive. In the transitive or discursive domain are our theories about the world both natural and social, and these can be contested and altered as we gain more knowledge or conduct research. The intransitive domain is the natural and social worlds exist regardless of our theories about how they work. Given this difference the 'world' (natural and social phenomena) should not be conflated with our experience of it (Archer, 1995). For the natural sciences, the transitive/intransitive domains may have a clearer interpretation, for example, human theory about the rotation of the earth around the sun is relatively recent, as it was previously thought that the earth was at the centre of the universe. As theories changed (transitive) with empirical research to explain anomalies in the theory of the earth's centrality, the underlying reality of the earth moving around the sun had not changed (intransitive), even as human thought about it did.

However, for the social sciences there is an additional problem, in that social structures in which we live are part of human thought and 'created' by human action or agency, so how can society be intransitive and able to be explained, as Bhaskar (1978) asks "What properties do societies possess that might make them possible objects of knowledge for us? How can we disentangle the ontology from the epistemology?" (p.27). For Bhaskar (1978) while the social and the individual are inter-related, humans do not create society but are born into it and are socialised into their society, but humans can then replicate society and/or transform or change parts of society to create different elements of society (Figure 2.3). There is a relational connection between agency and structure that lead to emergent properties, and it is these generative mechanisms that can be explained within the social sciences. Further, structure and agency operate within an 'open system' where boundaries can be

potentially infinite, whereas, the natural sciences operate within 'closed systems' with more precise boundaries in which it makes sense to investigate through the experimental method (Sawyer, 2004).

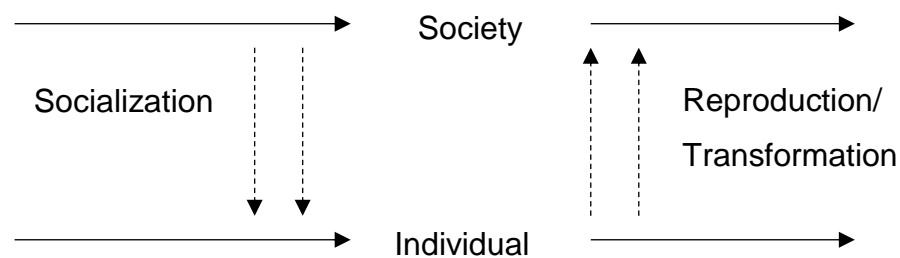


Figure 2.3: The Transformational Model of the Society/Person Connection (Bhaskar, 1978, p.40)

“Society is both the ever present condition (material cause) and the continually reproduced outcome of human agency. And praxis is both work, that is, conscious production, and (normally unconscious) reproduction of the conditions of production, that is society. One could refer to the former as the duality of structure, and the later as the duality of praxis” (Bhaskar, 1978, p.44). Within the social world, people’s roles and identities are often internally related, so that what a person can do, depends on their relation to other people or institutions. So, being a spouse cannot be explained at the level of the individual but only in terms of their relation to their partner, and vice versa. The powers they call upon depend partly on their relations to one another, and to relevant parts of the context, such as living in the same house.

2.4.3: Abduction and Retroduction

Danermark, Ekstrom, Jakobsen, & Karlsson, (2002) outline four ways to think about an object, two are familiar, induction and deduction, whereas the remaining two inferential processes, abduction and especially retroduction are crucial in critical realism thinking. These ways of thinking are linked to transfactual causal tendencies, that can exist without being actualised (i.e., mechanisms), but can be triggered when in the appropriate context. Abduction

or theoretical re-description is the process by which individual observations, such as results from qualitative interviews or data from a structured survey are linked to a more general and theoretical understanding of social reality. This process is different from induction, which is a way of inferring theory from the observed data, or deduction, which provides hypotheses about observations that are already based on a theory. In abduction, the intent is to produce new programme theories from the data (including pre-existing literature) that best explain the research evidence to date (Tavory & Timmermand, 2014). Modell, (2009) describes it thus, “abduction does not move directly from empirical observations to theoretical inferences, as is the case in purely inductive research, but relies heavily on theories as mediators for deriving explanations” (p.213), in other words, the initial programme theory guides the interpretation of the data, but the new data can also moderate the programme theory to develop a more robust explanation of events, or refined programme theory. Abduction is a process that permeates every stage of the realist evaluation approach, and according to Danermark et al, (2002) requires imagination and creativity on the part of the researcher, and as such makes the process of realist enquiry inherently complex and time consuming activity. “Re-description and re-contextualisation...give new meaning to already known phenomena and help social scientists to understand previously taken-for-granted phenomena in a novel way” (Meyer & Lunnay, 2013, p.5).

Retroduction is similar to abduction in that it requires creative thinking by the researcher but it is a more abstract form of inference, and a process that is central to critical realist analysis. Retroduction takes a broader inferential analysis than abduction, taking the process back to what must reality be like that make the causal powers or mechanisms are as they are, as a means of knowing the conditions fundamental to the existence of phenomena (Modell, 2009). Retroduction identifies patterns in different contexts over time through six strategies: counterfactual (and transfactual) thinking, thought experiments, social experiments, studying pathological circumstances and extreme cases, and comparison of different cases (Danermark et al., 2002).

2.5: Complex social Interventions

Critical realism as an alternative way of interpreting the world, and is linked to the complex nature of social interventions, particularly those that attempt to change peoples' behaviours (Michie, Johnston, Francis, Hardeman, & Eccles, 2008). Glouberman and Zimmerman, (2002) devised a typology that identifies three states: simple, complicated and complex. In a simple problem there is a 'recipe' approach, where following a set of procedures leads to the solution or objective. In complicated problems, Glouberman and Zimmerman (2002) describe the process of getting a person to the moon, where formulas and expert knowledge are required to design a rocket etc., complicated problems can be unpredictable but do have pathways that are coherent and can be worked through with the right level of knowledge. However, complex states are unpredictable, while expertise and experience can be useful, it is no guarantee that there is a successful or predictable conclusion, the authors' cite the rearing of children as an example of complexity, where 'success' with one child cannot predict subsequent 'successful' children. This typology is popular in evaluation science, but Mowles, (2014) questions its usefulness since in the social world following a recipe is a human process, where practice influences the rules and vice versa. Mowles (2014) also contests Glouberman and Zimmerman's (2002) example of taking people to the moon as a complicated problem, whereas it is a complex activity, as there is more to getting someone to the moon than just building a rocket, as the process entails negotiation and collaboration of all the people involved in the endeavour, which is a complex social activity. According to Shepperd et al., (2009) there is lack of consensus as to what constitute complex interventions but the revised MRC (2008) guidance on complex interventions outlined several components for healthcare services:

- Number of interacting components within the experimental and control interventions
- Number and difficulty of behaviours required by those delivering or receiving the intervention
- Number of groups or organisational levels targeted by the intervention
- Number and variability of outcomes

- Degree of flexibility or tailoring of the intervention permitted (Craig et al., 2013, p.588)

The authors go on to outline changes that prompted a revised MRC (2008) complexity framework that should begin with an understanding of the underlying theories that account for changes brought about by the intervention, as the quote below testifies:

The rationale for a complex intervention, the changes that are expected, and how change is to be achieved, may not be clear at the outset. A key early task is to develop a theoretical understanding of the likely process of change by drawing on existing evidence and theory, supplemented if necessary by new primary research. This should be done whether the researcher is developing the intervention or evaluating one that has already been developed (p.589)

2.6 Complexity and critical realism

This quote sits within the remit of realist approaches (Pawson & Tilley, 1997), however, Pawson (2013, p.49) is critical of the MRC features listed above, beginning with the insertion of ‘experimental and control interventions’, in that the overarching method is the RCT to explain complex interventions. Also in bullet-point number four, the emphasis on amount of inputs and outputs that make-up complex interventions is limited and should look for emergence or adaptive changes. Pawson (2013) recognised that there is a degree of flexibility in bullet-point five but he highlights the word ‘permitted’ again underscores the trialist mentality on complexity. In his book, Pawson (2013) devotes several chapters to complexity and using the acronym – VICTORE, making the argument for why health and social care interventions are complex and how a realist evaluation approach can help the evaluator understand “what works, for whom, and in what context”.

VICTORE stands for the seven features of complexity in health and social care evaluations encompassing the realist philosophy: Volitions, Implementation, Contexts, Time, Outcomes, Rivalry, and Emergence (Pawson, 2013). Volition (V) is the choices made by people involved in the programme, these are of course the beneficiaries, the stroke family composed of the stroke survivor and family carer and other members affected by the fallout from the stroke. However, these are not the only recipients, the health care practitioners (HCP) who administer the programme of support have ideas about how it should be implemented, as well as the researchers who designed the intervention and policy makers who commissioned it. Within the realist evaluation framework “...interventions do not work, it is the interpretations of their subjects that produce results” (Pawson, 2013, p.34). The intervention provides a ‘resource’ for the recipient to engage with or not, and to re-examine their preferences. Complex interventions that are sustainable have intricate implementation (I) chains that rely on various individuals and organisations to operationalise the programme, as Richards, (2015) discusses complexity should focus more on implementation rather than just the intervention as the MRC (2000, 2008) frameworks focus upon. Implementation is also the embedding of the programme into everyday health provision and requires the involvement of all stakeholders including the patient and their families at every stage of the process. Interventions are delivered within a context (C) that creates another layer of complexity. Pawson (2013, p.37) uses the four I’s to sketch the contour of the context:

- Individuals – characteristics and capacities of the various stakeholders
- Interpersonal relations – the stakeholder relationships that carry the programme
- Institutional settings – the rules, norms and customs local to the programme
- Infrastructure – the wider social, economic and cultural setting of the programme

Time (T) is the fourth component of realist complexity. It is a key element in stroke family support in a study by Cameron and Gignac, (2008) that outlined the changing needs of stroke family carers as they adapted across time to the effects of stroke on their relative, and as a result they required different supportive interventions. The fifth element of complexity is outcomes (O), and within stroke research these are contested as to their validity and reliability. Several systematic reviews have bemoaned the fact that the variety of instruments used to measure the outcomes from interventions make it difficult to compare studies (Visser-Meily et al., 2005). Intervention outcomes in stroke family support may also be different depending on who is asked as Boger et al., (2015) conclude from a systematic review of stroke self-management: “Patients’, families’, health professionals’ and commissioners’ views regarding which outcomes of self-management are important have not been clearly elicited” (p.2).

Rivalry (R) according to Pawson (2013) are the competing interests already in place that can interfere with the proposed ‘new’ intervention outcomes. In stroke patient and family care in the UK there are inter-professional teams that endeavour to deliver support in both hospital and community settings, indeed stroke care can boast the largest inter-professional team structure of any disease entity and as Hewitt, Sims, and Harris, (2014) assert: “Large inter-professional teams restrict the involvement and contribution of all team members. This often results in subgroups that are likely to reinforce uniprofessional boundaries” (p.13)

The final element in realist complexity described by VICTORE is emergence (E), which is a key principle in realist thinking, and as discussed in section 2.4.1, the resultant causal properties of a programme is greater than the individual components that make up the programme.

Within programmes that support stroke families the underlying components that make up the package can be interpreted in different ways along the chain of implementation, and so “...change the conditions that make the programme

work in the first place' meaning '...imperfect control over the outcomes" (p.42) (Pawson, 2013). An apt example of emergence that will be returned to again within this thesis is an intervention to support stroke carers by Kalra et al., (2004) that is considered by Bakas et al., (2014) to be one of the best designed RCTs in this area. The study trained stroke family carers in basic nursing procedures such as facilitating activities of living with the stroke survivor. Results at three and 12 months showed significant reduction in family carer burden, anxiety and depression with increased quality of life, similarly over the same time-period the stroke survivors reported better quality of life and psychological outcomes. However, a recent large scale pragmatic, multi-centre, cluster randomised controlled trial and cost effectiveness analysis (TRACS) (Forster et al., 2013) based on Kalra et al., (2004) single-centre individually randomised trial showed no benefit of the structured training to stroke family carers or the stroke survivors. Forster et al., (2013) state that the non-significance of the pragmatic trial was in part due to: "Caregivers need more than just an inpatient structured training programme to improve the patients' and their own outcomes. The integrated intervention approach might be more relevant, whereby initial hospital training is supported with follow-up training after discharge delivered by community-based teams" (p.2075)

The team who developed the TRACS trial incorporated a process evaluation study in parallel with the RCT (Clarke et al., 2014). In their analysis (Clarke et al., 2014) point to an extensive list of issues along the implementation chain, from lack of 'ownership' of the intervention by some senior therapists with several multi-disciplinary teams not fully understanding, engaging or committing to the intervention. Indeed, most of the nurses did not know about the training package, and when questioned they already thought carer training was happening, although the observational studies did not support such a contention. The process evaluation concluded that:

Despite preparing intervention unit staff through workshops and cascade training, TRACS could not replicate the motivation, commitment, and control over delivery of London Stroke Carers

Training Course evident in the Kalra et al., study where the same staff responsible for delivery and where intervention delivery was assured (Clarke et al., 2014, p.9)

The above pragmatic trail and its process evaluation encapsulates the complex nature of delivering intervention programmes for stroke families, and reinforces the necessity for a methodological approach that challenges this complexity head on, enabling a more nuanced understanding of 'what works, for whom, and in what context'.

2.7: Critique of critical realism

Critical realism combines realist ontology with an interpretative epistemology, where social structure occurs independently of present human action (Archer, 2010). Further, critical realists argue that ontology (theory of reality) should take precedence over epistemology (theory of knowledge) rather than the 'epistemic fallacy' that conflates the two processes (Bhaskar, 1978). It is here that Heidegger (Michel, 2012) takes issue with realists and anti-realists with the fallacy of 'ontological difference'. In this case 'entities' (something that exists) can be detached from human comprehension or knowledge as realists contend, but according to Heidegger (Michel, 2012) to become aware of an 'entity' only occurs through a specific form of entity, a human being. In other words, critical realism relies on a view of the world that is subject/object divided. There are subjects in the world together with objects and subject actions are constrained or enhanced by objects they encounter (Michel, 2012). The objects can be individuals, the law or government policies or cultural norms, and as such are researchable, as they are the object. However, the issue for critical realism is that the 'being' of the object is taken for granted; they are the 'reality' because of the already taken position as the object (Michel, 2012). So, social scientists can study the hospital as an institution without referral to human consciousness because it is 'real' and in the world, not requiring a subjective mental construction. However, according to Heidegger, a hospital does not have a reality outside human existence, so if there were no human beings there would be no hospital. This prosaic conclusion is nevertheless important as it

underscores the continued debate that there are several kinds of ontology, and the question of what is 'real' in science is still open to interpretation. However, the benefit of an attachment to critical realism as a philosophical grounding for scientific inquiry is pragmatism, with attempts to capture both sides of the positivist/interpretative analysis.

2.8: Evaluation research

Evaluation, according to Mark, Henry, & Julnes, (2000) is a process that attempts to understand the implications of social policies and programmes through systematic inquiry: "The ultimate goal of evaluation is social betterment, to which evaluation can contribute by assisting democratic institutions to better select, oversee, improve, and make sense of social programs and policies" (p.3). Scriven, (1967 as cited by Stufflebeam, 2001) identified two evaluation processes, formative, where there is an emphasis on programme improvement, and summative evaluations with a judgement of a programme's merit or worth. Patton, (2005) describes a third perspective on evaluation, that of knowledge development in which the focus is on developing and testing theories about social problems and interventions. This third purpose of evaluation research is important as it appraises the veracity of the assumptions that surround social policy interventions. Theory-driven evaluation such as Pawson and Tilley's (1997) realist evaluation attempts to foster a better connection between why an intervention worked in a particular context, looking into the 'black box' of an intervention. Within this study a theory-driven evaluation of stroke carer support interventions is designed to improve the bases of future programmes.

2.9: Realist evaluation

Realist evaluation is derived from critical realism incorporating many of its tenets, but is differentiated from critical realism through its concentration on theory driven evaluation identifying and analysing programme effectiveness; in essence 'what works for whom in what circumstances' (Pawson, 2003) rather than the analysis of other theories through a particular theoretical lens (Pawson, 2006). Pawson's (2006) critique centres on the normative stance taken by

Bhaskar's critical realism in that it analyses other theories from the perspective of a morally superior theory that is privileged by the researcher. In response to this 'failing' of critical realism, Pawson (2006) develops realist evaluation (scientific realism – working within an objective and neutral perspective) through a push to "...develop realism as an empirical method' in which, the adjudication between theories should be based on a coherent analysis of evidence through conceptualization, hypothesis making and the discovery of empirical patterns, basing this model on evidence" (p.19). Pawson's (2013, 2006) analysis of critical realism may be overstated in that Bhaskar (2009) reiterates that the social sciences cannot be value-free and this should be recognized.

Porter, (2015, 2017) has criticized Pawson's (2013) critique of Bhaskar's realism, attempting to show that Pawson has misconstrued Bhaskar's views. Essentially Porter (2015) argues that (Pawson, 2016) has turned the "critical' in critical realism to a form of "technocratic engineering" (p.79) rather than a more ethically orientated stance of critical realism. Pawson's (2016) rebuttal is that Bhaskar was essentially a philosopher, not an evaluation scientist, so his analysis does not tie in with what is required for the "practice of empirical research" (p.50). Indeed Pawson (2016) asserts that Bhaskar's critical realism takes a normative position that should not be a part of evaluation research, whereas realist evaluation lays the foundation for evaluators to apply realist thinking to their analysis. For this thesis the burgeoning realist evaluation literature in health and social care (Williams, Rycroft-Malone, & Burton, 2017) firmly puts this study's methodology in realist evaluation territory with the construction of CMOs, rather than Bhaskar's critical realism.

2.10: Components of Realist Evaluation

As briefly discussed in chapter one the main components of a realist evaluation is the context – mechanism – outcome configurations (CMOCs), which show how interventions are meant to work in which populations and under what conditions. These CMOCs can be viewed as mini-theories with each CMOC being the subject of an evaluation and is tested against the available evidence.

For example, when an intervention is introduced in a programme that is intended to support stroke family carers, there is a hypothesis of how the intervention will effect change in stroke carers' stress or burden levels. These hypotheses are traditionally rooted in the intervention ingredients such as education sessions providing problem-solving techniques will reduce stress through better coping skills. In Realist evaluation however, the intervention is a resource that is provided for the stroke carers and it is the decision-making that 'causes' the outcome. It is the underlying mechanisms that change people's decisions. The programme mechanisms are always present, they have latency, and are triggered (or not) in the appropriate context.

2.10.1: Mechanisms

Mechanisms from a realist perspective are generative and unseen, occupying the real ontological strata. Essentially, mechanisms describe what it is about a programme that makes it work. Mechanisms are located at the human level of reasoning and as such operate in complex social situations (Pawson, 2008), and are triggered under certain circumstance but not others. As Astbury and Leeuw (2010) state: "mechanisms in realist terms are ...underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest" (p.368). Mechanisms as described by Pawson and Tilley (1997) do not mediate or moderate a particular outcome but are hidden generators of particular outcomes; nor are they variables or intervention activities in an experimental design (Astbury & Leeuw, 2010). For mechanisms to be triggered they need to have the appropriate contextual conditions to operate.

An issue for evaluation research is how policies and programmes can have shared outcomes, such as reduced stress for stroke family carers. Vaessen and Leeuw, (2010, p.155) develop a framework derived from Coleman, (1990) and Hedstrom and Swedberg, (1998) in which there are three core social mechanisms as summarised in figure 2.4:

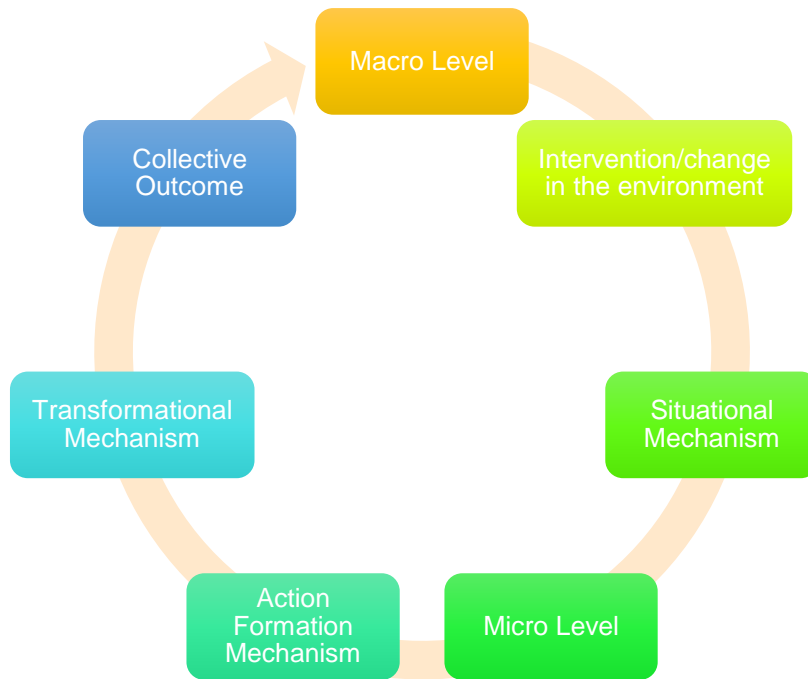


Figure 2:4: Typology of Mechanisms (Vaessen & Leeuw, 2010, p.155)

The situational mechanism links the macro and micro levels. The macro level comprises the structures that surround the individual person, such as the social, physical and institutional environment. An example of a situational mechanism in stroke would be the concentration of specialist acute hospital provision in a particular area. Service reconfiguration in London through centralising stroke services into eight hyper-acute stroke centres, stopping stroke provision in some hospitals saved 96 lives compared to standard care, with in-patient stays reduced by around a day and a half (Morris et al., 2014).

The action formation mechanism explains how opportunities and resources presented to individuals at the micro-micro level triggers change in the individual. An example is the provision of skill building interventions for stroke family carers aimed either at teaching specific skills to care for the stroke survivor were more likely to show a positive effect (Kalra et al., 2004). Providing such skills develops self-efficacy in the family carer that translates into reduced stress.

The transformational mechanism explains how changes in individual behaviours can link to achieve collective outcomes for members of a group.

This micro-macro link is the least understood of these social mechanisms but the process depends on how people are connected to each other through networks or hierarchies (Coleman, 1986). An example is the recent process evaluation of the multi-site pragmatic trial extending the work of Kalra et al., (2004) (TRACS) discussed in section 2.5.

This mechanism framework helps evaluators to identify and try to configure relationships between the policy level and individual behaviours. Bemelmand-Videc, Rist, and Vedung, (1998) have developed an interesting typology for social policy initiatives; 'sticks' (regulation), 'carrots' (incentives), and 'sermons' (information and education). These policy active ingredients can be used singly or in combination, providing different contexts that can trigger different mechanisms. Lacouture, Breton, Guichard, and Ridde, (2015) in a scoping review of the use of mechanisms in research using realist evaluation developed a definition of mechanism as: "A mechanism is an element of reasoning and reactions of (an) individual or collective agent(s) in regard of the resources available in a given context to bring about changes through the implementation of an intervention" (p.8).

2.10.2: Context

Of equal importance in realist evaluation is the context, and includes pre-existing conditions before an intervention is introduced. Several evaluation researchers have noted the importance of context to evaluation (Stame, 2004; Weiss, 1997), yet Fitzpatrick (2012) asserts that contextual factors that influence evaluation are rarely considered in much depth in the evaluation literature. Green, (2005) defines context as "...the setting within which the evaluand (the programme, policy, or product being evaluated) and thus the evaluation is situated. Context is the site, location, environment, or milieu for a given evaluand" (p.83). Greene (2005) categorizes five specific dimensions to context in evaluation:

- 1) demographic characteristics of the setting and the people in it,
- 2) material and economic features,

- 3) institutional and organizational climate,
- 4) norms for relationships in the setting,
- 5) political dynamics of the setting.

Realist evaluation perceives context as explaining different programme effects. Therefore, why some outcomes succeed and others do not depends on the context triggering the underlying mechanisms. Pawson and Tilley (1997) associate context with the “spatial and institutional locations of social situations together, crucially, with the norms, values, and interrelationships found in them” (p.216). For the evaluator the task is to identify those contextual elements that allow a programme to succeed or fail in the context-mechanism-outcome configurations (Pawson & Tilley, 1997). So the context in which an intervention is introduced needs to be identified, as (Pawson, 2006) states, “...outcome patterns are also contingent on context”, by “...constraining the choices of stakeholders in the programme” (p.24-5). Westhorp et al., (2011) outlined several questions that a realist evaluator should consider about context: which groups of people will the intervention work or not? When the intervention should be given, immediately after a stroke or when the stroke survivor is home? How much of the intervention is required, would a one-off educational interaction be sufficient, or would longer, more intensive counselling intervention be needed? These are the type of contextual questions that are important to ask since choices that people make are not limitless but contingent and constrained by pre-existing conditions.

2.10.3: Outcomes and demi-regularities

Outcomes in realist evaluation result from mechanisms being triggered in certain contexts that change human behaviour or thinking. For realist evaluation, the intention is not a one-off outcome but the production of cumulative outcomes. Realist explanations should produce patterns or regularities of outcomes, more precisely, demi-regularities (demi-regs). Demi-regs are not fixed or uniform but are transformative and transforming because they are formed in dynamic social systems (Pawson, 2010). Even though social systems are open systems, there are constraining elements that limit human

choices, which make-up the patterns and regularities of life. People have incomplete knowledge of context or they do not have the resources to change their behaviour, e.g., the knowledge or material resources. Given such resources in the appropriate context then mechanisms may be triggered that results in change.

2.11: Theory

Critical realism within social science research sees causality emanating from relational social structures based on the assumption of stratified reality (see Figure 2.1). It is the social action of 'actors' that can 'cause' generative mechanisms within social structures (Sayer, 2000). This implies that critical realism emphasises the interpretative meaning placed on social structures by the 'actor' (Ekstrom, 1992). 'Actors' have intentionality and formulate plans of action based on their interpretation of the social and structural context they are in. Such contexts can act as propellants or barriers to the planned action (Ekstrom, 1992). Therefore, causal observations within one intervention work and in other contexts they do not. The 'actor' has the ability to interpret the situation, and the role of the theory driven researcher is to decipher the generative mechanisms of action within the context. According to Ekstrom (1992) this capacity for interpreting the social/structural context by 'actors' within critical realism makes a distinction from the ideas presented by Merton (1965) with the theories of the middle-range. (Merton, 1965) grounded his social mechanisms within structural functionalism, and as a result they link back 'actor' behaviour to the higher level of the middle-range theory. As discussed by Pawson (2000) "Middle-range concepts may be said to be 'flattened' in the sense that they do not discriminate between the different layers of reality...Merton's key middle-range concepts ...have the role of epitomising rather than analysing social processes." (p.290). Pawson (2010, 2000) examination of Merton's middle-range theories concludes that he created and demonstrated their value to social science, but did not leave clues to their generation as "middle-range hypotheses" (Pawson, 2000; p284). As a consequence of his analysis Pawson (2010, 2006, 2000) established the amalgamation of Merton's middle-range theories and critical realism into

realistic evaluation, "...it follows that the quintessential strategy for theory driven empirical research is one of 'middle-range realism" (Pawson, 2000; p.284).

Middle-range theories are devices that bridge the gap between all-encompassing 'grand theories' of social science such as Freud's psychoanalytic theory or Marx theory of class structure, and the day-to-day decision making theories or heuristics humans use to negotiate their social world. Middle-range theories are those that link daily heuristics with the grand theory, an example includes Festinger's, (1957) 'cognitive dissonance theory' or Merton's (1965) own 'reference group theory'. Merton (1965) defined middle-range theories thus: "Theories that lie between the minor but necessary working hypotheses that evolve in abundance during day-to-day research and the all-inclusive systematic efforts to develop a unified theory that will explain all the observable uniformities of social behaviour, social organisation and social change" (p.39)

Pawson (2010) describes three characteristics of Merton's (1965) middle-range theories that make them suitable as programme theories. The first rule as Pawson (2010) labels them is the need for "sufficient abstraction" (p.172) in which the detailed empirical data can be formulated into a theory that can be generalised and transferred into other situations. The issue becomes the level of 'sufficiency' required to be useful. Pawson (2010) considers that 'sufficiency' is reached when the theory can be explanatory in different spheres of social life, but not all-encompassing as to explain everything in that sphere. In effect Pawson (2010) recognises the difficulties in exact definitions of what goes for middle-range theory, but we know it when we see it.

The second rule is 'logical derivation' in which questions or hypotheses can be logically derived or formulated from a restricted range of assumptions and tested through research and the evidence-base. These assumptions can be derived from the 'regularities' of social life in a particular culture. These 'regularities' or sequences of events are imperfect in the social world and are termed 'demi-regs' [demi-regularities] (Pawson & Tilley, 1998). Middle-range

theories explain, but more importantly attempt to predict these 'demi-regs' of social behaviour by searching for the generative mechanisms underneath the empirical. The context, mechanism outcome axis represents the elements that make up the patterning seen in demi-regularities (Pawson, 2000). In Sayer's (2000) terms the CMO configuration is a 'contingent causation' in that the generative mechanism is reliant on the context. This notion of contingency has been further extended to 'configurationally causation' (Pawson, 2010) in which there is not just one context, but outcomes come about within an array of contexts bound around one another as in a ripple effect.

Rule three according to Pawson (2010, p.181) is the "adaptive, cumulative explanation" nature of middle-range theories which recognises the notion that they are fallible and are to be considered as transformative theories that require modification as social regularities change. The important assumption here is that 'actors' are mindful of their social contexts and as a result can alter the 'demi-regularities'. Accepting this rule means that middle-range theory requires amendments through cumulative investigation. As figure 2.5 shows there is an initial set of middle-range theories that are altered through testing and examination of the evidence-base into a more refined set of theories, which can then act as another set of initial middle-range hypotheses. In this manner, predictive knowledge is built-up in a deliberate and cumulative process, but should not be seen as definitive (Pawson, 2010).

2.12 Programme theory and theory-driven inquiry

As previously discussed Pawson (2000) drew together theories of the middle-range with critical realism to form a realist evaluation approach to social science. Consequently Pawson (2010) aligns middle-range theory with programme theory delineated through the evaluation research literature, highlighting the similarities between the two, in terms of contingent and configurational causation as well as seeking out the generative mechanisms of the demi-regularities inherent in programme interventions. The *raison d'être* of theory-driven evaluation is to aid evaluation researchers understand the processes surrounding intervention implementation. In effect, recent theory-

oriented approaches have been looking into the 'black box' of interventions, focusing on the assumptions stakeholders use when confronted with new events. A pertinent definition by Funnell and Rogers, (2011) is 2A program theory is an explicit theory or model of how an intervention, such as a project, a program, a strategy, an initiative, or a policy, contributes to a chain of intermediate results and finally to the intended or observed outcome". (p.xix)

Theory-driven evaluation can be described as the 'white or clear box' approach to eliciting programme or intervention theory, and can be developed before implementation or after an intervention has transpired (Astbury & Leeuw, 2010). Prospective analysis of the programme theory is useful for all researchers and policy-makers to engage with. According to Cartwright and Hardie, (2012) policy makers need to ask themselves "the policy worked there, but will it work here?" (p.51) in other words 'effectiveness prediction'. To address this issue Cartwright and Hardie (2012) engage the concept of 'causal principles' that underlie the policy intervention, this concept is similar to Pawson and Tilley's (1997) 'programme mechanism', and consists of three elements. The first is that 'causal principles' are not universal and change from context to context. The second element to consider is that there is not one 'cause' in isolation but there is supporting factors or resources that influence the outcome. Finally, these supporting factors work together in distinct ways that lead to the desired outcome.

The above reinforces the idea that programme mechanisms are not visible as mediating independent variables within a programme intervention but are unobservable attributes that try to explain why variables are related (Astbury & Leeuw, 2010). A further distinction is also made between programme theory and programme logic models; in the latter, the components of the programme are described as inputs, activities and outputs, whereas the programme theory explicates the 'hidden' mechanisms that account for the outcomes of a logic model (Astbury & Leeuw, 2010).

2.13: Articulating an initial middle range theory (MRT)

The realist evaluation cycle as described by Pawson and Tilley (1997) and represented in Figure 2.5 begins with an initial middle range theory or hypothesis (specification, Pawson & Tilley, 1997, p.85).

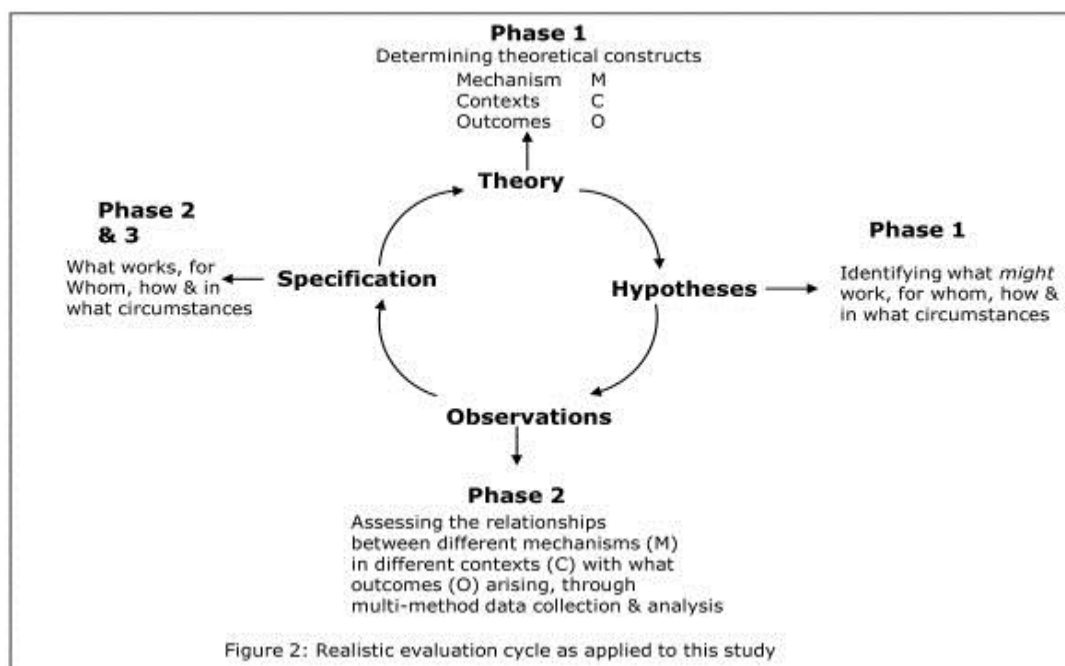


Figure 2.5: The realist evaluation cycle (Pawson & Tilly, 1997, p.85)

This initial theory is then challenged and tested in several cycles of empirical work (cumulation, Pawson & Tilley, 1997, p.121) to ascertain refined CCMOs (demi-regs) that can bestow a 'final' MRT (abstraction, Pawson & Tilley, 1997) leading to policy input and further research. Techniques for the construction of middle range theories is limited, and encompass interviewing policy makers, researchers and implementers of the intervention to ascertain their 'black box' theory of the programme. Techniques for constructing theories relate to several theory-driven perspectives, such as theories of change or programme logic (Weiss, 1997) and realist evaluation (Pawson & Tilley, 1997), however according to Blamey and Mackenzie, (2007) there are differences in their procedures. Theories of change focus their hypothesis on those articulated or surmised by the stakeholders, whereas realists are "more interest in identifying promising hypothesized causal triggers" (Blamey & Mackenzie, 2007, p.447).

Therefore, realist evaluators' opinion middle range theories, the generative causation. Similarly, Astbury and Leeuw (2010) draw attention to the assorted terminology used in theory-driven evaluation, implying that clarification can help explicate evaluation processes.

2.14: Conclusion

This chapter has set out the rationale for utilising a realist approach to the study. The epistemology and ontology of positivism and interpretivism was discussed and critiqued with critical realism presented as an alternative framework for conducting social research, with its reliance on generative mechanisms that produce outcomes under certain contexts. Realist evaluation is discussed with its contingent context-mechanism and output description of programme theory, and their usefulness in not just describing what works but how and to whom. Chapter three continues phase one of the study through conducting a realist synthesis of systematic reviews of RCTs that have implemented carer support for stroke families since the year 2000.

CHAPTER THREE: Realist synthesis of systematic reviews

3.1: Introduction

The purpose of chapter three is to report the findings of a realist review that contributed to the development of programme theories that highlight 'What works in supporting families affected by stroke, how and for whom?' This synthesis will address this question through an analysis of traditional systematic and meta-analytical reviews of family caregiver and dyad interventions on stroke survivor and caregiver outcomes.

As detailed in chapter two a realist approach is increasingly being utilised in health policy research as a way of gaining insight into complex social problems (Wong, Westhorp, Pawson, & Greenhalgh, 2013). The stress and burden of caring for a loved one following a stroke has been documented in chapter one and showed that the complexity of the caregiving situation has accounted for the limited effect of family stroke interventions over the past 30 years (White et al., 2015). A realist review is a theory driven and interpretative type of literature review that attempts to identify contexts in which generative mechanisms operate, whereas, a systematic review or meta-analysis collates all empirical evidence that fits a pre-specified eligibility criteria (Hopewell et al., 2010). However, compared to a traditional systematic review a realist synthesis (realist review or synthesis are used interchangeably - Wong et al., 2013) is iterative in nature and is concerned with literature that provides data on programme theory development. Therefore, a range of sources are included from stakeholder interviews, policy documents, opinion pieces and grey literature (Pawson, 2006).

3.2: Distinction between realist review and systematic review

The initial programme theories underlying this thesis draw on a realist review of completed systematic and meta-analytical reviews of interventions focused on adult family carers of patients who have suffered a stroke. Systematic reviews are a specialised form of narrative literature review that has specified criteria for identifying, extracting and analysing empirical research (Centre for Reviews and Dissemination, 2009). A meta-analysis utilises the same criteria as systematic reviews but in addition carry out a statistical re-analysis of combined data-sets. The expansion of systematic reviews acknowledges the complexity of much social and health research, and the difficulties practitioners have in identifying valid conclusions that may be implemented in practice. In a systematic review a pre-defined protocol is designed that clearly specifies the following:

- Unambiguous questions
- Inclusion and exclusion criteria (usually randomised controlled trials)
- Search strategy
- Study selection
- Data extraction
- Quality assessment procedures
- Synthesis techniques
- Dissemination procedures

The foremost justification for conducting a systematic review is to “... make a claim to tell us 'what works'. They are also often described as scientific hypothesis-testing tools” (Petticrew & Roberts, 2008, p.202). Petticrew and Roberts (2008) are supporters of systematic reviews in health and social care but their conclusions highlight the problems with the technique. They identify that systematic reviews struggle with identification of causal connections between input and output, “...have difficulty synthesising evidence on the intermediate determinants of health inequalities – such as employment, education, and other intermediate outcomes” (p.202). In other words,

systematic reviews cannot identify mid-range theories that are “embedded in an intelligent assessment of context...” (p.208).

In the wider field of evidence-based practice (EBP) systematic reviews, especially Cochrane endorsed, dominates medical and health care practice. As Green, (2000) has identified in health promotion research, the amassing of evidence about programme effectiveness results in “...a real danger of ending up with little more than a menu of proven interventions from which to select and without a rationale base to guide that selection” (p.129). There is increasing calls for a more nuanced approach to assess complex health intervention programmes (Pawson & Tilley, 1997). Rather than the emphasis on identifying a single distinctive programme feature that 'makes' the intervention effective, evaluators need to identify how and why programmes differ, and in which contexts or situations they vary. A further issue with systematic reviews has recently been identified, that of their impact on the design of subsequent primary studies. Habre, Tramer, Popping, and Elia, (2014) carried out a systematic review of the impact of a previous meta-analysis looking at the best way to prevent pain from the administration of the intravenous anaesthetic, propofol. The original meta-analysis conducted in 2000, reviewed 56 RCTs and showed that lignocaine was the best choice to limit the pain experienced from propofol administration. The systematic review of RCTs following publication of the original meta-analysis revealed that the publication of propofol trials had actually increased, these trials were also poorly conducted, and even the citing of the original meta-analysis in these primary studies did not have any influence on the “...design or relevance of subsequent published research” (p.4). Habre et al., (2014) recommend that funders and ethics committees should have a clearer grasp of the existing evidence to prevent unwarranted research.

Within a realist review, the emphasis is upon the mechanisms that trigger an outcome within certain contexts. These mechanisms in realist evaluations are not the interventions ascribed by the researcher, but is the action of the participants exposed to the experimental intervention. In other words, what triggered the participant to accept the intervention protocols (or not) (Pawson &

Tilley, 1997). Reasons why participants accept the programme is reliant on the context in which the intervention was initiated. As Pawson, (2002) explains: “In fact, it is not programmes that work but the resources they offer to enable their subjects to make them work. This process of how subjects interpret the intervention stratagem is known as the programme mechanism and it is the pivot around which realist evaluation revolves” (p.342).

As realist reviews are concerned with identifying programme theories that incorporate context, mechanism, outcome conjectures within an intervention to explain why such an outcome came about rather than just simply stating if the intervention worked or not. Or more precisely come to an 'undecided' as the quality of the primary studies leave many unanswered questions.

A major bias that can occur with systematic reviews is the problem of lack of uniformity among the studies or as Petticrew & Roberts (2006) state, “...lack of exploration of heterogeneity among the studies” (p.271). This same point is made by Shepperd et al., (2009) when discussing the usefulness of systematic reviews for complex, non-biomedical intervention reviews. They underscore the major threat to validity as judgements should be made as to the similarity between intervention studies to the one under scrutiny. The solution taken by reviewers' range from tightening review scope to contacting the research authors for specific information and being explicit in the review write-up, however Shepperd et al., (2009) acknowledge that these techniques are rarely used. Most systematic reviews concentrate on the internal validity of the research but can lack detailed description of the intervention. Indeed, in a review of systematic reviews by Moher, Tetzlaff, Tricco, Sampson, and Altman, (2007), concluded that readers should not accept the findings of systematic reviews without an analysis of their methodological rigour as there were large differences in their quality.

Since no two research studies in the social sciences can be ‘the same’; then it is a matter of methodological rigour from the reviewer and the level of critical analysis by research consumers, as to the robustness of any systematic review.

This is a key point raised by Pawson (2002) in his championing of realist reviews, in that this approach takes the underlying programme mechanisms as the “...locus of comparison” (p.344), rather than study homogeneity (Pawson, 2002). Taking a realist approach to the published evidence is to seek out contradictions in different studies and expose them to analysis, rather than present the ideal case from well conducted RCTs. In a discussion paper that debated methodological issues surrounding the synthesis of diverse evidence, Popay et al., (2006) acknowledged that realist reviews could be seen as the “third way in the synthesis of evidence on the impact of social interventions and programmes” (p.6), in that they provide the link between a wide-ranging narrative review and the highly-focused Cochrane style systematic review. As Pawson and Bellamy, (2006) make clear in the table below, the prime role of a realist review is to detect underlying mechanisms that can lead to mid-range theories of application. Through the process of realist synthesis and evaluation, programmes can be assessed for how they work in the setting of the intervention.

Approach	Unit of Analysis	Focus of Observation	End Product	Application
Meta-analysis	Programme	Effect size	Relative power of like programmes	Whole programme replication
Narrative review	Programme	Holistic comparison	Recipes for successful programmes	Whole or majority programme replication
Realist synthesis	Mechanisms	Mixed fortunes of programmes in different settings	Theory to determine best application	Mindful employment of appropriate mechanisms

Table: 3.1: Summary of alternative approaches to systematic review (Pawson & Bellamy, 2006, p.9)

One of the important differences between Cochrane type systematic reviews and the realist approach is the recognition that when examining social and behavioural intervention studies it is essential to understand why the 'actors' that partake in the intervention; researchers, policy makers, professionals as well as the participants act in the way they do within the context in which they operate. Context affects the scope and choices that 'actors' can make, limiting intervention impact in one study and enhancing participation in another study (Pawson, 2002). This however does not make RCTs ineffective, but prepares the reviewer to go beyond the internal validity issues and concentrate on why and in what circumstance the intervention worked, in other words, what effective resources the intervention brought to change participant behaviours. Wong, (2009) reiterates Pawson and Tilley (1997) mantra that it is the middle-range theories that attempt to explain and generalise 'actor' behaviours within intervention studies that need exposition. If policy-makers and researchers want to test out complex healthcare interventions then having a theoretical framework to underpin the intervention can help build more effective interventions in each context.

3.3: Structure of a realist review

A realist review is about theory and explanation-building through the inspection of underlying programme theories and then testing these candidate theories through an analysis of the available literature to decide if there are any demi-regularities that can explain behaviours (Pawson, 2006; Wong, Greenhalgh, & Pawson, 2010). Within a realist synthesis there are several systematic steps or stages that have been described (Pawson, 2006). These steps in a realist synthesis as articulated by Pawson (2006) are outlined in Table 3.2 and are compared to a Cochrane style systematic review.

Systematic Review Cochrane Handbook (2011)	Realist Synthesis Pawson et al (2004, p.14)
<ul style="list-style-type: none"> • Defining the review question and developing criteria for including studies 	<ul style="list-style-type: none"> • Clarify scope of the review – Scoping study <ul style="list-style-type: none"> • Identify the question • Refine purpose of review • Articulate key theories to be explored
<ul style="list-style-type: none"> • Searching for studies 	<ul style="list-style-type: none"> • Search for relevant evidence, refining inclusion criteria
<ul style="list-style-type: none"> • Selecting studies and collecting data 	<ul style="list-style-type: none"> • Appraise quality of studies
<ul style="list-style-type: none"> • Assessing risk of bias in included studies 	<ul style="list-style-type: none"> • Extract different data from different studies using an eclectic and iterative approach
<ul style="list-style-type: none"> • Analysing data (and undertaking meta-analyses) 	<ul style="list-style-type: none"> • Synthesise data to achieve refinement of programme theory (CCMO)
<ul style="list-style-type: none"> • Addressing reporting biases 	<ul style="list-style-type: none"> • Make recommendations with reference to contextual issues
<ul style="list-style-type: none"> • Presenting results and "summary of findings" tables and interpreting results and drawing conclusions 	<ul style="list-style-type: none"> • Disseminate findings and evaluate extent to which existing programmes are adjusted to take account of programme theories

Table 3.2: Processes undertaken in conducting a systematic review and realist synthesis

A realist synthesis approach to evidence evaluation is an evolving project building on the methodological marker laid down by Pawson and Tilley (1997), Pawson et al., (2004) in an ESCR research methods working paper. A recent publication by Wong et al., (2013) through the RAMESES group (Realist and Meta-narrative Evidence Syntheses: Evolving Standards) has produced a publication standard for realist reviews based around the PRISMA statement (Moher, Liberati, Tetzlaff, Altman & the PRISMA group, 2009). The statement

sets out what should be reported in a write-up of a realist review, and develop the realist synthesis methodology. In a recent scoping review of realist synthesis articles Berg and Nanavati, (2016) used the RAMASES standards to ascertain conformity to the standards. Their conclusion was that the analysis and synthesis of the selected studies were poorly described in most reviews, and there being limited uniformity of practice. This is recognised by the RAMESES group and to an extent is an inherent issue within the realist approach, as is the case with qualitative systematic reviews. However, having guidelines that indicate what researchers undertaking a realist reviews should be cognisant of is clearly important.

There have been a few studies that have evaluated the same interventions from a systematic review and realist synthesis approaches. Van Der Knaap, Leeuw, Bogaerts, and Nijssen, (2008) outlined a process for combining a systematic review with a realist approach, and a more recent unpublished PhD by Grove, (2011) that analysed repeat crime prevention interventions using a standard systematic review and comparing it to a realist synthesis approach. In Van Der Knaap et al., (2008) study they conducted a systematic review as per Campbell standard and then used the included studies to ascertain the social and behavioural mechanisms that are assumed to work in each of the identified studies. Following identification of the behavioural mechanisms that activated positive (or negative) outcomes, the related contexts underlying the mechanisms were then identified. The final step was the invocation of the concept of 'warrant' as described by Toulmin, (1958), specifically the 'because' part of the argument to explain why the mechanism worked in that context, acknowledging that this step is invariably inferred by the researcher as explanations are usually implicit in intervention studies.

Grove (2011), unlike Van der Knaap et al (2008), subjected her question about the evaluation of repeat victimisation prevention interventions into the two distinct review methods. The systematic review was completed first, using standard techniques, while the realist synthesis began with stakeholder input as described by Pawson et al. (2004). Indeed, the realist synthesis in Grove's

(2011) thesis did not utilise the systematic review data as did Van der Knaap et al (2008), but pursued Pawson et al (2004) realist outline by snowballing for literature following stakeholder discussion. The snowballing did include all the literature identified through the systematic review, especially studies that did not meet the inclusion and quality criteria, as well as other relevant research. The final stage in Grove's (2011) procedure was to integrate the programme theories extracted from the realist synthesis with the systematic review. However, this integration through review recommendations drew heavily on the realist synthesis outcomes, and perhaps negated the results obtained through the systematic review. Since a systematic review is a time-consuming activity, as is a realist synthesis, then there needs clarification as to the value of separating the procedures. Grove (2011) asserts that the two review approaches are complimentary, taking the established scientific rigour of the systematic review with the greater flexibility of a realist synthesis to detail the reasons why interventions work (or not). This "third way" as described by Grove (2011) using segregated procedures results in "...the benefits of the two approaches would be realised with minimum disruption to existing processes" (p.203). Certainly, a systematic review if properly conducted will identify a complete reference of the current literature that is useful for a realist synthesis.

The combination procedure described by Van der Knaap et al (2008) shows more practical promise, in that the identified studies included in the systematic review are then analysed in a realist manner, to ascertain programme theories. But again, limiting literature to the strictures of a systematic review limits the scope of a realist synthesis, unless there are further refinements of the conjectured CMOs through additional cycles of the evaluation. Following the above discussion there may be benefits to subjecting completed systematic reviews to a realist analysis. This methodological tactic, a realist review of systematic reviews of stroke family carer interventions combines some of the advantages described by Grove (2011) and Van der Knaap et al (2008). From Grove's (2011) perspective a range of completed systematic reviews would satisfy experimental rigour leaving the realist approach to pursue its epistemological path, of deciphering the embedded programme theories.

A key difference between the two approaches is that a realist synthesis attempts to explain why an intervention may have worked rather than just make a judgement whether an intervention has been effective (Pawson et al., 2004). Knowing some of the programme theories surrounding the intervention provides better-quality information for the clinician on how they need to adjust the intervention parameters for individual patient circumstances, as is usually the case in day to day practice.

3.4: Rationale for choosing a realist review of systematic reviews

In the RAMESES publication standard (Wong, Greenhalgh, Westthorp, Buckingham, & Pawson, 2013b) the rationale for a realist review should be discussed and justified as opposed to the use of other approaches. For this study, the focus is on how best health and social care professionals can support stroke families in their own homes. From the critical review of the literature discussed in chapter one it was clear that interventions in stroke care are complex requiring input from patients, professionals and family carers. The critical review identified many systematic reviews of intervention studies targeting stroke family carers and stroke survivors. Using the Medical Research Council (MRC) (2008) framework for developing and evaluating 'complex' interventions, Redfern, McKeivitt, and Wolfe, (2006) produced a systematic review investigating the theoretical and methodological quality of complex interventions in stroke care. The interventions were designed at changing the behaviours or beliefs of professionals, stroke survivors, and family carers. From the 67 studies included in their review they concluded that "...there was little evidence that authors considered the theoretical development, or the mechanisms by which the intervention was expected to influence outcomes". They further report "...complex health service interventions seem to be developed on ad-hoc assumptions, and evaluated using methods where at the end of the study it is impossible to understand the reasons for success or failure" (p.2417). From a realist perspective (as discussed in chapter two) there is a clear need to identify the generative mechanisms and contexts that would be needed to achieve outcomes that support stroke families.

3.4.1: Realist reviews of RCTs

In the literature to date there have not been any realist reviews that utilise a series of published standard systematic reviews or meta-analysis to delineate programme theories. Several realist reviews have used primary studies and some have exclusively used RCT studies, (Greenhalgh et al., 2007; Jagosh et al., 2011; Kane, Gerretsen, Scherpbier, Dal Poz, & Dieleman, 2010; Wong et al., 2010). These authors' have reported on the difficulties of looking for CMO configurations within RCTs. For example, Kane et al., (2010) commented that there was reasonable information about the intervention but limited for the context, partly due to the strictures imposed by the journal word limit but more importantly by the focus of researchers' who carry out RCTs on internal validity, and consequently limit discussion on contextual influences, only allowing them to devise limited generic hypotheses. These limitations are problematic for realist reviews of RCTs and Kane et al (2010) recommend that greater contextual information be included in such descriptions to help explain the 'why' question. The above constraints will impact on a realist synthesis of systematic reviews as the scope for included contextual information will be reduced further. So instead of attempting to extract CMO configurations directly from the systematic reviews as was the case in the three studies quoted above, it is more plausible to extract as much contextual information through delineating the fidelity of the interventions that will then feed into the programme theory together with the couple interviews (chapter four) and discussed in chapter five.

3.4.2: Implementation Fidelity

Implementation or treatment fidelity as defined by Bellg et al., (2004) are "...methodological strategies used to monitor and enhance the reliability and validity of behavioral interventions. It also refers to the methodological practices used to ensure that a research study reliably and validly tests a clinical intervention" (p.443). Through an evaluation of criteria that make up intervention fidelity the internal and external reliability of trials can be established (Carroll et al., 2007). The process of determining implementation fidelity can provide support that outcomes are attributable to components of the

intervention, and as such fidelity comprises the 'context' surrounding implementation. As Marchal, van Belle, van Olmen, Hoeree, and Kegels, (2012) comment it is "...useful to consider context elements as actors or other factors that are external to the intervention, present or occurring even if the intervention does not lead to an outcome, and which may have an influence on the outcome" (p.207).

Carroll et al., (2007) developed a framework to identify treatment fidelity in health behaviour intervention research. The framework comprises the following:

- Adherence or delivery incorporating:
 - Content of intervention: includes
 - Theoretical underpinning of the interventions
 - Training of stakeholders
 - Frequency: how often the intervention was delivered
 - Duration: how long a period the intervention is delivered
 - Dose or coverage: how often the intervention is presented

Lichstein, Riedel, and Grieve, (1994) argued for two additional processes:

- treatment receipt: assessing the participant understanding and ability to use treatment skills
- treatment enactment: the degree the participant applies the skills learned in treatment in his or her daily life.

Carroll et al (2007) account for these latter elements as mediating factors as shown in Figure 3.1. In addition to Carroll et al., (2007) fidelity framework, Leichsenring et al., (2011) included evaluating any theoretical constructs and mechanisms that constitute a supportive rationale for the intervention, which is an important consideration in realist evaluation.

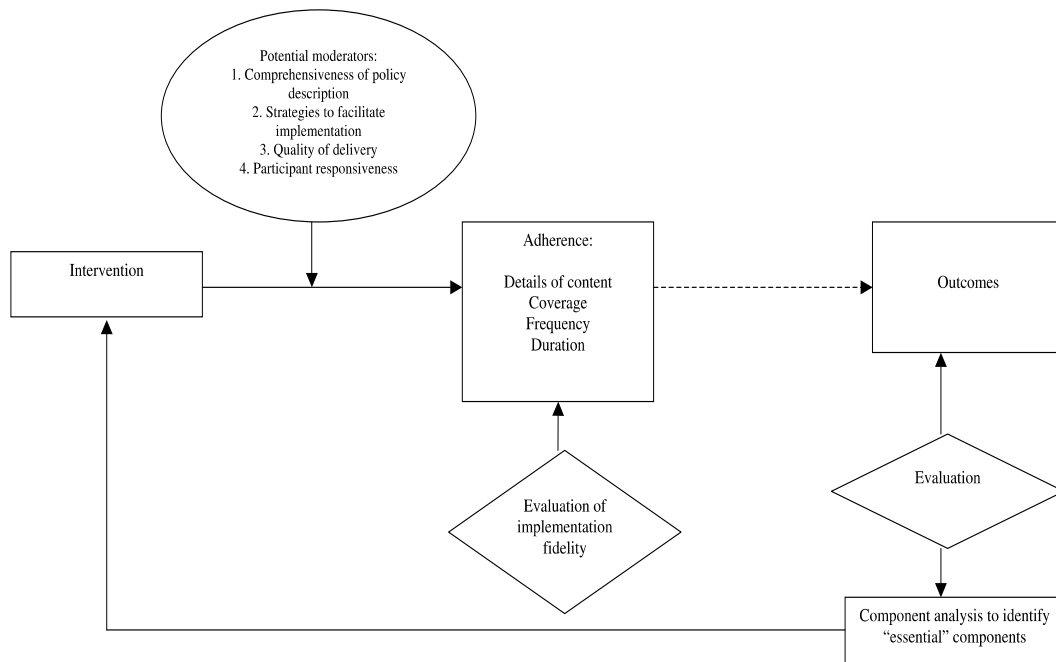


Figure 3.1: Conceptual framework for implementation fidelity (Carroll et al., 2007)

The criteria identified above was used to extract data from the included systematic reviews and descriptions summarised within logic models.

3.4.3: Realist review of systematic reviews

From the critical literature review in chapter one there were several meta-analytical and systematic reviews evaluating interventions supporting stroke families, as well as other long-term conditions such as, dementia, COPD and palliative care. The focus of a realist review is on synthesising programme theories, and many traditional systematic review authors in their conclusion sections speculate about the reasons for the review results over and above strict methodological limitations, and these could produce 'nuggets' of information (Pawson, 2006). Even though Pawson (2006) questions the logic of systematic reviews in their haste to reject 'poor' primary studies, there may be a case that using such traditional reviews through the realist lens can identify candidate theories that can be tested with service users. As far as it is known this is the first account of a realist synthesis of traditional systematic reviews. However, this is not the case for traditional systematic reviews and meta-

analysis as there are numerous examples of 'reviews of reviews' (Smith, Devane, Begley, & Clarke, 2011). The decision to undertake a realist synthesis of systematic reviews is to develop the methodological approach as encouraged by Pawson (2013). The RAMESES standard (Wong et al., 2013) recommend that searching for data in realist reviews should be iterative and "...may lie in a broad range of sources that may cross traditional disciplinary, program and sector boundaries" (p.8). The decision to concentrate specifically on systematic reviews of stroke family interventions can be justified because the critical literature review described in chapter one was broad in its scope, and the literature was then continually reviewed as the realist evaluation proceeded.

Further support of the process taken for this realist review is the belief by Pawson et al., (2004) that realist synthesis is an approach not a unified method, and as such "...a fundamental principle of realist reviews is that its findings are fallible...where reviewers challenge rather than police each other" (p.37), and further elaborate by stating that fully transparent decision making within a review is unattainable it is impossible.

3.5: Objectives and scope of the realist review

Theory formulation is a key component of a realist review and involves trawling the literature to find concepts and theories that attempt to explain how interventions work to support stroke families. This step involved a reading of a broad range of literature with the resultant theory being speculative until further refinement is achieved through the review and evaluation process (Pawson, 2002). The initial brief of this thesis was to look at how family carers are supported by health and social care professionals (H&SCP) following hospital discharge of their spouses. Through "mapping the territory" (p.80) (Pawson, 2006) (chapter one: 1.4) identification of theories and concepts that are relevant to carer support were outlined. The aim of the realist review for this study was to begin the development of candidate programme theories about stroke family support. As discussed above, delineating mechanisms through an analysis of systematic reviews would be very difficult, so the analysis of the review

focussed on context – outcome patterns that would, in combination with the initial couple interviews (discussed in chapter four) lead to programme theories of stroke family support synthesised in chapter five and then tested with stakeholders in subsequent longitudinal couple interviews and focus groups of service providers, to show what works, for whom, how and in which contexts.

Objectives of the review:

- Inclusion/exclusion criteria
- Search process
- Data extraction
- Analysis and synthesis
- Context formation

3.6: Inclusion and exclusion criteria for the realist review

The realist review of systematic reviews of interventions that support stroke family carers covered dates from 2000 to 2013. The year 2000 was taken as a benchmark because this was the first year that the National Clinical Guidelines for stroke was published for the UK, and the National Sentinel Audit of stroke was implemented and stimulated local stroke units to consider the quality of care they were delivering and put improvements in place. Inclusion criteria for the systematic reviews and meta-analysis were as follows:

- 1) Reviews had to follow a structured review process
- 2) Reviews had to include interventions that targeted stroke family carers only, or family carers with stroke survivors
- 3) The reviews had to discuss the findings for stroke family carers separately from stroke survivors
- 4) Reviews had to be RCT based
- 5) Publications had to be in English

Exclusion Criteria:

- 1) Reviews that included any other long-term condition, such as dementia or COPD
- 2) Reviews that only focussed on the stroke survivor

- 3) Reviews that did not articulate a structured approach
- 4) Reviews that did not focus on RCT studies

3.7: Search process

A literature search for articles published between 2000 and 2013 was conducted using MEDLINE, CINAHL, PubMed, Cochrane, EMBASE, Web of science, and Google Scholar.

The following search terms were employed:

Term	Boolean Logic Operators
Stroke	and
Family	or
Informal	or
Caregiver	or
Carer	and
Systematic review	and
Meta-analysis	or
Interventions	or
Randomised Controlled Trails	or
RCT	or

Table 3.3: Search terms for the realist review

The systematic reviews and meta-analysis that emerged from the search process were screened using the screening tool and was based on the inclusion/exclusion criteria already described.

3.8: Data extraction

According to Wong et al., (2013a) data extraction in realist synthesis “Describe and explain which data or information were extracted from the included documents and justify this selection” (p.9), and includes details of the

interventions and outcomes. Since interventions targeting family stroke carers are complex programmes (Rigby et al., 2009), a transparent process for data extraction is important. For this review the use of logic models was decided upon as a means of detailing the components of the interventions within each review. Logic modelling is a technique that systematically represents (usually graphically) an understanding of the inter-relationships amongst the inputs, outputs and outcomes of an intervention (Kellogg Foundation, 2004, p.1). The logic model links the problem (situation) to the intervention (inputs and outputs), and the impact (outcome); as can be seen in Figure 3.2, this is an example of the University of Wisconsin pipeline logic model, and is an extension of the Kellogg Foundation model (Funnell & Rogers, 2011).

Recently, Anderson et al., (2011) have discussed the use of logic models as a way of executing systematic reviews. Their rationale for the use of logic models in systematic reviews is in answer to the criticisms outlined in chapter two, that logic models with their explicit purpose of identifying underlying assumptions or theories of change that can "...make systematic reviews more transparent and ultimately more cogent to decision-makers" (p.34).

Kellogg Logic Model Template

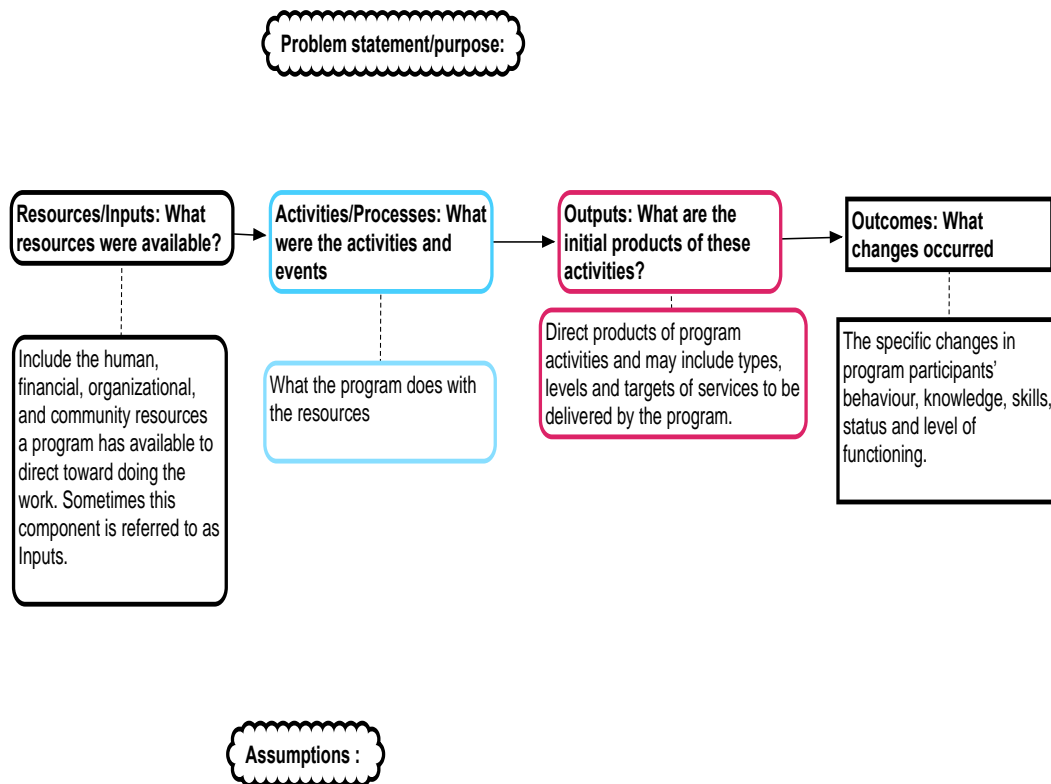


Figure 3.2: Kellogg Foundation logic model template

It is important to restate at this point that 'underlying assumptions' within theories of change analysis are not the same as the generative mechanisms of critical realism, as mechanisms are unobservable and should be inferred (Pawson, 2013). Unfortunately, Anderson et al (2011) do not make explicit how logic models can be interwoven with systematic reviews, just to say that there are manuals available that show how to construct these logic models (Kellogg Foundation, 2004). The suggestion is that logic models can be 'bolted' onto the included papers as an extra, but illuminating step in the review process.

3.9: Analysis and synthesis processes

Data synthesis and analysis in realist reviews usually proceeds iteratively and in parallel with the intention of applying realist principles to the data. The

synthesis of the extracted data were focused on answering the fidelity criteria to identifying context – outcome patterns that would feed into explanatory mechanisms when the couple interviews are included in chapter five. (Wong et al., 2013). The synthesis was undertaken by PRJ with the results regularly discussed with the supervisory team to ensure validity and consistency in inferences made. The questions addressed in the review are as follows:

- What types of interventions are utilised to improve stroke family lives?
- What theoretical perspectives underpin the interventions?
- How are the interventions executed?
- What is the impact of the identified interventions (how are outcomes measured)?

3.10: Search results

From the search 46 articles were found. Article titles and abstracts, if available were screened online. Following this initial screening 42 articles remained and the inclusion/exclusion criteria (section 3.6) was used on the retrieved articles, allowing for 4 duplicates, 38 systematic reviews/meta-analysis appeared relevant and full texts obtained. Of these 38 remaining reviews, 27 were excluded because they were qualitative or non-standard reviews, or included long-term chronic conditions other than stroke leaving 11 studies in the synthesis, detailed in the flow scheme below:

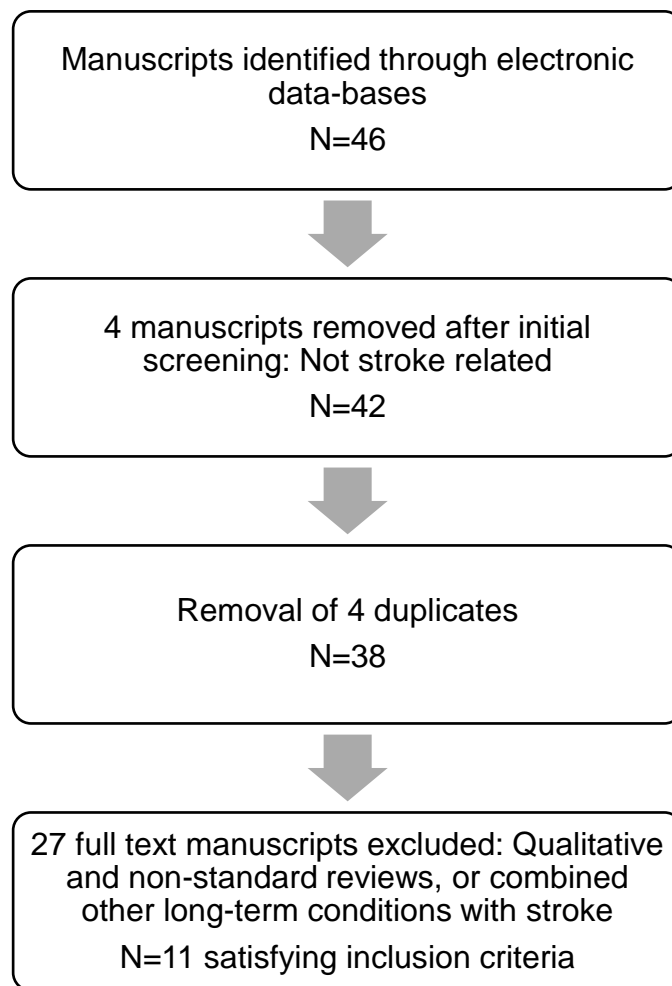


Figure 3.3: Flow chart of search results

The 11 included systematic reviews/meta-analysis are shown in Table 3.4 beginning with the oldest review article:

Bhogal, Teasell, Foley, and Speechley, (2003)	Systematic review
Lui, Ross, and Thompson, (2005)	Systematic review
Visser-Meily et al., (2005)	Systematic review
Brereton, Carroll, and Barnston, 2007)	Systematic review
Lee, Soeken, and Picot, (2007)	Meta-analysis
Eldred and Sykes, (2008)	Systematic review

Smith, Forster, and Young, (2009)	Systematic review
Ellis, Mant, and Langhorne, (2010)	Meta-analysis
Allison et al., (2011)	Systematic review
Legg et al., (2011)	Systematic review
Forster et al., (2012)	Systematic review

Table 3.4: The included systematic reviews identified from the search

3.10.1: Quality appraisal

In realist reviews the 'quality' of studies are not formally assessed in the same manner as for systematic reviews, but are rated for relevance in their contribution to theory building or testing, and rigour in which the paper is considered credible and trustworthy (Wong et al., 2013). As the realist review in this study uses traditional systematic reviews the quality of included RCTs have been screened.

3.11: Document characteristics

3.11.1: Introduction

A total of 140 studies were included in the 11 systematic reviews, but there was a large duplication of studies, as many of the 'best' studies were included in each systematic review. The United States of America (USA) and the United Kingdom (UK) accounted for over 90 studies, with Sweden and Holland making up the remainder of the European countries, and one study each for New Zealand, Korea, Taiwan and Thailand. The dates for inclusion in the reviews ranged from 1950 to 2012, Eldred and Clarke (2008) did not provide dates of inclusion.

3.11.2: Overview of each systematic review

Bhogal et al (2003) reviewed stroke interventions targeted at family carers and stroke survivors only, using the PEDro scoring system for study inclusion. Overall the review was of moderate quality as it was unclear what the inclusion

and exclusion criteria were and there was an emphasis on how the interventions impacted on the SS rather than family carer. The reviewers concluded that social support interventions improve mental outcomes for the SS and psych-educational interventions improves family functioning.

Lui et al, (2005) directed their review at problem-solving skills for stroke family carers. The review incorporated RCTs with qualitative and case study research, theoretical concepts identified within the studies ranged from stress-coping models to cognitive behavioural therapy and social problem-solving. The quantitative studies demonstrated that follow-up telephone problem-solving interventions were shown to offer better results than home visits alone, while the qualitative studies indicated that nurses who were proactive and friendly were well received by stroke survivor and family carers. Overall Lui et al, (2005) in line with all other reviews bemoaned the lack of detail in the studies they reviewed.

Visser-Meily et al, (2005) identified four intervention strategies that were utilised with stroke family carers: providing specialist services, psycho-education, counselling and social support by peers. The authors' overall conclusion was that none of the four intervention types were effective in reducing stroke carer problems, although the few studies that investigated counselling interventions did show some benefits overall. Visser-Meily et al, (2005) specified that these inconclusive results were due to insufficient intervention dose, or wrong timing to meet carer needs and insensitivity of outcome measures. A further deficiency of the included studies was the lack of separation of spousal and other relative carers. This last contextual feature may be an important factor in intervention effectiveness. The area where counselling interventions impacted included improvements in active coping three-years post intervention. Author recommendations include adequate assessment for carer vulnerability and counselling as a first approach to intervention.

Four of the most robust reviews concentrating on stroke families were the meta-analysis of Lee et al (2007), which included four studies, the Cochrane review

from Legg et al (2011) that included eight trials of non-pharmacological interventions for stroke family carers and was part of a PhD thesis, as well as a publication in *Stroke* (Journal of the American Heart Association). Ellis et al., (2010) together with Smith et al (2009), both Cochrane systematic reviews evaluating specific intervention types, stroke liaison workers, and information giving for stroke survivors and their family carers, respectively. These four reviews are banded together as they are the most scientifically valid studies focused entirely on stroke and family carers. In this respect, these reviews should have provided the best analysis leading to valid generative mechanisms, but this was not the case, apart from the Ellis et al, (2010) meta-analysis that did provide some mechanistic assumptions. Given the stringent criteria imposed by the other three reviews, there was little the authors could conclude as the efficacy of the interventions was poorly supported by methodological weaknesses in the included studies. This meant that speculating as to why the interventions worked or not was not forthcoming, only that 'tighter' RCT studies should be conducted in future.

Ellis et al., (2010) identified 16 RCTs that used stroke liaison workers to provide support for stroke survivors and their main carers. The meta-analysis included an opportunity for the primary study authors to contribute to the analysis through defining the type of support offered by the support workers and supply individual patient study data for further analysis. However, the meta-analysis was focused more on stroke survivor characteristics rather than family carers, to the exclusion of RCTs that did not include patient outcomes, but only family carer consequences. Again, the reviewers commented on study quality and reported that there was no overall benefit in the use of stroke liaison workers for both stroke survivors and caregivers. However, they did demonstrate an effect size of 11 fewer dead/dependent stroke survivors for every 100 patients treated by the support worker. As Ellis et al., (2010; p14) report this was an unexpected and 'considerable' result but gave no reason as to why this could have arisen, only equating it to the provision of early supported discharge programmes. The Legg et al (2011) review details how they assessed the variance of the included RCTs by using the I^2 statistic that quantifies the degree

of heterogeneity, with a cut off above 50% indicating significant discrepancy (Higgins et al., 2008). Of the eight studies incorporated in the Legg et al (2011) review, six could also have been included by Lee et al (2007), but the only two trials that covered both reviews were, Mant, Carter, Wade, and Winner, (2000) and Grant, Elliott, Weaver, Bartolucci, and Newman-Giger, (2002). The reviews identified a range of measures of carer burden and interventions within the RCTs analysed. The overall conclusion from the Legg et al, (2011) review was that there is insufficient data to support or refute the use of psycho-educational and support information to help stroke family carers, but vocational training did appear to improve carer stress, but based on one small study (Grant, 2004). In the Lee et al, (2007) meta-analysis the authors looked specifically at interventions directed at improving stroke caregivers' mental health as measured by the SF-36, giving rise to only four published studies. The psycho-educational interventions achieved better positive results than the support interventions, because of the former interventions having a clearer focus. As for the Smith et al, (2009) review, this again was very specifically targeted at the effectiveness of information giving interventions and included unpublished trails. Active information-giving strategies, incorporating carer and stroke survivor needs were seen effective in reducing stroke survivor depression and increasing stroke knowledge for family carer. Again, the review authors restricted speculation about 'why' active information giving may work recommending better RCT studies in the future.

The systematic review by Brereton et al (2007) again identified the poor quality of the included studies and the lack of appropriate theoretical framework that can help to identify what outcome measures are appropriate and sensitive to the intervention, rather than the 'shot-gun' approach of most studies. The authors recommend input from family carers into study design and that researchers should widen their conceptual frameworks to include relationship theory.

Eldred and Sykes (2008) is a narrative systematic review that included seven RCTs of psychosocial interventions for family stroke carers. Their results again

show contradictory findings among the included studies, especially on carer depression and burden, the authors speculate that time frame of intervention effects are important contexts to consider. So, interventions targeted at depression show a short-term improvement but is not sustained longer-term (i.e., >6 months), whereas problem-solving may have a longer-term benefit for perceived carer burden. This explanation could be feasible as perceived burden does decrease over the longer term due to stabilisation of the stroke survivor's physical condition but other issues linked with long-term caring can trigger depression in the family carer (Han & Haley, 1999). Other recommendations made by Eldred and Sykes (2008) include interventions that are more specifically targeted at carer characteristics such as gender, age, relationship to care-recipient and the degree of mutuality between main carer and stroke survivor.

The systematic review by Allison et al (2011) focused on interventions that utilised stroke support workers and case managers to transmit the intervention package to the stroke survivors and their family carers within the context of primary care. The clear conclusion reached by Allison et al (2011) was the lack of evidence that validates the use of support workers or care co-ordinators in implementing interventions directed at stroke survivors and carers. Again, the reviewers report on the robustness of the primary studies, in particular the lack of theoretical framework to guide intervention development. One mechanism that the reviewers provide for the lack of intervention effects is the limited involvement of the stroke survivor/carer's General Practitioner (GP). The GP, and increasingly primary health care teams play a key role in organising services within the UK (Simon, Kumar, & Kendrick, 2009) and as such the limited interaction between the intervention programme and the primary care team limits the effect of the intervention through continued support from the GP.

The Cochrane based systematic review by Forster et al., (2012) aimed to “assess the effectiveness of information provision strategies in improving the outcome for stroke patients or their identified caregivers, or both” (p.1). This review is an update of Smith et al., (2009), with the same reviewing authors

apart from the addition of one new author with the same review question, however there was no reference to the earlier paper. The Forster et al., (2012) review identified four new studies but their general conclusion was the same as for Smith et al., (2009) described above that providing information does not reduce burden or depression, but 'active' information giving with planned follow-up should be 'routine' practice. Each of the 11 systematic reviews are presented below in logic model format:

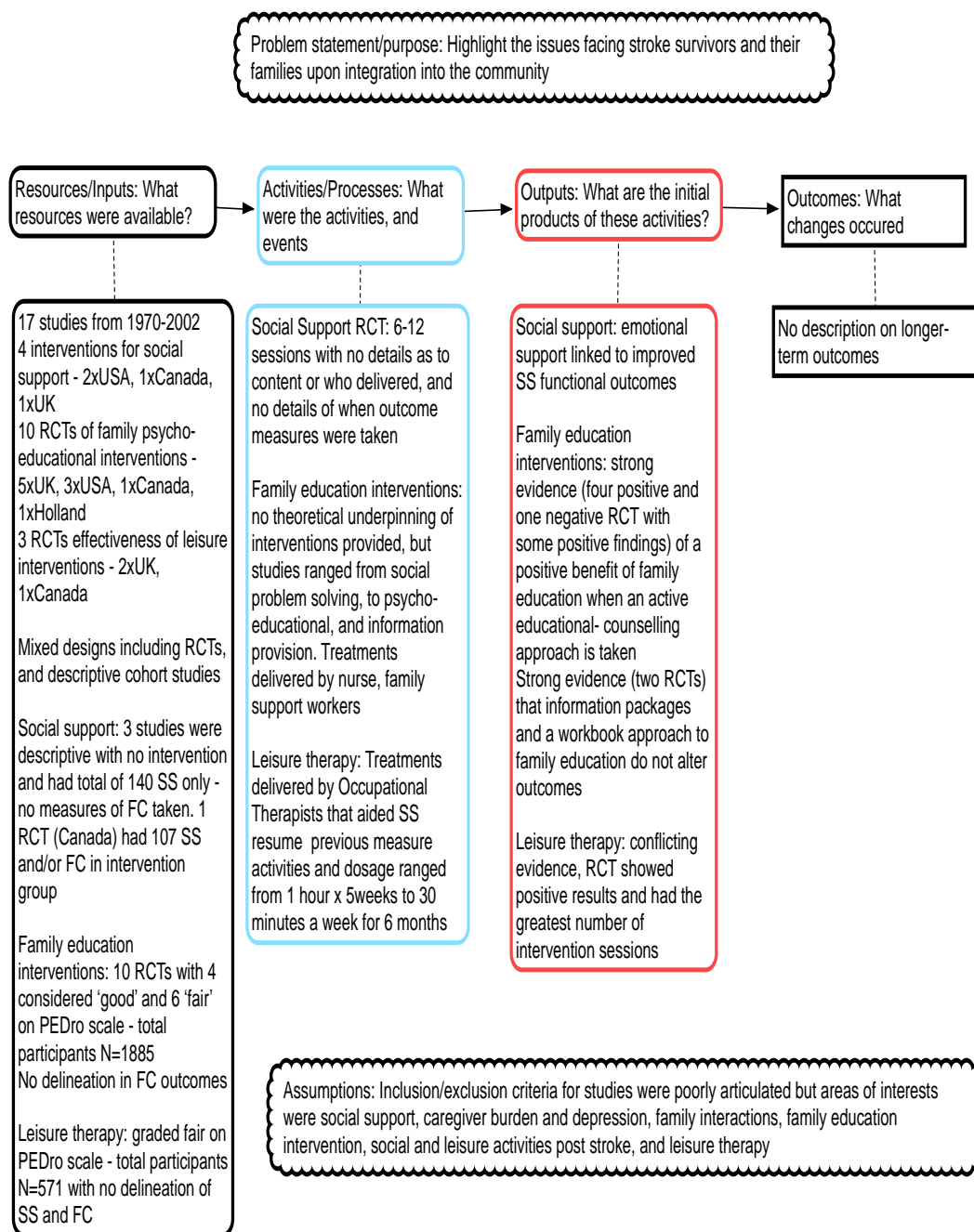


Figure 3.4: Logic model Bhogal et al., (2003)

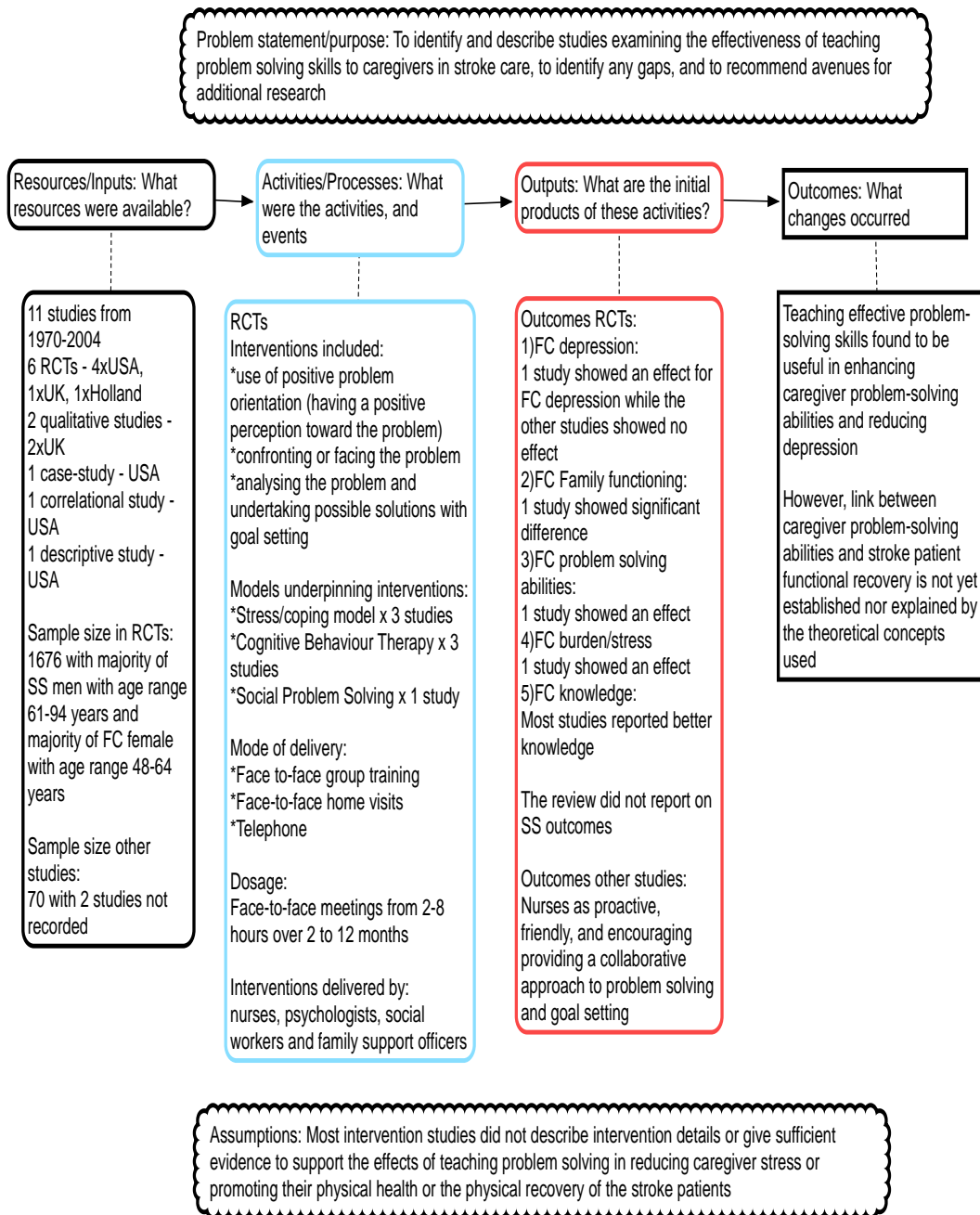


Figure 3.5: Logic model Lui et al., (2005)

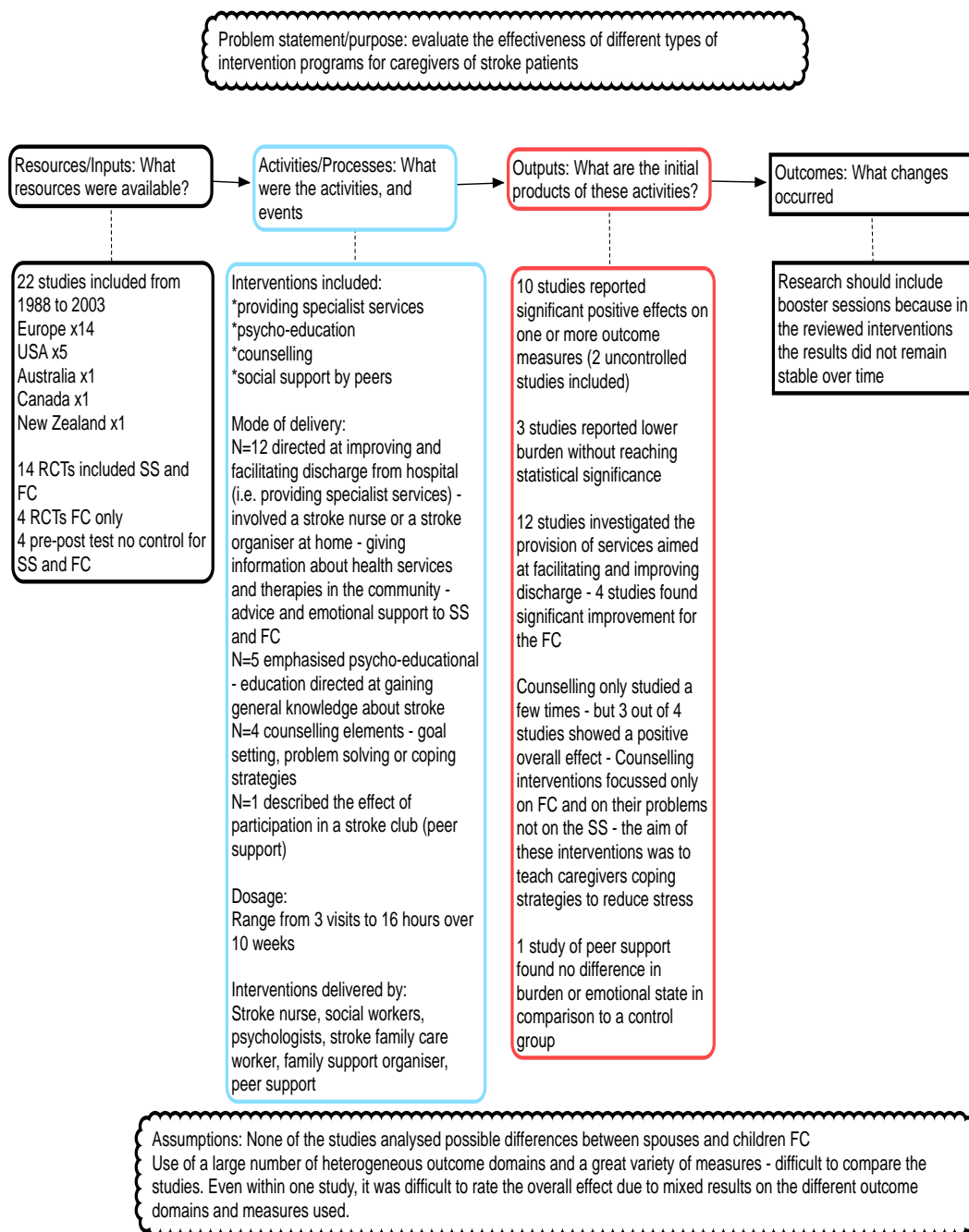


Figure 3.6: Logic model Visser-Meily et al., (2005)

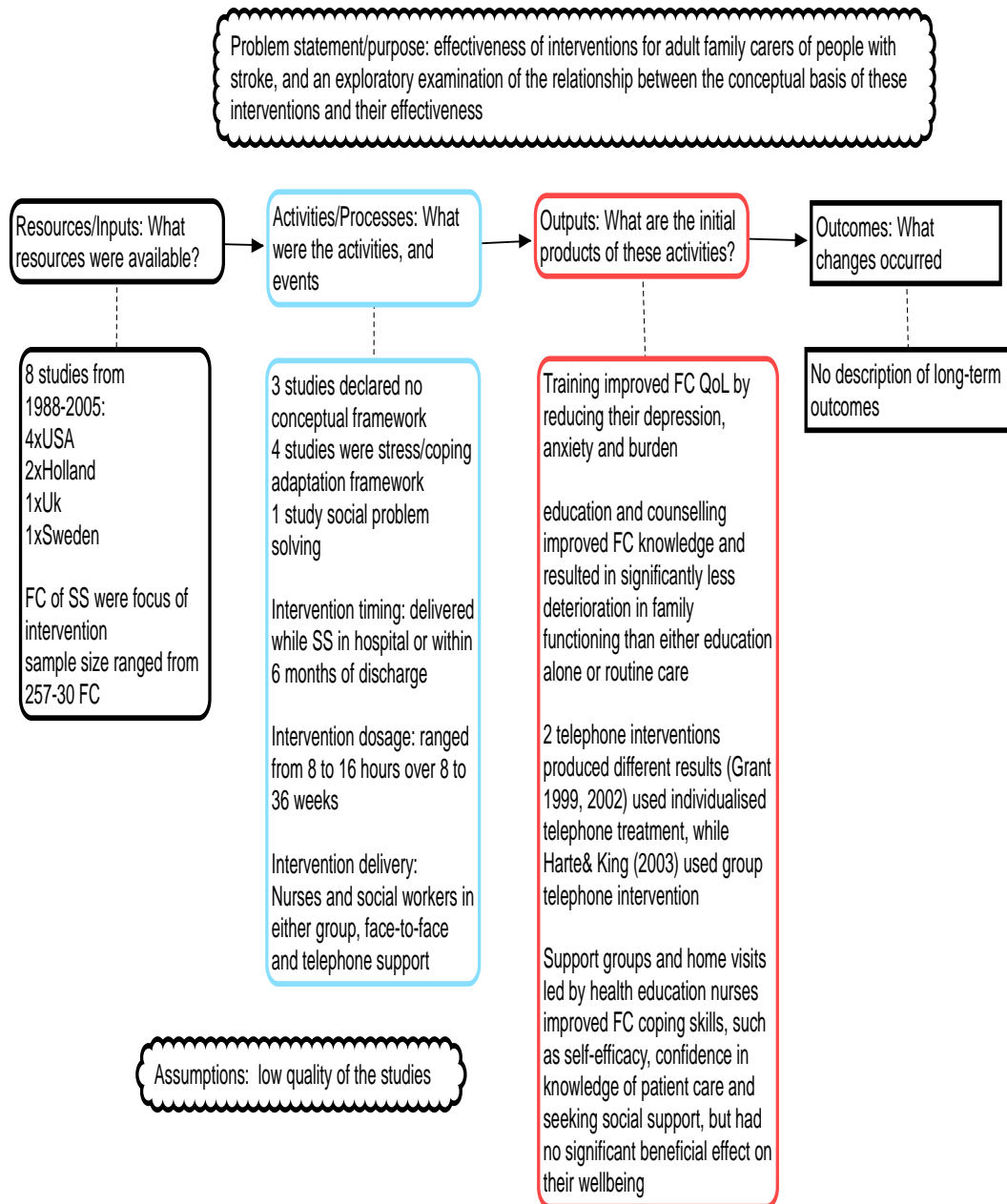


Figure 3.7: Logic model Brereton et al., (2007)

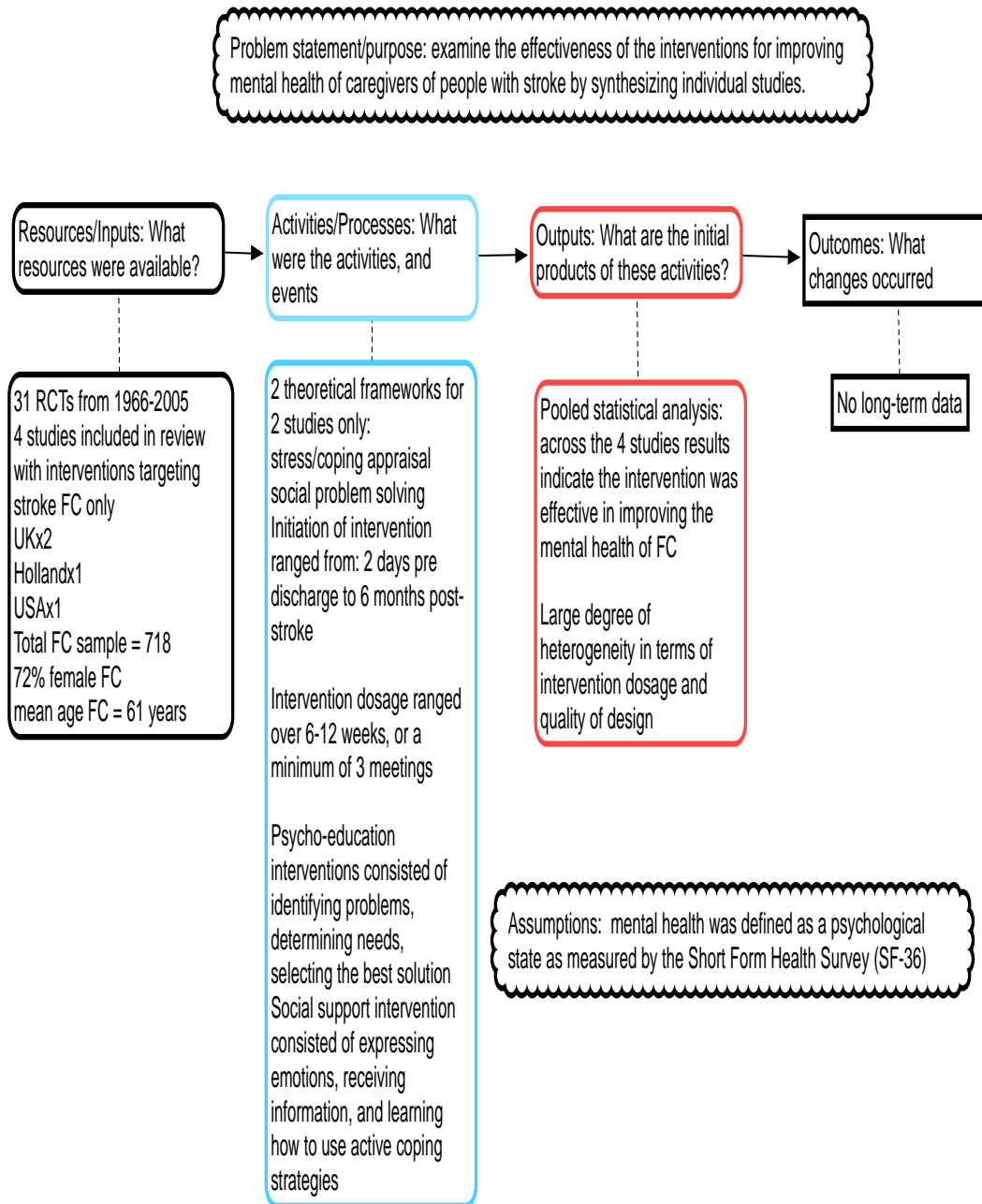


Figure 3.8: Logic model Lee et al., (2007)

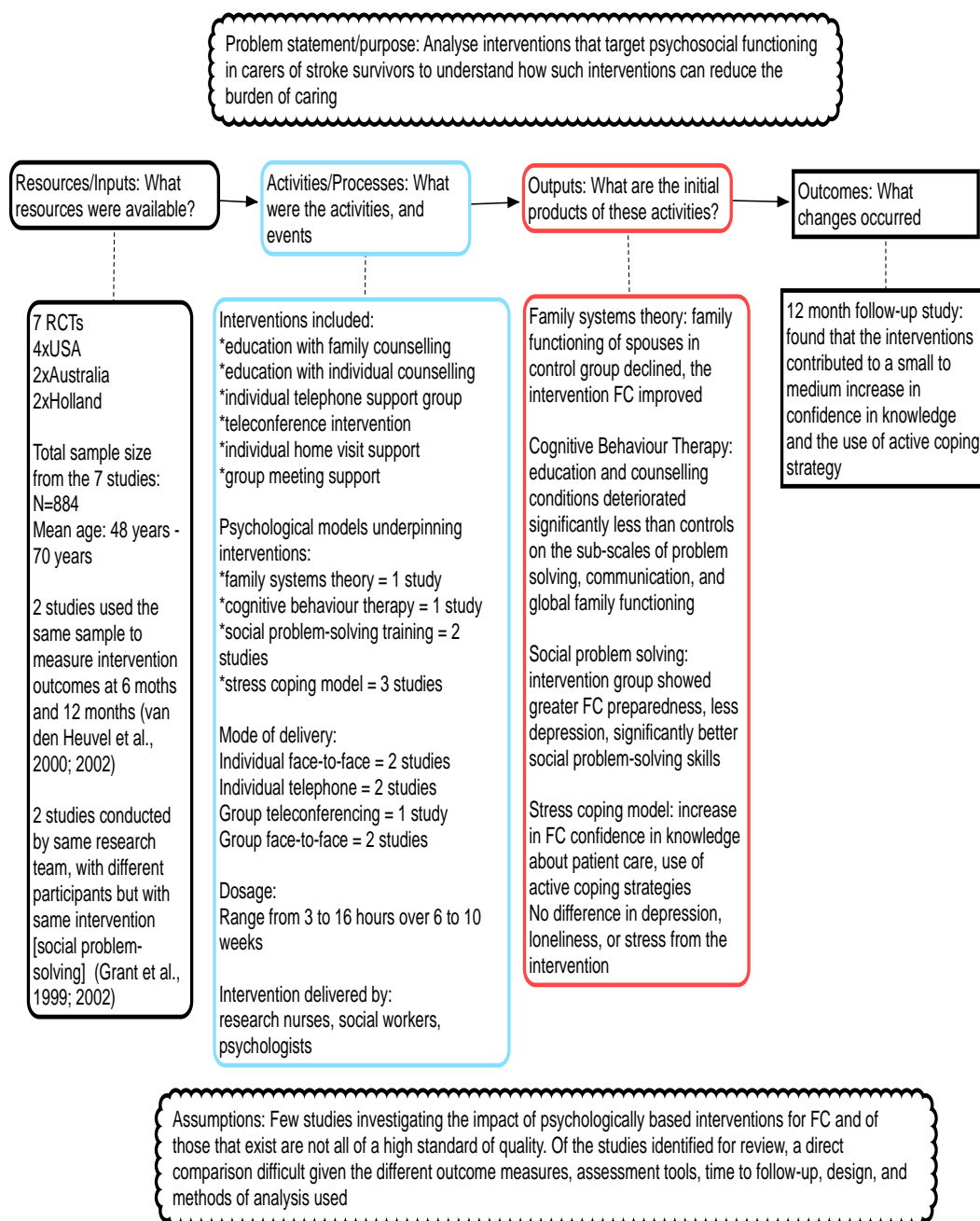


Figure 3.9: Logic model Eldred and Sykes (2008)

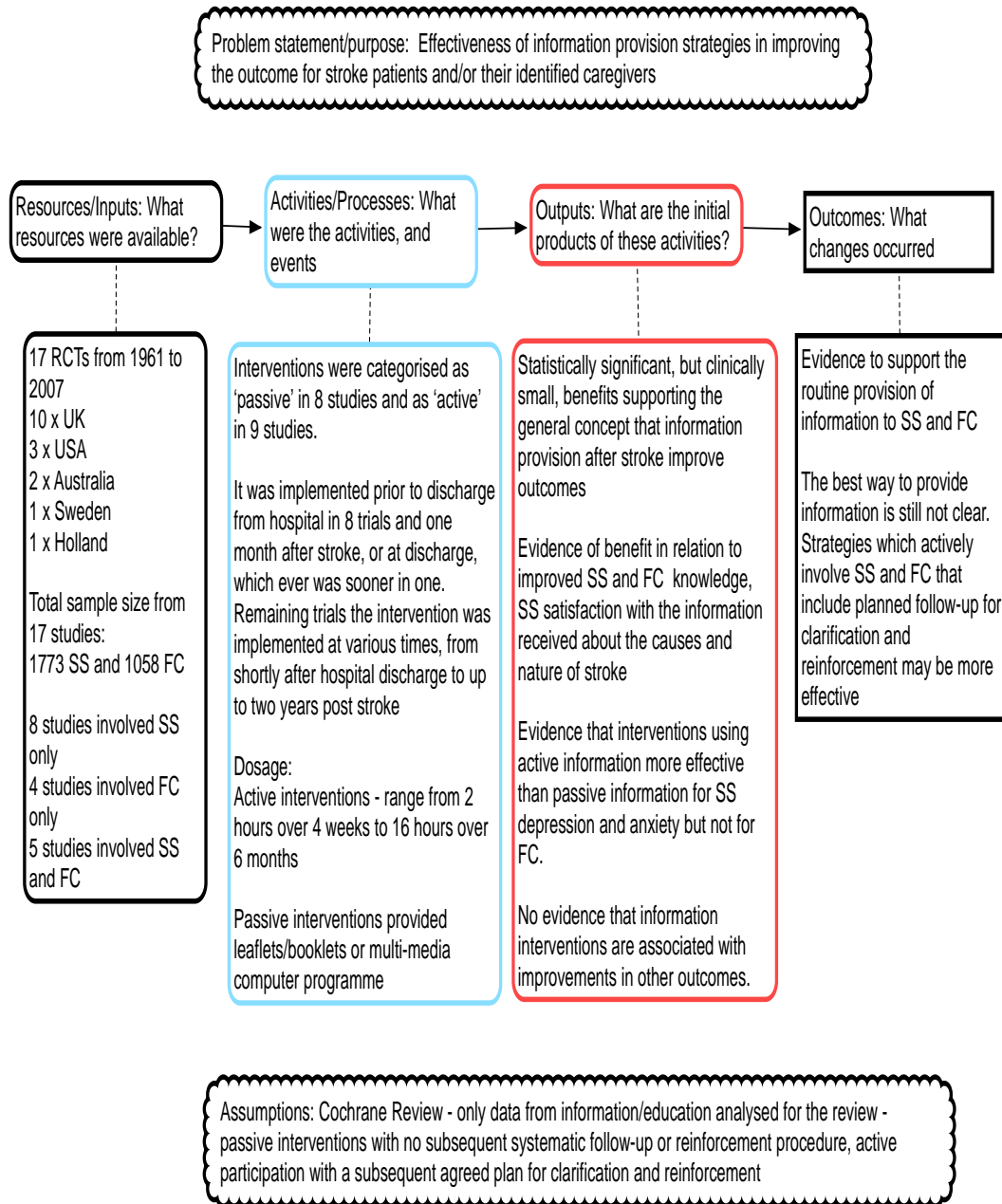


Figure 3.10: Logic model Smith et al., (2009)

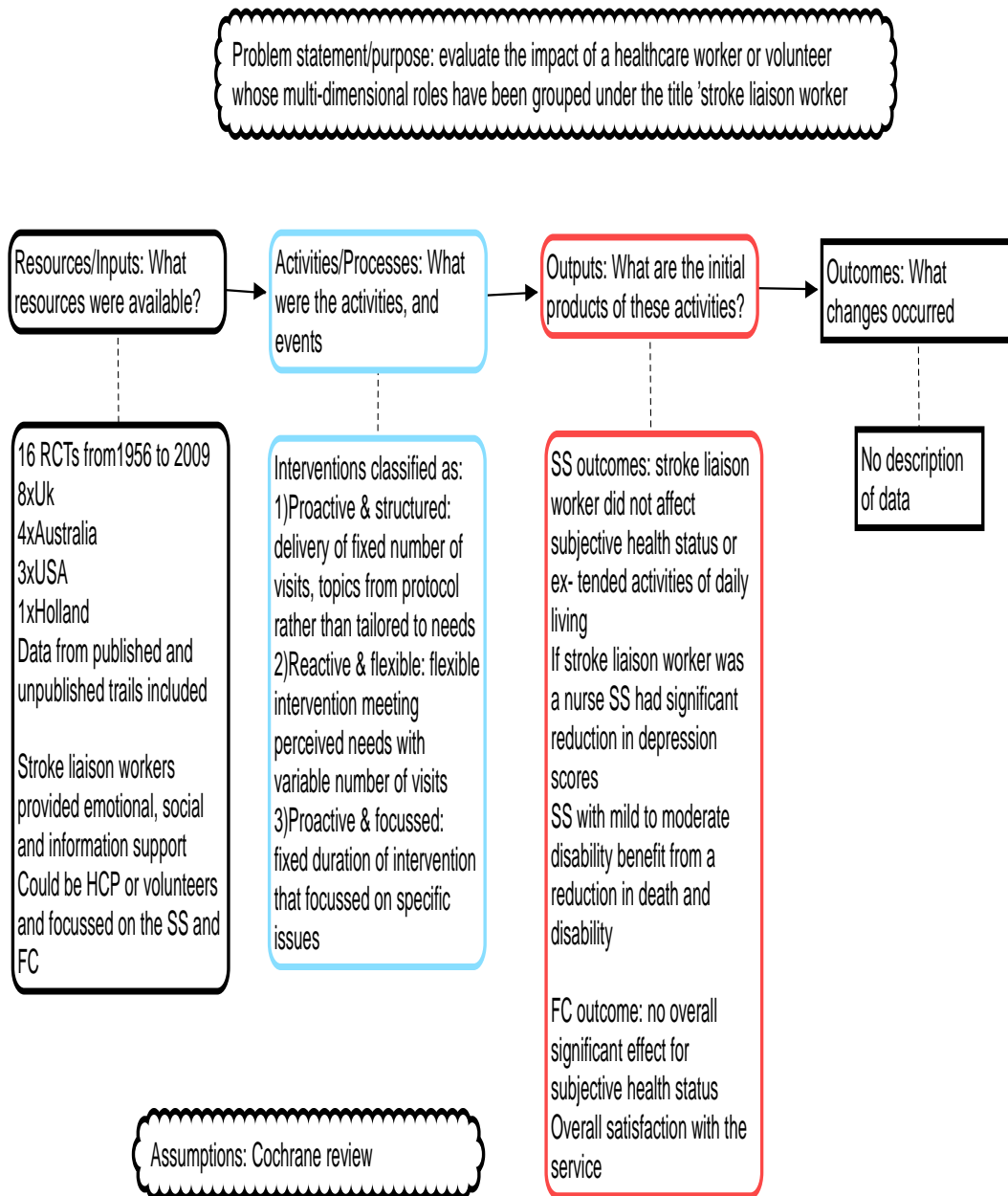


Figure 3.11: Logic model Ellis et al., (2010)

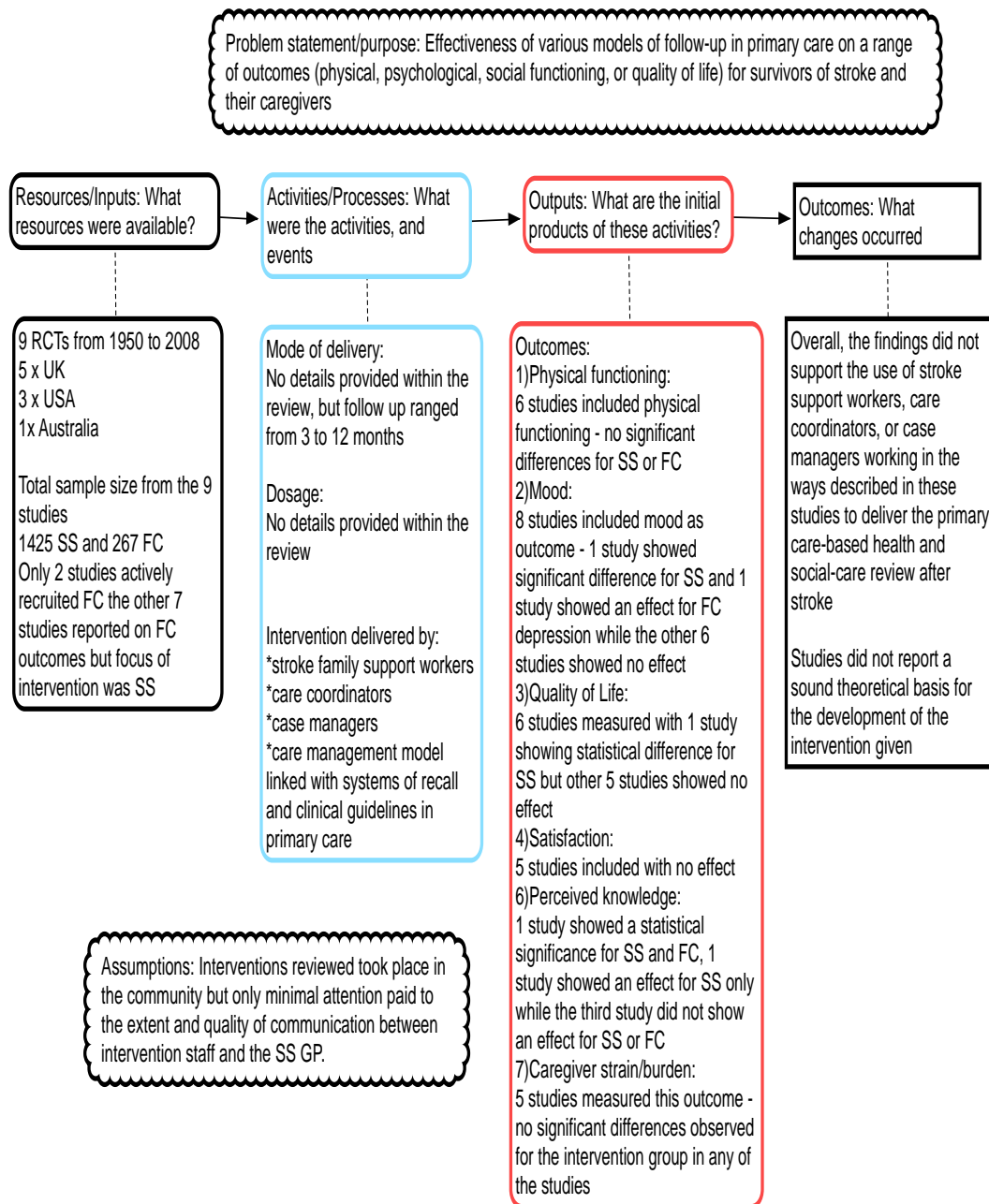


Figure 3.12: Logic model Allison et al., (2011)

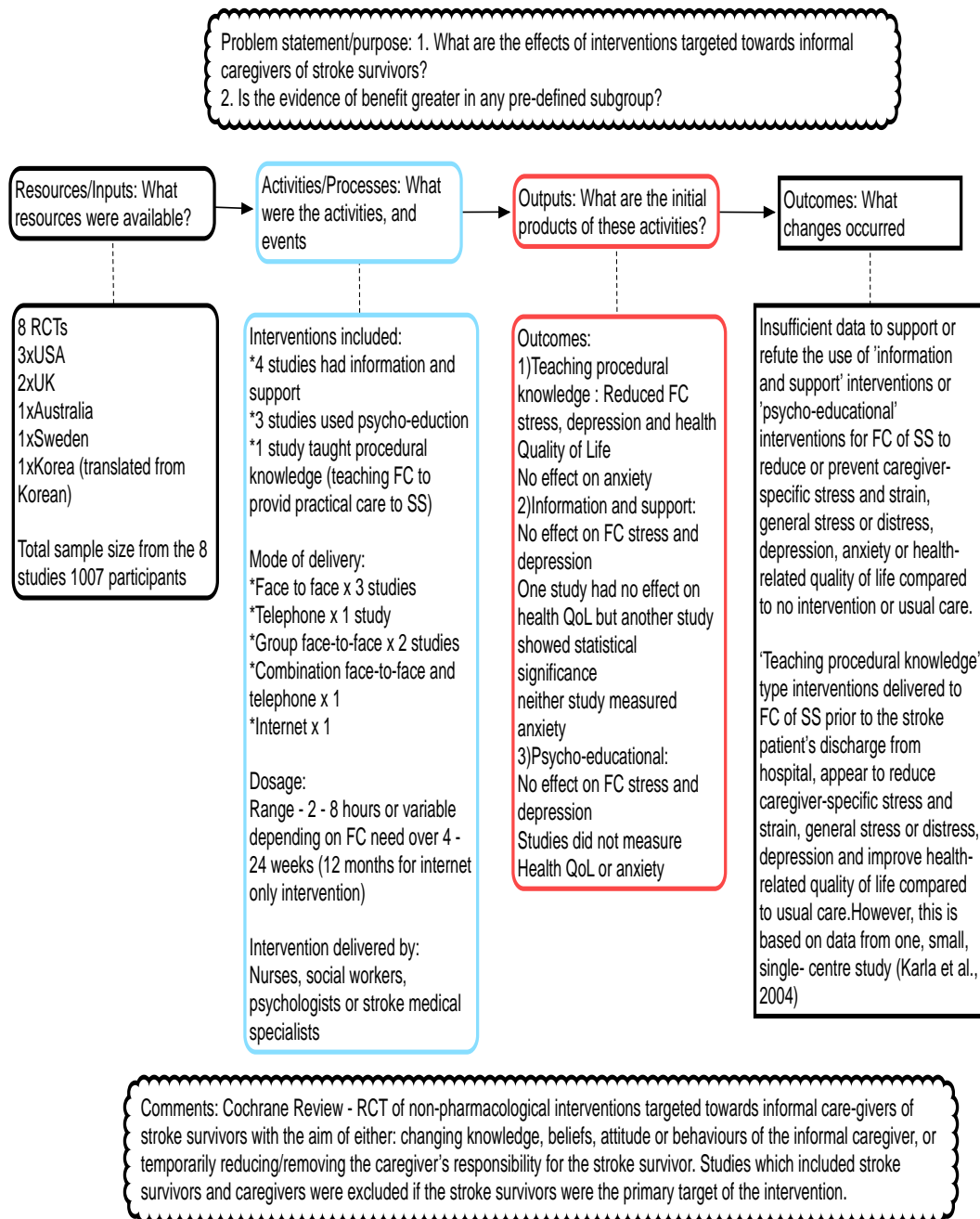


Figure 3.13: Logic model Legg et al., (2011)

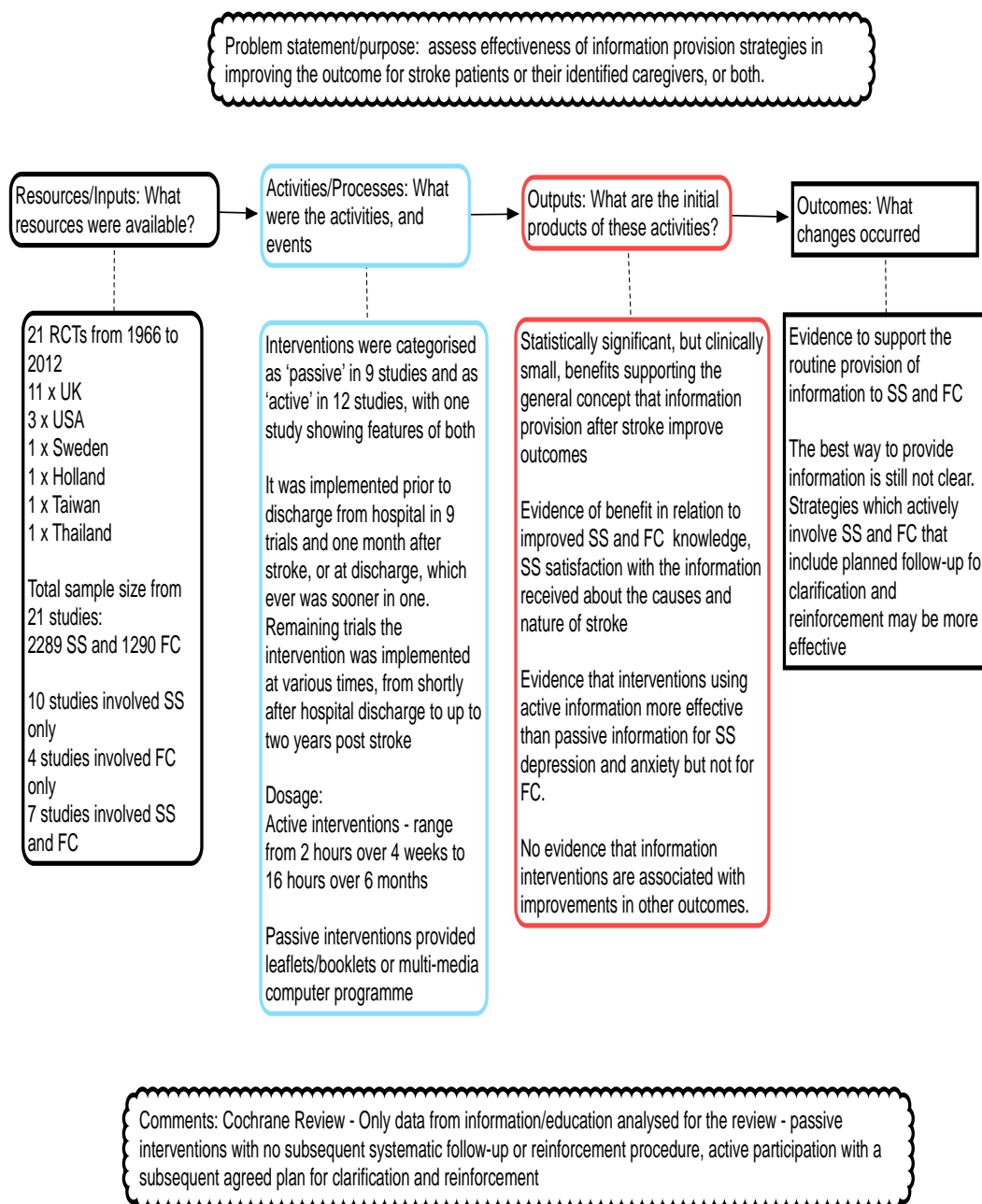


Figure 3.14: Logic model Forster et al., (2012)

3.12: Main Findings

The purpose of this review was not to draw out specific CMO configurations but to extract the context – outcome patterns that shape theories of how interventions work (Marchal et al., 2012). As discussed in section 3.4.1 the difficulties of drawing out mechanisms from realist synthesis of RCTs is potentially further amplified for systematic reviews of RCTs as the context is usually further stripped down. However, looking at implementation fidelity can highlight contextual issues, although according to Marchal et al., (2012) separating context and mechanism can also be a difficult process for realist researchers, and state that “Improving our understanding of the influence of the context on the outcomes of an intervention or on the problem at hand is, however, one of the key elements that set realist evaluation apart from effectiveness evaluations” (p.208). The elucidation of context – outcome patterns for interventions that support stroke families therefore lead to the development of an initial programme theory. Realist synthesis and evaluation begin with an initial or candidate programme theory that is then sharpened as the evaluation progresses. A programme theory is a set of assumptions that explain stakeholder hypotheses of how the intervention achieves its expected outcomes. The programme theory is then employed to direct the collection, analysis and synthesis of data that advances the theoretical underpinning of intervention implementation and impacts. Using the implementation fidelity criteria discussed in section 3.4.1, each systematic review logic model was analysed through the implementation fidelity criteria for contextual – outcome structures that accounted for the success or otherwise of the included studies.

3.13: Interventions utilised to support stroke families?

3.13.1: Intervention types

A variety of intervention types were applied to support stroke survivors and family carers ranging from, psycho-educational information, skill building, and group support, with most studies incorporating multiple intervention stratagems. Psycho-educational interventions deliver knowledge about a variety of issues related to the stroke and stroke survivor such as, managing medications and

personal care, lifestyle changes and community resources, managing emotions and behaviour, and effects of living with a stroke survivor on the family carer. Most of the psych-educational interventions also provided emotional support through a variety of counselling methodologies.

Skill-building interventions involve strategies that assist families to problem solve, and communicate with health and social care providers. Families are also taught active coping skills that attempt to reduce stress. The skill-building interventions also cover hands-on training in practical skills that help the stroke survivor such as reinforcing therapy techniques and assistance with activities of daily living. Support interventions include engaging with peers for support and advice through group or online discussion forums.

3.13.2: Mode and place of delivery

Mode of intervention ranged from face-to-face interactions, telephone contact or small groups. Several studies used a blend of methods to deliver their interventions, such as beginning with a group session, then follow-up with telephone contact. Group interventions could be professionally lead or facilitated by a trained layperson who had experience of stroke, depending on the main purpose of the intervention, to provide specific information on stroke or emotional support. Face-to-face interventions could be delivered in the hospital before stroke survivor discharge or in their own homes, again many studies used a combination. Group interactions were mainly delivered in the hospital or outpatients departments, meaning that the stroke survivor and carer needed to have the means to reach the destination, with some studies arranging this as part of the intervention. A further issue emerging from group intervention studies was the possible attrition rate particularly if it was the carer spouse as the focus of the intervention, many spouses would have to arrange for someone to be with the stroke survivor so they could attend. For the telephone mode of delivery, could be individual phone calls or they could be group based, removing the need for the family carer to leave the stroke survivor. Within the 11 systematic reviews discussed in this realist review there was only one study that included web-based or e-mail/blog based interventions (Pierce,

Steiner, Khuder, Govoni, & Horn, 2009), which proved to be non-significant, but there have been a few recent RCTs which evaluate such interventions, again with equivocal results (Smith et al., 2012).

3.13.3: Who delivers the interventions?

In most studies the intervention was delivered by nurses, physiotherapists, occupational therapists, social workers and psychologists, or a mix in a multi-disciplinary team, but the main staff to deliver interventions were nurses who were involved in stroke supervision. In a few studies trained laypersons were used as family liaison or support organisers, and these personnel were usually part of the intervention outcome. All personnel who delivered the interventions had some form of training in the intervention strategy, and was discussed in some detail in a few studies but sparsely reported in others. Only a minimal number of RCT studies described procedures that ensured the 'correct' implementation of the intervention throughout.

3.13.4: Timing and focus of the interventions

Most interventions were administered within one to three months' post-stroke, following a first stroke. Up to the first six months appeared to be a cut-off point for recruitment and administration of the intervention, only a limited number of studies included stroke survivors who were up to three years' post stroke (Heuvel et al., 2002). No study included stroke survivors who had a second or subsequent stroke. About half the RCT studies focused their interventions directly for the family carer and the other studies also included the stroke survivor. However, within those who included stroke survivor and family members there was variance in how much the intervention was geared towards the family carer.

3.13.5: Dosage and durability of interventions

The dosage or frequency with which the intervention was administered ranged from 0 to 15 sessions. Zero sessions were seen in studies that incorporated a family support worker, in that the stroke family had to contact them for the intervention (Dennis, ORourke, Slattery, Staniforth, & Warlow, 1997). Most

studies had a range of intervention frequency of between four to nine sessions but some had up to 16 sessions, and lasted from 35 to 60 minutes each on average. Durability is a measure of how intervention activities remain effective in the long term. Very few studies assessed this measure, only the outcomes once the intervention was completed. Two studies, Mant, Winner, Roche, and Wade, (2005), and Heuvel et al., (2002) did measure durability at 12 and six months respectively, and both papers reported little difference from their immediate outcome results.

3.13.6: Characteristics of stroke families

Sample size in the studies ranged from 300 (Karla et al., 2004) to 39 (Draper & Brocklehurst, 2007), but most studies had participant numbers under 100. The demographic characteristics of the caregivers were approximately 75% female, and around 65 years of age with the stroke survivors being older on average, the analysis within the RCTs of carer outcomes did not distinguish between the gender of the family carer. Limited information was provided on the race/ethnicity composition of the participants (mostly coming from studies from USA), and no study reported on same-sex couples. Some RCTs within the systematic reviews included only carers in their interventions, but most involved both stroke survivor and informal carer. A further issue was the pooling of spousal and other family members together, no RCT differentiated between the two in their analysis. A few systematic reviews commented on this (and gender differences) in their discussions, recommending that future RCTs should consider such separation as the relationship between spousal carers (including distinct gender perceptions) and adult children to the stroke survivor is different, with both groups having different responsibilities and therefore needs.

3.13.7: Outcome measures

Nearly all the systematic reviews commented on the array of outcome measures that were included in the RCT studies (for both stroke survivor and family carer). These ranged from depression and anxiety, caregiver burden, psychological distress, stroke survivor functioning, life satisfaction, health-related quality of life (HRQL), caregiving mastery, and family functioning.

Additionally, there were also different scales used to measure the same outcomes that made comparisons difficult for the systematic review authors, an exception was the meta-analysis by Lee et al., (2007) which targeted RCTs (n=4) that used the short form health survey (SF-36) to measure the mental health interventions of stroke family carers as the primary outcome measure. Lee et al., (2007) concluded that there were benefits to the interventions, but the quality of future RCTs needs improvement.

3.13.8: Intervention theoretical frameworks

Several systematic reviews discussed the issue of theoretical or conceptual underpinning of the included interventions within their reviewed RCTs. Most reviews concluded that there was a paucity of discussion within the RCTs as to the theoretical bases of the interventions. Where the RCT mentioned a conceptual framework, many relied on the stress – coping theories of Folkman,(2008) or Pearlin, Mullan, Semple, and Skaff, (1990) stress theory, whereas in other RCTs the theory was implied from the outcome measured used or intervention content.

3.14: Related literature on interventions to support stroke families

3.14.1: Introduction

Intervention studies over the past 15 years have attempted to mitigate the effects of carer burden in chronic illness patient (Brodaty, Green, & Koschera, 2003). However, as Han and Haley (1999) point out research on stroke has not provided adequate insight into how family caregivers adapt to their caring role over time, only identifying short-term benefits of certain interventions. Sörensen, Pinguart, and Duberstein, (2002) provide a very useful typology of carer intervention strategies that they utilized in their meta-analysis. Sorensen et al (2002) identified six different intervention approaches to carer support:

- Psycho-educational: includes a structured educational programme and help for caregivers to respond to stroke survivor problems.

- Supportive: both professionally based approach and/or peer-led support to provide a platform for carers to voice their concerns and develop coping strategies.
- Cognitive/behavioural approach (problem solving/stress and coping): These intervention approaches includes professional counselling and improve problem-solving abilities to overcome the burden of caring.
- Skills training: Any intervention that is designed to improve the care recipient behaviour that then will reduce family carer burden.
- Multi-component: This typology encompasses several the interventions described above as a structured programme.
- Respite care: These interventions are designed to 'remove' the stroke survivor away from the family care context for a period to give the family carer some relief (Respite care has been discarded in this synthesis as it is not relevant in the present context)

Sorensen et al (2002) in their meta-analysis identified five outcome measures related to their influence on the family carers that should result from the interventions. In their discussion (Table 3.5), Sorensen et al., (2002) demonstrated that all interventions had an overall small to moderate effect, with the cognitive/behavioural and psycho-educational interventions showing the most consistent positive results across all variables. In summary, multi-component interventions had more impact than single interventions, with longer-term input again faring better.

Type of Intervention	Burden	Depression	Subjective Well-being	Ability/ Knowledge	Social Support	Satisfaction from caregiving
Psycho-educational	X	X	X	X		X
Supportive	X			X		X

Cognitive/behavioural	X	X	X	X		X
Care-recipient skills			X			
Variables						
Multi-component	X		X	X		
Group					X	
Individual	X		X			
Longer duration	X	X				

Table 3.5: Linking types of interventions and variables to family carer outcomes

3.14.2 Theoretical perspectives which underpin family carer interventions

3.14.2.1: Introduction

A key feature of a realist synthesis approach to systematically reviewing the literature is its theory driven nature (Astbury & Leeuw, 2010; McCormack, Wright, Dewar, Harvey, & Ballantine, 2007; Rycroft-Malone, Fontenla, Bick, & Seers, 2007). Indeed, one of the criticisms of a conventional systematic review is its favouring of the randomised controlled trial (RCT) over other methods. The RCT does not require there to be a theoretical foundation for the interventions to work, if the study has sound internal validity and reliability (Pawson, 2006). Similarly, a few narrative and systematic reviews of stroke family carer interventions have recommended that future research in this area would be strengthened with interventions based on a theoretical model (Eldred & Sykes, 2008; Rigby et al., 2009; Smith et al., 2009; Visser-Meily et al., 2005).

Theoretical models that are utilised in family carer interventions to ascertain why certain interventions worked within certain contexts (Pawson, 2006). Without a theoretical base, there is limited understanding of why an intervention worked and more importantly how the intervention can be effectively utilised

outside the experimental artefacts. Several different theories have been utilised to focus family carer interventions in stroke and other long-term conditions (Lutz & Young, 2009).

3.14.2.2: Stress-coping model

The most cited theoretical framework is the stress-coping model devised by Folkman (2008). The stress-coping framework links to the perceived stress experienced by family carers and attempts to reduce the burden by initiating interventions that increase coping, through problem solving skills and educational advice. The transactional model of stress highlights the role of individual cognitions in the stress response, primarily through appraisal of the context or situation. The first stage is primary appraisal where the individual (through emotional responses) decides if the situation is a threat or is benign. If the stressor is judged to be threatening then the individual will proceed to a secondary appraisal that decided if the individual has the necessary coping skills/strategies to deal with the stressor. According to the model the stress response can take several forms

- Direct action
- Seeking information
- Doing nothing
- Developing a means of coping with the stress

The secondary appraisal incorporates an appraisal of the individual's coping resources to manage the stressors. Again there are several ways of coping

- Approach Vs avoidance
- Problem focused Vs emotion focused
 - Problem focused is action orientated to reduce demands of the stressor or to increase the resources to manage the stressor
 - Emotion focused involves attempts to manage the emotions evoked by the stressful event, using both behavioural and cognitive strategies, such as talking to a friend (behavioural) , or thinking about the problem in a different way (cognitive), recasting the crisis/burden as a challenge or feeling of being needed.

Several factors have been shown to influence which coping strategies are used:

- Type of problem
- Relationship problems evoke emotion focused approach
- Age
- Middle-aged use more problem solving while elderly used more emotion focused
- Gender
- Women more emotion-focused men more problem-focused but not conclusive
- Controllability
- Problem-focused if individual believes the stressor can be changed but emotion-focused if they believe the problem is out of their control
- Available resources
- Social support – this concept can be separated as framework in its own right?
- Time
- Education
- Money

In these theories, stressful events are defined as those that are appraised by the individual as being threatening or harmful and unable to be managed successfully. Once an event has been appraised as stressful, the theory suggests that coping responses will be implemented. These coping responses will then determine the course of psychological and social recovery. Lazarus and his colleagues (Lazarus, 1993a) proposed that positive appraisal and effective coping will be facilitated through access to sufficient personal or environmental "coping resources", such as social support, family cohesion, financial security, self-esteem and community services. It is suggested that these factors encourage individuals to perceive their circumstances as less threatening and more able to be managed successfully, leading to better adjustment (Kendall & Terry, 1996).

3.14.2.3: Cognitive behavioural therapy (CBT)

Cognitive and behavioural theories are linked to the stress-coping model described above, as it attempts to change the family carer's perception of the situation they are in (Brodaty et al., 2003). Training in problem solving, counselling and cognitive retraining are important intervention strategies that help carers focus on time-management, overload and emotional reactivity (Zarit & Femia, 2008).

CBT focuses on the development of personal coping strategies that target solving current problems and changing unhelpful cognitions that influence behaviours. It was originally designed to treat depression, and is now used for a number of mental health conditions (Woodford, Farrand, Watkins, Richards, & Llewellyn, 2014). This process involves a trained therapist to guide the person through the various problem-solving tasks to re-orientate thoughts and beliefs about the situation they are in. Recently Coull and Morris, (2011) have provided evidence from a systematic review that CBT-based guided self-help interventions (CBTsh) using tailored workbooks can be as effective as a face-to-face meeting with the therapist.

3.14.2.4: Family systems theory

The principal goal in the family systems approach is to achieve a rich characterization of the interplay among relationships and individuals in the whole family unit, with a specific focus on identifying relationship structures, interpersonal boundaries, power distributions, and communication patterns (Cox & Paley, 1997).

Tsouna-Hadjis, Vemmos, Zakopoulos, and Stamatelopoulos, (2000) reported different effects associated with different types of family support. Higher levels of instrumental support had a significant and positive effect on both functional and social status in the first 6 months following stroke, but had less impact on depression, whereas emotional support had a different pattern of influence. High levels of emotional support had a significant impact on both depression

and social status in the first three-months post stroke, and on functional status from 3 to 6 months.

The McMaster Family Therapy (Ryan et al., 2005) developed an approach to working with families, that included experience with psychodynamic, interactional, and systems models. These diverse theories were synthesized into the McMaster model that is a family systems approach wherein the therapist maintains open and clear communication with the family during treatment. According to the McMaster model, and in contrast to psychodynamic/psychoanalytic models, insight into the problem is neither necessary nor sufficient for change to occur, but, rather, the therapist directs the family's attention to assist them to change the family dynamics that allow or encourage the undesired behaviour. The shift from the psychodynamic origins of the McMaster model to a more systems/behavioural approach aligns it closer to the social problem solving model.

3.14.2.5: Social support

One consistent conclusion demonstrated by the research literature is the positive relationship between social support (both functional and psychosocial) and carer outcomes. However, intervention research that have attempted to improve social support do not appear to have consistently or significantly improve those outcomes (Salter, Foley, & Teasell, 2010).

According to Weiss, (1982), adult attachment is expressed when individuals display need for ready access to the attachment figure, desire for proximity to this figure, and an increase in discomfort and anxiety when the attachment figure is inaccessible. Only certain close relationships, such as marriage or committed non-marital relationships, function as relationships of attachment. In the absence of such relationships, individuals report feeling lonely, and this loneliness is not reduced by friendships. Friendships, however, prove to be of importance in a somewhat different way.

Individuals who were without access to a community of others-who, because they had moved from some distance away, currently had

neither friends nor kin nor co-workers also reported distress. Unlike loneliness, their distress could not be allayed by the availability to them of an emotionally intense sexual relationship. What they lacked might be characterized as 'affiliation' - associations in which shared interests and similarity of circumstances provided a basis for mutual loyalty and a sense of community. (Weiss, 1982, p.74)

An important point of Weiss's (1982) discussion is that attachment and affiliation appear to be different types of bonds among adults, both of which have emotional significance and are worthy of further study.

3.14.2.6: Social problem solving

A special form of problem solving, called social problem solving has been used in a few stroke carer interventions (Grant et al., 2002). (Chang, D’Zurilla, & Sanna, 2004) developed the concept and defined it as “the process of problem solving as it occurs in the natural environment or 'real-world'...one's adaptive functioning in the real-life social environment”. There are three major concepts in the model:

- Problem-solving
- The problem
- The solution

Problem-solving as defined by (Chang et al., 2004) is “the self-directed cognitive-behavioural process by which an individual, couple, or group attempts to identify or discover effective solutions for problems encountered in everyday living” (p.12). Problem solving is a conscious and rational activity to change the situation for the better; particularly the decrease in emotional distress the unsatisfactory situation creates. Implicit in this definition of social problem solving is the logicity of individual thinking. This concept of rational decision making does contrast with several theories used by family therapists including the IMAGO model (used by RELATE). The IMAGO relationship therapy (Hendrix, Hunt, Hannah, & Luquet, 2005) originates from psychoanalytic principles, which does not view behaviour as rational.

A problem is defined under Chang et al., (2004) model is “any life situation or task that demands a response for adaptive functioning but no effective response is immediately apparent or available...” (p.12). Social problem solving consists of two processes, problem solving and solution implementation requiring different skill sets. Problem-solving skills are general in nature whereas solution implementation is situation specific, and are therefore problematic skills to master.

3.14.3 How are the interventions executed?

A family caregiver's stress is best described as a multi-dimensional problem (Pearlin et al., 1990). Well-being results from the dynamic interplay of multiple stressors and the resources that are available to mediate them. The stressors or risk factors that are present vary considerably from one caregiver to the next and over time. It may be that multidimensional interventions are more effective than one-dimensional programs because they have a greater chance to touch on a caregiver's problems (Low et al., 1999). Many intervention trials use a scripted protocol that allows little flexibility. This approach ensures fidelity to the treatment plan and makes replication possible. However, such a rigid approach cannot respond to individual treatment needs (Visser-Meily et al., 2005).

In addition to the issues cited above, other problems in the design of caregiver intervention studies have contributed to the modest or negative outcomes seen in many studies (Zarit & Femia, 2008). An example of a study design matched to treatment goals is a randomized trial for the treatment of depression in which participants meet the operational criteria for depression set out by the Diagnostic and Statistical Manual of Mental Disorders. The participants have the problem depression that is treated in the study. But in a typical study of stroke caregivers that intends to reduce their depressive symptoms, eligibility for participation is likely based solely on being a caregiver, even though depression is a common problem for family caregivers it is not universal, and many caregivers in the sample will not be depressed. Therefore, they will not

show any improvement in their level of depression. In fact, treating them for a problem they do not have may even worsen their situation.

Most interventions for caregivers seek to improve an outcome, such as depression or burden, by addressing risk factors for that outcome. Risk factors have included a lack of information about stroke and about community services; difficulty managing the cognitive and behaviour problems of a person with stroke; inadequate support or assistance; misunderstandings and conflicts between the caregiver and other family members; and the inability of the caregiver to carry out other activities, such as work. The problem with this approach is that it assumes these risks will be present for all caregivers. However, studies indicate that the extent to which any risk factor is present or problematic varies among caregivers (Green & King, 2007). Behaviour problems, for example, are common in people with stroke and are a major risk factor for burden and depression in their caregivers. Yet some caregivers report that their relative has few behaviour problems (Greenwood, Mackenzie, Cloud, & Wilson, 2010) they can manage these problems and do not need skill-building or other interventions in this area.

Why would caregivers participate in a treatment trial if they did not have major emotional distress or burden or if they were not struggling with many of the typical risk factors? Researchers' assume carers are seeking help for other concerns that were not addressed by the intervention or were hoping the treatment would prevent their situation from becoming worse. Instead of determining caregivers' goals, researchers have often imposed their own goals on them. The results of the discrepancy between researchers' goals and those of caregivers can be seen in some studies of caregivers who were assisting relatives with disabilities severe enough to qualify them for institutional care. The caregivers were not told that the goal of the intervention was to delay or prevent nursing home placement by providing community-based services. Furthermore, the caregivers were not asked whether they were currently considering institutional placement or wanted to delay it. Not surprisingly, these

studies found the intervention had no effect on subsequent placement (Ostwald, 2009).

Caregivers may be husbands, wives, daughters, daughters-in-law, sons, siblings, grandchildren, or people who are not relatives. The obligations and commitments for providing care that are expected of the person in each of these relationships differ. Caregivers also differ among themselves in their other obligations and in the resources, they have for providing care. For example, spouses who are retired may have time to provide care, but they may have health problems of their own that limit their physical capabilities. Daughters are more likely to have competing obligations in their work and family roles, and they may be more willing than spouse caregivers to use outside help to supplement care, so they may approach caregiving very differently from husbands and wives? Other notable differences among caregivers are related to ethnicity and socioeconomic status. Few intervention studies have taken these differences into account (Gaugler, 2010).

3.15: Analysis of individual RCTs

3.15.1: Introduction

As a further examination of the context – outcome patterns, several RCT studies which were the most frequently cited in the 11 systematic reviews were analysed in greater detail to ascertain if any mechanisms could be extracted. Six generally positive studies (statistically significant) and four negative studies (statistically non-significant) were included and described below.

3.15.2: Positive studies

3.15.2.1: (Evans, Matlock, Bishop, Stranahan, & Pederson, 1988)

This study employed two intervention cohorts against a control group, education only and education and counselling. The participants, stroke survivors and their carers were randomly assigned, and their characteristics were similar across the groupings. Most family carers were females (>90%), with approximately 80% being married. Given that the control group only

followed usual patient medical rehabilitation, this study's focus on the family carer is an important contextual feature of the interventions. Both intervention arms demonstrated improved family functioning scores over the control cohort at six and 12 months, with the education/counselling showing greater benefits. The education only intervention engendered a recognition and appreciation in the family carer the influence that the stroke was having on their spouse. This recognition of behavioural changes would attenuate family conflict thereby improving communication and increased involvement by the carer in the stroke survivor's condition. The education and counselling intervention triggered the above reactions in family carers together with greater self-awareness of their responses to stressful family situations emerging post-stroke. Coupled with personalisation of the problem-solving skill sessions, which developed greater self-efficacy and confidence within the carers' thereby improving their behavioural control in the readjustment of family roles.

3.15.2.2: (Grant et al., 2002)

Again, a study based in USA that incorporates a problem-solving approach to family carer issues. In this study Chang et al., (2004) social problem solving conceptual framework was employed. 74 participant couples were enrolled into the intervention, with 91% being female carers, however spouses only represented 41% of the cohort, the rest being mainly daughters. Again, there were three cohorts, the intervention group received an initial structured three-hour face-to-face training with a nurse who taught and made the participants practice positive problem assessment and problem solving coping skills. The problem assessment involved looking at the issues they faced with a positive orientation. Following initial instruction, the intervention cohort was followed-up through weekly telephone calls for three weeks than biweekly phone calls for six weeks, in which the carers were asked to identify issues pertinent to their current situation. The second intervention was a 'sham' telephone contact group following the same pattern as the intervention, but only gathering information related to health professional visits during the preceding interval. The third cohort was the control group receiving usual discharge procedures. The initial three-hour training session by the nurse carried out in the carer's

home enhances carer trust in the nurse's competence when dealing with the problems arising from the caring process. Similarly, the focus on reinforcing positive cognitive strategies in dealing with difficulties boosted resilient responses, focusing on the affirmative aspects of caregiving rather than maladaptive. The telephone problem solving partnership that was personalised to the carer's issues triggered a sense of self-efficacy, a sense of being able to deal with specific day-to-day problems. Similarly, the telephone contacts were flexibly applied so that if the carer was busy then they could be rescheduled. This flexibility over telephone contact triggered a perception of control by the carers over the process, which improved their general well-being. As the initial three hour, face-to-face training enhanced carer trust, the telephone consultation limited direct social contact that reduced carer embarrassment or shame in discussing sensitive topic areas such as anger and frustration with the stroke survivor with the nurse.

3.15.2.3: Mant et al., (2000, 2005)

This study was based in the UK and evaluated the impact of a family support organiser (FSO) on the well-being of SS and primary family carer. The participants in this study comprised a more equal distribution of male/female stroke survivors that resulted in greater percentage of male carers at 35%. Relationship of carer to the stroke survivor was approximately 60% spouses and 30% adult child, there was no breakdown as to the gender composition of these groupings. This study adopted an unstructured intervention programme that relied on the discretion of the Family Stroke Officer (FSO) in terms of the nature and frequency of interactions. Average 'dosage' calculated at 1 hospital visit, 1 home visit, and 3 phone calls. The results demonstrated improvements for the family carers in terms of greater social activities and quality of life, as well as satisfaction with knowledge of stroke although they did not display better knowledge than the controls. There were no benefits for the stroke survivor apart from "...possibly less depression..." (Mant et al., 2000 p812). The presence of the FSO evoked feelings of self-esteem and self-worth in the family carer that resulted in improved perception of quality of life. The FSO's reinforced carer coping responses through their perceived access via telephone leading

to less stressful episodes (“if needed I can talk to them on the phone”). The 2005 report on a twelve-month evaluation of the original study showed that carer outcomes were like the six-month outcomes, but again no benefit accorded for the stroke survivor.

3.15.2.4: Clark, Rubenach, and Winsor, (2003)

In this study, the focus was on stroke survivors and their spouses, the intervention was a social worker trained in education on stroke and family counselling and stroke related stress, delivered through three, one hour sessions over a five-month period in the couple's own homes. However, it was not clearly stated in the article if the sessions were delivered to the couple together or individually, the assumption given the theoretical framework of family therapy is that it was dyad based. The primary outcome of family functioning as measured on the Family Assessment Device (FAD) improved, as was some improvement in stroke survivor Barthel scores at six months. However, there was no significant effects on depression, anxiety, mastery or health status. Face-to-face counselling on perceived couple stress plus practical coping suggestions of information package triggered self-efficacy in coping with the consequences of stroke. Improved patient functioning prompted better behavioural control over lifestyle changes by the couple (e.g., weight control). The lack of impact of the counselling on couple depression and anxiety scores may be the continued trauma upholding the grief response following the stroke.

3.15.2.5: Hartke & King, (2003)

This study was carried out in the USA, and consisted of eight, one hour group telephone based interventions. The telephone group consisted of between three to six carers facilitated by two professionals whose background was either psychology, social work or nursing. The intervention was structured over the eight sessions, but each carer was asked at initial assessment (before intervention) to produce a list of stressful problems in caregiving. The carers were also issued with a stress manual and a relaxation tape, together with the names and phone numbers of their group, so that they could contact each other

outside the telephone sessions. There were 88 caregivers mostly white females, 70 years old on average, who had been providing care for an average of 3 years, although 25% of the participants had been caring for under six months. Hartke and King (2003) acknowledged the partial success of their intervention in that the primary outcome of stress reduction was achieved although over time it was not significantly different. The carers in the treatment group when interviewed were very satisfied with the intervention and appreciated the safe environment for 'venting emotional feelings', so this context of partial anonymity, emboldened the carers' to discuss their stress-related feelings with the group. Compared to the control group whose perceived burden scores increased, the intervention group remained stable so the authors speculate that the intervention prevented rather than reduced the accumulation of strain over time. The mechanism which could account for this is derived from social comparison theory, via downward comparison effects within the group, where carers' rated their situation as being 'better' than that of the other spouses.

3.15.2.6: Karla et al., (2004)

This study based in the UK was highly rated by many of the systematic reviews as being methodologically robust. The control group of family carers (n=149) received usual care consisting of information on stroke and its consequences, prevention and management goal setting for rehabilitation and discharge planning. Encouragement to attend nursing and therapy activities to learn about patients' abilities and informal instruction on mobility, and activities of daily living tasks. Advice on community services, benefits, and allowances, including contact information for voluntary support services for care givers.

The intervention group of family carers (n=150) received usual treatment, with additional training in pressure area care, manual handling, and personal care. These structured interventions were delivered by an appropriate professional giving three to five sessions depending on need, with each session lasting 30-45 minutes, although there was no information as to whether the professionals received any training for intervention procedures. The intervention took place

within a hospital rehabilitation unit with a further home visit following discharge to reinforce skills learnt. Outcome measures were as follows: for the stroke survivor, death or institutionalisation, modified Rankin scale, Barthel index and Frenchay activities index for function, hospital anxiety and depression scale for mood, and EuroQol visual analogue scale for quality of life. For the family carers the Frenchay activities index for function and social activities, hospital anxiety and depression scale and caregiver burden scale for emotional health, and EuroQol visual analogue scale for quality of life. These measures were taken at three months and 12 months following intervention.

Eighty-six percent of the stroke survivors were male with mean age of 76 years, with Barthel index scores at one week post-stroke for both intervention and control groups above moderately disabled level. However, even though the intervention was targeting the primary family carer, there were no details of carer mean ages, gender, socio economic status or ethnicity apart from indicating that for over 60% of patients the spouse was the main family carer, with no differentiation of outcome results for spousal carers and other family members. Results at three and 12 months showed the carers who received the intervention had significantly reduced burden, anxiety, and depression scores, improved quality of life and satisfaction. Stroke survivor results at three and 12 months showed better quality of life and psychological outcomes, but mortality, care home admission, and disability were not influenced by the intervention. Even though the intervention was targeting the family carer, it was the stroke survivor who was the focus of the intervention through delivery of practical nursing care. The intervention may have triggered carer self-efficacy that reducing perceived burden and stress, and may have triggered greater self-esteem as the health professionals incorporated the family carer into their relatives' care. For the stroke survivor improved psychological health may have triggered greater feelings of attachment or mutuality because their family carer (spouse) was taking an active part in their rehabilitation

3.15.3: Negative studies

3.15.3.1: Smith, Forster, and Young, (2004)

The objective of this UK study was to evaluate the impact of an educational package delivered to stroke survivors and their main family carers before discharge home. The study consisted of 170 stroke survivors and 97 carers in total randomised into the two groups, with the intervention consisting of a specially designed stroke information manual and educational meetings every 2 weeks with a stroke multidisciplinary team in a hospital dayroom (20 minute sessions but no record of how many meetings). The control group received usual procedures. The information manual contained information on the causation and consequences of stroke, stroke recovery, financial benefits, and relevant services with a specific section for carers. The manual was designed by consulting qualitative literature about stroke recovery and interviews with 30 stroke survivors and carers. The overall result was non-statistical differences in stroke knowledge at three and six months, for either stroke survivors or carers, however there were effects on the anxiety scores but not depression on the Hospital Anxiety and Depression (HAD) scale for stroke survivors only. Possible mechanism for the intervention reducing stroke survivor anxiety because the programme elicited feelings of perceived social support through the incorporation of the main family carer in the process. For the carers' the anxiety and uncertainty of managing their relative at home elicited anxiety that negated any benefits from the programme. Failure to increase stroke survivor and family carer knowledge about stroke may have been due to the limited opportunity for them to personalise and adapt the content of the programme to their own needs.

3.15.3.2: Heuvel et al., (2002)

In this Dutch study, 187 close caregivers of first time stroke survivors were recruited through their general practitioners (GP) who looked after a stroke survivor whose first stroke had occurred between 1992 and 1996 and were over the age of 45 years at the time of the stroke. Seventy-one percent of carers were female with mean age of 64 years, majority were partners but no figures provided. Stroke survivors were 71% male, no mean age provided but mean

time since stroke was 3.5 years at intervention. Participants were divided into three groups, n=100 in group program (8x2hrs), n=49 in home visit program (4x2hrs) and n=38 in control group. Intervention based on 3 elements: 1) expressing emotion 2) receiving information 3) learning active coping strategies. Information topics covered causes of stroke/progression and consequences for social networks, caring for the stroke survivor (lifting etc.), caring for self, handling stress and specific active coping. The programme was based around Lazarus and Folkman's stress/coping theory with the nurses who delivered the intervention given two days training. Both the group and home-based individual interventions contributed to a small to medium increase in knowledge, confidence and use of active coping strategies and social support of the family carers after six months when compared to the control group. Results at six months for both group and home interventions achieved a small to medium increase in confidence in knowledge and the use of one active coping strategy with younger female carers (<65yrs) benefiting the most, with no other benefits noted. Possible mechanisms for these results could stem from the experienced carers already adopted satisfactory coping and stress reduction strategies that resist new coping interventions. Younger family carers obtained greater benefit from the intervention through generating greater self-efficacy and confidence in meeting the needs of their relatives. Close geographical proximity between the family carers triggered perceived social support. Group support programmes that include participants with similar attributes (age, gender) generate positive self-evaluations (social comparison theory) in family carers coping.

3.15.3.3: Rodgers et al., (1999)

A British study with a total sample of 176 divided into 107 carers in intervention group and 69 in control group. Mean age of stroke survivors was 75 years with 51% being female, as for the family carers their mean age was 58 years and 70% were female, with 44% being spouses. The lower mean age for the family carer indicates that they were daughters or daughters-in-law. Intervention consisted of one, 1 hour small group education session for in-patients and carers, followed by six, 1 hour education sessions following discharge to carers

only (provided by a member of the stroke team) and carried out in the hospital outpatient department, with transport provision to facilitate attendance. Topics included stroke knowledge, awareness of available services, and time for caregiver questions. The stroke education package improved patient and informal carer knowledge about stroke and increased some aspects of satisfaction with services, this was not associated with an improvement in their perceived health status. Indeed, social functioning, as measured by the SF-36, for the intervention carers was lower than in the control group. The delivery of the stroke educational programme outside the home suspends other social activities for carers because it elicits feelings of guilt in asking others to stay with their relative on numerous occasions leading to a decline in requests for such support. Informal support in a small group setting within the Stroke Educational Programme may have initiated feelings of stress or negative self-evaluations (social comparison theory).

3.15.3.4: Forster and Young, (1996)

This UK study reported on the use of specialist nurse support for patients with stroke and their family carers in the community. Two hundred and forty stroke survivors aged 60 years or over were randomly allocated to control group (n=120) or intervention group (n=120). 55% of the participants were male stroke survivors and median age of 73 years, with 35% of the stroke survivors living alone. In the article, there was very little detail about the family carers, with the thrust of the study directed at the stroke survivor. Five nurses experienced in stroke care, attended a two-day counselling training course. The intervention delivered by these nurses consisted of:

- Visit 1 (within one week of recruitment) Introduction Identification of the other community staff involved in patient's care Identification of immediate problems Provision of information booklets
- Visit 2 (one week later) Follow up of early problems Review of patient's need for aids-for example, adapted toilet seats, high seat chairs. Advice on benefits Review of patient's or carer's previous week's experience
- Visit 3 (one month later) Goal setting with emphasis on maximising social activities and relief for carer

- Visit 4 (two months later) Information, advice, and active support to improve patient's socialisation and relief for carer
- Visit 5 (three months later) As for visit 4
- Visit 6 (six months later) Information and advice about holidays Advice about driving (as needed)
- Visit 7 (12 months later) Review

There was no indication if the main family carer was present during the intervention visits. Evaluations were completed at six and 12 months, stroke survivor wellbeing was not improved, only social activities increased for the intervention group as compared to the control (only those with higher Barthel scores). Carer outcomes were measured through the General Health Questionnaire and there was no statistically significant improvement at six or 12 months. Possible mechanisms for intervention failure may be due to insufficient triggering of carer self-efficacy and confidence in dealing with the issues resulting from the stroke, as the focus was on the stroke survivor the needs of the carer were secondary to the project team and therefore the specialist nurses. Intervention dosage and timing may have been insufficient to engender adequate carer trust in the specialist nurse. The intervention may not have addressed the esteem needs of the carer as they struggle to come to terms with the effects of their relative's stroke on their lives. It takes time for stroke survivors and their family carers to find or regain 'meaning' or purpose within their life following the stroke.

3.16: Analysis of findings

From an analysis of study fidelity identified in the logic model representation of the 11 systematic reviews, several context – outcome (CO) patterns can be discerned. These CO patterns are important as they form key elements of realist analysis. Active engagement of stroke families in the intervention through tailoring psycho-educational information to the needs of the family is an emerging contextual component, as it allows the family to feel in control of the implementation process leading to better psychological health for the stroke survivor and family carer. It appears that generalised or standard information giving does not lead to any benefits for the stroke survivor or family. Targeting

of the intervention is an important contextual factor. If the intention is to improve family carer psychological health then the intervention should be directed at the family carers. Through this intervention approach stroke family carer feel that they are an important part of the rehabilitation process, resulting in reduction of perceived burden. A context that includes face-to-face interaction between the stroke family and health professional combined with telephone followed-up improves family carer psychological health.

3.17: Discussion and reflection of realist synthesis of systematic reviews

The decision to carry out a realist review of standardised systematic reviews of interventions that help to support stroke families was reached through the outcome of the wide-ranging literature review discussed in chapter one that mapped the territory and highlighted the burgeoning number of systematic reviews already available on the topic. The realist review strategy employed in this study does not follow the exact course of Pawson's (2006) approach and elucidated in table 3.1. This realist review was more restrictive in that a defined set of criteria were used to search the literature, i.e., standardised systematic reviews and meta-analysis of stroke carer interventions (Wong et al., 2013). However, this review did not follow the aggregative, a priori conceptual framework of systematic reviews but the realist, configurative approach to the development of theories that sits in the realist perspective discussed in chapter two. This realist review of systematic reviews, links the literature reviewed in chapter one and the stroke couple interviews described in chapter four leading to an articulation of key theories about how interventions that support stroke families are assumed to work. These programme theories were then tested and refined in the longitudinal couple interviews (chapter six) and the health and social care professional focus groups (chapter seven).

As far as is known there has not been any literature that has attempted to develop a realist synthesis utilising published systematic reviews and meta-analysis. Eleven reviews were included from 2000 to 2013 that comprised at least one intervention study targeted at stroke family carers. The reviews were

of varying scope and quality in their appraisal criteria. Indeed, the reviews in which the most stringent criteria were applied proved less speculative as to possible mechanisms underlying intervention outcomes. All the reviews had difficulty in extracting valid information from the included studies to make any but tentative claims as to effectiveness of the interventions. Areas of criticisms related to the poor quality of many of the RCT studies due to the heterogeneity of samples. A recurring complaint was the lack of conceptual or theoretical frameworks to guide the proposed intervention. However, when there were identifiable theories they did not appear to produce any better outcomes, mainly due to the inappropriate or insensitive outcome measures, the variability in the dosage and timing of the intervention, and the short outcome follow-up timeline. All the reviews recommend further improved quality RCT studies to overcome these issues, however, a few of the reviews did indicate that a better understanding of the way intervention theories work is required. It is not clear if the theories that have been espoused are appropriate models for reducing stroke family carer distress, as some have been criticised for being too individualised, not taking enough account of the dyadic nature of the care situation (or triadic, if health and social care professionals are included). A further criticism is the 'golden-bullet' approach to interventions in that one type of intervention strategy will work for most family carers over the whole time of their caring. As Clark, (2013) has stated components of complex interventions in health and social care should be looked at in well delineated parts rather than as a complete package.

The extraction of the CMOs from this review was iterative and was a difficult process. The amount of detail included was too broad to identify all but generalised contexts and outcomes, but was also a problem with the lack of specificity within the primary studies that all the reviewers alluded to. A further issue that emerged was the 'saturation' of CMOs. This effect, similar to qualitative data collection (Braun & Clarke, 2006) results when no new or relevant information emerges with respect to the programme theory. It is not surprising that this occurred as the same primary studies was included in many of the systematic reviews. The value of locating programme theories within

published systematic reviews and meta-analysis is beneficial if there is clear evidence of efficacy of the interventions, but if the evidence for efficacy is inconclusive as in this case there may be limitations in the quality of the data available for extraction. As an additional strategy to tease out context-outcome patterns, an analysis was made of the most frequently occurring primary studies included in these eleven systematic reviews, which did help understanding of how the intervention may have worked. In conclusion, the use of systematic reviews for realist analysis is problematic as the context is stripped out even more than for the analysis of the original RCT studies. If a realist review of systematic reviews is conducted then there needs to be a good understanding of the broad range of literature surrounding the interventions. Without the critical review described in chapter one, the analysis of the realist review of systematic reviews would have been even more challenging. The next chapter looks at the analysis of the first couple interviews, which then leads into chapter five and the construction of the initial programme theories.

3.18: Conclusion

This chapter began with a discussion of the distinction between systematic reviews and a realist synthesis. A realist synthesis of family carer systematic reviews was conducted, and included 11 reviews from 2000 to 2013. Because intervention RCTs and consequently systematic reviews limit discussion of context, data extraction looked at implementation fidelity within each review and presented in a logic model format. Additionally, the most cited RCTs from the 11 systematic reviews were analysed further to develop context-outcome patterns that will feed into the initial programme theories together with the preliminary couple interviews (chapter four) and the critical literature review (chapter one). The next chapter details the dyadic interviewing of six stroke couples, which completes phase one of the study.

CHAPTER FOUR: Preliminary couple interviews

4.1: Introduction

This chapter presents a description and analysis of the initial six couples who agreed to be interviewed. The purpose of these interviews was to gain an understanding of the effects of stroke on family relationships and the role health and social care services played in supporting their recovery. Specifically, this analysis will answer question two within the thesis:

- How do family carers and stroke survivors' experience the effects of stroke and the available services offered over the long term?

This tranche of interviews feeds into the programme theories that incorporated the findings from the realist review in chapter three. Before presenting the analysis itself, brief pen-portraits of each couple is provided to offer the reader a context and insight into the lives of the participants. These pen-portraits lead to a reflective account of experiences during these interviews based on a research journal collated throughout the thesis.

4.2: Purpose of preliminary couple interviews

Pawson and Tilley (1997) suggest that study participants have difficulty providing insight about contexts other than their own circumstance; however, knowledge of individual backgrounds can be used to elicit contextual boundaries. The initial couple interviews would form the basis of subsequent longitudinal meetings with these same couples to develop and test the programme theory; therefore, it was important to establish a rapport with the couple to enhance later consent and participation. Additionally, the interviews 'fed into' the initial CMO's together with the meta-realist synthesis discussed in chapter three., and the critical literature review described in chapter one. The specifics of the realist interview described by Pawson and Tilley (1997) will be discussed in chapter six when reviewing the longitudinal couple interviews that

test and refine the emergent programme theory. The research questions for the initial interviews were constructed as follows:

- Ascertain the effects of a stroke on couple relationships and the wider family
- How the stroke has affected family functioning through utilisation of the McMaster Family system approach
- How have the couple adapted to their life together following the stroke

4.3: Realist methodology

Realist evaluation depend on the assumption that it is our (and others') theories that make sense of observations and regularities within the social world. It is the role of research and the collection of data that moderates posited theories, not in a single all-encompassing experiment or study but as a gradual, evolving process in an accumulated fashion (generative) that leads to better, but not absolute, explanatory theories (Pawson, 2013). Given this take on evaluation science it is important to consider the 'realism' of research design. Iosifides (2011) contends that the interpretive perspective of science has 'hijacked' qualitative research as its 'own', preferred research design, whilst the positivist camp has commandeered quantitative designs. However, as Iosifides, (2011) argues both interpretivism and positivism reject the realist version of causal events. Pawson (2013) argues, taking Popper's, (2002) perspective, that 'theories make sense of observations', rather than the positivist mantra that data espouse theories with unilinear causality. Correspondingly, qualitative research, such as in-depth interviews or focus groups, are executed to gain an understanding of participants' 'multiple realities' of the social world rather than the realist understanding of diverse interpretations of the same reality (Stake, 2010). As has been discussed in chapter two, realist evaluation is method neutral, the stipulation is that the most salient approach is applied to the problem under investigation (Pawson & Tilley, 1997). Within realist evaluation the method of data extraction is not pre-determined, quantitative or qualitative methods, but is pluralist and method is decided by its aptness to the research questions being asked (Pawson & Tilley, 1997). However, Pawson and Tilley, (1997) go further and state that the purpose of "...data collection approaches

such as interviewing stakeholders in realist research is to confirm, reject and adapt the researcher's programme theories" (p.155). Within realist evaluation it is the CMOCs that are central with stakeholders' contribution ranging from sense-checking the programme theories through their own experiences, to fashioning emergent ideas (Manzano, 2016).

The question then becomes how can the use of qualitative research methods be justified in a realist evaluation approach to stroke family carer interventions? As Maxwell (2012a) outlines 'causation' is a prickly issue amongst qualitative researchers, and has emanated from the account of causation (successionist theory) first articulated by Hume (1739/1978) and Mills (1843/1988) that saw causation as the '*constant conjunction of events*' of observable regularities between variables, and justifies the pre-eminence of the RCT within health science research. Given this approach to causation then the interpretivist objection to causality is understandable, but Maxwell (2012a) articulates that with a reorientation of 'causality' by critical realism towards a 'generative' understanding that sees causation as the identification of demonstrable processes in particular contexts, which produce certain outcomes, the objection is removed (see table 6.1). Generative causation disconnects the positivist restrictions of eliminating confounding variables, by placing context at the centre of causal explanation. In addition, realism views context to include peoples' preferences and beliefs encapsulated within generative mechanisms that lead to certain outcomes. However, for the above points to be accepted by qualitative researchers, they would need to accept realist argument about the nature of reality discussed in chapter two, that would not tie in with constructivist ontology.

Paradigm	Generative realist
View of reality	Produces a series of theories that correspond to the underlying processes that cause people to behave in regular ways
How knowledge is created	Identifies causal processes by investigating the different circumstances in which they are produced reliably
Methodology	Uses the method that best allows a process to be reliably activated and the identified hypotheses to be selected or rejected.
Intervention	A programme that creates a cultural, social and personal context in which a process is activated that leads to particular patterns of outcomes being sustained, developed or blocked.
Progress	The development of interrelated theories so that imaginary hypotheses are rejected and real ones confirmed.

Table 4.1: Generative realist paradigm (taken from Matthews, 2003, p.63)

4.3.1: Qualitative realist research

Maxwell (2012b, 2005) outlined an interactive model of qualitative realist research design as described in Figure 6.1. The goals, conceptual framework and research question are the thoughts that underpin the researcher's conception of the study while the method is both the researcher's judgements and the actuality of the data collection process; whilst validity looks at the connection between the inferences drawn from the study to the phenomenon examined. Maxwell (2012b) asserts that these five components of research design are not fixed and linearly tied to each other, from goals to validity but are an 'interacting' system that influence one another throughout the study.

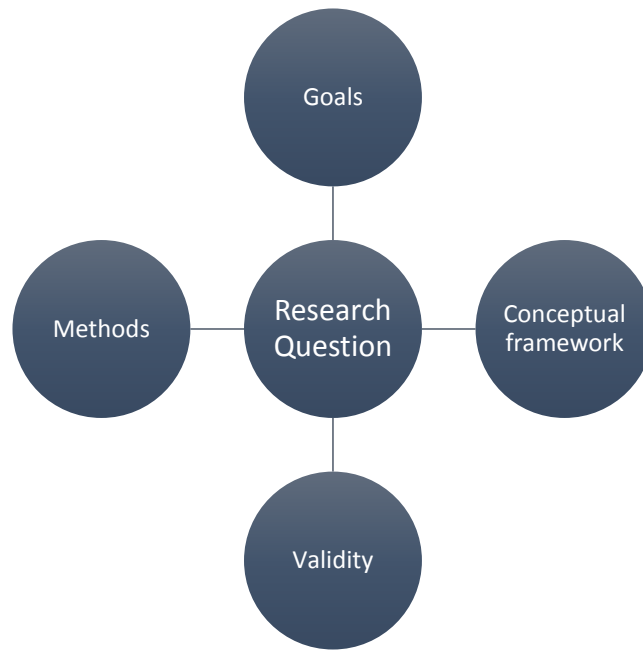


Figure 4.1: An interactive model of realist research design (Maxwell, 2012, p.78)

Goals are the beliefs and values the researcher or research team bring to the study and according to Maxwell (2012b) these are important to realist design in that it lets the researcher ‘acknowledge’ their beliefs about social mechanisms so as to clarify their role within the process. Goals are linked closely with the conceptual framework and are associated with the personal experiences of the research team, and the existing empirical and policy literature. It is asking the question ‘what do you think is going on within the study’. Within this study the sequelae of stroke from both a professional and academic standpoint led to the observation that stroke is a ‘family affair’. Family caregivers are often ill prepared to manage the complex problems and post-discharge care needs of stroke patients (Hartke & King, 2002; King & Semik, 2006). Family caregiving is closely linked to the stroke patient’s physical, cognitive, and psychological recovery. But carers experience a sense of burden and depression, decline in physical and mental health, reduced quality of life, and isolation (Simon et al., 2009). Interventions targeted at family stroke carers have to date had only a limited impact on carer stress and burden (Brereton et al., 2007). Also, the literature has predominantly centred on the burden of stroke family care, but increasing interest is now focussing on the positives of caring for a relative,

leading to fostering resilience in carers. The interconnectedness of family carer and stroke survivor is also being recognised within the stroke research community and is beginning to advocate the use of dyad-based studies to articulate why some couples are resilient and others less so (McCarthy et al., 2011).

The research question within Maxwell's (2012b) interactive model is iterative in nature and is connected to every component of the model. This study seeks to understand the mechanisms and contexts involved in the implementation of intervention programmes that target spousal carers of community stroke survivors. In so doing the study endeavours to understand the complex social processes occurring within a social system, and to identify causal factors that reside within social relationships and organisational structures. Therefore, a generative view of causation rather than a successionist view is needed to gain some understanding of the complexity surrounding intervention programmes. Interventions are 'theories' inserted in open, social systems that impinge on the way interventions are executed from that originally envisaged by policy makers and research team, to the professionals who put the intervention into operation, to the participants who take-up or reject it (Pawson et al., 2004). Explanations are sought regarding the factors underlying family stroke carer outcomes, and these explanations consider ways interventions are delivered and embedded within a programme, as well as the social and cultural conditions that are necessary for the programme to be delivered effectively to produce the outcomes. A realist evaluation approach involving the formulation of context, mechanism and outcome conjectures (CMOC) and the testing and refining of these explanations, will meet the aims of this study. The nature of the CMO propositions therefore frames the research strategies needed to seek the relevant evidence to support or refute the propositions.

4.4: Dyadic Interviewing

According to McCarthy, Lyons, and Powers, (2011) stroke rehabilitation research requires a change in its methodological approach, from investigating the family carer or the stroke survivor as discrete units, to a couple-based or

dyadic orientation. Becker and Useem, (1942) defined the dyad thus, “when intimate, face-to-face relations have persisted over a length of time sufficient for the establishment of a discernible pattern of interacting personalities” (p.13). A key component of this definition is the formation of couple inter-dependency over time, where a spouse's values and feelings are qualified through interpretation of their partner's attributes, and vice versa. McCarthy et al., (2011) identify several reasons for shifting focus to the interplay between stroke couples including the central role spouses have in stroke survivors' rehabilitation process, the emotional effects of 'being cared for' and the burden of caregiving, as well as the limited effectiveness of interventions targeted at stroke family carers. This approach is linked to the social-contextual model of psychological burden, including depression (Townsend, Miller, & Guo, 2001). The argument is that the social context produces and sustains psychological states through involvement in day-to-day roles and social systems. Within the context of the marriage relationship research has shown that the spouse's psychological state remains a significant predictor of the partner's symptom intensity, with changes in the mood of one partner predicting changes in the other (Berg Meegan & Deviney, 1998; Bookwala & Schulz, 2000; Townsend et al., 2001). Concurrent with the above argument is the idea that 'families' are increasingly defined by 'doing' family things rather than being a family' (Finch, 2007). This view of the family is associated with a set of activities derived from the social interaction of individuals within a context that moves sociological thinking from looking at the family as a ridged institution, to seeing the family as a fluid and diverse entity (Finch, 2007).

From the above literature, interventions dealing with the burden and stress of being a stroke family carer or stroke survivor ought to involve a developmental and contextual approach (Berg & Upchurch, 2007). The underlying framework that links the coping process following a stroke requires the collaborative efforts of the couple in the dyadic relationship. The model proposed by Berg and Upchurch, (2007) as depicted in Figure 4.1, sees the interplay between the dyad as they appraise and adjust to the problems faced together rather than observed at individual level. This interplay is influenced by several social-

contextual processes such as culture and gender, to the quality of the couple relationship and the specifics of the chronic illness (Berg & Upchurch, 2007; Figure 4.1). This perspective influences the focus of interventions to alleviate psychological stress; increasingly there is evidence from cancer and cardiovascular couple interventions that show targeting of psycho-educational support at the dyad had greater benefits for both parties (Scott, Halford, & Ward, 2004). Perceiving interventions as couple orientated has reinforced awareness of sustaining resilience in the coping process (Baik & Adams, 2011). The 'couple-hood' (Hellstrom, Nolan, & Lundh, 2007) and 'enrichment' (Cartwright, Archbold, Stewart, & Limandri, 1994) approaches have been advanced as ways of enhancing interventions with family caregiving.

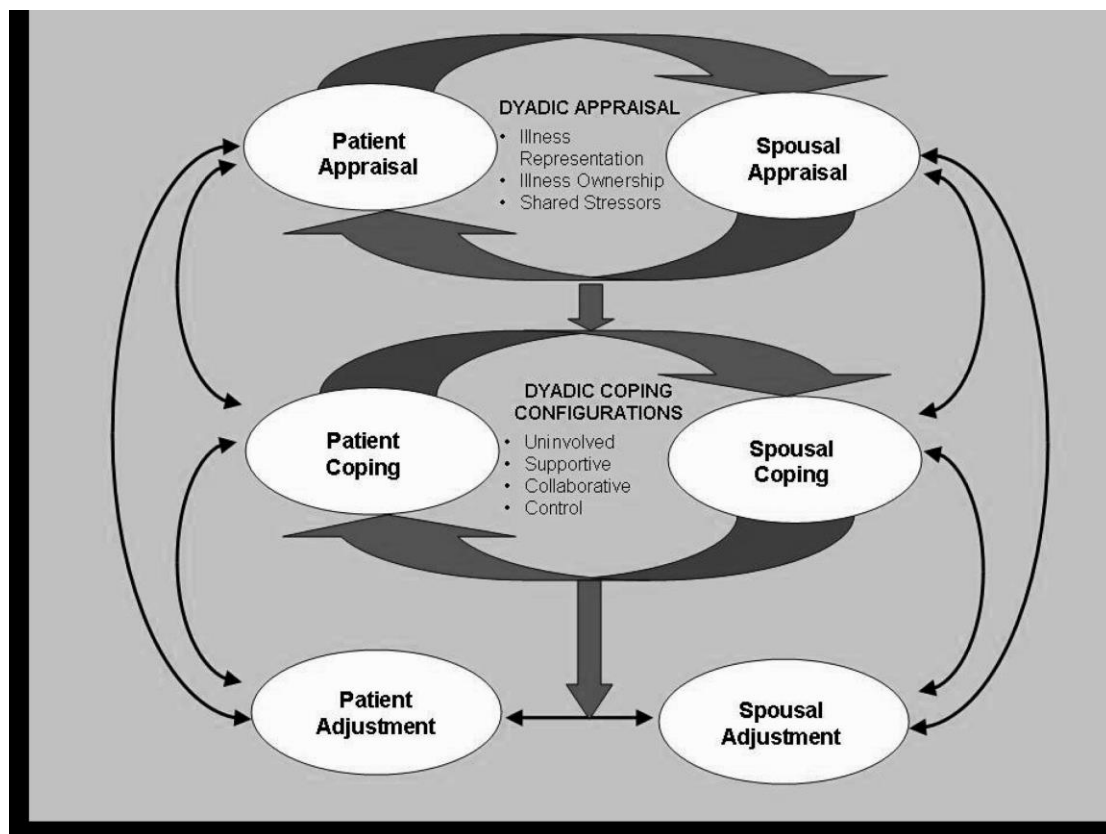


Figure 4.2: Dyadic appraisal, coping, and adjustment in couples (Berg & Upchurch, 2007, p.933)

The 'couple-hood' perspective relates to the process by which couples try to maintain their relationship together (Hellstrom et al., 2007). In their qualitative study of dementia families, Hellstrom et al., (2007) outlined couple-hood as

containing elements of resilience and reciprocity. Resilience manifested through 'making the best of it' that comprised of 'life's little pleasures; searching for the positives; and living for today' (p394). Reciprocity was conceived 'as talking things through' and 'being affectionate and appreciative' (p.393). Enrichment as described by Cartwright et al., (1994) is the provision of meaning within caregiving/receiving activities, and located in the shared symbolism of mutual day-to-day activities. As Berg & Upchurch (2007) state, couples who endure 'chronic illness' are affected by social and cultural factors, but also by more personal issues such as their relationship with their partner, and the ways they relate towards each other. Given this perspective a couple-orientated approach to stroke family intervention becomes necessary.

4.5: Types of dyadic research processes

Allan, (1980) identified the main benefit of joint interviews between married couples as an account of the interactive relationship between the couple. This is not just non-verbal observations, but the joint narrative descriptions that arise through the interaction. Dyadic research designs are suitable for reviewing important concepts such as 'similarity, discrepancy, mutuality, complementarity, and reciprocity' (Maguire, 1999, p.214). According to Thompson and Walker, (1982) the dyad or relationship can be the unit of analysis at any level of the research process from conceptualizing the problem through methods used, to analysis and interpretation, they suggest the following as essential characteristics of dyadic research:

1. The problem is conceptualized at the level of the relationship – the pattern between two people.
2. The sample of participants is contingent upon involvement in representative relationships, although one or both members may be chosen as informants.
3. Regarding measurement, one or both members of a relationship may be assessed on self, other, and/or the relationship.
4. The analysis is interpersonal or inter-dyadic, providing information about the pattern between individuals or between relationships.

5. Interpretations of the data and implications refer to the relationship between two people. In other words, all components of study must be at the level of the dyad. (p.890)

Essentially the research study should be 'relationship' focused, so that patterned interdependence can be described, and is best attained through interviews that enable discussion.

In the literature, there have been several variants of studies purporting to use dyadic research and include the following formats (Thompson & Walker, 1982; Valentine, 1999; Wittenborn, Dolbin-MacNab, & Keiley, 2013):

- Seeing each partner separately then compare transcripts
- Interview partners separately, then reflect each partner's views in subsequent individual interviews
- Interview each partner separately, then as a couple
- Conjoint interviews, then interview the partners' separately
- Conjoint interviews only

As can be seen, the broad range of approaches to the concept of dyadic research delivers different strengths and weaknesses. The advantage of interviewing the couple separately lies in the level of confidentiality that can be attained so enabling the partners to talk without constraint, particularly if it is a sensitive issue or one partner is dominant within the relationship. However, apart from the first and final technique, there is always an issue of maintaining confidentiality for the interviewer, how revealing should they be about what was discussed? Likewise, if the participants know that the interviewer will be reflecting issues back to the partner, then there may be an illusion of frankness that is not justified (Forbat & Henderson, 2003).

According to Bjornholt and Farstad, (2012) there are distinct advantages to conjoint interviewing that outweigh their disadvantages. One advantage is the "cueing phenomenon" (p.5) that occurs when discussion by one partner triggers

an interchange between the couple. Bjornholt and Farstad (2012) question the assumptions that the couple will attempt to present a united front to the interviewer, or that one partner will dominate the discussion. They do not discount that there can be a power differentiation that can bias a dyadic interview, but in their experience this is rarely the case, with partner's willing to discuss disagreements.

4.6: Recruitment and Ethical considerations

Researchers have a responsibility to carry out their studies to an ethical standard, following guidelines articulated by ESRC research ethics framework (www.esrc.ac.uk), professional organisations (NMC, 2016) and the National Research Ethics Service (NRES), which is represented by the Local Health Board ethics committee. Recruitment of participants to the initial couple interviews was achieved through a project that was investigating 'sources of support after stroke' funded by the North Wales Research Committee with Professor Christopher Burton as principal investigator. This project had already gained ethical approval on 12th January 2009 (REC: 08/WNo01/44) and the couple interviews were an amendment to the protocol receiving approval on 19th June 2009.

Ethical practice entails priority given to participant wellbeing both physical and psychological (Green & Thorogood, 2009). The four central principles of medical ethical conduct revolve around the concepts of autonomy, non-maleficence, beneficence and justice (Page, 2012). The principle of autonomy is based on respect for the person and their capacity for making decisions about their life. Within health research, autonomy is achieved through informed consent, and in this thesis separate participant information sheet for both stroke survivor and family carer were distributed to prospective couples, together with separate consent forms (appendices: 4.1, 4.2, 4.3, 4.4). For these couple interviews both parties had to agree to be interviewed together. As a further safeguard (also evident in the longitudinal interviews described in chapter five) a model of continuous consent was enacted rather than viewing consent as a once only occurrence.

The principle of beneficence requires, other things being equal, to do good, or what will further the patient's interest. The principle of non-maleficence is to avoid harm to the patient or participant. Both principles rest on the fundamental importance of what is in the patient's or participant's interest (Page, 2012). Doing good and causing no harm to research participants requires researchers to think about the 'value' of undertaking such research, in-depth qualitative interviews with no obvious direct benefits. Gysels, Shipman, and Higginson, (2008) conducted a study with 104 participants into the effects of qualitative interviewing with families where a patient was undergoing palliative care. Their results showed that the participants had not been affected by the interviewing process, indeed some felt more empowered (p.4). Similarly, Pleschberger et al., (2011) reporting on six European qualitative studies using interviews with older people at end-of-life, showed that participants and their carers valued the research encounter. The value of this thesis can be assessed if the rationale for using realist evaluation produces representative mechanisms that can feed back into interventions that may show greater effectiveness in relieving stroke family carer burden.

According to a literature review carried out by Allmark et al., (2009) there are specific issues related to dyadic interviewing in relation to confidentiality if the researcher probes into areas that may expose privacy that one interviewee would prefer to keep private. Within this study questions were asked that was inclusive of both parties and the interviewer was sensitive to the replies given by the couple.

An issue raised by Pleschberger et al., (2011) was the need for reciprocity felt by the researcher towards their participants. Part of this mutuality was to allow the participants to tell their story, and be allowed an emotional release, which then can impact on the researcher. (Dickson-Swift, James, Kippen, & Liamputtong, 2007) explored the issues researchers faced doing qualitative research on sensitive topics, through interviews with 30 qualitative health researchers. Using a grounded theory approach, they developed several

themes including, rapport development, use of researcher self-disclosure, listening to untold stories, feelings of guilt and vulnerability, leaving the research relationship and researcher exhaustion. In their discussion, Dickson-Swift et al., (2007) recommend that researchers should have a formal mechanism to support their practice, within this study such support was provided by the monthly supervisory process. Allmark et al., (2009) in a literature review of ethical issues within in-depth interviewing highlighted a problem pertinent to this study, the 'dual role' issue, as the researcher is also an experienced nurse lecturer, a fact known to the participants. Conflict can exist between adherence to a code of professional conduct (NMC, 2016) and the role of researcher. This conflict was debated within the supervisory process, with the overall principle of 'doing no harm' uppermost in the researcher's mind. Also within the participant information sheet and reiterated verbally to the participants was the caveat that if the researcher felt there were any serious issues of harm then the participant's medical general practitioner would be informed. (Page, 2012) to this 'dual role' issue is that of therapeutic support, as the researcher is not qualified as a therapist this would breach NMC (2016) code of professional practice. The role of therapist and being open to the participants' concerns may be conceptually and practically difficult to achieve, but the researcher's experience in nursing and education did offer some proficiency in recognising a move into a therapeutic role that could then be addressed. Following each interview, literature would be left with the participants specifying the local RELATE centre and Stroke Association details if the couple felt they required more support. Tillman-Healy, (2003) observed that to carry out successful in-depth interviews the researcher needs to develop 'counselling' like skills, especially active listening.

The final ethical principle is that of justice (Page, 2012), which requires that health care practitioners and society in general treat cases equally. For the present study justice rested on the concepts of confidentiality and anonymity. Within this study participants' digital audio recordings were wiped clean once transcribed, with participants being anonymised within the transcripts, with the use of pseudonyms within written reports (Richards & Schwartz, 2002). All

participant data were kept and analysed on a password protected desktop computer and locked filing cabinet in a locked office. No data were kept on laptop computers or portable storage devices. Within the principle of justice or equality, Hughes, Hope, Reader, and Rice, (2002) have studied the ethical dilemmas of family carers of dementia sufferers, and concluded that family carer opinion on ethical issues can conflict with that of professionals, and arise out of the relational context between care-recipient and family carer, issues such as feelings of guilt, reciprocity, and best interests. Some of Hughes et al., (2002) sample of family carers were conflicted in what was deemed best interest for the care-recipient and what was in their best interest, yet others stated that their spouse's best interest coincided with their own. This study highlights the added ethical complexity that is generated when dyads are the focus of the research.

Recruitment for the couple interviews was taken from an approved larger study on stroke that included Public and Patient Involvement (PPI) as advised by the 'Research Governance Framework for Health and Social Care for Wales' (Welsh Assembly Government, 2009). A purposive sampling strategy (Patton, 2002) was taken to obtain couples who had a first-time stroke six months previously. Six couple participants agreed to the in-depth qualitative interview, and their description is given in Table 4.1 (* couples continuing with subsequent QLI). Convention has now moved to the use of pseudonyms to represent participants in qualitative research, rather than numerical differentiation (Braun & Clarke, 2006).

Couples (SS=Stroke Survivor)	Ages at time of stroke	Barthel Score (range 0-20: lower scores indicating increased disability)	FAD Score (range 1-4: scores 1-2 unproblematic family functioning. Scores 3-4 problematic)
Couple 1* • Mary (SS) • John	74 73	18	1.5
Couple 2 • Ian (SS)	35 30	15	2

• Katie			
Couple 3*			
• Martha (SS)	86	14	2
• Jim	85		
Couple 4			
5. Maggie (SS)	45	16	2
6. David	48		
Couple 5*			
• Dennis (SS)	79	13	3
• Helen	75		
Couple 6			
• Mark (SS)	69	15	2
• Sally	66		

Table 4.2: Description of preliminary couple participants

Potential participants were recruited through the larger study, by the research assistant charged with data collection. Each couple were asked if they would like to proceed to another interview conducted by a nurse lecturer looking at how families cope with stroke, if they agreed they were also asked to fill in the short version of the Family Assessment Device - General Functioning Scale (FAD) (Ryan et al., 2005) (appendix 4.5). The names and addresses, with the Barthel and FAD scores were passed on to the researcher who then sent out the requisite participant information sheets and consent forms to both stroke survivor and family carer, together with a stamped return envelope. Following receipt of the consent forms, a telephone call was made to arrange a date and time for the interview. As all participants wanted the interview to be conducted in their own home, the University's handbook for 'social and community based field research' was followed to ensure safe practice

In semi-structured interviewing "...the researcher sets the agenda in terms of topic covered, but the interviewee's responses determine the kinds of information produced about those topics." (Green & Thorogood, 2009, p.94). The interviews were organised around a critical core set of key themes (appendix 4.6), which were developed from the critical literature review (chapter

one) and the Family Assessment Device (FAD) (Ryan, et al., 2005). However, this structure allowed for flexibility to respond to issues raised by participants. Probes therefore were responsive to the participants' own issues, maintaining active listening and empathy (Green & Thorogood, 2009). Throughout the interviews the researcher was aware of the sensitive nature of the topic area, that of family relationships. The researcher positioned himself as someone whose background was a health care professional, so bound by professional ethics of confidentiality. These factors, together with the researcher's age relative to the couples, shaped the data obtained and was reflexively incorporated into subsequent analysis. The interview guide was designed around the Family Assessment Device (FAD), and was researcher determined, the interview was much more conversational in practice. This was partly due to researcher anxiety in making a 'good' impression and needing to build trust, so allowing participants space and permission to discuss their perspectives as to how the stroke had affected them. In retrospect, these initial couple interviews would have benefitted from a less structured approach, with general questions such as: 'can you tell me what the last few months have been like for you?', which could then be built upon leading onto topic areas pertaining to the Family Assessment Device, rather than the specificity implied in appendix 4.6 (Green & Thorogood, 2009)

Following arrival at the participants' home, the researcher accepted a cup of tea and asked if they were happy to go ahead with the interview. Restatement of the confidentiality of the digital audio-recording and subsequent transcriptions was given, together with a copy of their signed consent forms, and reiteration that they could withdraw from the interview at any point. The initial question was to ask the couple about events leading up to the stroke and subsequent rehabilitation. There was little realisation that this question unleashed a large amount of narrative by all the couples, "...they wanted to tell their story..." Listening to the digital recordings it was evident that there was a need by the researcher to have limited their responses to the question; however, the judgement was to allow this latitude to enhance rapport and future participation.

Following completion of the interview, contact addresses were given for the local RELATE service and Stroke Association details. After each interview the researcher allowed enough time to write notes that described feelings about the interview, and the couple, noting down aspects of the interview that would be useful to pursue through listening to the audio-recording. These notes were more akin to a research diary rather than field notes in ethnographic research, although the researcher applied the distinctions articulated by (Silverman, 2000, p.142), to diary completion as detailed below:

- Short notes at the time (these were one or two words scribbled on the interview guide)
- Expanded notes made as soon as possible after each field session
- Fieldwork journal to record problems and ideas
- Provisional running record of analysis and interpretation
- The use of a research diary proved valuable and the researcher went through two A5 note books during the study, and provided a reflective account of the 'highs and lows' of the process.

Each couple interview lasted 60 to 90 minutes, and transcribed verbatim by a confidential contracted transcription service based in North West England. The researcher also listened and re-listened to each audio-recording taking detailed notes. Transcriptions were inputted into Atlas.ti (v.6), a qualitative data analysis software manager (Friese, 2012). There is debate about the use of computerised software in qualitative analysis. Arguments range from strengths that include quick searching for codes in large data sets, facilitate visualisation leading to better theoretical development; to limitations such as 'distancing' from the data (less immersion) and over coding, using features of the programme that are not required for the study aims (Braun & Clarke, 2013). In practice the use of computer assisted analysis relies on the interpretative processes of the researcher, and requires them to take responsibility in their judicious use of the tool.

4.7 Analytical framework

This part of the study was not testing CCMOs but collecting data to begin the process of developing programme theories for support of families affected by stroke. However, there is a debate about how qualitative interviews should be analysed in a realist framework (Emmel, 2013). Maxwell, (2012) discusses the realist perspective to qualitative analysis by linking two analytical procedures used in qualitative research, categorising and connecting approaches. Categorisation is the most common form of qualitative analysis and is the familiar coding process (Braun & Clarke, 2013), whilst connecting approaches look for the significance of the narrative communicated by the data. Categorisation looks for similarities in the data set independent of space and time associations, whilst connecting (contiguity) strategies assume "...a real connection or association that is not a matter of similarity." (Maxwell, 2012, p.109). The significance of Maxwell's (2012) argument is that coding data disassociates the context in that the themes generated from the codes are 'connected' by the categories rather than the data. Connecting approaches such as narrative analysis are: "...less concerned with the structure of the text and more with the meaning of that text for the participant" (p.116). However, connecting strategies can have their problems in that it can limit the ways a text can be framed, as the narrative is linked in a linear, interviewee perspective. Within this data set, analysis included categorisation using the thematic analysis approach espoused by Braun and Clarke (2006).

4.8: Couple pen-portraits

To provide the reader with a sense of each couple's background, pen-portraits are presented. The first named of the couple pairs is the stroke survivor, and those assigned an asterisk consented to the longitudinal interviews.

Mary and John*

Mary and John moved into the area some 30 years ago and live in a bungalow near the coast, they had been married for over 40 years. Mary's stroke began when she was out shopping with her dropping her purse and carrier bag several times. She felt 'funny' and needed to get out of the shop back to her car where

she sat for 10 minutes and then drove home but said "...it was the hardest drive I ever...had to concentrate the whole way...". Her husband phoned the GP who suspected a stroke and sent her to hospital, by this stage Mary was unable to walk but was fully conscious. Mary stayed in hospital for 4 days over a weekend so that she could have a scan before coming home. On discharge Mary's Barthel score was 18, and she was back driving seven months following the stroke and discharged from consultant care. However, symptoms persisted for Mary in that her memory was not as good post-stroke and she was susceptible to mood swings. At time of first interview Mary was beginning to feel central post-stroke pain. Mary and John have two children and several grandchildren who live some distance away, but have a supportive network that includes the local church community. Mary and John continued to be a part of the study, but when I returned to commence the longitudinal interviews, Mary had suffered another much more severe stroke with a Barthel score of 5.

Ian and Katie

Ian and Katie were the youngest couple (35 and 30 years). Ian's Barthel score was 15, needing help to go upstairs and a walking stick to maintain balance. Until his stroke Ian was in full time employment as a driver for a local builder's merchant, and his return to work was not secured, but his employers had kept his job open. Katie was pursuing every avenue to secure financial allowances, mainly through the Citizens Advice Bureau (CAB). Ian's main issue, six months' post-stroke was his eyesight, as he had vision field loss in both eyes, he was also depressed and suffered cognitive lapses such as forgetting he had put on a frying pan etc. The couple had a five-year-old daughter and Katie was expecting twins in about seven months. They had been a couple since late teens but were planning to make it 'official' in a few months' time, before the birth. Unfortunately, I could not include Ian and Katie in the longitudinal interviews as I lost touch with them. They had moved to a new house and GP surgery leaving no forwarding details.

Martha and Jim*

Martha and Jim were the oldest couple (86 and 85 years) with Martha having a Barthel score of 14, caused by some bladder incontinence and balance issues. The stroke happened on a Saturday with Martha relating how "...I remember Jim talking to me but I couldn't tell what he was saying it was a foreign language..." Martha became unconscious and Jim called the 'out of hours' service who sent an ambulance that brought her into hospital where she was very drowsy for several days but was discharged eight days later. Again Martha related she had memory problems that were slowly improving, but still 'felt emotional' from time to time. The couple lived in a bungalow in an isolated area about four miles from the nearest shop, their two children and grandchildren lived about a four hour drive away, with their daughter spending long periods in France. Jim had had a myocardial infarction about 3 years previously and Martha was his main carer, as became obvious in the longitudinal interviews Jim had dementia and at each interview his condition worsened which was a source of anxiety for Martha.

Maggie and David

Again, a young couple, with Maggie being 45 years when she had her stroke (Barthel score of 16). The couple ran a Bed and Breakfast establishment in a popular coastal town, and had a 12-year-old son. Maggie related how the stroke manifested itself, "...oh I said, my leg's falling and then I just said I must have leaned on something and had a trapped nerve...oh my arm's funny as well and I then got very confused..." Following 5 days in hospital Maggie was discharged, her present symptoms include memory problems, and anxiety, so much so that the couple were thinking of selling the business and moving back to England to be nearer their families. When contacted to ask consent for the longitudinal interviews Maggie declined further participation.

Dennis and Helen*

Dennis had a Barthel score of 13, mainly due to mobility and incontinence problems. This couple were the only ones to return a problematic family function score of 3, indicating some family tensions. It became apparent that these

tensions were due to Dennis's change of personality following his stroke in that he could become 'abusive' towards his wife and family, on occasions. The couple had a daughter who lived close by and was very supportive of her mother.

Mark and Sally

The final couple also lived in a rural village with a pub and general store. Mark and Sally (69 and 66 years) had lived in the area for about 12 years following Mark's retirement. Mark's recollection of events was of his wife going shopping and he having a shower in which he began to feel unwell, his wife on her return asked him several questions such as his age: "...and I couldn't believe it that I was that old I thought I was 30...and I had lost about four hours from when the GP came and when I went to hospital". Seven months' post-stroke Mark continued to have cognitive problems with problem solving and memory. The couple declined participation in the longitudinal interviews, partly due to them moving back to be nearer their daughter in England.

4.8.1: Researcher experiences

As an experienced nurse lecturer and health visitor communicating with families rather than patients, I was comfortable interviewing these participants in their own homes, which also provided a better insight into their circumstances. However, there are differences, as a health professional you are providing a service for the recipient, whereas in research the participants are assisting the researcher through supplying information and knowledge without necessarily any direct benefit for themselves. Also as (Jack, 2008) discusses nurse researchers face role conflict as participants' may turn the interview into a clinical or counselling session, and recommends that the nurse-researcher take a reflexive stance that attempts to identify possible biases.

The interviews were based on the McMaster model of family therapy, and there were 'delicate' questions about the relationship between the couples that I needed to frame as sensitively as I could, but this also heightened my trepidation. I was also conscious that I wanted to maintain the couples' 'on side'

so that they might agree to continued participation in subsequent interviews. All the couples were relatively open about their relationship, and revealed much about their life together through the course of the interview. For some of the couples' I felt that 'talking' about the experience was cathartic in that they also had an opportunity to reflect back over the past months. The joint interview approach did highlight some aspects of the stroke experience that surprised each partner, usually in a positive way. An example was the gratitude the stroke survivor felt for the support of their spouse throughout. I also felt privileged that they were willing to be so forthcoming and a real attachment was built between two of the couples who continued with the longitudinal interviews. The only couple where there was tension was Dennis and Helen, and I was relieved that this was not my first interview. The interview was not as free flowing as the others, resulting in greater interviewer discourse. I was therefore surprised they consented to the longitudinal interviews.

The interviews with the two couples under 65 years challenged my own stereotype of who suffers from a stroke. I was aware of the statistics (30% under 65 years have a stroke) but these interviews showed the different problems they experienced, and I was disappointed they could not continue in the longitudinal study.

A further issue that I reflected upon related to my age as interviewer rather than my professional background. I was over 55 years of age at the time of these interviews and I speculated if this had a positive or negative impact on the participants' as compared to a researcher in their mid-twenties? The literature offers little in relation to this age discrepancy question, but does discuss issues related to interviewer and participant gender or race; suggesting that researcher and participants should share attributes to improve the quality of the data collection (Lumsden, 2013). This is particularly apposite in this study as sensitive issues surrounding couple relationships would be discussed, so having a narrower age gap between the interviewer and the older couples enabled both parties to 'understand' the historical context. Indeed, following the interviews and listening to the recordings, I felt I may have let the couples' 'go

on' too much about their experiences, and not reign them in sooner during the interview. However, when detailed analysis was undertaken the very richness of the data were apparent.

In summary, the couples in the initial interviews were a heterogeneous group, which impacted on the way the interviews were conducted, letting them tell their own story allowed the narrative to flow, but I was appreciative of the semi-structured interview format that enabled me to adhere to the research questions. Some of the limitations of the methodology will be considered in the discussion chapter.

4.9: Initial coding using the Family Assessment Device (FAD)

To become conversant with the dataset, the transcriptions were read several times. The initial coding frame centred on the six FAD dimensions (problem solving, communication, roles, affective responsiveness, affective involvement, and behavioural control). In the McMaster model these six dimensions represent key areas of family functioning for both 'normal' and 'distressed' families. Data from each transcript was divided into a unit of analysis based on the six FAD dimensions, these data segments were then assigned a code that reflected one of the six dimensions. Following several iterative stages and consultation with supervisors the codes were refined until they ascribed the dimension (appendix 4.7).

4.9.1: Analysis

'Following data coding into meaningful groups based on the FAD dimensions (appendix 4.7), this data set was used to identify relevant patterns across the data. This stage involved categorisation of the different codes into potential themes, and collating the relevant coded data extracts within the identified themes, so that different codes were combined to form an overarching theme and sub-themes (Figure 4.3). This process was aided through the use of mind-maps to organise themes into theme-piles. Through an iterative process and

discussion with supervisors the themes were revised several times, resulting in the final thematic map represented in Figure 4.3 (Braun & Clarke, 2013).

4.9.2: Strengths and limitations of the FAD coding frame

According to Braun and Clarke (2013) ‘...data do not speak for themselves; you speak for the data. That is what analysis is.’ (p254). Though the use of the six FAD dimensions’ were convenient in the initial phase of coding the transcript data, their development into themes proved more restrictive. Because of this constraint, the development of the themes became increasingly iterative, so that they adequately captured the data. The transcripts were the ‘voice’ of the couples, and as such needed to be embodied in the analysis, requiring greater adaptableness in theme development.

4.10: Descriptions of themes

According to Braun and Clarke, (2013) themes have to have a clear focus, scope and purpose, “...providing a rich, coherent and meaningful picture of dominant patterns in the data...” (p.249). The overarching theme that developed from the data is that of ‘Reconstruction’ and contained two sub-themes, ‘Identity’ and ‘Managing Relationships’, with a visual representation provided in Figure 4.3, that includes section sub-headings to aid clarity.

4.11: Reconstruction

Reconstruction is the rebuilding of family life following the stroke. Reconstruction is a persistent theme within the chronic illness and disability literature, including stroke (Bury, 1982, 1991; Ellis-Hill & Horn, 2000; Greenwood et al., 2010; Jones, Mackenzie, Greenwood, Atkins, & Habibi, 2012; Rolland, 1994b). The couples had to adapt all aspects of their life to reshape the way they interacted with their partner and wider social world. As these interviews were conducted about six or seven-months post-stroke, the success of reconstruction depended on differing contexts such as age, gender, and quality of marital relationships. Reconstruction is also a process, which is not linear or predictable and does not result in the exact same pre-stroke life,

but a reconfigured or repaired life (Brereton et al., 2007). The purpose of reconstruction is to try and establish a sense of meaning and coherence again following the shattering stroke event. The main theme of reconstruction had two distinct but related sub-themes that the couples had to reconfigure to repair their life narrative.

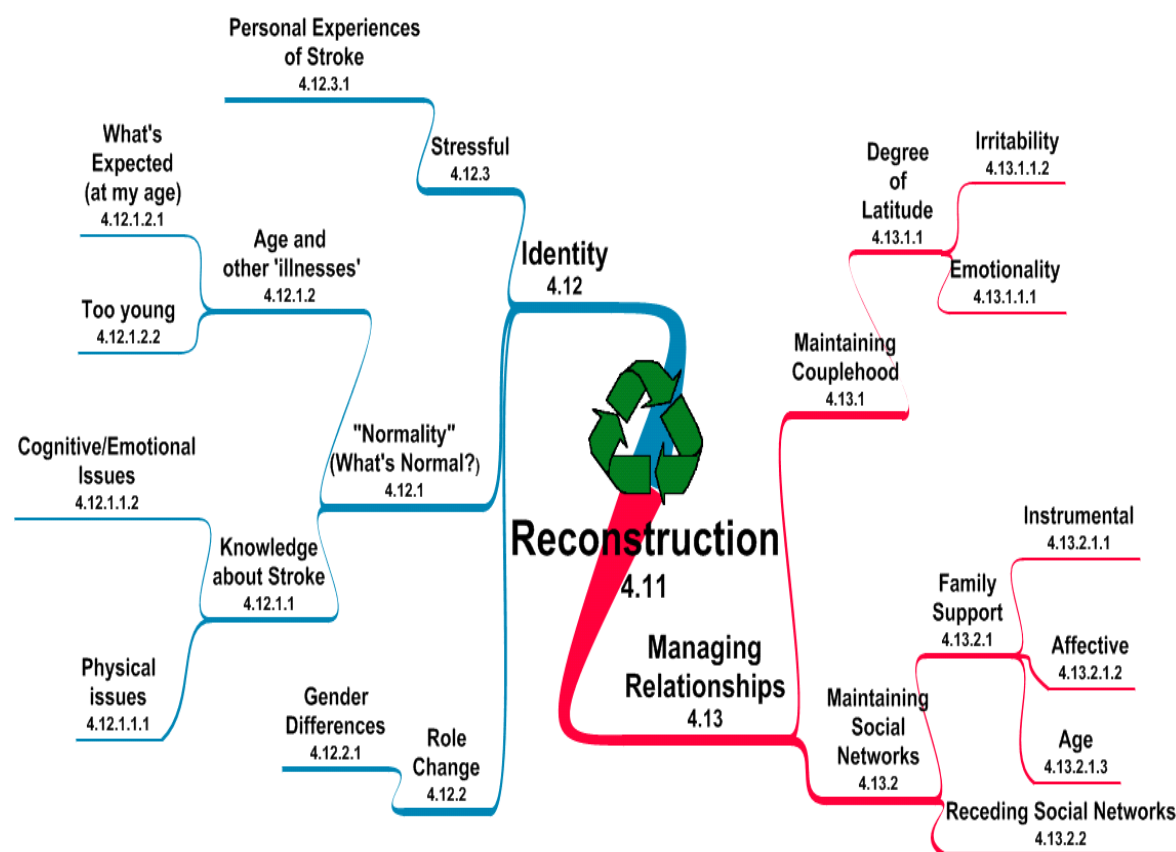


Figure 4.3: Thematic map of the overarching themes for initial couple interviews

4.12: Identity

Because of the sudden onset of stroke the couples had no time to prepare for the changes it brought to their life together. Coming to terms with the changes imposed by the stroke affects the way the stroke survivor and spouse constitute meaning and purpose in life. Identity is a concept that defines the idea of self as distinct from other objects in the world (Burkitt, 1991). It is a key psychosocial concept for maintaining our integrity as a person that can be disrupted through changes in social roles, physical and mental fitness, as happens in a stroke, so the person who loses this continuity of the self needs to regain a sense of self

in order to maintain stability as a person (Charmaz, 1994). The loss of previous identity is perhaps obvious for the stroke survivor who struggles with changed physical, emotional and cognitive deficits, but identity perception of the spousal carer is also affected (Hole, Stubbs, Roskell, & Soundy, 2014). As well as individual identity relating to the stroke survivor and spousal carer, long-term partnerships also have a sense of themselves as a couple, seeing the spouse as part of the self (Badr et al, 2007). Couple identity involves seeing the relationship between the two people being incorporated into self-identity (Acitelli et al, 1999). The first descriptor for 'Identity' within the data analysis is that of 'normality' and is characterised by 'age', 'knowledge of stroke', and 'other illnesses'

4.12.1: Normality (what's normal)

'Normality' or 'what's normal' relates to the need of the couples' to assess the stroke in terms of what is 'normal' experiences for a stroke survivor, in order for them to compartmentalise the stroke, in an attempt to normalise their life. It consists of inter-related categories, knowledge about stroke, issues around age and the ageing process, and locating problems to other illnesses or conditions. Seeking normality was an attempt to keep the stroke experience as just one facet of an otherwise intact self.

4.12.1.1: Knowledge about Stroke

4.12.1.1.1: Physical issues

All the interviews with the couples began with a description of how they experienced the first symptoms of their stroke. In all the stories, there was little realisation what was happening as Mary relates:

"...if the old (grocer shop) open I only want a few vegetables and a bit of fruit, if I can get a parking spot fairly close I'll pop in there and save time. So I went in and as I walked into the shop I felt peculiar and I didn't realise it but I'd obviously lost control of holding, I dropped my purse twice, I dropped something like that and looking back I had to laugh because

the people behind me, I think they must have thought I was drunk, they didn't know me at the shop, you know, and there was a lady behind picking up my glove and my purse and then I dropped...I couldn't...I put in the collie quite easily because it's quite big and in the end I was thinking I'm feeling...I've got to get out of here, I won't pick up the apples, I'll take a bag, dropped the bag of apples, you know, and in the end somebody behind me said I'll take your basket to the little cashier thing and the man who happened to be sitting down, who owns the place, said 'Are you alright? Shall I see you to the car?' and I said, 'No, it's just round the corner, I'll be alright when I get outside' and I went round the corner to the little car park which is by the bus stop, you know, it wasn't very far. Sat in the car, now I think I probably sat in for 10 minutes but I have no real idea. I sat there, felt a bit better and drove home but it was the hardest drive I've ever - I mean I concentrated all the way home..." (Mary)

Following this episode, Mary's husband, John phoned the GP who asked her to be brought down to the surgery where he suspected a stroke. However, following consultation he said for them to go back home and if Mary experienced worsening of her condition then they should go into hospital.

"...I was slurring my speech as well, I don't know, you don't know what you're doing yourself you see. He (John) rang the doctor and the doctor said, 'Bring her down', I went down and I'd had a report coming out of the doctors from people who've said your feet were going all over the place Mary but the doctor said I think you've had a stroke and you're getting help because in fact I was still going, you see, he said if it gets any worse, Friday afternoon of course, get in touch and get to the hospital. By the evening it was getting worse, by the time I

got back he (John) were literally lifting me around weren't you, I don't think I could walk..." (Mary)

It was later that evening that Mary went into hospital.

Ian was another stroke survivor whose 'symptoms' lasted for about two months, complicated by pneumonia, before he went into hospital as an emergency to discover he had had his first stroke before Christmas, and it was now February:

"Yeah, just this overwhelming sort of feeling, it's hard to explain, just like a vibration in the side of my head, I thought, what was that, you know, didn't really know. Then I came down didn't I and you said I looked white as a sheet, like something really strange has happened..."

"Yeah, he (GP) said, I'll send you for an eye test because, you know, there could be some sort of pressure on your brain or something which is causing visual problems, I didn't really think too much of it apart from this continued tiredness which continued, you know, day after day, I was in work and...I was driving and I kept having to pull over, you know, every three quarters of an hour, every hour and just close my eyes and drift off to sleep and I couldn't understand what was wrong with me...I went back on the 5th of February to see him again and which I saw another doctor, the woman doctor said she was going to give you a blood test for the swelling on the brain...Yeah, because she assumed there was some sort of, because it was an optical problem, she assumed that's that what it'd be. And then I got pneumonia...Yeah, and I said, I think, you know, she said, oh you've possibly got a chest infection, done an x-ray, yeah...She said, yeah, you've got pneumonia come back and get more antibiotics..."

“...I was, you know, vomiting and horrible illness. Went back and got antibiotics, came back here and I said, I need to go back to bed because I’m still tired, got ready to go to bed and then bang, this huge seething pain and this time boom, a light went off, this upper vision completely went above so peripheral vision all above and down this side, down the right hand side completely. And then all the colours changes, the contrast, so it’s as if somebody had, as if now there was a bright light in here and somebody switched that off and all you’ve got now is natural light so it was like that, all the colours changed, they all dulled down and then the thing, and then I just came and that’s what...”

“...I went to the hospital, I was confused in the hospital. And they basically just said, right, they sent me straight for a scan on my brain and they basically just gave me aspirin, put a blanket over me and that was it...It showed I had had a stroke in the December and if it had been treated then...” (Ian)

All the couples had been discharged from stroke consultant care at six months, except for Ian who was under the management of an eye specialist. All couples reported that the GP was their main source for continuing treatment and advice. It became apparent that the couples were vague in their knowledge of the effects of stroke in the longer term. This vagueness related to physical matters and more especially cognitive/emotional side-effects. An example is Mary who in the past three weeks had begun to suffer quite severe central post-stroke pain that is neuropathic in origin (Kumar et al, 2009), but the couple did not link this to a stroke side-effect:

“And now of course I’ve got this burning pain as well which is not helping because, you know, it’s sort of, you know...so that’s depressing” (Mary)

4.12.1.1.2: Cognitive and emotional issues

Little recognition by health and social care professional was given to emotional lability, as Martha commented that neither the GP nor other health professionals she contacted noticed her emotional state:

“The emotional side came into it, when the man from the stroke club (Stroke Association) came at first, he came in and he hadn’t been in many minutes and he said, oh dear you’ve got a weepy eye haven’t you? Now nobody else noticed it but he did and I said, yes, but not many people have noticed that and he said, no people don’t, but I’m trained to look, you see. So he could see that. Now it doesn’t happen very often now but when I first came home I was very conscious of it, you know. But it’s not being prepared for it...” (Martha)

This was clearly an issue for Martha and if there had been some education or advice it may have alleviated the distress. Similarly, Maggie and David were unaware of the symptoms leading to a stroke:

“Well we’d just been sat down in the flat hadn’t we? We’d got like a guest house full of people, we’d been sat in the flat, they’d all gone out and we were just having, I said I’ll get up for chips... about half eight, nine o’clock...”

...Yeah, and then I said, oh I said, my leg’s falling and then I just said it feels like I must have leaned on it and trapped a nerve or something. And then I said, oh my arm’s funny as well, so David had then called some friends who came down and then he called another friend because I began then to get a bit confused and he rang them as well...” (David)

A further issue was the limited extent the spouse was incorporated into any discussion related to the stroke survivor's condition and management as Sally intimates below:

“When he actually had the stroke, when he was in hospital and as I say was in this very confused state and he kept crying all the time, breaking down and crying, which you know, obviously upset me, so I would've liked to have asked them, is this a normal thing with stroke patients, do they just keep breaking down all the time” (Sally)

A similar story was given by Katie:

“Yes, especially in the first few weeks, yes because you're a bit in the dark aren't you and as Ian was saying they only discussed it with him and I felt that it would've been helpful, as a carer to have known a bit more really” (Katie)

Jim was also not included in any dialog, he was prevented from attending a consultation with his wife at the local hospital for check-ups, principally for her diabetes, and as Jim was the driver it meant that Martha missed appointments. As became apparent in the subsequent longitudinal interviews Jim was becoming increasingly vulnerable to the effects of his worsening dementia:

Jim: Oh yes, I got, it was quite a little shock really because I just assumed they would accept us both, but they didn't include me so I thought, I'm only a chauffeur and not a...

Martha: But it's too far and you see Jim isn't very reliable to say, oh I'll go out into (town) for a couple of hours because he could forget where the place was, or, you know...

A further issue that emerged during this initial interview was the lack of overall psycho-educational input from the health and social care professionals. This may have been due to the relatively high Barthel scores, with the professionals concentrating efforts to those with greater functional disability? The participants were provided with literature but it was not read or only vaguely recalled:

There was something in the information pack because there was a section on it and we'd had a bit of a laugh really because I'd read it out, I said, eh, there's even a section on your sex life, so I said about that and David had worried that if we had sex that obviously it'd bring on another stroke or something ...I don't know where the pack is now" (Maggie)

Again, the limited attention placed on the literature and advice given in the hospital appeared to be due to the lack of specificity of the information, it was not tailored to their needs, or provided at the right time to be acted upon:

Mark: Oh yes, in hospital, they were very good and I had a lady that sat with me for some time in hospital saying...but when you read through it a lot of it, I didn't think it mattered to me, because I didn't...

Sally: You didn't think it didn't related to you because you weren't physically affected.

In summary, this lack of knowledge or vagueness as to the effects of stroke left the couples' attempting to explain their symptoms either in terms of the stroke

or other aspect of 'normal' life such as the ageing process and other 'illnesses' discussed below.

4.12.1.2: Age and 'other illnesses'

4.12.1.2.1: What's expected (at my age)

For the older couples (Mary/John, Martha/Jim, Dennis/Helen and Mark/Sally), normality was linked to age perception and co-morbidities that were present before the stroke. They connected the stroke as a part of growing old, with its associated ill-health and disability, requiring stoic acceptance. A common exhortation from all the participants, even the ones under 65 years related to memory and getting old, but recognising that the stroke had made memory loss more pronounced, as the following quote testify:

"Mark: But, I don't think the memory is the stroke that's, you know because I'm getting old.

Sally: It's the combination isn't it I think.

Mark: And not being able to go out in, you know for walks and things. I have got sluggish and I think if you keep physically, you're mentally more alert, if you're physically fit you become more mentally alert, so I'm just hoping that, you know, when it gets a bit warmer we can start going..."

'Mark' identified his memory failure to age and lack of general physical fitness, with the hope that if he can improve his fitness levels it will improve his memory. However, 'Sally' did recognise the effects of stroke on her husband's memory, but 'Mark' once again attempted to limit the impact of the stroke to downplay the effect of the stroke on his life as a possible means of retaining his identity.

4.12.1.2.2: Too young

Even though the two younger couples did refer to 'getting old' as an explanation for their cognitive deficits following the stroke, they also recognised the shock of getting a stroke at their age, thinking it is not 'normal' but a disease of the elderly, the following quote from Ian (35 years) demonstrates:

...When we'd got (to hospital), they showed me like a picture, a computer screen of a picture of my brain basically with two bits burnt out and they said, that's the first one and they said, this is the one you've just had now, you've had two TIAs and what's happened now is I'm completely blind peripherally above and down the side so I had a stroke at my age... it's too young" (Ian)

Again, Ian's perceptions of his age in relation to the stroke was reinforced by health care professionals' themselves, which may have stigmatised him as being 'abnormal', adding to his loss of confidence:

"Yeah, and they all say the same thing, you're too young, you shouldn't be here, you know, and you get that sort of attitude from the nurses and that which, wow, he's young" (Ian)

Maggie who was 45 years at the time of her stroke cites age and menopause as contributory factors for her memory problems (mild expressive aphasia):

"Interviewer: Yeah. How about your memory and so on, do you find that?"

Maggie: I was senile before [all laugh]. I can't say, my memory is worse but I can't say whether that's because of my age, it sounds really silly but I'm like 45 and I think I'm more

hormonal, probably that and certain things which are forgetful, I don't know whether it's anything to do with that or whether it's just my age. Things like that, I don't know, I haven't, I couldn't tell because of my age..." (Maggie)

Maggie and Ian both utilised the internet for further information, particularly looking for what was 'normal' in terms of stroke problems:

"Yeah, but I think the internet's a wonderful thing as well...look up on the internet and I look it up and luckily I'm not one of these that'd read into, I've got every symptom going or anything like that, I read into it, oh well it looks like a few people have had it like that and it's perfectly normal and all that" (Maggie)

4.12.2: Role change

A change in spousal roles following a stroke is well documented and was evident with the couples in these interviews (Smith et al, 2004). Social roles are the responsibilities and expectations people adopt in certain situations including family related tasks. When the stroke survivor is discharged from hospital these role descriptors can change and shift, with the stroke survivor relinquishing some of their previous role responsibilities and the spousal carer taking on-board these roles in addition to their other roles (Plank, Mazzoni, & Cavada, 2012). Of interest within the analysis described here is that of gender differences in the surrendering of certain roles and responsibilities.

4.12.2.1: Gender Differences

The clearest indication of the alterations that the couples' had to make was in their structural roles within the family the gendered role patterning within the couples in this study was particularly striking and manifested itself in two ways, the necessity for the women who suffered the stroke to strive and sustain their

previous role within the family, and the male stroke survivors to relinquish their roles in favour of their spouses. The impact of this on the female stroke survivors was an increase in anxiety, as the following quote by Martha highlights:

“Well my concern when I was in hospital was, oh who’s going to look after Jim’s tablets (for heart problems) who’s going to look after Jim you know...” (Martha)

Similarly, Maggie felt she could not take the time needed to recuperate after discharge from hospital and insisted that she continue to carry out her duties in the guest house she and her husband owned:

“so that is a case of I lasted two days and then I said, I’m going to have to do it and do some work because I was worrying about the money side of it as well and if we have to turn people away and stuff like that” (Maggie)

The above is contrasted with Ian who was the youngest stroke survivor at thirty five years, who suffered cognitive difficulties and depression:

“...so I’m not sure if the memory thing is even the brain’s way of coping, of telling you to don’t worry about that, maybe the brain can sense that worrying is causing harm... which is quite a nice place to be” (Ian)

Because of Ian’s approach, his partner Katie had to pick up the ‘worry’ and deal with the financial issues that faced them:

“Can’t pay mortgage, got to phone them up, can’t pay this, got to phone them up and it’s frightening” (Katie)

Mark was another male stroke survivor who had lost interest in maintaining a wider social network:

“Sally: Because there again really you’ve gradually not made an effort, have you?”

Mark: No.

Sally: You know we’ve got friends in (location) and I’ll say, we’ll pop over and see them, but you’re not, you can’t be bothered let’s put it that way.

Mark: Um, I was very gregarious at one time.”

The above analysis about the way the female stroke survivor motivation to maintain previous family roles and the male stroke survivors to relinquish them, has not been documented in the literature on gendered caring within stroke. The implications of this process links with the stressful nature of this role change.

4.12.3: Stressful

All the couples’ unsurprisingly, reported that recovery from the initial stroke experience had been stressful, and is described in most of the literature for stroke survivors (Murray et al, 2003; Ostwald et al, 2009) and family carers (Greenwood, Mackenzie, Wilson, & Cloud, 2009). Within the present analysis, the female stroke survivors attributed their stress more to their spouses’ ability to cope with the limitations of their stroke, as Martha’s quote demonstrates:

“And then I worry terribly about how he’ll cope as I can’t do so much around the house and... but I now have a cleaner...I

have a cleaner now but she's on holiday for a fortnight so we have to put up without cleaner..." (Martha)

And from Mary who had recovered well, but still needed some assistance:

"Yeah, and I'm doing most of the things that I did before, yeah. But we do do things...certainly we've got our own lives and we've always been very independent people I think is what we could honestly say so it's just carried on like that I think. And now he has to do more for me now...he hurts when he's (John) not independent and that causes some stress" (Mary)

Maggie also found it stressful in discussing her worries with her husband, David:

"...but I just have to keep it to myself, if I say one word about this, worrying about that and then it'd become his worry and his worry would feel like ten times more onto me" (Maggie)

Maggie's reaction to her husband's worry and its effect on her, resulted in a 'protective buffering' style of coping (Coyne & Smith, 1991), attempting to hide her concerns, not to protect her spouse but to protect herself. It was surprising she articulated this sentiment in the presence of her husband but David did not respond to it, nor did the interviewer pursue the topic, due to its sensitivity for their relationship. It appeared that Maggie was atypical in relation to the other couples' who communicated based on 'active engagement', where both parties discussed issues that concern them and is a more positive coping strategy. This comment by Maggie in her husband's presence may have been an attempt by her to push the communicative strategy between them to a more problem focused coping approach rather than the emotion focused she had pursued. The source of stress for the female stroke survivors' is contrasted with the male

stroke survivors who felt stress in terms of its impact on their activities of daily living, as Ian describes:

Yeah, that's a problem, because you know for years obviously in a routine, getting up, going to work, having a laugh in work, you know, meeting people and now the only time I ever seem to go out is for medical appointments, you know, hospitals, doctors and it's stressful.... it's pointless, you know, it seems pointless, what's the point"

Mark was also worrying about his loss of 'words', with his wife reflecting her stress at his memory problems:

Mark: "And the stroke, I probably if I hadn't the stroke I might've been able to cope better with it..."

Sally "And I think you're worrying inwardly aren't you about losing your words and getting things muddled up?"

These findings again point to different perspectives between male and female stroke survivors in their perception of stress. Female stroke survivors found the effects on their spouses as a source of stress for them, whereas male stroke survivors became stressful through limitations of their previous, pre-stroke abilities. This has not been reported in the literature previously, and can be illustrative of the gender differences discussed above.

The pattern of stress articulated by the spousal carers (both male and female) was concern about the stroke survivor's 'state of mind' as Katie laments:

work, but you (Ian) get so depressed because you've got nobody to talk to all day and I get home and I'm tired and I

don't want to talk about anything because I've been in work all day, so that's a bit stressful." (Katie)

Which is echoed by John:

"That things have started going downhill again with Mary and I don't know whether this is to do with the stroke itself or whether it's something else but it is worrying..." (John)

4.12.3.1: Personal experiences of stroke

A feature of these couples was their prior experiences of stroke within their families, as David explains:

"My dad had about 6, 7 strokes, like, I presume like Judith's just had, a mini stroke and bounced back from every one. Mum had one, paralysed her, she had another, it killed her and then my dad he died of renal failure eventually. and that's why on the night, I looked at her and she was having her stroke, because it was a stroke...the doctor down there (hospital) said that she's having a stroke, the bottom fell out of my world because I thought, Jesus, you know, thinking straightaway I thought of my mum and dad, but completely different." (David)

Mary also relates her previous experience with family members having a stroke and the pressure it put on her as a daughter and wife:

“I think you have to realise that those years that mum had her stroke I was doing full-time, my two boys were eight and 10 when mum had a stroke, I was doing a full-time teaching job and backing dad up, we had no time, I mean literally I had no time other than my job, my dad and mum and we managed to keep ourselves together, you know, but that was, if we’re honest that was how it started where we became quite independent in many ways and I think it’s, you know, we’ve just learnt to cope do that but we can, we do, we go on holiday together, I mean we do things together but it hasn’t got to be” (Mary)

Mary’s experience of helping her father care for her mother while maintaining her own family life through building a coping mechanism based on ‘independence’ that was helpful for them now in adapting to her stroke. Again Faircloth, Boylstein, Rittman, Young, & Gubrium, (2004) also describe previous experiences with chronic illness and stroke as a moderating factor in the biographical disruption thesis.

Within this section the couples’ ability to cope with the stroke demonstrated a lifetime perspective in the process of reconstruction which includes the physical, social and medical (Radley, 1994).

4.13: Managing Relationships

The second main theme to emerge was that of ‘Managing Relationships’ which included 2 sub-themes of ‘maintaining couplehood’ and ‘maintaining social networks’.

4.13.1: Maintaining Couplehood

Individual, one-to-one interviews and focus groups are customary in social sciences research, and has been a feature of family research for several decades. Increasingly within the chronic health field there is a recognition that

the relationship between the coping of one spouse and the adjustment of the other spouse (Kasle, et al., 2010). Indeed, couples who cope best 'cope in partnership' viewing the stressful situation as 'our' problem.

Dyadic closeness or couple mutuality within chronic illness has been defined as "...a positive relationship quality of connectedness, is marked by the reciprocal sharing of thoughts and feelings in close relationships" (Kasle et al., 2010: p.93). Studies have shown that the quality of a couple's relationship is linked with better outcomes for the care recipient and spousal carer (Kasle et al., 2010). Within the context of stroke Godwin, Swank, Vaeth, and Ostwald, (2013) showed that the perceived closeness of the relationship between the stroke survivor and spousal carer, the less stress and burden was felt by both parties. Within the present study, the couples focussed on 'negotiating a changed context', in which both partners' choreographed their emotions and reactions to maintain their relationship together. The key category within this theme was the 'degree of latitude' offered by both partners.

4.13.1.1: Degree of latitude

4.13.1.1.1: Emotionality

The degree of latitude is the extent to which each partner was willing to compromise the emotional outbursts of the stroke survivor or spousal carer. The quote below by John relates to Mary's angry outbursts when she was irritated or became over-tired. This emotionality was not a feature of Mary's character pre-stroke, but John made allowances for these flare-ups to maintain their relationship:

"...I know her (Mary) sufficiently to allow it also, roll over and knowing that things will get better in time but yeah, it is a distressing feature which doesn't register in terms of medical treatment or anything" (John)

4.13.1.1.2: Irritability

Likewise, Mary recognised her increased irritability and emotionality was creating tension and was appreciative of her husband's tolerance:

“And, you know, I'm very conscious that this is me different and I then say I'm sorry, I blew on that and I didn't intend to sort of thing, I don't know why I did and all this sort of thing so I think we've got it sorted out to a certain extent, well I hope so but we both are conscious of it and I know John's conscious of it” (Mary)

This reciprocal balancing was replicated for all the couples, but it had its effect on each partner's psychological functioning and as demonstrated previously there was only limited professional support for the couples in this aspect of their rehabilitation:

“Well it's hard work, emotionally it's hard because, you know, dealing with the CAB (Citizens Advice Bureau) now and sorting out the house and I've got the twins coming and I envy you (Ian) sometimes because you're just completely gone, get on with it and you're happy” (Katie)

4.13.2: Maintaining social networks

The second sub-theme was managing relationships outside of the couple, and related to immediate family, and wider social networks.

4.13.2.1: Family support

4.13.2.1.1: Instrumental

O'Connell and Baker, (2004) showed that the stroke survivor and spousal carer valued the input of their families in providing both emotional and instrumental support, and if this was lacking then it impacted negatively on the spousal carer.

This was also the case with the couples in these interviews, but clearly there were differences between the younger couples Ian/Katie and Maggie/David and the older couples on whom they drew support from. The older couples had lost their parents years previously so relied on their grown-up children, whereas the two younger couples depended on their parents for immediate support. All couples commented on how their families rallied around when the stroke occurred, many family members lived a considerable distance from their parents:

“But yeah, you know, like they just dropped everything when I phoned up mum and dad came down straightaway, on the first morning and then phones her mum and her mum just packed her bags up then and came down, she was there within...” (David)

As indicated previously Dennis and Helen had a troublesome relationship because of the personality changes following the stroke, so Helen relied heavily on her daughter to mediate and help support her in providing care for Dennis:

“Not too far away, no, she’s (daughter) marvellous with us really, she’s really really marvellous, I don’t know what we’d do without her, she is...Yes, and she’s got a very good husband as well and he doesn’t, you know, he’s very good I must say so” (Helen)

There was again a gendered element to these family relationships in that mother/daughter dyads were clearly manifest in providing emotional support for the female stroke survivor and female spousal carer.

“Jim: Yeah, so she would, obviously spends quite a lot of time on the telephone to the daughter.

Martha: Yeah, my daughter.

Jim: They’re very very close.

Martha: And I’ve got a granddaughter who’s very, we’re very close to as well aren’t I, yes”

4.13.2.1.2: Affective

Older mothers and adult daughters express strong expressive ties and demonstrate higher dependence on the other for emotional and instrumental support when compared to other family dyads, including fathers and sons. Adult daughters are often the preferred source of support by both mothers and fathers (Shim, Landerman, & Davis, 2011). It appeared that six months following the stroke the emotional support provided by the mother/daughter dyad continues even though instrumental support may have receded. What was also apparent through the interviews was the lack of this emotional support from daughters to their fathers whether the stroke survivor or the carer. However, it cannot be ruled out that this was not the case, but reinforces the literature of the gendered nature of women in maintaining family networks.

4.13.2.1.3: Age

The younger couples had additional responsibilities related to maintaining family relationships in that they had young children, Maggie/David had a 12-year-old son and Ian/Katie had a five-year-old daughter, and were expecting twins. There is only limited discussion in the stroke literature of the effects a stroke on a parent can have on young children and adolescence. According to David their son had adapted well to his mother’s condition in the past six months:

“He handled it very very well, Maggie didn’t obviously, we took him visiting and Maggie didn’t see him other than when he went visiting, he was, he’s 12 isn’t he, well he was 12 at the time, he was acting as though he was 20. You would never have known his mum was in hospital, never have known at all, he was great, absolutely fantastic, and he has, I mean they’re dead close anyway and they still bloody cuddle each other on the settee and they’ll cuddle each other before he goes to bed, he doesn’t come nowhere near me [laughs] to be fair. I think I had one cuddle all the time she was in hospital, but yeah, he’s really good with it. I mean even to a point where we have a laugh and a joke over it and because he’s quite, he’s 12 years old, he’s a typical lad and he’s quite boisterous and I’ll say, be careful with your mum, she’s disabled, well we roll around then laughing don’t we and we bounce this off everybody, you know, he gets it bounced off him, I get it bounced off me and we just, you know, life goes on, you’ve got to get on with your life basically” (David)

As their son was not part of the interview and Maggie did not comment on David’s perception it is difficult to gauge how well their son is adapting. Unfortunately Maggie and David declined to be involved in the subsequent longitudinal interviews so that this area could not be further explored.

For Ian and Katie who already have a five-year-old daughter there were noticeable changes in her behaviour which concerned Ian and Katie and is seen in these two quotes:

“Ian: I think to be, it’s a strange situation because the role seems to have changed slightly, my little girl, she’s nearly five and she has changed towards me.

Katie: Yes, quite a lot.

Ian: She doesn't see me as being the authority figure any more.

Katie: No, I am now.

Ian: Which is quite weird, because I think she sees Kate doing so much now and so she's lost that sort of where if I tell her to do something she won't until Kate says, you listen to your father, you do that and then she'll do it.

Katie: She calls him little daddy.

Ian: And also over the last six months she's seen me, you know when I first had the stroke the amount of sleeping I was doing when I got out of hospital, she's basically just seen me constantly in bed, you know, sleeping and it's after that she's seen a weakness in me and I think she's.

Katie: And she was drawing pictures of us as a family and it was always of you lying down...But all of a sudden she's been drawing you biggest in the picture standing up, so in her mind you must be getting stronger...so she's visually showing you that's how she's thinking.

Quote 2

Ian: Yeah, but when I was speaking to, well looking on the internet, you know it could take up to ten years for brain injuries like that to, I haven't got ten years, you know [laughs], well I have got ten years, I'm 37 but I don't want, you know, children to grow, you know, oh what was your dad like, oh he was a miserable git, you know, always ill or never took us anywhere and couldn't do anything...I don't want that, I would

rather than thinking, oh I never saw my dad, he was always out working but he was a good provider, he put a nice roof over our head and there was always food there and holidays, that's what I want them to remember, not, you know, some little guy who couldn't remember anything.

As the last quote also displays Ian's traditional gendered role perception in that it is the man who is the 'good provider'. The couple were expecting twins in seven months' time, and this contributed to Ian's depression, even though Katie was looking forward to him being at home to help. It was unfortunate that Ian and Katie moved out of the area and were not traceable, so further interviews could not be conducted. The impact on children whose parent has had a stroke is under-researched and is an area that requires further study to develop appropriate support intervention services for this important group as the numbers at risk of stroke in the 18-50 age group are increasing.

4.13.2.2: Receding social networks

The wider social networks were also deemed important by the couples for instrumental support and maintaining social and leisure activities. Again, in the early stages friends and colleagues did help out:

"and I think I got back here about four or five o'clock in the morning from hospital, obviously I've got to get up and do breakfast (owned guest house) so there's no point going to bed, friends of ours came in and they just said, we're doing breakfast you just stand out, so I just went upstairs, absolutely fell to pieces... (David)

"Jim: Yes, our neighbour at the end.

Martha: Yes, she came to see.

Jim: (Name) came to see what was the matter, what was going on and if whatever we needed.

Interviewer: And during this time of course you were sort of sleeping in and out of, obviously.

Martha: Yes, I wasn't knowing what was going on, but everybody was turning to and it's funny how things happen isn't it that like (Name) just phoning me, she found out and so of course she took over running Tom about, he wasn't driving because he was upset and, you know...she'll still do some shopping for us if she's going into (Town)"

However, the social networks were already in recession at the time of interview, mainly due to reduced mobility in getting out to previously enjoyed leisure activities, or not being back at work among the friends he socialised with as in Ian's case. Others such as Helen, perhaps due to the friction within the relationship made a point of meeting her friends for coffee every week, as well as trips out with her daughter:

"Helen: But now I do go out and I go out every week, go and see my friends and things like that and I can drive my car and he has the morning for himself at home because I think that's better really.

Interviewer: Yeah, and you find going out every week with your friends, is a relief as such, there's a?

Helen: Oh yes it is. Because they've got something nice to tell me and, you know, we're all different. So that's quite nice really.

This routine was not the norm for the other couples and this deliberate policy of maintaining her social network was a way Helen could carry on with her caring function.

However, for Mark, even though he had opportunities to socialise he withdrew from the experiences, much to Sally's concern:

Sally: No, not at all. Because there again when you went down the pub the other week and normally you would've stayed what an hour, and you were back sort of in a quarter of an hour, can't be bothered with them.

Mark: Well I don't go there.

Sally: No, you don't go there very often.

Mark: When I was fitter I used to like to go into a pub, you know after work and have a chat, but it doesn't interest me anymore, I can't be bothered.

Sally: Well it worries me that he's not mixing.

Mark was an engineer before retirement but continued to carry out building jobs around the house until his stroke which interfered with his problem-solving abilities and physical strength. Again, Mark's reluctance to continue his previous leisure activity may be linked to gender perception, with the stroke seen as exposing his weakened male physique with implication for his self-esteem and increased risk of depression.

4.14: Conclusion

Chapter four outlined the benefits and limitations of interviewing couples together. Ethical issues related to conducting dyadic interviews was discussed, and included pen portraits of each couple. The interviews were transcribed and analysed using thematic analysis with an initial coding frame developed from

the 'Family Assessment Device' (FAD). The overarching theme was 'reconstruction', with two sub-themes of 'identity' and 'managing relationships'. The findings from this chapter will be collated with the realist synthesis and critical literature review in chapter five to develop the initial programme theory.

CHAPTER FIVE: Initial Programme Theory Development

5.1: Introduction

Drawing on the principles of realist evaluation this chapter discusses the surfacing of an initial programme theory from the literature reviewed in chapter one and the emergent CMO configurations that could be extracted from the realist synthesis of systematic reviews of stroke interventions and the initial couple interviews. The purpose of a realist evaluation approach is to identify “what is it about a programme that works for whom, in what circumstances, in what respects, over which duration” (Pawson, 2013 p.15). Before outlining the initial programme theory, there is a need to discuss the way validity and reliability or rigour is assessed in realist evaluation.

5.2 Validity and reliability issues in realist evaluation

A realist evaluation framework is a theory driven approach to evaluation that begins with “...fragile ideas...to be tested and refined through engagement with evidence” (p.6) (Emmel, 2013). The initial programme framework and CMOCs that help in explaining what mechanisms work in helping stroke families cope with the longer-term realities of a stroke are developed in this chapter. Accessing this 'evidence' in realist research is unhampered by methodological dogma in that the choosing of a method is only guided by its relevance to testing the initial programme theories, qualitative or quantitative methods can be utilised (Pawson & Tilley, 1997). However, important criteria in any study regardless of methods used are its validity and reliability, these terms are however contested in qualitative research as they were originally applied for positivist epistemology (Winter, 2000). For qualitative research methods, as implemented in this study (face-to-face interviews and focus groups) the standards need to be adapted to fit-in with its epistemological roots, and 'trustworthiness' is a way of judging the validity and reliability of qualitative research (Guba & Lincoln, 2005). 'Trustworthiness' can be addressed through

four constructs, although a fifth construct was later added to address criticisms that imposing a checklist, however broad goes against the relativism of constructionist epistemology (Hammersley, 2007):

- a) credibility (in preference to internal validity);
- b) transferability (in preference to external validity/generalisability);
- c) dependability (in preference to reliability);
- d) confirmability (in preference to objectivity).
- e) authenticity (researcher has demonstrated a range of different realities)

Even with the above caveat, there are doubts about the need for formalised evaluation criteria for validity and reliability as the following quote from (Rolfe, 2006) demonstrates, “Rather than searching for an overarching set of criteria by which to judge the validity of qualitative research, we should perhaps acknowledge that there is a multiplicity of (so-called) qualitative paradigms, each requiring very different approaches to validity. Or, put another way, there is no qualitative paradigm at all, so that each research methodology (and perhaps each individual study) must be appraised on its own merits” (p.310).

The above stance has been challenged by Porter, (2007) using realist perspectives to question this ‘laissez-faire approach’ and his discussion hinges on the link between practice and knowledge, in that practitioners need to be assured that their knowledge base is credible within the multiple perspectives outlined in realism. Indeed, Pawson, (2003, p.ix) outline a criterion based approach that addresses the rigour of research in realist evaluations, the TAPUPAS acronym:

- Transparency – is it open to scrutiny?
- Accuracy – is it well grounded?
- Purposivity – is it fit for purpose?
- Utility – is it fit for use?
- Propriety – is it legal and ethical?

- Accessibility – is it intelligible?
- Specificity – does it meet source-specific standards?

5.3: TAPUPAS

5.3.1: Introduction

The TAPUPAS ‘standards review group’ (Pawson et al, 2003) was set up by the Social Science Institute for Excellence in an eight-month project that attempted to answer questions related to social care ‘where does knowledge come from, who does it belong to, and how do we judge its value’? The project was in two parts, stage one used a scoping review to illuminate the types of knowledge available for social care, while the second stage delved into the assessment of the quality of this diverse knowledge base. Even though the accent was on social care, the structure can still be used in other service related disciplines, as the purpose of the review was to aid all stakeholders involved in care to reflect on the quality of different types of knowledge presented to make informed practice decisions. Stage One identified the ‘research, experience and wisdom’ that make up the social care knowledge base that addressed organisations, practitioners, the policy community, researchers and users and carers (vii). A scoping review and relevant social care stakeholders were interviewed to draw up the final five categories of knowledge as indicated in table 5.1:

Source 1	Source 2	Source 3	Source 4	Source 5
Organisational	Practitioner	Policy Community	Research	User & Carer
Knowledge gained from organising social care	Knowledge gained from doing social care	Knowledge gained from wider policy context	Knowledge gathered systematically with a planned design	Knowledge gained from experience of and reflection on service use

Table 5.1: Sources of knowledge (Pawson et al 2003, p.4)

Within this thesis if social care is substituted for stroke care then the issue of rigour can be applied using TAPUPAS, which was the objective of the second stage of the project. The organisational knowledge source represents the governance framework that underpin the organisation's activities. The practitioner perspective reflects their practice knowledge derived from appropriate evidence-base and day-to-day interpretation of the organisation's objectives builds up a 'tacit' knowledge base (Smith, 2001). For H&SC practitioners this knowledge base can be akin to the 'street-level bureaucrat' that gives the practitioners some discretion in how they comply with organisational objectives (Lipsky, 1980). Policy level knowledge is broad and within the H&SC perspective is initiated by government and professional organisations, this knowledge is then interpreted by the organisations and practitioners responsible. The research category of knowledge is based on inquiry that covers RCTs, systematic reviews as well as the increase in realist approaches, within medicine it is the positivist tradition of knowledge that is preeminent. Finally, and perhaps most importantly is the knowledge base of the users and their families of the intervention programmes provided for them. There is increasing recognition of their contribution to developing interventions and practice with most major health research funders requiring input from these stakeholders in proposal submissions. The rationale of Stage Two of the review was to develop a framework for assessing the quality of the different types of knowledge within the classification outlined in Stage One. Again, the review group interrogated the literature about the principles and standards underlying each source of knowledge that resulted in the TAPUPAS criteria.

5.3.2: Description of TAPUPAS

- Transparency: this is the recognition that the generated knowledge base can be adequately scrutinised, so that it is clear how the 'knowledge' was obtained. Within this thesis, it is the documentation of the processes that occurred to produce the revised programme theory.
- Accuracy: similarly, the 'knowledge' claimed in the thesis can be seen to be faithful to the comments made by the participants.

- Purposivity: this is the standard where the approach taken is 'fit for purpose' in this thesis is the assumptions based around critical realism and the methods used that develops the programme theories that explain better family interventions in stroke.
- Utility: is 'knowledge' that can be used in appropriate contexts. This thesis produced programme theory that can assist stroke practitioners and researchers to better implement their interventions with stroke families.
- Propriety: the production of the knowledge base should demonstrate that it has been produced legally and ethically with due regard for the participants involved. Within the thesis, the appropriate ethical approvals were undertaken as well as the maintenance of the highest ethical principles in dealings with vulnerable families.
- Accessibility: the description and tone of the thesis is written in a style appropriate for the intended audience, with later opportunities for dissemination to specific groups.
- Specificity: does the knowledge generated apply to those intended, organisation, policy, research, practitioners and users/carers. This is linked to accessibility in that different aspects of knowledge are more pertinent to the different sources who use the information, and as such the recommendations from this thesis will attempt to address the different stakeholders.

5.3.3: Triangulation

Triangulation in qualitative research is a means of challenging biases that may emanate from just looking at one perspective, so through triangulation there is the prospect of gaining a richer understanding of how stroke couples and H&SCP perceive the impact of stroke, and how families can be subsequently supported (Green & Thorogood, 2009). According to Denzin (1989) there are four types of triangulation: use of different methods, in this thesis, interviews and focus groups. Data triangulation made up of diverse sources of data, the stroke couples, professionals who help stroke families, and literature on stroke family interventions. The third type of triangulation is the use of different research investigators, which was not utilised in this thesis, and fourthly,

theoretical triangulation. Taken together, this represents a way of articulating the contingent programme theories that attempt to explain how interventions can be better applied in stroke family care.

5.4: Context in health and social care interventions

This thesis embodies a realist evaluation approach to interventions that can help stroke families in their recovery from the stroke incident, particularly the longer-term consequences. As such the thesis is also a process evaluation whose aims is to understand the functioning of interventions, by examining implementation, mechanisms that produce the impact within their contextual influences. Within process evaluation stakeholders such as policy makers, managers, practitioners, researchers, and clients can understand some of the components that can make an intervention effective (or not). There is a degree of unpredictability, and non-linear outcomes in implementing social and behavioural health interventions as they are presented into open not closed systems, where there are very diffuse boundaries with the intervention operating as a 'resource' for the various stakeholders to use or not (Sheppard, et al; 2009). Because the interventions are introduced into pre-existing open systems it is essential that stakeholders can have some notion of why the intervention worked (or not), and will it work in different contexts, with different sets of practitioners, organisational structures and clients. Embedding complex interventions such as family support following a stroke into organisational settings is a complex task (Clarke et al., 2014b). Context according to Pettigrew, Ferlie, and Mckee, (1992): "...refers to the 'why' and 'when' of change and concerns itself both with influence from the outer context (such as the prevailing economic, social, political environment) and influences internal to the focal organisation under study (for example, its resources, capabilities, structure, culture and politics)" (p.54).

Within complex health or social interventions limits the range and choices the stakeholders can make to utilise the intervention resources, since critical realism considers the interplay between structure and agency as central tenets of the approach (Archer, 1995). This idea of structuration (Giddens, 2009)

where there is interplay between human agency (micro level) and context (macro level), also leads to an elaboration of what is meant by context. Within realism, it is not just the environment surrounding the individual or group but includes cultural and relational factors. There is a 'recursive relationship' between the individual/group and their social system. Bhaskar (1998) also highlights the importance of the relational nature of structures in society that can limit individual agency but does not determine them as people can change. From a more psychological perspective (Bandura, 2008) also recognised the importance of agency and environment (structure) in producing behaviours in his social-cognitive theory and triadic reciprocal causation. Within this perspective people do not react to environmental events; they also make their own environments and act to change them. The person's history and motivation will determine which environmental events will be attended to and interpreted, organised, and acted on. Positive or negative feedback from behaviour, in turn, influences people's thinking and the ways in which act to change the environment. Linking back to programme evaluation Pawson and Tilly (1997) state, "Realistic evaluation involves the researcher learning the policy, practitioner and participant ideas that constitute the program and govern its impact. These theories are not just constructions: they describe understandings of real social forces affecting the thinking and action of agents" (p.207).

5.5 Developing the Programme Theory

What constitutes theory, middle-range theory and programme theory has been discussed in chapter two (section 2.9). The rationale of realist evaluation is to search for programme theories that explain why interventions work in supporting stroke families and in which contexts they may work. In realist terms this involves the exposition of underlying mechanisms that are triggered in certain contexts. Programme theory consists of a set of statements that explain how, why and under what conditions a programme or intervention (in the case of this study support for stroke families) will produce the desired effects, and describe what needs to be done to bring these effects about. For Pawson (2003), if a programme provides "...people with these resources it may change their behaviour" (p.472). Pawson (2003) views programmes as theories and

that the purpose of the evaluator is to test the programme components to build theory. The process is shown diagrammatically in figure 5.1:

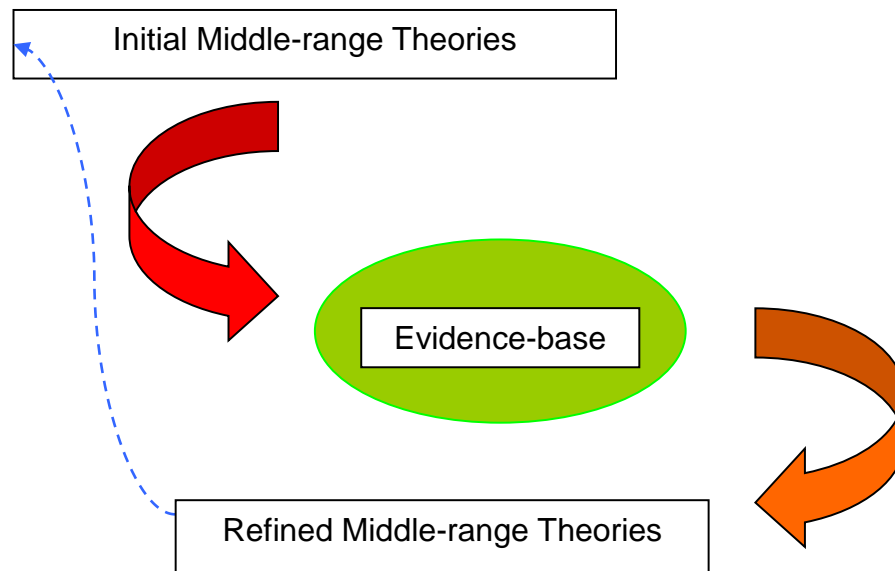


Figure 5.1: The process of refining programme theories

The development of the initial programme theory will be drawn from the literature review in chapter one, and is developed further in the next section detailing middle-range theories from the literature. The realist review (chapter three), and the preliminary couple interviews (chapter four) will also form the basis of the initial programme theories. From this initial programme theory, the context-mechanism-outcome propositions will be tested with the longitudinal couple interviews (chapter six) and the practitioner and RELATE focus groups (chapter seven).

5.6: Conceptual frameworks on caregiving

With this consideration, the initial middle range theory in this thesis on support for stroke family carers draws on four interlinked conceptual frameworks, the first articulated by Schulz, (2000) looking at intervention approaches to

caregiving in dementia, secondly, (Rolland, 1994b) chronic illness and the life-cycle framework. The third framework draws on illness narratives Hyden, (1997), and Kleinman, (1988) and in particular the work of Bury, (1982) and biographical disruption. The final framework is increasingly being cited as important for underpinning positive adjustment among caregivers of resilience. These conceptual frameworks provide a basis for articulating a starting point for identifying the generative theories that trigger outcomes to interventions that focus on stroke family carers. Each of these theorists perceives chronic illness management within the family and takes as their conceptual root a family systems approach. Family systems theories have their basis in (Von Bertalanffy, 1969) general system theory that operate in complex, open, biological systems, contrasting with the physical sciences, which functions within 'closed' systems. The section finishes with a brief discussion of resilience that leads into the mid-range theory of 'stroke family carer support to reduce carer burden and increase well-being'.

5.6.1: Schultz et al (2000) 'Why do people help?'

The central theme of Schultz et al (2000) framework is to explain various perspectives on why people help others in adversity, specifically families looking after relatives with chronic illness. The theory focuses on motivation to help, that has two basic tenets, self-serving motivation and altruism. A self-serving hypothesis identifies people's motivation around the idea of self-interest, either rewards (internal [avoiding guilt] and external [payment]), and are highly influenced by prevailing social norms (Schultz, Nolan, Cialdini, Goldstein, & Griskevicius, 2007). By contrast altruism is the ability to adopt the perspective of the other, more vulnerable person. (Post, 2002) defines the act of altruism as "someone who does something for the other and for the other's sake, rather than to self-promotion or internal well-being..." (p.53). According to Batson, Oxford, and York, (2012) actions are altruistic if the actor intended to improve the well-being of the recipient in a voluntary and non-rewarding manner. (Batson, 2010) set up a series of experiments to show that all altruistic behaviours are self-serving. His evaluation of these studies changed his opinion and led to the development of empathy-altruism hypothesis that explains

altruism in the context of empathy. Empathy-helping relationships have been criticised by those who maintain it is still a subtler form of self-serving motivation. Batson et al., (2012) recognised the paradox but according to May, (2011) the egotist explanations for the empathy-altruism hypothesis of (1) relieving personal distress or aversive arousal, (2) avoiding feelings of guilt, (3) avoiding social disapproval, (4) gain recompense, (5) gain a mood-enhancing experience have not been shown to be valid explanations for Batson's (2012) experiments, with the requirements for altruism being the recognition that the 'other' as in need and valuing the other's welfare. Madsen et al., (2007) have looked at altruism and kinship, and found "unequivocal experimental evidence" (p.339) that affiliation moderates altruistic behaviour and acts as a reference point in decisions about reciprocity, and obligation towards others.

Related to their discussion of altruism, Schultz et al (2000) associate the effects of caring with a stress-coping model (x-y-z stress model (Elliot & Eisdorfer, 1982)). The model in Figure 5.3, highlights interaction between the individual and the environment in that potential activators (x), which in this case is the family relative who has sustained the stroke, provokes an individual's reaction (y) to the activator, the family care-giver's adaptation (positive or negative), that then leads to potential consequences (z), stress and burden, or resilience. In addition, the consequences are also affected by mediators that act as a 'filter', which moderates the three antecedents of the model. These mediators are linked to individual personality as well as family interaction and structure. The simplicity of Schultz et al (2000) framework belies the complexity of the situation that family carers and care recipients face when confronted with a serious health condition. It is this complexity within family care-giving that Rolland's (1987) framework of chronic illness and the life cycle is a useful guide.

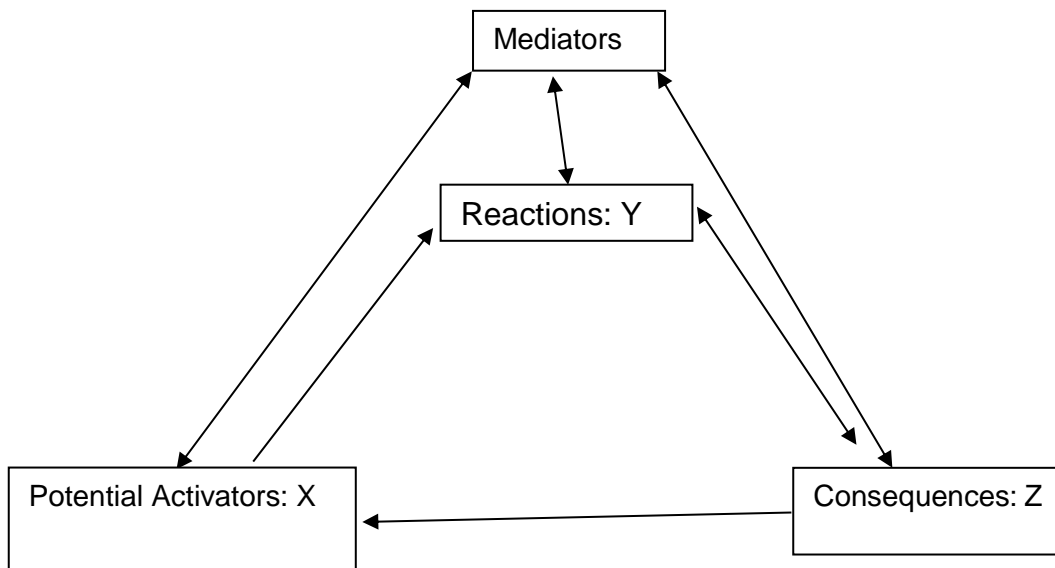


Figure 5.2: x-y-z stress model (from Elliot & Eisdorfer, 1982)

5.6.2: Rolland (1987/1994) chronic illness and the lifecycle

Rolland (1994: 11) developed a 'family-systems illness model' that describes how a chronic illnesses individual and family functioning as they attempt to adapt to the disease. This model is psychosocially grounded, as it attempts to explain and address the psychological outfall on families of individuals with a chronic illness. Rolland (1984/1994) developed a 'psychosocial typology of chronic illness' that is summarised in table 5.2:

	Incapacitating	Incapacitating	Non-incapacitating	Non-incapacitating
	Acute	Gradual	Acute	Gradual
Progressive (fatal)		Lung cancer with CNS metastases AIDS (HIV) Bone marrow failure	Acute Leukaemia Pancreatic cancer Metastatic breast cancer Malignant melanoma Lung cancer Liver cancer	Cystic fibrosis

Relapsing (fatal)			Incurable cancers in remission	
Progressive (shortens life-span/fatal)		Emphysema Alzheimer's disease Multi-infarct dementia Chronic alcoholism Huntington's chorea scleroderma		Juvenile onset diabetes (Type 1 diabetes)
Relapsing (shortens life-span/fatal)	Angina	Early multiple sclerosis Episodic alcoholism	Sickle cell disease haemophilia	Systemic lupus erythematosus
Constant (shortens life-span/fatal)	Stroke Moderate/severe myocardial infarction	PKU and other congenital errors of metabolism	Mild MI Cardiac arrhythmia	Haemodialysis treated renal failure Hodgkin's disease
Progressive (nonfatal)		Parkinson's disease Rheumatoid arthritis osteoarthritis		Non-insulin dependent diabetes (Type 2 diabetes)
Relapsing (nonfatal)	Lumbosacral disorder		Kidney stones Gout Migraine Seasonal allergy Asthma Epilepsy	Peptic ulcer Ulcerative colitis Chronic bronchitis Irritable bowel syndrome Psoriasis
Constant (nonfatal)	Congenital malformations Spinal cord injury	Cerebral palsy	Benign arrhythmia Congenital heart disease	Malabsorption syndromes Hyper/hypothyroidism Pernicious anaemia

	Acute blindness/deafness Survived severe trauma and burns Post-hypoxic syndrome			Controlled hypertension Controlled glaucoma
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Table 5.2: Categorisation of chronic illnesses by psychosocial type (based on Rolland, 1994, p.34/5)

The above typology is based on four characteristics - onset, course, outcome, and degree of incapacitation. The typology attempts to map out the most critical ways a chronic disease affects not only the family system but also the individual family members. From this typology, Rolland (1994) developed an assessment and treatment guideline for dealing with the psychosocial effects of chronic illnesses. Disease onset refers to the time dimension of how different forms of chronic disease are manifested. Families must adapt differently when the onset of a disease is rapid and acute (as in a stroke) as opposed to when it is gradual (as in Alzheimer's disease).

Disease course denotes differences in chronic disease progression so, Alzheimer's disease becomes worse over time, with osteoarthritis remaining constant or stable over a relevantly long time frame. In other conditions such as certain forms of cancer entail periods of relative stability interrupted by dramatic setbacks or relapses. Yet other conditions such as Type 2 diabetes are relatively predictable over time. Stroke is always acute, and with improved assessment times, and thrombolysis more people are surviving the initial period, but still having cognitive, behavioural and emotional consequences (Wolfe et al., 2011b).

Outcomes of chronic diseases can be roughly categorised as fatal, contributing to a shortened lifespan, or nonfatal in their predictable ultimate outcome. Although many chronic diseases (such as diabetes) may shorten the life span and even be fatal in the long run, such nonfatal diseases offer neither a predictable timeline of death nor emerge as the principal cause of death (e.g.,

osteoarthritis). While conditions such as pancreatic cancer, have a high likelihood of death, calling for adaptive demands by the individual and family system that are related to end of life issues.

The disease categories described by Rolland (1994) in table 5.2 are not fixed as changes in disease patterns, expert opinion and advancing medical technology modify condition criteria. Stroke is in the 'Acute - Constant (shortens life-span/fatal)' category that continues to be apposite. However, AIDS or HIV is now becoming increasingly nonfatal in developed countries thanks to antiretroviral therapy (Knoll, Lassmann, & Temesgen, 2007), so could be moved to the 'relapsing (shortened life-span/fatal)' category. In contrast asthma is in the nonfatal relapsing column, but according to *Asthma UK* there were over a 1000 adult deaths from asthma in 2010, and could legitimately be placed in the 'relapsing shortened life-span/fatal' column. The psychosocial typology of a given disease is largely a function of the interactions between the four key dimensions of disease identified by Rolland (1994): onset, course, outcome, and degree of incapacitation.

Aligned with Rolland's (1994) typology are the components of family functioning, including communication patterns, roles, family belief systems, and family life-cycle/patterns. The components described by Rolland (1994) link with the Family Assessment Device (FAD) based on the McMaster model of family functioning (MMFF) (R. Ryan et al., 2005). The FAD assesses 6 dimensions of family life: problem-solving, communication, roles, affective responsiveness, affective involvement, and behavioural control, (there is also a general functioning category). The FAD is a robust measure of family functioning used routinely in stroke research (Epstein, Baldwin & Bishop, 1983; Epstein-Lubow, Beevers, Bishop, & Miller, 2009). A more detailed overview of the FAD will be presented in chapter four.

5.6.3: Chronic illness as narrative and biographical disruption

Bury's, (1982) concept of "biographical disruption" has been an important model for studies investigating chronic illness experiences, including stroke (Hyden,

1997; Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004). The model suggests that a person's knowledge of self and their social world is 'disrupted' by the illness experience. It also proposes that the 'taken for granted' understanding of daily life is also dislocated, requiring a reassessment of personal and family biographical details. The model also addresses the harnessing of resources; material, cognitive, and emotional is needed to 'heal' (repair) the disrupted biography. This description ties in with the idea of 'narratives' and 'narrative reconstruction' (Bury, 1991; Radley, 1994; Rolland, 1994) that in part draws on Kleinman's (1988) 'illness narratives' as an essential component in adaptation to the chronic illness. A recent study by Kuluski, Dow, Locock, Lyons, and Lasserson, (2014) using Bury's (1984) disruption model, showed that 'young' (under 55 years) stroke survivors who were one to 12 years post-stroke at interview, experienced the 'chaos narrative' (Frank, 1995), undergoing periods of frustration linked to their fear of 'becoming a burden' (Charmaz, 1983) to spouses/partners and children. Kuluski et al., (2014) assert that the long-term emotional effects of stroke need psychosocial support to re-connect with their social networks.

However, Williams (2000) critiques Bury's (1984) thesis in that biographical disruption fails to contextualise how an individual's biography has already been shaped by the life they have led. The contextual nature of biographical disruption was the outcome from a qualitative study by Pound, Gompertz, and Ebrahim (1998) with 40 elderly (mean age 71 years) stroke survivors in the east end of London. Conducting in-depth interviews ten months post-stroke found that instead of a dramatic life disruption, the participants showed a sense of "resignation and pragmatism, not as something which could be bracketed off from the continuous ebb and flow of their lives, but which was fundamentally part and parcel of it" (Pound et al., 1998: 498). Pound et al., (1998) selected perceived community support and age as mediators in reducing the biographical disruption. The community around the east end of London have had historically a deep sense of community with the neighbourhood having been a productive area for sociological research in the UK (Townsend, 1957; Young & Willmott, 1962). Pound et al., (1998) quote Cornwell (1984) "...many

inhabitants of the East End entered into some relationship with the myth of the East End” (p.502) that may account for downplaying the effects of the stroke. Being older when experiencing a stroke was also identified as mediating ‘disruption’, partly this is because as people get older they expect to suffer from ‘illnesses’, but also according to Pound et al., (1998) living to an older age has prepared individuals to deal with life events. Pound et al., (1998) do not evoke resilience in their discussion but their analysis does equate with aspects of the concept.

In a later qualitative study by Faircloth et al., (2004) with 40 (mean age 67 years) stroke survivors, showed that age was again a contextualising factor that changes the biographical disruption explanation into ‘biographical flow’. The participants’ experienced stroke as a continuum along a ‘getting old’ narrative, as Faircloth et al., (2004) describe it, “The direct effects of stroke are not constructed as life altering, but rather given meaning within a social context that places narrative importance on other challenges and social contingencies” (p.253). Again the authors do not allude to resilience, but the notion of biographical flow rather than disruption in elderly stroke survivors does augment the prospect of seeking a salutogenesis or ‘strength-based’ approach to stroke management rather than a biomedical focus (Antonovsky 1987; Berg-Weger, Rubio, & Tebb, 2001).

Greenwood and Mackenzie (2010) provided a detailed meta-ethnographic review of the qualitative literature on informal stroke caregiving between 2006 and 2009. They reviewed seven studies, synthesising the data that utilised both induction and interpretation, identifying themes of biographical disruption which involved change and loss in roles, sense of identity and relationships. They also identified adaptive strategies employed in reaction to these changes and of acceptance and personal growth as a result.

5.6.4: Resilience

Resilience according to Windle, (2010) and Ungar, (2011) is a complex concept having vague definitions, with the majority of resilience research pre 1990

originating through studies on children and their positive adaptation despite a damaging upbringing (Tusaie & Dyer 2004). Much of the literature identifies resilience as resulting from interaction between genetic endowment, individual differences and environmental factors (Herrman et al., 2011). Recently other disciplines have investigated resilience with the elderly (Alex, 2010; Hicks & Conner, 2013), palliative care (Monroe & Oliviere, 2007), chronic pain (Sturgeon & Zautra, 2010), family resilience (Zaider & Kissane, 2007), and family carers (Payne, 2007; Windle & Bennett, 2012).

Through a concept analysis incorporating a systematic review and workshops with service users, Windle, (2010; p163) arrived at a definition of adult resilience:

“Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity. Across the life course, the experience of resilience will vary” (p.163).

The important notion behind resilience as opposed to hardiness (Kobasa, 1979) is the ‘process’ nature of resilience rather than a trait that an individual possess, although as Hicks and Conner, (2013) identify, resilience does encompass trait-based concepts. In the context of ageing Hicks and Conner, (2013) also performed a concept analysis and identified several factors related to resilient ageing. They developed a resilient ageing model as depicted in Figure 5.3:

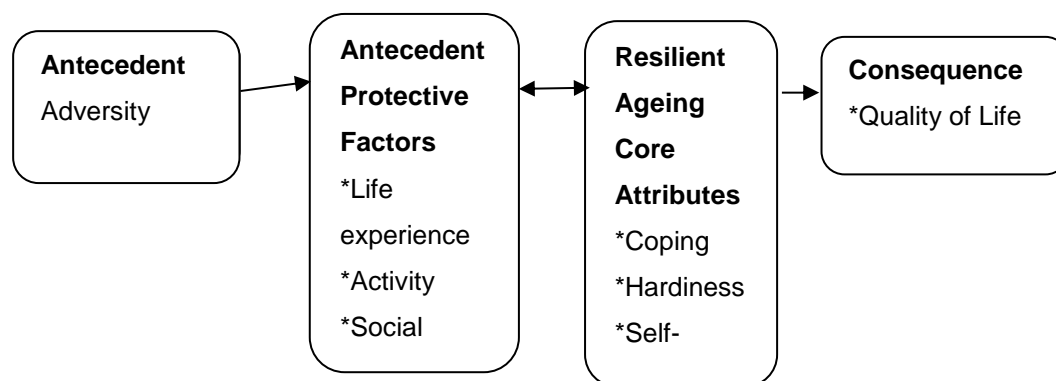


Figure 5.3: Resilient ageing model (Hicks & Conner, 2013, p.7)

When a person faces an adversity, its consequences (quality of life) is affected by previous life experiences, levels of activity or physical functioning and perceived social support. These protective factors then influence and are influenced by the core resilient attributes of;

- Coping: process of 'cognitive and behavioural efforts to manage psychological stress' (Lazarus, 1993, p.237).
- Hardiness: having the traits of commitment, control and challenge (Maddi, 2013)
- Self-concept: a trait, 'a person's perception of himself' (Shavelson, Hubner, & Stanton, 1976, p.441).

Hicks and Conner, (2013, p.7) produce a definition of resilient ageing as follows, "...a process an older person endures beyond physical, psychosocial or cognitive adversity, through protective factors that influence the attributes of coping, hardiness, and self-concept, in the person's quest towards quality of life." Resilience in the elderly population is seen as a process, which is influenced by environmental and personal factors. Interestingly evidence from recent childhood resilience research is citing environmental or contextual factors as being crucial in effecting resiliency (Ungar, 2011). This switch to a context-based perspective of resilience away from a trait or personality focus raises the prospect of establishing mechanisms for change that can foster and support resilient behaviours. Ungar, (2011) describes the processes of navigation and negotiation as key factors in resiliency. Navigation being the ability to access resources that are supportive, together with negotiation or the contextualisation of these resources to best meet their individual needs. This theoretical analysis emphasising the importance of the environment, provides a basis for designing and directing interventions or services for those in need that activates resilient behaviours. The key issue is the identification of the mechanisms that can foster these outcomes within defined contexts.

One contextual resource of importance to care-recipients is that of the family and a spouse or partner, so maintaining family or couple resilience is important.

In relation to families Zaider and Kissane, (2009) have summarised some of the components associated to family resilience. In the face of a major disruption the family needs to adapt and cope with the stressors (Rolland, 1994), as such Zaider and Kissane (2007) describe resilience within families as "...essentially a relational event, in which acts of connection and collaboration take centre stage" (p.70) Family resilience focuses on several interlinked processes that are associated with the family's life-cycle stages. The processes include family flexibility in their reaction to stressors, open communication patterns, shared time and leisure, and shared routines and rituals such as anniversaries (Black & Lobo, 2008). In relation to spousal couple resilience Badr, Acitelli, and Carmack Taylor, (2007) conducting a survey on participants with chronic diseases and their spousal carers measuring a range of problems including mental health, couple identity, primary/secondary stressors, and carer stress. Of the 92 carer participants there was a relationship between the couples' who saw themselves as a couple rather than an individual within the relationship and they showed a positive association between self-esteem and capability with better mental health scores. This mutuality links with couple resilience and dyadic coping in which there is "...interdependence of the spouses, their common concerns, and their mutual goals - stimulate a joint problem-solving process and common, emotion-focused coping" (Bodenmann & Randall, 2012, p.33).

Developing the resiliency of family carers in stroke Haley et al., (2009) conducted telephone interviews with 75 stroke family carers, eight to 12 months' post-stroke and identified that 90% of the carers had an increased appreciation of life through feeling needed and appreciated. In a more recent study utilising the same cohort of stroke participants Roth et al., (2013) in a large epidemiological analysis of 3,500 stroke caregivers using a propensity-matched sample of non-caregivers and a proportional hazards model failed to identify any caregiver subgroups (including those who were stressed) with increased rates of death as identified in an influential study on dementia family carers by Schulz and Beach, (1999) whose participants' suffered a 63% higher mortality rate than non-carers. Roth et al., (2013) reported that stroke family

caregivers had an 18% reduction in death rate compared with non-caregivers. This study can be critiqued in that the stroke caregivers demonstrated a range of caregiver burden and stress, together with limited time-scale of caregiving. Also, the care-recipients were not homogeneous in severity of cognitive impairment, and the researchers looked at mortality rather than morbidity, which does not have a linear relationship with mortality. Of interest however, is that the study did not measure couple or family relationship processes or functioning as a variable, this aspect given the forgone discussion leaves several questions of why these stroke carers showed better mortality figures? In a telling quote from their discussion Roth et al., (2013) state the following, "...when caregiving is done willingly, at manageable levels, and for individuals who are capable of expressing gratitude, it is reasonable to expect that health benefits might accrue in those situations" (p.1577), which links back to Schultz et al (2000) discussion on altruism.

A further aspect of strength-based assessment that requires clarification is the concept of post traumatic growth (PTG) and its relationship to resilience. (Tedeschi & Calhoun, 2004) define PTG as "...positive psychological change experienced as a result of the struggle with highly challenging life circumstances or traumatic events" (p.1). Both concepts have similar perspectives but resilience is seen as being present throughout the disruptive experience, whereas PTG occurs following the experience, as a result of grappling with the trauma, which then may result in future resilient behaviour when adversity strikes again (Hallam & Morris, 2013). In a recent survey, Hallam and Morris (2013) gave a postal questionnaire to 71 stroke family carers who were looking after a relative 18 months post-stroke. The questionnaire had several scales including the Barthel index, post-traumatic growth inventory, multi-dimensional scale of social support, the rumination and adult carer quality of life scales. Findings showed that PTG was demonstrated by the stroke family cares and were related to meaning making and reflection or ruminating on their situation. Hallam and Morris, (2013) recommend that service providers need to reinforce this positive reflection through active listening, and a narrative approach to management through exploration of narrative diaries.

5.6.5: Initial mid-range theory

The above frameworks, altruism, family lifecycle, illness as narrative and resilience can now be formulated into an initial theory:

'If family carers and stroke survivors are to be supported in the longer term, leading to reduced carer burden and stroke survivor stress, health and social care providers need to recognise the contextual nature of stroke recovery that depends on the relational nature of family caring, the interruption in the family's life-story requiring a re-negotiation of autonomy and role, including an appreciation of the resilient nature of family adaptation'.

5.7: Surfacing initial CMO configurations

These next sections will surface initial CMO contingencies from the realist synthesis of systematic reviews of stroke interventions (chapter three) and the initial couple interviews of stroke survivors and family carers (chapter four). Realist principles provided the conceptual tools to explore the 'black box' of these complex interventions. The realist approach focusses on certain mechanisms that may be considered key in achieving intervention aims. These mechanisms are linked to specific contexts derived from the realist review and couple interviews that are then tested and refined in the subsequent couple longitudinal interviews and health care professional focus groups.

5.8: CMO contingencies derived from the realist synthesis

5.8.1: Bhogal et al., (2003)

The review by Bhogal et al., (2003) identified improved mental health scores for stroke survivors and reduced family carer burden through active involvement of participants in educational-counselling interventions. These interventions enhanced feelings of mutual support and goal-direction amongst stroke survivor and family carer. The counselling approach that incorporated the family also improved stroke survivor mental health through enhancement of perceived

emotional provision from family carer involvement in the rehabilitation regime. Providing leaflets or generalized information to stroke survivors or carers did not improve any outcome measures because of the failure to elicit personal relevance or involvement in the information provided. Studies that focus on maintaining good family functioning, through improved understanding and communicating of needs improve the quality of life for both stroke survivor and family carer. These interventions help to generate mutual support and improved appreciation of concerns between couples.

5.8.2: Lui et al., (2005)

The review by Lui et al., (2005) identified a range of studies, from RCTs to a case study of stroke carer interventions, however the interventions chosen were based on problem solving approaches. The reviewers concluded that problem solving interventions especially via telephone improved caregiver problem-solving/coping abilities and reduced depression. However, there was no reduction in perceived stress or burden. The teaching of problem-solving skills via telephone enhances family carer self-efficacy in dealing with stress. Moreover, health professionals with a positive and supportive attitude to their coaching inspire in family carers and stroke survivors an optimistic approach to their condition that improves overall mood. A supportive attitude by professionals to both family carer and stroke survivor can also enhance self-esteem in the carers and increase self-efficacy in the stroke survivors that again improves depression. Providing a collaborative basis for problem identification and goal setting evokes feelings of control over their care management that improves problem-solving abilities.

5.8.3: Visser-Meily et al., (2005)

The above review focussed on four different types of interventions that addressed stroke family carer outcomes. The overarching conclusion from the reviewers was that there is insufficient evidence to infer the efficacy of stroke family carer interventions. However, Visser-Meily et al., (2005) identified that counselling based programs directed at the carer did indicate benefits in terms of stress and perceived burden. Directing interventions that help stroke family

carers improve their coping responses modifies their perceptions of the situational tasks to more optimistic attitudes and builds an increased sense of self-esteem as their individualised needs are considered by the health professionals. Likewise, tailoring educational content to carer needs at time of stroke incident triggers a sense of being involved in the caring partnership providing a degree of control and self-efficacy that results in improved family caregiver mental health.

5.8.4: Brereton et al., (2007)

The studies reviewed by Brereton et al., (2007) centered on interventions that wholly targeted stroke family carers (spouses and siblings). Despite the poor quality of the RCTs the reviewers identified some positive benefits. The educational/counselling intervention strategies improved family functioning through elicited understanding and tolerance in the carer of the stroke survivor's behaviour and condition because of the stroke. Equally, targeting the stroke family carer through skills training interventions enhanced self-efficacy by increasing the carer's capabilities in responding to their relative's needs that resulted in greater satisfaction increasing the carer's general sense of well-being. Having health professionals' tailor or focus on the needs of stroke family carers' boosted their feelings of self-esteem through recognition of their contribution to their relative's care, again improving their sense of well-being. Studies that utilised support group interventions may not have activated sufficient comparison effects in the family carers that accounted for the limited improvement in well-being.

5.8.5: Lee et al., (2007)

The overall conclusion tendered by Lee et al., (2007) was an improvement in family carer mental health as measured on the SF-36. The meta-analysis was based on four interventions, two studies having structured psycho-educational programmes with the other two using a social problem solving programme delivered close to the stroke incident. However, two of the studies (Grant 2002; Mant et al., 2000) had positive results in their analysis, but the other two studies (Rogers et al., 1999; van den Heuvel et al., 2002) had non-significant statistical

results. These four studies will be discussed in greater detail later in this chapter as they represent some of the intervention studies referred to most in the systematic reviews covered.

This positive outcome of improved mental health for family carers in the meta-analysis, given the degree of heterogeneity between the studies was achieved through tailoring the intervention to the perceived needs of the family carers. This process was a feature in all the four studies and indicates that tailoring interventions trigger a sense of control in family carers that enhance their self-efficacy in dealing with the short-term consequences of stroke on their relative, thus leading to improved mental status.

5.8.6: Eldred and Sykes (2008)

Eldred and Sykes (2008) concluded that short term interventions based on skill and educational/counselling interventions for stroke family carers can achieve better family functioning delivered via telephone either individually or to groups. In the short term these interventions activates greater self-efficacy in the family carer over their caregiving tasks and the triggering of family carer reappraisal of their situation providing greater perceived control over their emotions.

5.8.7: Smith et al., (2009)

The main result from the Smith et al., (2009) Cochrane review on information and educational interventions in stroke showed that active involvement of the family carer and stroke survivor generated a small improvement in their knowledge about stroke and overall satisfaction. This intervention would enhance family carer self-efficacy and triggered a sense of self-understanding in the stroke survivor of the effects of stroke on their functional and emotional responses. Likewise, the improved stroke survivor depression scores would have amplified in the stroke survivor perceived social support from the family carer.

5.8.8: Ellis et al., (2010)

The secondary analysis showing that nurses as a professional group impacted on patient depression suggests attributes of delivery style rather than content. A positive and flexible manner by the nurse support worker linked to their legitimacy in stroke rehabilitation elicits hope and optimism for improved recovery in stroke survivors. The support of the liaison worker generates greater feelings of self-esteem in the carer as there is recognition of their input, resulting in satisfaction with the service. Provision of social support visits over a longer timeframe would reduce the feelings of social isolation through development of therapeutic relationships that affirms stroke survivor and carer self-worth. The reduction in dependency and death in stroke survivors with mild to moderate difficulties garners feelings of security in the stroke survivor and family because of the 'monitoring' or 'surveillance' function of the liaison worker. Within this context, the liaison worker would be able to identify deterioration in stroke survivor health and refer for appropriate management

5.8.9: Allison et al., (2011)

This review underlined the wider setting as a factor in limiting the success of the included studies. The lack of cognisance given to the communication networks that surround RCT interventions affect the uptake of the intervention by the participants because primary health staff who encounter the stroke family do not reinforce the message of intervention delivery. Types of communication could be formal, where mechanisms would involve knowledge sharing in scheduled team meetings with primary care staff. Informal forms of communication through contact on an ad-hoc basis would engender trust between the primary care team and intervention personnel.

5.8.10: Legg et al., (2011)

Generally, the authors demurred from supporting the practice of using non-pharmacological interventions for stroke carers, mainly due to limitations of study design. One included study did show that skills training provision for the family carer reduced their perception of stress, and the intervention may have

triggered greater mastery in dealing with instrumental tasks, thus increasing self-efficacy.

5.8.11: Forster et al., (2012)

The main result from the Forster et al., (2012) Cochrane review, are unchanged from the Smith et al., (2009) review discussed above and reiterated here. The purpose of the review was to assess the effectiveness of information and educational interventions in stroke and showed that active involvement of the family carer and stroke survivor generated a small improvement in their knowledge about stroke and overall satisfaction. This intervention would enhance family carer self-efficacy and triggered a sense of self-understanding in the stroke survivor of the effects of stroke on their functional and emotional responses. Likewise, the improved stroke survivor depression scores would have amplified in the stroke survivor perceived social support from the family carer.

5.9: CMO contingencies derived from the interviews

The emergent CMO configurations from the initial couple interviews are also highlighted in 'what is it about a programme that works (or not) for whom, in what circumstances'. From the analysis in chapter four, the developed themes illustrated in figure 5.4 correspond to some of the identified issues raised in the realist review of stroke intervention studies.

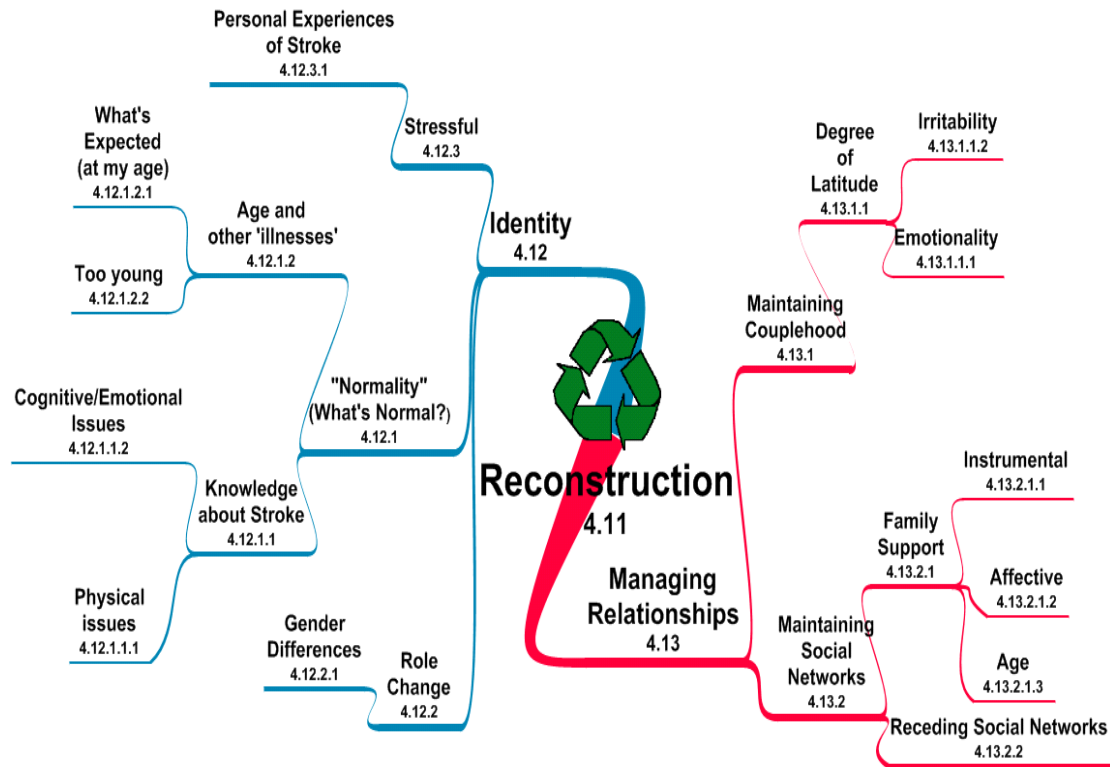


Figure 5.4: Themes from first couple interviews (discussed in chapter four)

The couple interviews had specific participants in that all were spouses (or long term partner Ian and Katie), as compared to the systematic reviews which were heterogenic and included spouses and adult children.

5.9.1: Changing perspective from family to spousal carer

It was through the development of the initial programme theory and the analysis being dependent on spousal perspectives, rather than the more generic main family carer that changed the narrative thread of the thesis from families to couples. This focused down the CMO contingencies, which from a realist perspective was beneficial for the delivery of a more specific programme theory. However, the emergent CMO configurations would only apply to spousal couples, as the familial context surrounding relationships between spouses and those between parents and children are distinct.

5.9.2: Inclusion of spouse in stroke related management

From the interviews, it was clear that little tailored information and minimal support had been provided at hospital discharge. The information that was given were leaflets from the stroke association, which none of the participants could remember. The source of professional advice following discharge from hospital was the general practitioner (GP), who was held in high regard by stroke survivors and their spouses. Those GPs who managed the stroke survivor also included the spouse in their discussions, which was appreciated by the participants. In contrast hospital related appointments tended not to include the spouse, which was a source of concern as the spouse felt excluded since the stroke affected them as much as their partner. These feelings echo the literature in that stroke should be considered a 'family affair' and as such a therapeutic triangle of care ought to be the norm (Rolland, 1994).

5.9.3: Gender perspectives

There were clear differences in the way female stroke survivors and spouses perceived their role and the changes brought about by the stroke. Female stroke survivors still felt responsible for family domestic provision and broader family functioning, whereas male stroke survivors felt able to relinquish previous family roles. This brought added stress to the older female stroke survivors as they struggled to come to terms with adapting to their stroke and still 'looking after' their partner through a traditional family role model. For the female participants (stroke survivors and carers) it was the extended family (especially adult daughters) or close friends who they turned to for emotional support. The spousal carers (male and female) were anxious about their partner's changes in cognition or behaviour and inability at times to differentiate between what could be stroke related and age related, with many couples blaming changes on growing older.

5.9.4: 'Timing it right'

The education and information that the couples require changes as the immediate rehabilitation period comes to an end (approximately 6-months post stroke). From the interviews, there was an indication that the emotional and

relationship issues between the couples were more important than physical functionality, these elements of stroke adaptation were not raised by health care professionals, including GPs.

5.10: What works? for whom? in what context?

Table 5.4 describes possible CMO contingencies that may be operating when delivering supportive interventions for stroke families, especially spousal couples. Each element does not stand alone and is envisaged as a 'package' of contexts and mechanisms that should be delivered to the couple in adapting to their stroke. However, the focus of the interventions would change as the couples' progress from the acute to long-term life with stroke.

What works?	For whom?	How?	In what circumstance?	Outcomes
Active and targeted problem-solving and skills training sessions (basic nursing skills)	The couple	Generates feelings of confidence/self-efficacy and being valued by the HCP	If delivered over 5-9 sessions over a 3-month period post-stroke	-improved engagement with treatment -improved mental health -reduced family carer burden
Tailored counselling or psycho-education strategies in partnership with the couple including guidance on stress coping recognising differences in emotional needs related to gender	The couple	Generates tolerance to the SS predicament	Initiated by HCP through preliminary face-to-face meetings with the couple and then continued by telephone and/or e-mail over longer term	-reduced depression -improved family functioning -reduced stress
HCP recognise changed family roles and circumstances including changes in SS behaviour and cognition due to the stroke and include the spouse in care management decisions	The couple	Enhances feelings of mutual support, affinity and understanding between SS and spouse	Delivered by HCP, at the appropriate stage in the stroke trajectory meeting the continued needs of the couple.	

Table 5.4: What worked, for whom, how and in what circumstances?

5.11: Conjectured CMOs

From the above analysis, it is now feasible to develop conjectured CMOs that attempt to explain how supportive interventions provided by H&SCP can help stroke couples obtain a better quality of life. The process of developing conjectured CMOs in a realist evaluation approach is through abduction, already described in chapter two, but in summary it is a method by which individual observations, such as results from qualitative interviews or data from a structured survey are linked to a more general and theoretical understanding of social reality, dependent on theories as mediators for deriving explanations. Within this study, the linking of the realist synthesis, conceptual frameworks and initial couple interviews.

5.11.1: Conjectured CMO¹

Context: service provision that recognises the importance of a family based approach to rehabilitation

Mechanism: engenders feelings of empowerment between the couple

Outcome: reduced family stress

5.11.2: Conjectured CMO²

Context: health and social care professionals need to attend to the changed domestic roles and responsibilities between the stroke survivor and family carer, taking into consideration the gendered nature of the change, tailoring information to meet needs and concerns throughout the rehabilitation process.

Mechanism: generates self-efficacy and confidence in the stroke survivor and family carer

Outcome: leads to improved engagement in therapeutic treatments

5.11.3 Conjectured CMO³

Context: health and social care practitioners should provide emotional, and problem orientated support to the stroke survivor and carer, focussing on issues related to changed cognition and behaviours of the stroke survivor

Mechanism: kindles a sense of coherence and meaning in stroke survivors and family carers

Outcome: builds greater resilience, reducing the stress and anxiety experienced by couples

5.11.4: Conjectured CMO⁴

Context: maintaining long-term (over six months), professional contact with the stroke couple through use of telephone and on-line communication

Mechanism: prompts feelings of perceived social support

Outcome: Improves family wellbeing

5.12: Conclusion

Validity and reliability within realist evaluation was discussed, using TAPUTAS as a way of addressing rigour in realist research. Four conceptual frameworks on caregiver support were discussed and emerged into an initial mid-range theory. Four conjectured CMOs that attempt to explain how supportive interventions provided by H&SCP can help stroke couples obtain a better quality of life was articulated from the critical literature review, the realist synthesis and the preliminary couple interviews. The next chapter discusses the methods employed for the second phase of the study that refines and extends the initial programme theory

CHAPTER SIX: Methods

6.1: Introduction

This chapter details the methods that were used to refine and extend the conjectured CMOs outlined in chapter five that explain how programmes work in supporting stroke couples in the community. In this study, the initial programme theories were developed through an examination of the broad literature in the critical review (chapter one), the realist synthesis of systematic reviews that analysed interventions that support stroke families (chapter three) and the initial stroke couple interviews (chapter four). Refining the CMOs was achieved through an iterative approach that alternated between longitudinal couple qualitative interviews (LQI) and four focus group interviews consisting of health and social care professionals (H&SCP) from four different stroke units, together with one focus group with RELATE (originally the National Marriage Guidance Council) counsellors. The research process for CMO refinement is described in figure 6.1:

The purpose of programme theory refinement in a realist evaluation is to interrogate the theory through collecting empirical data from a variety of sources that potentially could comment about the underlying theories. Realist theory proposes that different stakeholders have distinctive information because of their singular roles in the program (Westhorp et al., 2011). As Pawson and Tilley (1997) state "...the goal has never been to construct theory per se; rather it has been to develop the theories of practitioners, participants and policy makers" (p.214). In this study, the stroke families are interviewed for their long-term perspective of living with stroke and experiencing the interventions delivered by H&SC professionals; whilst the stroke professionals have a view on service provision in day-to-day practice. Through this iterative process of couple interviews followed by service provider focus groups, the conjectured CMOs could be developed leading to a refined programme theory. This process also triangulates the data that promotes an understanding of the reasons for the complexities of that reality.

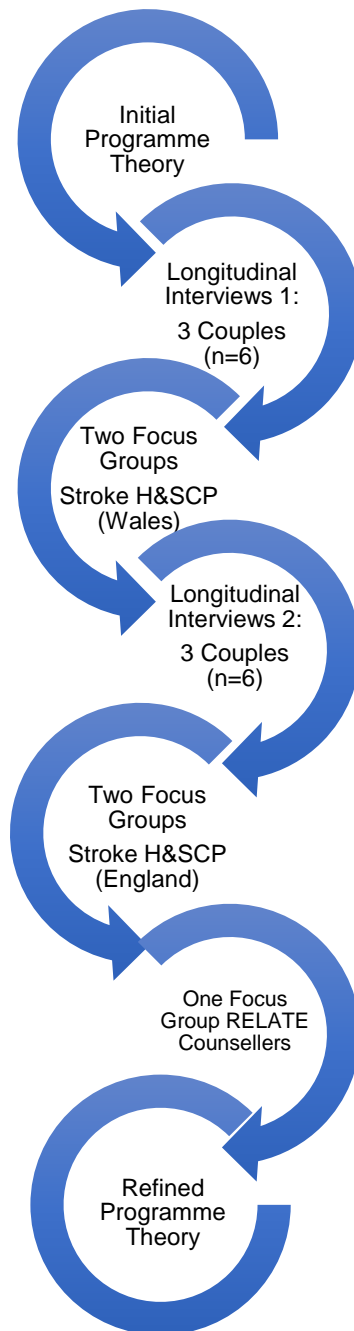


Figure 6.1: Research process flow chart for initial programme theory refinement

6.2 Qualitative longitudinal research

The ontology and epistemology of qualitative research has been discussed in chapter two of the thesis. In this section, the justification for applying a longitudinal method to the collection of data within a realist evaluation approach is articulated. According to Sobh & Perry (2006) the choice of methods used to collect data have to be linked to the ontology and epistemology of the overall

research paradigm. The three elements (ontology, epistemology and methodology) need to be aligned to provide coherence for the research design. For critical realism, it is the acknowledgement of the combined effects of underlying social structures and mechanisms that result in imperfect patterns of experience that are contextually contingent. Within this study, it is the intention to develop and refine programme theories about which mechanisms may work for spousal carers of elderly stroke survivors to improve life satisfaction. From an ontological perspective realist researchers view 'social reality' as pre-existing but with many different human perceptions of that reality, including the researcher's, so within the research paradigm, they enter data collection with prior theories (ontology). So realism research has to develop a "*family of answers*" that covers several contingent contexts and different participant perspectives, which lead to a 'cumulative' set of answers, or '*partial truths*' rather than absolute or definitive conclusions (Pawson and Tilley, 1997, p. 152; Pawson, 2013, p.192).

Murray et al., (2009) support the use of interviewing patients with chronic conditions over a sustained time line, providing among other benefits, better understanding of changes in illness experience, and deeper relationship between researcher and participant facilitating trust when confronting sensitive issues. Indeed Murray et al., (2009) consider serial interviews the best approach at evaluating complex processes within health evaluation. Farrall (2006) defines qualitative longitudinal research (QLR) as "...a range of mainly in-depth interview-based studies which involve returning to interviewees to measure and explore changes which occur over time and the processes associated with these changes" (p.2). He goes even further, linking Pawson & Tilley's (1997) view of structure and agency via structuration in realist evaluation and the ability of QLR to render the processes involved. Structuration was developed by Giddens, (2009), and accounts for social life by suggesting human action and social structures are connected to each other, and it is the replication of the activities of individuals that reproduces these social structures.

Corden and Millar (2007) envisage QLR as concentrating on how individuals change over time within complex settings, which is an important issue in current policy debates, where behaviours are seen as the focus of intervention to achieve policy aims [UK Government's Behavioural Insights Team, (Team, 2010)]. Using QLR provides a means of accessing the relationship between the stroke survivor and spouse over time, and enabling insights into how the couples explain and reflect on their stroke experiences. This study seeks to understand the complex social processes occurring between stroke couples, identifying causal factors that reside within social relationships that enable the development of middle-range theory relating to the successful implementations that can reduce family carer burden and improve stroke survivor care. The aim is for the findings from the QLR to inform the development of a 'programme specification' to establish the objective of identifying what works, for whom, in a particular set of circumstances. Pawson and Tilley (1997) propose that the aim of data collection in realist evaluation is to capture those elements of the participant's understanding that are relevant to the researcher's theory. Since data collection is theory led within realist evaluation there is little relevance in gathering participant life histories or narratives per se, but rather to capture which aspects of participants' beliefs are relevant to the context-mechanism-outcome configurations being tested. However, as QLR is well suited to accessing subtle and sensitive information about how stroke couples behave and adapt, then descriptive, life-course narrative have to be a part of the process, especially during the initial dyadic interviews to establish rapport and trust at the very least (Holland, Thomson, & Henderson, 2006; S. a Murray et al., 2009). Within this study, subsequent couple interviews drilled down towards the programme theories, refining the CMOCs and moving away from initial life narratives and towards a realist approach to the interviews.

Pawson & Tilley (1997) developed a way to view realist interviewing that is described in figure 6.2, involving two features of data collection; the "*teacher-learner function*" and the "*conceptual refinement process*" (p.165). In the teacher-learner phase the researcher asks questions that reflect the CMOCs

(chapter five), while the refinement phase allows stakeholders to comment on the concepts raised.

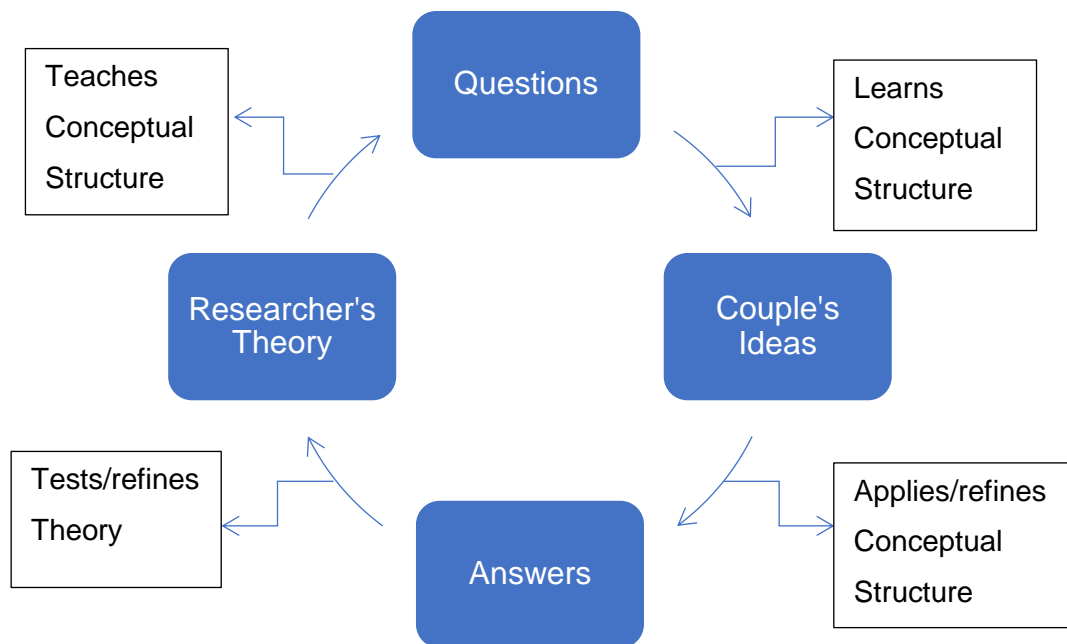


Figure 6.2: Structure of realist interview (Pawson & Tilly, 1997, p.165)

In realist interviewing it is the programme theories that drive the process and is therefore researcher lead unlike constructivist accounts that have a heavy emphasis on what the participant sees as important. In the teacher/learner mode the researcher explains the elements of the programme theory to the participant to the extent that they are aware of the concepts so that they can tell the researcher how they apply in their situation (Pawson & Tilly, 1997). For the conceptual refinement stage the participants then articulate their attitudes and thinking towards the elements of the programme theory that either agrees or disagrees with the researcher's interpretation. It is here according to Pawson and Tilly (1997) that "...conditions for mutual understanding to emerge" (168).

6.3: Data collection

The issue for this part of the study is how to present the conjectured CMOs to the stroke couple in a way that is meaningful to them. Pawson and Tilly (1997) see this process as evident in that asking clear questions to participants usually

provides an honest answer. This process is applicable to the service providers who participate in the focus groups but it is less clear if this technique will apply to the stroke couples. Following discussion with the supervisory team the idea of centre stage diagramming was decided upon (Williams & Keady, 2012).

6.3.1: Centre stage diagramming (CSD)

CSD is a technique developed by Williams and Keady (2012) that allows participants to be equal partners in life-narrative research. CSD was developed in response to Charmaz's, (2006) critique of Glazer and Strauss, (1967) classic grounded theory method. In classic grounded theory, the idea is to develop mid-range theories from empirical data that are overlaid with sociological theory, as such it is the researcher's analysis of the theory which is paramount rather than the participants who supply the data. However, Charmaz (2006) saw dangers in this approach and intimated that the participants should have equal status in theory development. To this end, Williams and Keady (2012, p.218) devised the CSD approach to elicitation of such co-produced data, through a visual mapping of participant thinking. CSD involves the researcher asking two interlinked questions 'i) *what* is the centre stage storyline in the lived representation of the phenomenon under study? and ii) *who* is centre stage in that lived experience?' The 'what' and 'who' are then depicted on a large blank sheet of paper representing a theatrical stage where the participants can place the concepts or elements that are of concern to them at the centre of the stage and other concepts are relegated to the wings. Williams and Keady (2012) used their technique with patients living with late stage Parkinson's disease (PD) over a series of longitudinal meetings to gain a perspective of how changes in their condition affected their lives.

6.3.2: Procedure

For the realist interviews with stroke couples, the CSD was presented to the couple in an adapted fashion. Instead of the couple devising concepts on a blank sheet of paper, the researcher presented them with a sheet that already contained the elements of the conjectured CMOs described in chapter five and

depicted in figure 6.3. The CMO elements are located at the edge of the stage with only the stroke survivor and spouse depicted in the middle of the stage.

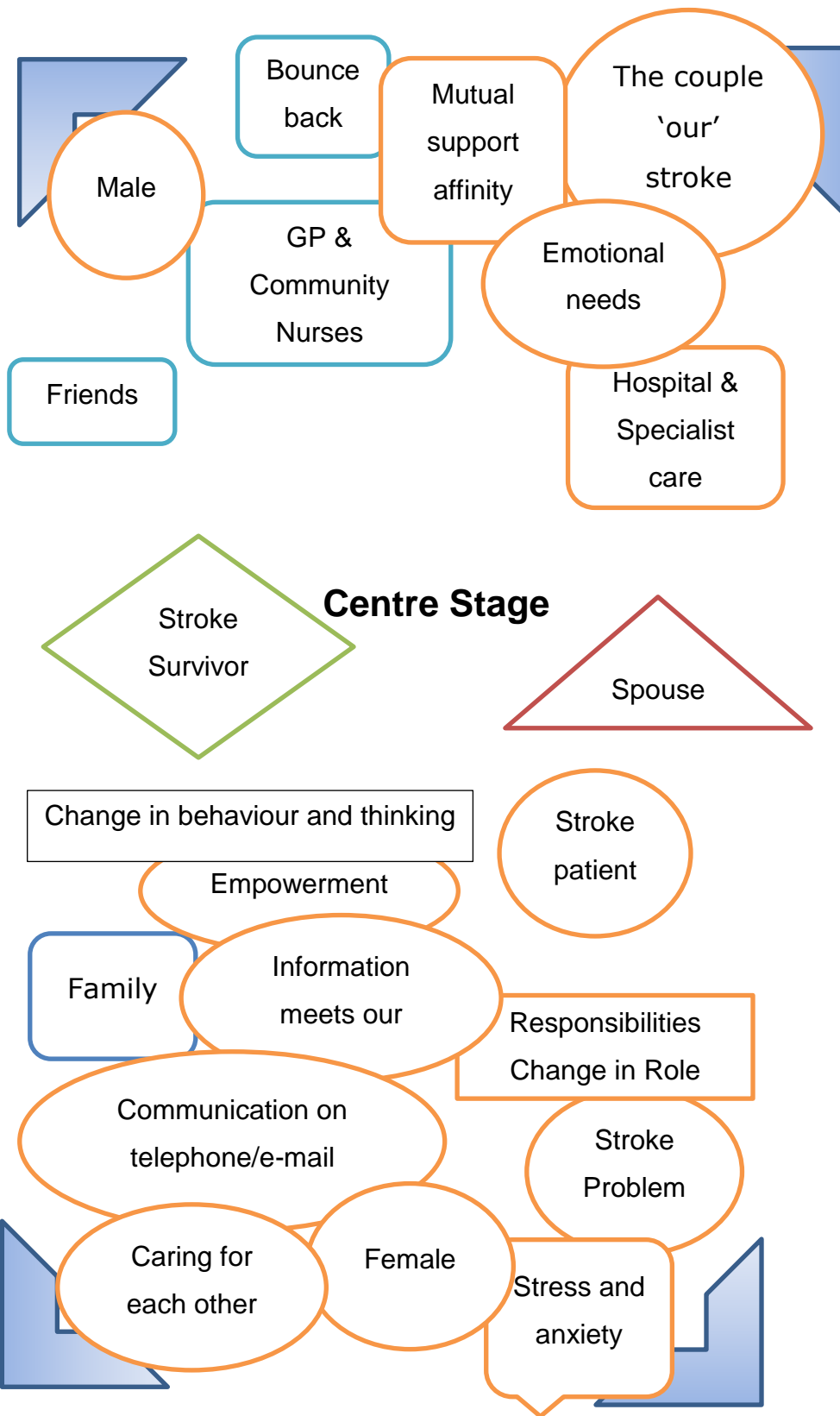


Figure 6.3: Template for Centre Stage Storyline

Blank A3 sheets of paper were used to explain the elements that made up the programme theory. Once the couple understood the conceptual structure the researcher asked them to arrange the elements that related to their situation explaining why they positioned the elements as they did. In practice the researcher drew the elements on the A3 paper where the couple indicated. The interview was also audio-recorded. This procedure was carried out with all three couples at both interview points.

6.3.3: Participants

Of the original six couples who participated in the initial interview, only three couples consented to carry on with two further interviews: Mary/John, Martha/Jim, and Dennis/Helen. The other three couples did not want to continue for several reasons. Ian and Katie the youngest couple were not traceable, and contacting their GP indicated they had moved from the area to another practice. Mark and Sally did reply to the initial letter, but declined as they were moving to the south of England to be near their daughter. The final couple Maggie and David did not want to continue and this was conveyed through a letter from their GP.

6.3.4. Ethics

Ethical approval for the couple longitudinal interviews was obtained from the local ethics committee. The ethics committee agreed to the longitudinal interviews on the proviso that the stroke survivors' GP was contacted before an approach was made to the couple to ascertain their suitability to continue (appendix 6.1 and 6.2). Each couple were sent participant information sheets and consent forms (appendix 6.3 and 6.4)

6.3.5: Data analysis

Data from the couple interviews were transcribed and uploaded onto ATLAS.ti software (Friese, 2012) to help organise the analysis. Following this, the transcripts were read several times to become familiar with the data. Realist research is about underlying contexts and mechanisms, its analysis is not a technical process consisting of coding verbatim text, and it is an iterative

process looking for 'nuggets of information' (Pawson, 2006) that can help refine the conjectured CMO configurations. Because of this, analysis of the centre stage diagrams and related interviews with the couples needed to reflect the initial programme theories, and so template analysis was chosen as a method to code the transcripts (King, 2000). A fuller description of template analysis is provided in section 6.7 below as this was also the approach chosen for the stakeholder focus groups.

6.4: Focus Group as method

To further develop the initial programme theory as outlined in chapter five, Green and Thorogood, (2009) describe a focus group as an "...assemblage of people who come together (6-12 participants), guided by a facilitator to discuss a specific topic of interest to the researcher" (p.127). The focus group has been a stalwart of qualitative health research (Ryan, Gandha, Culbertson, & Carlson, 2013), as a way of engaging group interactions and, within this phase of the study to locate further programme theories. Morgan and Bottorff, (2010) identify several uses for focus groups including the generation of ideas and issues with a service or programme.

In this study, the focus groups comprising of H&SC practitioners were constituted as heterogeneous convenience samples as this was pragmatically the only way to obtain a group of H&SC professionals in an efficient manner. However, as the four H&SCP focus groups were recruited from different stroke teams from two health care organisations, two based in north Wales and two located in southern England, there would be less of a bias.

6.4.1: Sampling

The focus groups were recruited through contacts known to the researcher and as such were a sample of convenience, but also purposive in that the informants were all experienced stroke H&SC personnel who made appropriate stakeholders to comment on the conjectured CMOs.

Location	Staff
North Wales Stroke Unit 1 n=5	1xNurse (grade 7) 1xNurse (grade 6) 1xNurse (grade5) 1xSenior Physiotherapist 1xSpeech Therapist
North Wales Stroke Unit 2 n=9	1xNurse (grade 7) 1xNurse (grade6) 2xnurse (grade5) 2xHealth Care Assistants 1xSenior Physiotherapist 1xOccupational Therapist 1xSocial worker
South of England Stroke Unit 1 n=11	1xNurse (grade 8) 1xNurse (grade6) 3xnurse (grade5) 2xPhysiotherapist 2xOccupational Therapist 1xSpeech Therapist 1xStroke Family Worker
South of England Stroke Unit n=8	1xNurse (grade 7) 3xnurse (grade5) 2xPhysiotherapist 1xGeneral Practitioner 1xSocial Worker

Table 6.1: Stroke specialist health and social care professional focus groups

6.4.2: Ethics

Research governance agreement was sought and given through the requisite Health Boards and Trusts. The senior nurse in each stroke unit was sent a covering letter, participant information sheet and consent forms (appendix 6.5 and 6.6). Following a two week period the senior nurse was again contacted and when more than four H&SC professionals agreeing to participate, dates

were set and the interviews were conducted in an appropriate room at the location of each stroke team. The consent forms were collected from each participant before beginning the focus group.

6.4.3: Procedure

The two north Wales focus groups were conducted following the first couple interviews, and the analysis from these interviews were incorporated into a topic guide (appendix 6.7). As this is a realist focus group, the researcher used the teacher/learner – conceptual/refinement strategy to obtain clarification from the group participants as to their understanding of the concepts. Pawson and Tilley (1997) view the participant's expertise as being grounded in their experiences of how interventions or policies or service delivery impacts on them, rather than their 'knowledge' of why or how they impact in the wider context. This interpretation is also taken up by Archer (2003) who looks at the critical realist interview as a 'reflexive' account. By reflexivity Archer (2012) means “the regular exercise of the mental ability, shared by all normal people, to consider themselves in relation to their (social) contexts by way of internal conversation” (p.1).

In practice each member of the focus group received a copy of the context and outcomes construct (appendix 6.7) and following a brief introduction to realist methodology, each context – outcome construct was discussed in turn with the researcher facilitating and explaining each set in greater detail. The second set of focus groups located in the south of England were conducted following the final couple interview (figure 6.1).

6.5: RELATE focus group

The final focus group in this study was that involving RELATE counsellors. The rationale for using RELATE is their expertise with couple therapy in the UK. As originally the National Marriage Guidance Council, it is considered the largest such organisation in the world (Butler & Joyce, 1998). In recent years, there has been an increase in its involvement with couples and spouses whose partners have disabling chronic illness, including dementia and stroke. As the

conjectured CMOs were being refined there were clear elements relating to relationship issues between stroke couples. Obtaining the views of experts in couple therapy was a way of acquiring greater clarity as to the programme theory.

RELATE counsellors receive a minimum of two years training, both theoretical and practical leading to a 'certificate in couple and marital counselling'. The therapy framework used by RELATE counsellors is eclectic but is mainly drawn from family therapy and systemic theory (Butler & Joyce, 1998). In general, the therapy process is made up of three phases:

- Phase one is the exploratory stage and is the time when the counsellors gain a comprehensive description of the relationship, identifying areas that may need consideration.
- Phase two is the development of clients' understanding of how their behaviours may contribute to each other's perceptions. It being the therapist's role to 'present the client to themselves'.
- Phase three is the final stage where the couple and therapist work together to operationalise the required changes, including modifying roles and habitual patterns of behaviour, finding better ways to meet each other's needs.

With increasing issues around chronic illness and longevity, RELATE have developed a 'Caring and Sharing' service at some of its locations, where family carers can avail themselves of the trained counsellors to explore their concerns and anxieties.

6.5.1: Procedure

RELATE headquarters were contacted and asked if they would be prepared to allow some of their counsellors who were experienced in dealing with spousal carers or couples who had had a stroke. Following discussion an ethics proposal was sent to the RELATE's educational department for verification. On approval from the department (appendix 6.8), a location in northwest England was contacted as they had experience of counselling couples with chronic

illnesses. A covering letter, participant information sheet and consent forms (appendix 6.9 and 6.10) were sent to the manager of the relevant RELATE centre for distribution to therapists. Contacting the manager after two weeks identified three counsellors prepared to participate in the focus group. The focus group was conducted in a quiet room at the location, with consent forms collected beforehand. The researcher again followed the same format as for the other focus groups with the topic guide distributed to the three counsellors and the researcher facilitating discussion.

6.6: Data analysis

For Pawson and Tilley (1997) analysis in realist evaluation is to identify whether participants' experiences of the intervention progress the identified programme theory, through the interplay between the empirical data and the abstracted conjectures. For this stage of the study the analysis is dictated by the programme theory derived from the realist review and initial couple interviews. To enable this interaction thematic analysis was again employed however, Braun and Clarke's (2013, 2006) version (as discussed in chapter four) was considered too fixed in its development of coding structures, so as to remain close to the data. For the purposes of the analysis at this stage of the study it was important to strengthen a-priori coding, and template analysis provided the means to accomplish a theory-driven evaluation (King, 2000). According to Brooks and King, (2012) "The essence of template analysis is that the researcher produces a list of codes (their 'template') representing themes identified in their textual data...involving a hierarchical structure". (p.1/2) Epistemologically template analysis fits into a realist account of human action through "...the use of strong, well-defined *a priori* themes in analysis..." (Brooks, McCluskey, Turley, & King, 2015, p.205). Using the CMOC template (table 6.4), the longitudinal couple interviews and stakeholder focus group transcripts were analysed to refine the context–mechanism links. The transcripts were examined for evidence that supported or not the presence of each of the context, mechanism or outcome features, listed in the template, in each stakeholder's experience of living with stroke over the longer term.

<p>Conjectured CMO¹:</p> <p>Health and social care professionals need to tailor information to meet needs and concerns of the stroke survivor and family carer throughout the rehabilitation process (Context)</p> <p>Generates self-efficacy and confidence in the stroke survivor and family carer (Mechanism)</p> <p>Reducing anxiety and improved engagement in therapeutic treatments (Outcome)</p> <p>-----</p> <p>Conjectured CMO²:</p> <p>Health and social care practitioners should provide emotional, and problem orientated support to the stroke survivor and carer, focussing on issues related to changed cognition and behaviours of the stroke survivor (Context)</p> <p>Instils a sense of coherence and meaning in stroke survivors and family carers (Mechanism)</p> <p>Builds greater resilience, reducing the stress and anxiety experienced by couples (Outcome)</p> <p>-----</p> <p>Conjectured CMO³:</p> <p>Maintaining long-term (over 12 months), professional contact with the stroke survivor and family carer including the use of telephone and on-line communication (Context)</p> <p>Prompts feelings of perceived social support (Mechanism)</p> <p>Improved stroke survivor and family wellbeing (Outcome)</p>
<p>Conjectured CMO⁴:</p> <p>Health and social care professionals need to attend to the changed domestic roles and responsibilities between the stroke survivor and family carer (Context)</p> <p>Engender feelings of mutuality between couples (Mechanism)</p> <p>Reduced family stress (Outcome)</p>

Table 6.2: Initial template of CMOCs developed from the realist synthesis and first couple interviews

6.7: Conclusion

This chapter detailed the methods used in the second phase of the study, the refinement of the initial CMO contingencies. The next chapter will report on the findings, leading to the refined contingencies.

CHAPTER SEVEN: Findings

7.1: Introduction

This chapter reports on the findings from the couple longitudinal interviews and the service provider focus groups, including RELATE counsellors described in chapter six. The chapter discusses the accumulation (cumulation) of CMO configurations as analysis moves to and from couple interviews to the service provider focus groups. Pawson and Tilley (1997: 115) consider 'cumulation' as a way of focussing down on the CMO configurations. They see this process as a way of overcoming the issue of 'generalisability' from a constructivist and positivist perspective. Constructivists, as detailed in chapter two do not perceive generalisability from their studies as being logical given their ontology of there being no external reality only that which is perceived, which leads to specification of greater detail about the contexts. Alternatively, positivists believe in an external world so generalisation from one study to the large population is their goal. This goal is achieved at the expense of context and relies on successionist causal explanations. Realist evaluation solution is 'cumulation' in which there is a 'transfer of ideas' rather than data from one study to the next, with the organising framework of CMO configuration patterns. These patterns are processed in 'cumulation' through abstraction. Pawson (2013) defines abstraction as "...the thinking process that allows us to understand an event as an instance of a more general class of happening" (p.89). Essentially the process of abstraction and 'cumulation' result in middle-range theories. The next sections of this chapter will give an overview of the couple interviews and focus groups, and then will use abstraction as a method of focussing down on the conjectured CMOs.

7.2: Descriptive findings from the couple longitudinal qualitative interviews

7.2.1 Changes in stroke survivor and family carer

A potential bias within longitudinal research on persons with chronic conditions is the alteration in the illness severity, which can affect cognitive and/or physical

health. Stroke is not a stable condition and there can be further episodes which affect the stroke survivor's ability to participate over the longer term. Coupled with the age grouping of the participant's co-morbidities can also affect the family carer and changing the nature of subsequent participation. However, as Pettigrew (1990) argued longitudinal qualitative research gives a perspective on the process-based and multi-faceted nature of change, the causes and impacts of change across time can be explored. Thus, QLR is about the process of changing - not change as a one-off event (Pettigrew, 1990). So, it is 'change' that is important to analyse in the relationship between the stroke survivor and their main family carer.

There had been changes in two of the couples between the first longitudinal interview and the final interviews. For Mary and John there was a traumatic event in that Mary had another stroke, but this time it was much more severe, leaving her with profound mobility problems and aphasia. Mary's Barthel score of 6/20 as compared to 16/20 at the initial interview. Mary was in a wheel chair and was incontinent of urine, having to use a catheter. Mary's aphasia was problematic to her and hampered the final interview as it was difficult for her include to converse. The other couple whose circumstances changed, though less dramatic was Martha and Jim, in that Jim who was the spousal carer after Martha's stroke was developing vascular dementia that resulted in him being increasingly forgetful and in a role reversal being looked after by Martha. Jim was now not permitted to drive, which had caused issues as the couple lived in a very rural part of north Wales. However, neighbours helped with this and Martha had learnt to use an *iPad* so that she could order groceries on-line and have them delivered. These contextual changes are the reality for stroke survivors and their partners, which is not well reported in the literature.

7.3: Description of Focus groups

The four health professional focus groups consisted of hospital based stroke teams, located in North Wales and South of England. The four units were configured as for delivering acute stroke care with added community support. Three of the units, NWU1, SEU1 and SEU2 extended their services into the community for up to six months, whereas NWU2 provided specialist community

support for the first six weeks following hospital discharge. However, all four units had an acute care orientation in their service provision with long-term management provided by the GP and primary care team.

7.4: Description of RELATE focus group

The three RELATE team counsellors that participated in the focus group located in the North West of England and all had experience with counselling stroke and dementia family carers as they participated in RELATE’s ‘caring and sharing’ service financed by the local council.

7.5: Abstraction of CMO¹

The remainder of this chapter discusses each of the four initial context-mechanism-outcome configurations and their refinement into the final CMOs through the examination of the couple longitudinal interviews, H&SC focus groups, and the RELATE focus group. Each initial and final conjectured CMOs are presented side-by-side in table format, followed by the analysis.

Initial CMO¹	Final CMO¹
Health and social care professionals need to tailor information to meet needs and concerns of the stroke survivor and family carer throughout the rehabilitation process (Context)	Tailoring information and problem-solving strategies in partnership with stroke survivors and their family carers at key transitional stages during the rehabilitation process (C)
Generates self-efficacy and confidence in the stroke survivor and family carer (Mechanism)	Generates self-efficacy, and confidence in the stroke survivor and family carer (M)
Reducing anxiety and improved engagement in therapeutic treatments (Outcome)	Reduces feelings of anxiety for stroke survivor and family carer with improved engagement in the rehabilitation process (O)

Table 7.1: Final CMO¹

The initial CMO¹ identifies the importance of tailoring the information provided by H&SC professionals to the needs of the stroke couples. The CMO was developed from the realist synthesis literature and proved to be a robust intervention strategy (Ghazzawi, Kuziemy, & O'Sullivan, 2016). Tailoring information to the stroke survivor and family as appropriate was also a theme developed by the initial couple interviews discussed in chapter four.

7.5.1: Tailoring information from the couple perspective

Customising information to the needs of each couple was viewed as important, as this quote from Martha and Jim demonstrate:

Martha: yes the doctors and nurses were very good about that (giving information) and they were good with Jim telling him about how I was coming along. You see Jim can't remember as well as he could can you...

Jim: Aye

Martha: They didn't give him too much but enough to make him happy and not worried

Jim's vascular dementia was a great concern to Martha, with his memory problems now preventing him from driving. Asked about how the information she got from the hospital after her stroke helped her:

Martha: well they gave me little tips about how to get out of a chair and bed...and they said if I did these exercises (demonstrated)... I I would be able to get over the stroke quicker...so I did them and Jim helped me didn't you...

From this interchange providing information that the couple could comprehend and understand was important in getting the couples to engage with the rehabilitation process.

John, also saw advantages in obtaining information about Mary's second, more severe stroke:

John: But I think the normal turn round business (in acute stroke ward), even perhaps with a severe case is something like four to six days but because of difficulties of accommodation elsewhere you were in, I suppose you went in for at least three weeks and whilst I was there I determined to find out all I could about the background to this (stroke) and asked to use the medical library. This caused consternation. Apparently nobody has asked to use the medical library previously and I had to get all sorts of agreements that I would abide within certain limits and assure them that it was a genuine enquiry and I was able to spend two or three afternoons in there mugging up on the background to the position we suddenly found ourselves in. Curiously enough it's all come together again this morning when the local GP spotted that Mary is now on Citalopram which she's been on for the last two years ever since this thing started (first stroke) and he said do you really need that any longer and I could vaguely recall enough about these sort of antidepressant drugs from that period and was able to talk with him in an informed sort of way.

This long quote reveals several issues that are addressed in CMO¹ in that John was problem orientated and liked to rationalise issues they faced as a couple, so he may have been atypical in seeking information from the hospital's medical library, but finding information that related to his wife's circumstances did enhance John's confidence in dealing with health professional staff and increased his engagement with his wife's therapy. Asked if the staff in the hospital answered all his queries, John said they did not have the time to go into the detail he wanted to, hence the medical library option. John also admitted he may be unusual in wanting to know so much medical information,

but he had worked as an 'orderly' in a hospital in the past and liked to know as much as possible so he could better help Mary's recovery. Mary's first stroke was not severe, still being able to drive a car, asked if they had been told about the possibility of a second stroke by health care staff, John indicated they had not been told, but now he wanted to make sure that he did not leave anything to chance:

John: you see now I've got much more that I need to do for Mary with this second stroke, and I wanted to do my best so so getting as much information as I can will do this...and the physiotherapist shows me what I can do to get Mary back to standing by-her-self from a chair...she is getting there...

Having full knowledge of how a stroke can affect his wife generated much pride in their achievements as a couple in the eight months following this second stroke:

John: ...I'm very very proud as I've explained to you that we're now beginning to feel our wings and this is both of us in being able to go. Mary went to an old student's reunion this weekend in (place name) for instance and immediately before Christmas we went down to (place name) which is our family home and stayed in a hotel because there was nobody there with a bedroom which was suitable for giving us accommodation but we were able to see a lot friends and this is rehabilitation of a sort... just feeling able, you can get out and visit places.

For Dennis and Helen, also received specific information from their GP about Dennis's speech problem that reassured them as to the cause of his dysarthria that reduced their anxiety:

Helen: ...his speech really, he's hard to understand when people come here we can just wait and like the doctor said that can just pass over...

Interviewer: Yeah. You seem okay now though?

Dennis: yes

Helen: ...yes sometimes it's terrible it goes up and down...we asked the doctor you know and and he said why is this happening? And and he said it was the stroke made the muscles weak in his face and lungs

Interviewer: Is it? It goes up and down does it?

Dennis: Sometimes I can't hardly speak.

Helen: the doctor (GP) said he would try and get a speech therapist to him but said there was a long waiting time...but he said not to talk when he's tired and to talk slowly that helps him...

7.5.1.2: Combined centre stage analysis of CMO¹

The centre stage diagram in Figure 7.1 is a combined illustration from the three couples relating to CMO¹ showing what was important to the couples about tailoring information.

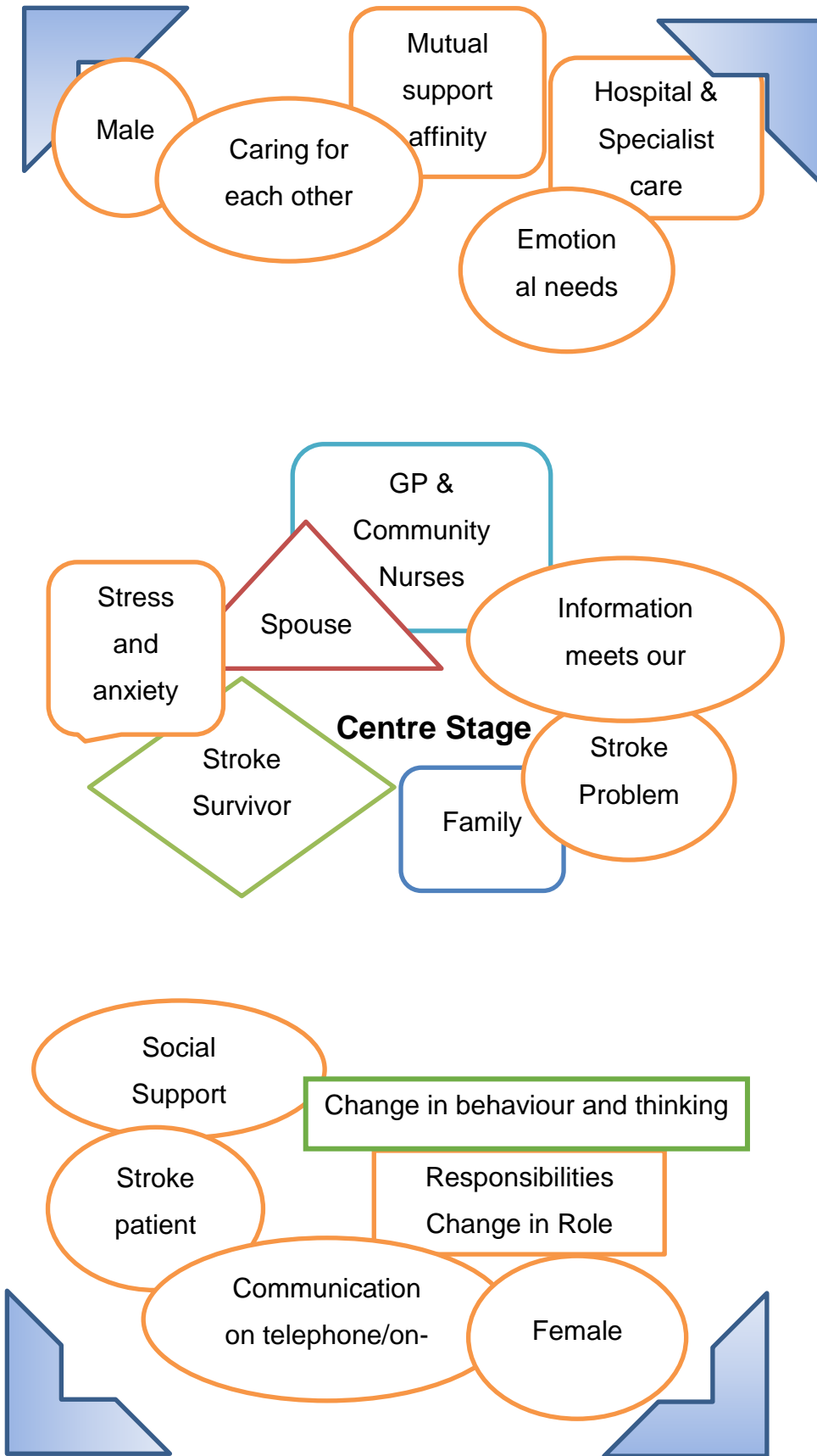


Figure 7.1: Combined couple centre stage related to CMO¹

Overall, the couples appeared to agree that the health care professionals did meet their needs regarding stroke. As will be seen in CMO² most of the information provided was largely medically grounded, addressing and monitoring their physical condition, such as blood pressure, rather than their psychological needs. It was the primary care team who provided information at this stage in their stroke trajectory, and this was even the case for Mary, ten months following her more severe second stroke. Stress and anxiety was still evidently felt by the couples

7.5.2: Findings from the four stroke teams related to CMO¹

The responses to the above CMO¹ configuration of tailoring information for stroke survivor and family carer needs was acknowledged as being an essential function for all team members. They also recognised the anxiety and stress that affected the family of the stroke survivor throughout the hospital experience and their need for information throughout the rehabilitation process:

'That's what I normally do otherwise loads of inappropriate information that they got to wade through...so I take bits out and cross things out depending on the patient so that the therapy becomes something they can achieve...through setting the right goals it builds up confidence' (NWU1: P)

'I think a lot of the anxiety comes from the unknown really and not understanding what's going on and things like that isn't it, I would say you need to try and reassure them and the family'
(NWU1: N)

These quotes represented the sentiments of the other professional focus groups, recognising that the therapy and the information needs to be adapted so that the stroke survivor and family can see gains and recovery through their rehabilitation.

A key context that emerged was the differences between staff who predominantly worked at the acute phase of the stroke in hospital, where the stroke survivor was being stabilised and those professionals who concentrated on longer term rehabilitation when the patient returned home.

'and I think early on some of the medical issues are upfront aren't they...it's all about how are they going to survive? What sort of stroke? What happens etc., the treatment and I think that kind of fades a bit as you go on down the journey, then other things come up don't they?' (SEU1: N)

'I think from my point of view where I go in later and my sort of information and advice that I'm dealing with is very low key compared to what's gone on the hospital and all the medical stuff because I'm helping people with claiming benefits and housing and, I get involved in all sorts of weird stuff but all that stuff is important later on whereas initially none of that is important...' (SEU2: N)

These responses were prompted by the 'uncertainty of prognoses' at this early acute stage where the professionals were aware of the 15% mortality rate for stroke at one month (Lee, Shafe, & Cowie, 2011). This experience influenced the type of information that the professionals were willing to provide but was contextualised by what the patient or family asked the team.

'I mean a lot of it depends on the condition of the patient obviously and how much information they're able to take from what we're saying. Some of them clearly are gonna have, you know they're either communication or cognitively impaired and sometimes they're just so medically unwell that you know they're not in any state to sort of take on board much meaningful information. From the family's point of view we get

asked quite early on, you know are they gonna get better and what's the prognosis which is often obviously very difficult.'
(SEU1: N)

'depends on how bad the stroke is...also what they are asking us at the time as well...It's not generic it's related to them...you've got to make it so the patient and family are motivated to get better unless you can motivate them your therapy isn't going to cut it' (NWU2: P)

The second quote above highlights the way that tailoring of the therapy and information to both the stroke survivor and family is a way of getting them engaged in the treatment regime. Timing of information was also seen as an important factor in tailoring the material given to the stroke survivor and family.

'Information needs to come at different time points as well...although you might want to give lots of information it can be overwhelming...important to give information at the right time point as well' (NWU1: OT)

This perspective from the healthcare professionals leads to issues around information being missed or not given, leading to anxiety for the stroke couples as they are not aware of how the stroke affects their lives in the longer term. For those professionals who worked mainly with stroke survivors once they were home often noted that the stroke survivor and family had forgotten a significant amount of information that they were given when in hospital.

'How much is taken in though then, I'm not quite because sometimes like weeks later we'll get the same questions, so I think it's looking at the time limits given maybe, you know when there's a lot going on' (SEU1: ST)

This was a contextual feature that was apparent for those professionals who were involved in longer term rehabilitation, once the stroke survivor was home. It was at this stage that the impact of the stroke was felt by the family leading to anxiety and stress.

'Yeah. Quite often when they go home it's a bit of a reality check really and there are a lot of things that obviously are dealt with in the hospital that suddenly become, you know we try and anticipate for everything but once they go home, it's a very different reality and there are a lot of things that you can cope with here that perhaps haven't been picked up for the family...' (SEU2: P)

'I had a patient very recently who told me that he was doing really well, having spent nearly five weeks on the unit, came back to clinic, he told me it all going great, his wife then burst into tears and told me how hideous it had been for those two or three weeks because she didn't cope, it completely disrupted her routine and while she loved him to death and wanted him at home she felt as if she wanted to send him back because she wasn't coping with him' (NWU2: N)

A further way that health professionals attempted to tailor information is to describe where in the brain the stroke occurred and how this then affects the stroke survivor so the couple have a better understanding of why certain behaviours happen:

But I think I tend to try and come back to the ... actual, you know, education about what ... what the Stroke's actually done, and so then what features they're seeing and then how that impacts on things, to try and make sense of what they're

seeing as well. So I try and bring it back to that, to ... almost simplify it, say well if this is what's happened to you and this is what's happened to your brain, and then that would be a result of that, and try and make sense of it so it's just ... you know, particularly some of the cognitive issues, I think people often see it as a personality thing, or the ... you know, they're being mean to me, or ... they won't let me sleep, or ... you know, and they find it quite hard to identify that as being to do with the Stroke. So I try to kind of link things back to the ... physiology of what's happened to them I suppose can sometimes make it more manageable for people (SEU2: N)

The professionals, however felt they had to balance being realistic about the stroke survivor's prognosis while also appearing positive, a case of realism tempered with positivity, again to sustain motivation in the rehabilitation process:

...information there's quite a lot of expectation that people reassure almost too much... everything's going to be fine because actually I don't think we're often realistic enough, people say it's gonna be really difficult but that's normal considering what's happened and this is gonna be really difficult like in not in a negative way but to actually say this is normal, that this is gonna be hard, I think that would make the wife feel less like there's something wrong that they're failing.'
(SEU1: N)

'if it's going to be a bad stroke and the outlook not good then we have to be realistic but not too negative...need to give the family some hope but it's a fine line' (NWU1: P)

In conclusion, the stroke professionals were sensitive to providing information and therapy goals that the stroke survivor and family could comprehend as the rehabilitation process proceeded. But they were also aware that issues such as the severity of the stroke and future prognosis being difficult to assess hampered their ability for openness in providing information. This perspective was used to sustain hope and motivation in the rehabilitation process by the stroke survivor and family.

7.5.3: Findings from the RELATE focus group on CMO¹

From the counselling perspective, there was agreement that tailoring of information was essential for the couples. However, in their experience not enough time was taken to allow the caring spouse to 'acclimatise' to their new circumstance because of the stroke:

Yeah, and I think ... I think generally when ... when something like that, when a Stroke happens or when ... when erm, it becomes part of the family system, all the information that's thrown at the carer just goes straight over their head.

Erm, and its ... it takes them quite a long time, in my experience, to ... to get their head around what's happening to them and their partner and how Erm, much things have changed... when we've got them, the ... the carers that I've worked with have just been really grateful to be able to ... almost organise their thoughts...(C1)

Echoing the stroke professionals, timing of the information was central to the process of tailoring and the health care system was not structured to allow this longer-term process to materialise:

And I think it's about timing, the key ... erm, dynamic is timing you need to give them the appropriate information when they are ready for it and this can be some time later...(C2)

...the providers that are out there providing other services, that if the couple don't... take them up immediately then they're kind of ... it feels as if they've lost it, the ... the carer feels right, well it was offered and now ... you know, is it still available? And actually I think some of the response from the people who are providing the care, they ... an assumption is made that the care isn't wanted because it's not taken up immediately... (C3)

I was going to say that I would suggest that rather than waiting for the carer to come back and seek help, that there should be something in place where they are checked on on a regular basis...where the system has something in place that checks up on them assess them you know six months or 12 months down the line... because they would feel valued, they would feel like their needs are ... you know, they're not necessarily having to go out and ask, but someone is coming in and saying 'How are you doing?', 'Do you need some support now?', 'Can we do anything more for you? (C3)

The RELATE counsellors' perspective was on the longer-term provision of information and support and they were aware of the lack of health care provision to provide. Also, due to their specific remit, the counsellors were relating the support from a psychosocial standpoint rather than a functional or medical perspective. As see in CMO² below this was the needs expressed by the couples at their stage in the stroke trajectory.

7.5.4: Summary of CMO¹

All three groupings, the stroke couples, health professionals and counsellors, recognised the importance of providing targeted information and treatment for the stroke survivor and family. Tailoring was achieved through a sensitive assessment of the stroke survivor's severity and prognosis as well as what they and the family asked them. Because of the uncertainty felt by stroke professionals working in the acute phase of the stroke trajectory, they were reticent in how much information they would provide, as they did not want to allow the stroke survivor and family to lose hope about future outcomes. The health professionals needed the couples to gain confidence through achievement of rehabilitation goals, so that they engage with the treatment regime.

7.6: CMO²

Initial CCMO ²	Final CCMO ²
Health and social care practitioners should provide emotional, and problem orientated support to the stroke survivor and carer, focussing on issues related to changed cognition and behaviours of the stroke survivor (Context)	Providing emotional support for stroke survivors and family carers that highlight positive and valued aspects of day-to-day life and relating with reference to cognition and behaviour of the stroke survivor (C)
Instils a sense of coherence and meaning in stroke survivors and family carers (Mechanism)	Instils a sense of coherence, meaning and hope in stroke couples (M)
Builds greater resilience, reducing the stress and anxiety experienced by couples (Outcome)	Builds greater resilience and personal resources with improved life satisfaction (O)

Table 7.2: Final CMO²

7.6.1 CMO² from the couple perspective

In the couple longitudinal interviews using Pawson and Tilly's (1997) 'teacher – learner' interview approach with the centre staging method clearly identified issues related to emotional changes over two years following stroke. Helen had discussed Dennis's mood changes since the stroke in that he becomes irritable and bad tempered when he is unable to carry out certain tasks such as opening a can or water tap. This was in sharp contrast to Dennis's demeanour pre-stroke in that he had a quiet disposition, letting issues 'ride over him'. Health care professionals had not discussed the possibility of mood change because of a stroke with Helen or Dennis, and they had not sought the advice of their GP but it was an obvious worry to them:

Helen: Because you think to yourself oh yes is he going to have another stroke because of this, this is where things happened. You know when he gets in a temper and you think, then you think now will he get another stroke over this sort of thing. But I don't know what's really happened...

Interviewer: nobody talked about mood changes?

Helen: We haven't heard nothing at all¹

Another couple, Martha and Jim also discussed mood changes since her stroke, again she had not been told about the possibility of such symptoms. In part Martha saw it as a sign of her age (84 years), but also it reflected the stress she felt in coping with Jim's increasing forgetfulness because of his vascular dementia:

Martha: I get, you know anxious, well let me give you an instance like this lunchtime I said to him I've been doing those

¹ Following this interview, the researcher indicated that they should see their GP to discuss these mood changes

tablets and they do, they don't get me down but you've got to concentrate all the time. If somebody speaks to me I miss which tablet I've put in, you know and so, and by the time I'd finished and it was about half past eleven, quarter to twelve I went to get lunch and I came in and I said to him will you give me a lift with lunch because I'm tired. And he said yes, didn't you?

Jim: Aye.

Martha: And he came in and he stood at the kettle and he couldn't think what to do. I understand this normally but you see I was getting cross because he hadn't even gone and got the tablecloth. I get cross with him. It's not his fault that I get cross it's something he can't help

Even though the community nurses came regularly to treat Jim's leg ulcer, which had become infected over recent weeks, and the GP visiting every month mainly to monitor Martha's blood pressure. Martha did not broach the issue with the health professionals, and they in turn had not discussed her psychological needs, now as a stroke survivor and 'carer' for her husband. Asked if she would appreciate the GP discussing her anxiety about Jim, she replied:

Martha: I think yes, because they might be able to do something for him that helps, but his age doesn't help at eight-eight...for me I I wouldn't want tablets but talking about things with them might be good...but they are very good to us the doctor has started coming every few weeks, every four weeks to see us which is, has been very good so he's been good too.

This reticence to discuss her anxiety with health staff was partly due to Martha's sense of obligation to Jim as a long-standing married couple of over 40 years,

and it was her place to look after her husband, come what may. The couples in this study were elderly couples, all over the age of 75 years, and age was considered a factor in the mood changes experienced by all the couples. For the three couples, there was limited information provided from health professionals relating to psychological aspects of life with stroke. John identified poor communication when Mary had her second, more severe stroke, and echoes the way health professionals perceive the acute phase of a stroke as a medical emergency, with the psychosocial issues for family and stroke survivor left until this is less uncertain:

John: Well my own feeling is that we didn't really get a great deal of information about how the this stroke would change her... but then there are reasons for that so I wouldn't hold it against anyone particularly. First of all, I found out belatedly that Mary's stroke was considerably pretty bad initially and we were far more concerned with simply getting life processes to continue...

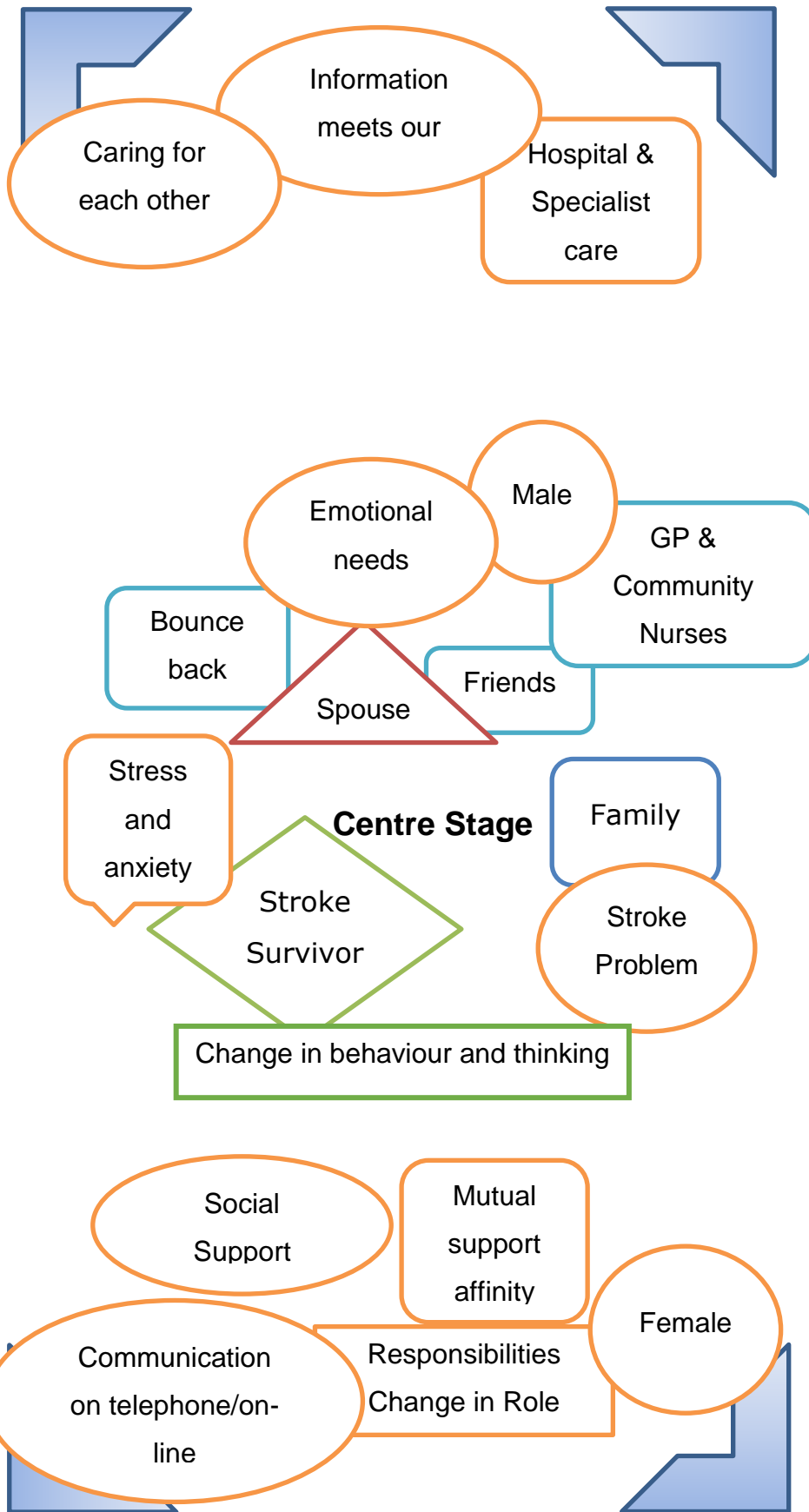


Figure 7.2: Combined couple centre stage related to CMO²

From the combined centre stage diagram in Figure 7.2, the couples, especially the caring spouses had increased anxiety due to the cognitive and mood changes that persisted a long time following the initial stroke. Martha was in a different position than the other stroke survivors in that she was also a 'carer' because of Jim's increasing issues with his dementia. Fortunately, Martha's functionality following her stroke was good but she did admit to mood changes and increased irritability, as was the case for Dennis and Mary. For John, with Mary's second more severe stroke there was an understanding that in the hospital focus had to be on maintaining life. For all three couples, it was primarily their family and close friends who provided emotional and psychological support, which helped them sustain their 'caring' role with their spouse:

Martha: Yes and immediately, immediately I phone one of them when something goes wrong they're here. You know, when Jim fell last time I phoned and it was (daughter's name) that was available then and I said I'm going with dad to the hospital, I'm waiting for the ambulance and she said I'll meet you there there's no question about it, you know? Oh I think I'd be lost without the family support... and I can pick the phone up and moan at them you know...and it lifts you up giving you a boost...

Again, John reiterated how close friends were supportive to the couple, not just with instrumental support but listening to them:

John: Well possibly that backs up this idea of me recognising just how valuable close friends have been. Of course on the other hand as I've said when I found myself up against it I didn't think twice about pussyfooting around and saying we have a little difficulty here would it be possible for you to, I would simply say you've got to help. But then again I think

that's also a measure of the sorts of relationship, I couldn't say to anybody and they did more than get us supplies they also sit and listened to my moaning...

John also showed his problem-solving, and pragmatic approach to the circumstance the couple found themselves in. The literature on gender and stroke highlight differences between male and female carers, with males being more problem or task focussed and female cares being emotional-focussed (Calasanti & King, 2007). John also saw his pragmatic strategy as a way of making sense of the issues the couple were facing.

John: We're we don't seem to have had that many real obstacles really, there are usually ways around them or alternative strategies that we looked for and used these to make sense out of what is going on...

For Helen, her daughter who did not live far, was the one she leaned on for emotional and instrumental support, but she also realised that she could not rely too heavily as this would be unfair burden for her daughter:

Helen: You know like if anything like happens to my husband like you've had two or three sort of things happen, I mean (daughter's name) come, she comes and she phones the doctor. She says right I'll be there now with him, she does, you know, take him straight away then I must say...(daughter's name) is the one that helps me manage I couldn't carry on if she was not here she she lets me talk at her and that makes things more normal you know...but I try not to ask them too much just when it's nothing else...they've got their own lives...children to look after

7.6.2: Findings from the four stroke teams related to CMO²

As was seen from the couples' perspective information about stroke and its effects were mainly medically driven, the psychological information and support was limited, particularly in the acute phase. Health professionals recognised there were emotional issues but time and focus on getting the patient stabilised were limiting factors in its low priority:

We have individual meetings with individual families don't we, I mean anybody that's got longer term rehabilitation need we always try and have regular, we call them progress meetings where we bring the patient if they're able to participate but definitely the families and carer together with the team and we discuss how the person is, what their impairments are, what that's likely to mean, you know, what do they feel about the future, have they thought about whether or not they feel they can manage to care for the person, once they go home or if not, what alternative thoughts are they having and then we sort of carry that process on every few weeks or so. So in terms of their needs for help, we probably identify it, emotionally I think that's another matter because...because we really aren't involved with the person in the longer term once they leave here so we're not in a position to be offering ongoing emotional support. We do whilst somebody's obviously in hospital with us and there have been occasions where we've used our colleagues in the Stroke Association who usually offer a postage charge service actually in hospital where we felt there's been a particular need for additional support but we don't really have much contact once they leave the hospital (NWU2: N)

Asked what health professionals thought were potential emotional problems, it was related to the unknown and whether the couple could adapt to the issues presented by the stroke linked to cognitive and behavioural changes in the

stroke survivor. Many health professionals likened the process of adapting psychologically to the stroke through Kubler-Ross (1969) grief model with the couple having to work through the process.

I think it's the adjustment isn't it, like I say the grief and the kind of anger kind of process, yeah that this has happened and, you know this is how things are and I think it's they can't make sense of it as well, you don't know if things are ever gonna get back to normal for them what was normal for them now isn't, you know I think that's the the problem of what cognitive and behaviour changes affect the patient can affect adaptation...(SEU1 N)

Even though there was low priority given to the emotional effects of the stroke during the acute phase, there was real impact for the health professionals who carried on the rehabilitation process once the stroke survivor comes home. These aftermaths had to be dealt with by the health professionals as the emotional consequences of the stroke hindered the impact of the rehabilitation:

Because we follow them up at home...you're going into their home now and they often find, unless they, sometimes they have family, a big family but sometimes they don't want to lean on them either but also they just don't have anyone to talk to about it and we often get a lot of that coming on top of us and obviously we're going out there to try and help as therapists and sometimes you just go out there and you end up just talking through these things, so sometimes that's every time you go because it's just not, they're not kind of coping and moving through it....and our job really there is we're going in for rehab for the patient who's had the stroke, I know you take into account the family but our role is really, is we have for the patient and you can quite often like you say

spend time with the family and the relative rather than going there to do your rehab (NWU1: P)

The way health professionals attempted to overcome these emotional issues raised by the couple relied on listening and reassuring them that their feelings are 'normal' given their circumstances. Also by reassuring the couple that health professionals do not expect them to be perfect or they are not doing their best, but to focus on the achievements that are being made, rather than what has been lost, so that the situation the couple find themselves in is made more comprehensible:

I think listening is a big thing, just being there to listen to their concerns and their worries and acknowledging what a massive life change it is for them as well and being there to say, you know this is normal, those feelings of guilt, those feelings of anxiety and frustration that, 'why has this happened to us', are normal and being that professional saying it's okay to feel like this it's normal to feel like this, I think...and they're quite surprised, I think that this is normal that you feel like that, and I said, you know, 'I've had so many people in your situation', and she's like, 'really, it's not just me'...this helps make sense of what's happened for them it it links with everyday life not weird or abnormal...(SEU1: P)

yeah I think you have to focus on how they are doing every day...the little things that they need to concentrate on how their improving and coping...I think this focusses them more so they see things getting back to the way they were rather than what they've lost...(SEU1: P2)

Health professionals clearly recognised the emotional issues raised by the effects of a stroke on the couples, and this had an impact on the stroke survivor's treatment and outcomes. There was a sense that there were different priorities at different phases of the stroke trajectory, in the acute stage where the focus was on stabilising and assessing the patient's functional condition and the psychological issues could be left until later when the stroke survivor went home. However, this attitude although understandable, did impact on longer term rehabilitation activities, which had to be addressed by health professionals who undertook treatment during this phase. Attempting to address the emotional aftermath of stroke, health care professionals used their experience to listen to the couple's problems, to normalise their experience, so they could continue adjusting to their post-stroke circumstance.

7.6.3: Findings from the RELATE focus group on CMO²

The RELATE counsellors recognised the emotional needs of stroke couples, indeed if the stroke family carer, usually the spouse came to their sessions, it was a measure of how far emotionally and psychologically the spousal carer had gone.

It's the last resort in some ways if they come or referred to us, so yeah they're at breaking point or beyond it...so there are real emotional issues there...so we need to build them up again and just feeding them by saying, you know, 'You are doing a good job' and ... and working with all the stresses of ... the guilt and shame...(C1)

Maintaining resilience was one of the key elements in what the counsellors were trying to achieve with the spousal carer during their counselling sessions:

I erm ... well doing the proper counsellor answer, it's what resilience means to the client. What is resilience to them?

How much can they take? Every person has their own different tolerance; I think culture does play a big part in it, I think some people have different levels and have different tolerances to things. And it's ... increasing their own inner strength to the great extent that they have, but also getting them to recognise, going 'Okay, there's a limit', resilience is not endless, there's a limit to how much you can take. And it's almost going 'Okay, we can make the best of what you have within yourself and empowering you to do that, but then take a step back and recognise that actually saying 'No' or ... kind of asking for support isn't failing, isn't a break in your resilience, it's just recognising that it's not endless (C2)

The counsellors, comparable with views expressed by some of the health care professionals were attempting to restore 'normality' for the couple. Being able to see their lives as 'normal' again that there is a purpose to the relationship was seen as repairing the emotional damage brought on by the stroke.

... makes such a massive difference to them feeling (spousal carer) valued, like we were saying before, which would increase their resilience rather than feeling like a slave... if you get them to see this as a process of re-establishing relationships not not the same one as they had necessarily but one that they are valued in and they can live with as a real couple...(C3)

7.6.4: Summary of CMO²

There was clear separation for healthcare professionals between the stages of stroke rehabilitation, in that the acute phase was medically driven and emotional needs of the couple were secondary, to be 'managed' at a later phase when the stroke survivor is at home. However, this perspective had an impact on treatment and therapy in that health professionals could not focus on

functional rehabilitation until they had attended to these emotional needs. The three couples still reported unresolved emotional changes more than two years following the stroke, and the service did not appear to address these needs. The focus of health professional interventions and RELATE counselling in providing emotional support was to ‘normalise’ the experiences for the couple. Normalising couples’ emotions within the context of stroke, enables the couples to making sense of their situation that may go some way to improving their quality of life together.

7.7: CMO³

Initial CCMO ³	Final CCMO ³
Maintaining long-term (over 12 months), professional contact with the stroke survivor and family carer including the use of telephone and on-line communication (Context)	Maintaining longer term (over 12 months) professional contact with stroke couples that includes the use of telephone and on-line communication technologies (C)
Prompts feelings of perceived social support (Mechanism)	Prompts feelings of perceived social support (M)
Improved stroke survivor and family wellbeing (Outcome)	Improved stroke couple wellbeing and independence (O)

Table 7.3: Final CMO³

7.7.1 CMO³ from the couple perspective

This CMO looks at the importance of longer-term contact for stroke couples with professional health and social care services. All three couples appreciated the support that their primary care team provided for them. The support was orientated around physical needs, rather than psychosocial as outlined in CMO¹. The practice teams were very accommodating in visiting the couples in their own home:

John: We get a telephone call every so often from the local practice, I had one this morning actually to somebody say, 'are you all right?' and I did mention just one little item about Mary's pain...and the GP was prepared to come out and do it here, I explained that at a pinch I could get Mary down to the surgery but it's a little bit, 'oh, don't worry,' they said, cutting me short, 'we'll send the GP out to you,' and the GP was very understanding...and we jiggled your painkiller tablets around a little bit didn't we? She was very helpful with that.

Martha: I think my family feel this as well, we couldn't have had better service (primary care team). I mean over two years the nurses were coming dressing Tom's leg and he's got another sore on his leg, it doesn't give him anything to worry about very much but he grazed his leg, he fell off the bed. You see he's like me, he hasn't got much balance and he fell off, he was sat on the side of the bed and fell off and, just the carpet grazed the skin So I phoned on the Tuesday and I said I don't think it's anything to worry about but I'm telling you there's a graze on his leg. I've been treating it over the weekend with Germolene and I said if you want to call when you're passing to have a look at it or, but I said you know about it, I'm not keeping it 'til it's gone bad and then telling them. And she said I'm coming up today so she came up and she put a dressing on his leg and she did say she was coming today but like me she didn't think it was necessary.

The support proffered by the community health team may also be linked to the age of the couples, all were frail elderly and had various co-morbidities to manage, which may have necessitated more input from the GP practice compared to younger stroke couples. However, contact from family and friends

were highly valued by all three couples for emotional and instrumental support, even when they lived some distance away. Perceived social support was enhanced through use of communication technology such as the telephone in that friends and family could be called upon to provide help when needed:

Helen: You know like if anything like happens to Dennis, our daughter (daughter's name) is just on the phone and she comes right away...it's a big comfort knowing she's on the end of the phone...

It was surprising given the couples' ages, that other communication technologies were also employed in enhancing support needs, not only emotional but instrumental. Martha had been given an iPad by her daughter who taught her how to go on-line to order food shopping to be delivered to their home as they lived in a very rural location. The use of on-line shopping and home delivery meant that Martha and Jim were self-sufficient and able to live in their own community for longer than may have otherwise been the case. At 84 years of age Martha had also learnt to use 'FaceTime', an application that provides face-to-face communication, and she could use this to talk to their daughter and grandchildren. John and Mary also made use of Skype to talk to their children and grandchildren on-line, as well as ordering food delivery.

From the combined centre stage diagram in Figure 7.3 below, keeping in touch with the primary care team and family and friends through various communication technologies was identified as a very important means of maintaining social support, both emotional and instrumental. All three couples received telephone calls from their GP practices on a reasonably regular basis, and for two of the couples there was regular home visits from the GP. When a situation arose for the couple these practices attempted to accommodate them on the same day. The couples believed that having access to their local GP practice and using the internet as a means of sustaining social network meant they were able to continue living in their own homes.

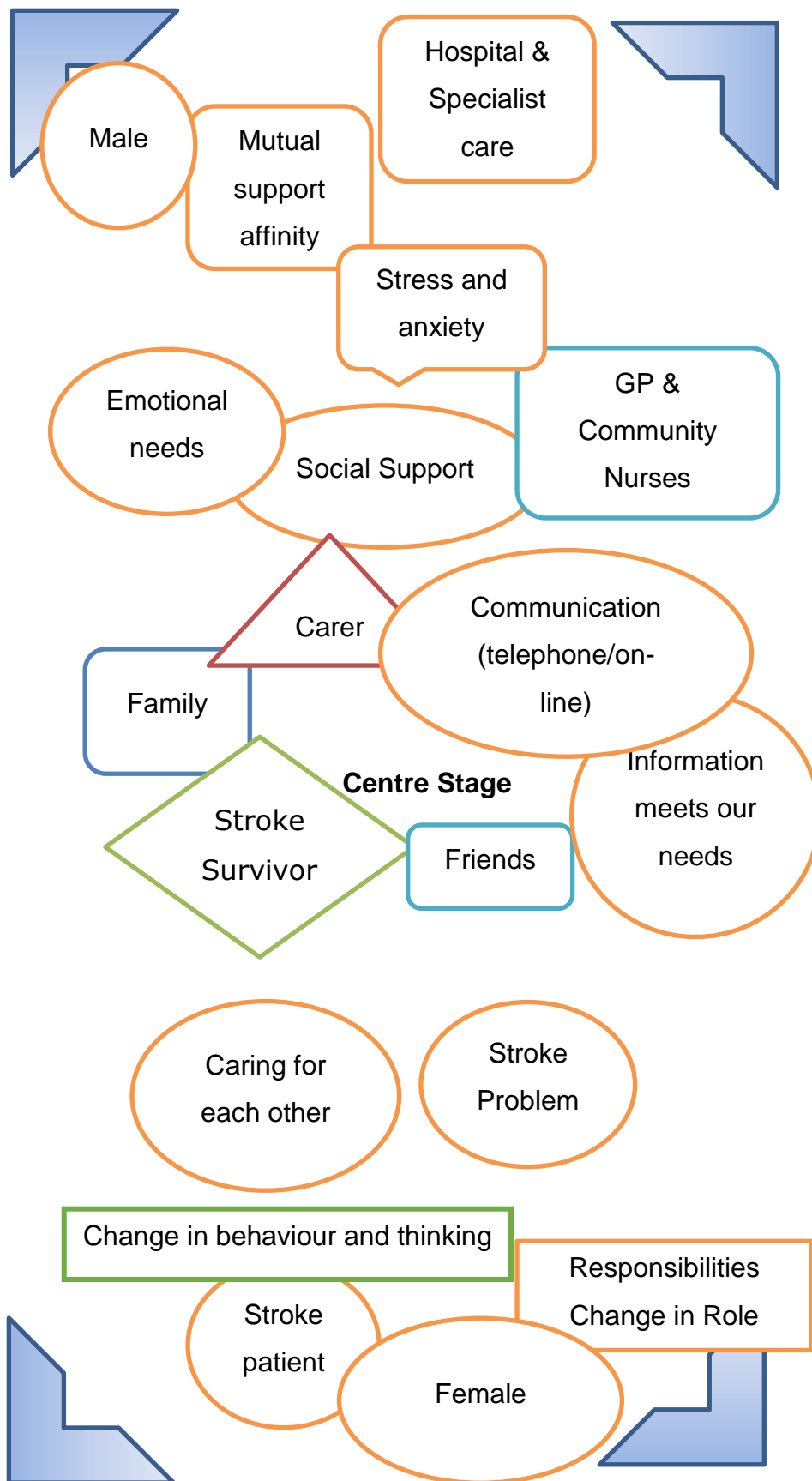


Figure 7.3: Combined couple centre stage related to CMO³

7.7.2: Findings from the four stroke teams related to CMO³

From the four health professional focus groups it was apparent that communication technology did play a part in their interaction with stroke survivors and family carers. There were two types of support the health professionals discussed, support that was related to patients and families themselves forming an informal group, and the support they as health professionals offered to the stroke families:

... use things like 'Facebook' and ... you know, they're a bit more isolated in the house, and they'll chat to people virtually more. I think it is something that you know, is being used more and more as well. So there's like...but in most of the groups of patients that I work with, they've actually set up forums now, so they'll have like a 'Facebook' chat group...and they'll chat and share...Yeah the Stroke Association has a blog doesn't it as well and that sort of thing, but...or just a few of them will just meet up, that they know they've met on the ward and things...(SEU2: P)

Yeah. So, like sometimes, sometimes they'll get in touch on the phone out of the blue...and then some people just ask a quick question, be reassured and other times they'll just pour their heart out but then they kind of feel better, so I kind of give quite a lot of support over the phone (SEU1: N)

Some health care professionals thought there were advantages in using communication technology such as e-mail for stroke survivors as compared to telephone or face-to-face meetings:

No people are really using them a lot now (e-mail contact) and not just young strokes it's older carers as well...some

have more problems processing how they think, that actually doing it on a screen they can take their time and sort of write things down slowly and formulate questions, so I've been using that a bit more. Initially I was a bit sceptical but actually it has worked quite well and some people really use it
(NWU1: N)

However, the communication with stroke families was ad hoc rather than a structured or service driven intervention. All health professionals in the four focus groups provided contact telephone numbers and e-mail addresses for the stroke families to contact them, however relatively few used this. Communicating with the acute hospital stroke team was also based on the relationship between the stroke family and the health professionals, the better or more intense the relationship the more likely the stroke family would contact them. As seen above, from the couple interviews it is the GP and primary health care teams that provide support:

Yeah, I think there's something that should be there (long term contact). We have the six weeks and then all of, because our services goes up to six weeks once they're home and then after that if there's therapy needs we will kind of direct them to the next kind of stage of that, obviously if there's no therapy and they've kind of reached either their potential or their goals or whatever, then we will stop and I think they find that quite a bit daunting as well isn't it and we don't really, they've obviously got our number so if they want to they will contact us...surprisingly not many do...depending how involved we've been and how close we've kind of got to them... (NWU1: P)

Developing peer support groups between stroke families that included communication technology was considered an important function for the acute

stroke team to provide. This provision was a way of counteracting the lack of formal support once the stroke family were at home, it was evident that the health professionals saw limited scope of providing a service because of economic factors:

There is pretty much ... yeah its ... I think it will continue to diminish as well (service follow-up), so I think the only thing we can do is try and link people up, like buddy people up almost with each other, because I don't think there's going to be structured services. It's not going to you know, there isn't the money is there, so I think, where we can, if people have met up and things, to try and nurture relationships that have happened when they've been in rehab or on the ward...it kind of seems to formalise it a little bit if we encourage it, and using e-mail and 'Facebook' is a way they can keep in touch with each other... (SEU1: N)

...the people that don't have the ability to cognitively contact you again even though they're struggling, there's not particularly a great system in place for that because we couldn't have a capacity to contact everyone vulnerable and they are, you know they often will really deteriorate and we don't know because they've not got the cognition to be able to contact you or the communication sometimes so in an ideal world if we had some kind of reviews for those people that couldn't call you that would be great because we tend to pick them up when they've actually deteriorated significantly and we'll pick them up through the GP or a district nurse or something and actually if we'd been able to see them sooner we would be able to prevent what's happened (NWU1: P)

Some health professionals debated whether it was beneficial to provide longer term support structures as this may encourage dependency on service provision instead of enhancing greater self-management:

But that's a balance to isn't it because I'm not sure I agree about always increasing the duration because you don't want to create dependency either do you, so there's that balance isn't there with helping people sort of move on with their lives and feel in control, feeling empowered to pick up the phone or look for those services so I think it is a fine balance (SEU1: N)

Also, the type of support was questioned, as the quote below summarises the needs of the stroke family should be assessed and the appropriate support be then given:

But again does it not depend on the quality of that contact, because you know, you could have, you know, a domiciliary carer going in for fifteen minutes every single day that hasn't even got time to talk to you, but you could have somebody going in once a fortnight that's got an hour to sit and chat that might be actually more beneficial than having increased contact that's meaningless in terms of what they need from that contact (NWU2: N)

The health care professionals also saw the importance of communication technology as a way of enhancing social support to stroke survivors who had severe communication issues that enabled them to maintain contact with their wider social networks:

Actually that comes back to the technology thing, we were working with a chap in the community who's long term, who's work colleagues funded an iPad for him and we were then able to put an app on that their colleagues could then keep in

touch with him...it was an app that was appropriate for this gentleman with his communication and cognitive difficulties and so they felt there was something they had in common and they could keep in touch with him...(SEU1: ST)

7.7.3: Findings from the RELATE focus group on CMO³

From the RELATE counsellors' perspective communication technology was not a part of their day-to-day work with their clients and questioned its feasibility in the service they provided. All three counsellors recognised the usefulness of such technology for supporting stroke couples given the pressure on the health service:

We don't use a lot of e-mails or telephone counselling it tends to be face-to-face as you can see their body language...how their struggling to get it out to you can't do that so well over the phone (C3)

I can see how it would be good to be able to use e-mail to contact your GP or whoever, I have e-mailed my GP once for a query and it was useful but not sure if it works for more serious personal issues... you'd want to have face-to-face...(C2)

It could be a useful way of maybe identifying if someone is in serious trouble and then you can dig a bit deeper and provide a more personal support to them (C3)

7.7.4: Summary of CMO³

Maintaining longer term professional contact with stroke couples was believed to be important for maintaining stroke couple independence in their own home,

but was constrained by economic factors. Increasing use of communication technology was seen as a positive development that was encouraged by health professionals during the acute phase of the stroke, particularly as part of a local peer support network. The use of communication technology as a screening tool was seen as a possible means of identifying vulnerable couples who could then be targeted for further support. From the couple perspective, being able to stay in contact with health care professionals, family and friends through technology was critical to maintaining independence in their own homes. The technology not only supplied emotional and professional support but also provided instrumental support through home delivery of food shopping. In essence this CMO³ shows that provision of longer term professional support for stroke couples could be achievable through technology.

7.8: CMO⁴

Initial CCMO ⁴	Final CCMO ⁴
Health and social care professionals need to attend to the changed domestic roles and responsibilities between the stroke survivor and family carer (Context)	Service provision that recognises the changes in domestic roles and responsibilities between stroke survivor and partner, through a family or couple-based approach to treatment and care, emphasising stroke survivor and partner strengths as a couple rather than as separate individuals in their adaptation to the effects of stroke (C)
Engender feelings of mutuality between couples (Mechanism)	Engender feelings of mutuality and affinity between couples (M)
Reduced family stress (Outcome)	Reduces perceived stress for the stroke couple that improves family functioning (O)

Table 7.4: Final CMO⁴

7.8.1 CMO⁴ from the couple perspective

The interviews with the three couples identified changes in family roles and responsibilities. For the stroke survivors, Dennis and Mary it was a reduction in their role from their pre-stroke situation, whereas Martha had to take on greater role responsibilities because of her husband's continued cognitive decline. For example, Martha had to make sure that Jim took his medication appropriately, having to set up weekly dosette boxes to remind her how many tablets he needed to take. Martha was also concerned that getting ill again would impact on Jim, perhaps forcing him into a home:

Martha: Because, alright I'm don't feel too well at the moment but it's nothing like it was...because I was worried about Jim. He doesn't know whether it's dinner time or teatime quite often do you?

Jim: Not, not with any great accuracy, no.

Martha: Some days he can. No. He can't look after himself was my thought, you know, well I I can't be ill...who knows his tablets and he has to be kept an eye on...if I can't cope he may go into a home and and I don't want that

Similarly, for Helen, following Dennis's stroke he was not able to drive so she had to rely more on her daughter to take her shopping. Helen had also taken over looking after the household finances, which had been Dennis's responsibility:

Helen: Oh yes I have to do the books now as he can't concentrate, my daughter helps so I know where I am with the money.

However, Helen felt that Dennis should do some chores around the house that were not ones he had done before his stroke:

Helen: Yes like hoovering. I [inaudible 15:58] you do a bit of hoovering this morning. He'll do a bit of hoovering then, you know, he'll do it, that's good, he's done something you know... that helps me out and keeps him moving...

Dennis: Yes I need to help out can't leave everything to her to do...

This reciprocal arrangement was demonstrated by Martha and Jim, in that he helped with setting the lunch and dinner table for Martha. For John and Mary, it was now more difficult for Mary to share household responsibilities, however, John did not view it in this way but said he was just happy that Mary was still able to talk to him and they were able to be together:

John: I don't think of it as me doing everything we have taken vows and it's very very important that we are a team. Mary still expresses her opinion and we still make joint decisions together for which I am grateful because I'm anxious to encourage Mary to speak and to express her opinions and feelings as much as she possibly...

Mary: We have a good talk...here don't we

John: and the odd 'cwtch'...(colloquial welsh for cuddle)

It also became apparent that the stroke had brought Mary/John and Martha/Jim closer together as a couple. Even though Mary's second stroke was severe leaving her incontinent and in a wheelchair, John and Mary were resilient in facing their second adaptation to stroke:

John: ...it all seems to be a rather pessimistic attitude that's being put out which squares I think with what you were trying to say previously. Our experience for what it's worth is that it's hardly been uplifting, it's hardly something you would want to happen but it hasn't deteriorated our relationship in any way and I would like to go on record as saying that in fact it has strengthened and elaborated our relationship quite noticeably. Well, we're both more sympathetic and understanding of each other, is that not right?

Mary: Yeah, I think so...it has made us closer

John: And one just got on with it and it's had its ups and downs, not all that many downs and there have been little highlights and I'm hoping we're going to get one the week after next when we go away for a holiday together.

This relationship affinity was echoed by Martha who reflected on how tenuous life can be and that looking after her husband was something she wanted to do:

Martha: I think when there's two of you, if there's two of you you can work together we have been married for over 55 years and we know our little ins and outs, you know. We can look out for each other and know how we are...looking after Jim is my responsibility and I want to do my best for him with what we've got left

Even for Helen and Dennis who had a score of two on the Family Assessment Device (FAD) General Functioning Scale (Ryan et al., 2005) which indicates problematic family functioning brought about through Dennis's mood changes since the stroke. There was still a feeling of obligation that a married couple had responsibilities for each other:

Helen: Yeah, yes definitely even though he gets cross, bad tempered you you still have to look after him...you just can't leave things...

Interviewer: How do you feel about that, do you...

Dennis: Well I realise what I've done afterwards...and Helen has a lot to put up with...

Whether feelings of obligation to the relationship is desirable? It highlights the complexity of couple relationships and as in Martha's case, Helen viewed her relationship with Dennis as being together as a married couple. It was evident that how the pre-stroke relationship is perceived influences post-stroke attitudes, that loyalty to one another was an important part of a relationship. Couples commented that caring for each other was a natural phenomenon as they had been married for so long, and that the stroke was just another issues they had to deal with as they got older:

Helen: you just can't give up...married over 40 years and he was a good man always food on the table and good to (name of daughter)...so even if he's changed you carry on...

From the couple perspective, there was consensus that the family and especially the couple as a dyad should be considered in decisions made about rehabilitation. All three couples reported that most of the time health care staff did recognise the importance of maintaining dialogue and information with the couple:

John: yes I think we should have the family involved especially since Mary had her second stroke as I am the one that can communicate her needs

Martha: with Jim the way he is the doctors need to talk with me as well about his tablets...and they do

In relation to their GP practice, John felt satisfied with their inclusion:

John: most times they're pretty good at including me especially since Mary had her second stroke and she can't get to the phone and down to the surgery by herself

However, the service was not universally perceived as being helpful, as the focus was on the needs of the stroke survivor rather than the spouse:

Helen: I don't seem to have a lot of help off them (GP surgery) like that you know at the moment...with feeling anxious about him... Perhaps they are busy, you know, aren't they? Some people say they're not, some people say the only thing you've got to do is keep nagging and nagging and you can't.

There did appear to be limited focus on psychological issues of both the stroke survivor and spouse. Martha recounts how her husband Jim lost his way in the local town due to his worsening vascular dementia and fell in the high street:

Martha: ...anyway we got him (Jim) home and the doctor came the same day and when he saw him a couple of days later he said his knee was getting better to have, he's eighty eight now and he was shocked weren't about you losing your way...anyway I was worried but the doctor didn't say anything about that...how this makes me worried...

There was a consensus from the couples that the physical aspects of stroke and chronic disease management were adequately managed, but there was a deficit in psychological care, including how the couples were coping. There was a clear disparity between how the couples described themselves within this process.

Helen: You know the hospital were good about getting Dennis on his feet again and things like that but you know his bad temper they said nothing and that causes trouble more than him not being able to walk far...

John: Well I'm sure they (health professionals) see me as the carer and I have no objection to that at all but by and large I think it would be nice if they asked how we are coping with this as a couple...

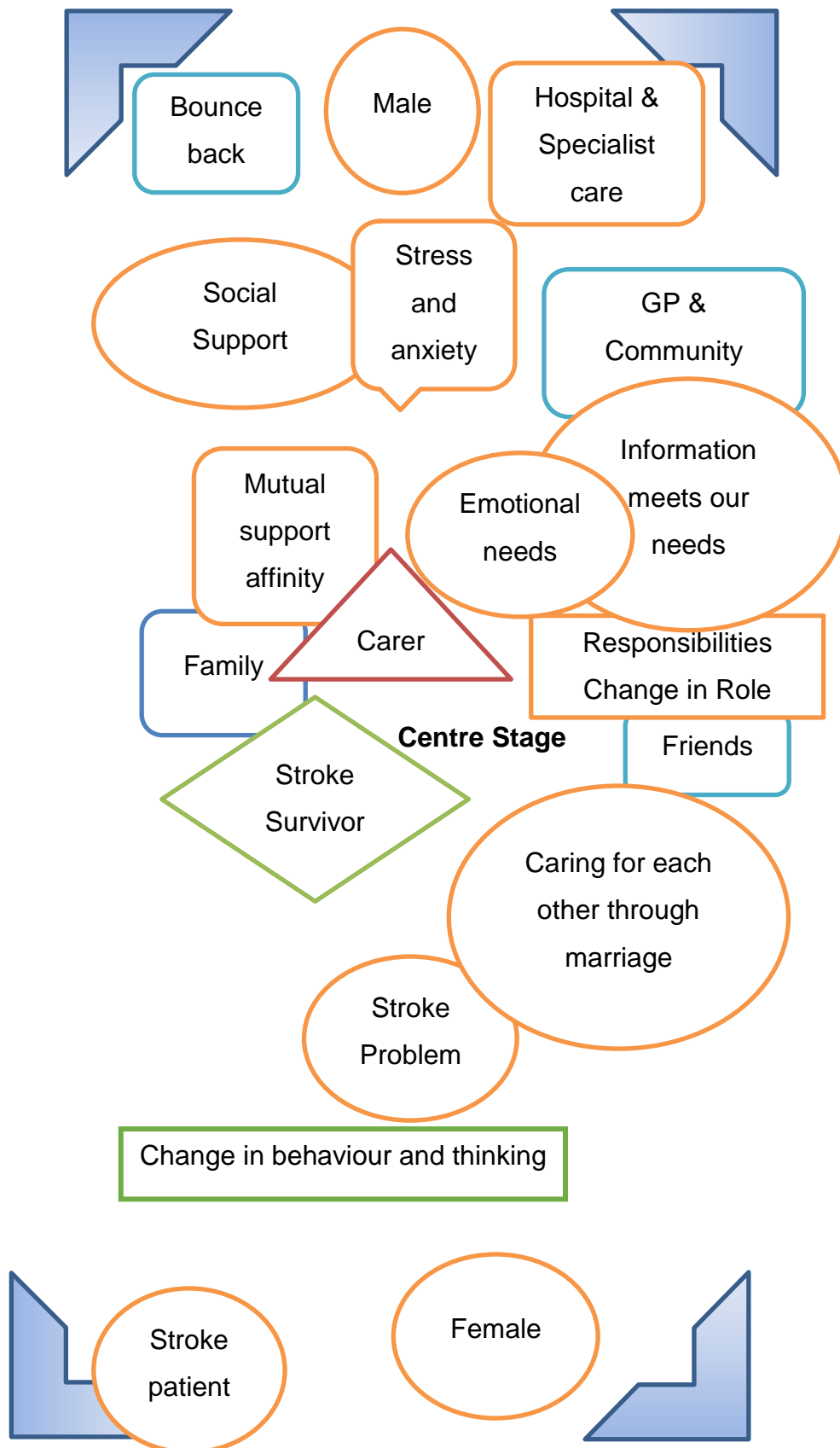


Figure 7.4: Combined couple centre stage related to CMO⁴

From the centre stage diagramming in Figure 7.4 above, changes to domestic roles and responsibilities was a feature of life following the stroke. The three couples had been married a long time (range 45 – 55 years), and this length of relationship was viewed by the couples as fundamental to adapting to the impact of stroke on their lives. The relationship the couples had built up through their marriage sustained them through the rehabilitation process, particularly emotional support that was not readily available from health professionals. The mutual support was demonstrated through their knowledge of each other's behaviours and habits through living together. Changes in behaviour and mood post-stroke was balanced against the experiences of the relationship pre-stroke, through a deep commitment to each other and through obligation as a spouse.

7.8.2: Findings from the four stroke teams related to CMO⁴

There was recognition with all four professional focus groups that the family were essential to the rehabilitation process. If the stroke survivor had no family near them than this impacted on their therapeutic goals for the patient, as this quote identifies:

And I think in terms of therapy we couldn't do therapy any other way, like when you actually write goals and try and look at projected outcomes, you'll be doing that in mind of thinking of the family role and who's got, who's there to support them can the spouse cope, and it would very much change their rehab if you weren't doing that. Because there are some people that don't have any and it massively affects the ability for us to rehabilitate someone and the likely outcome when there's no one to work with them so it think it's integral I'd say from the start, I don't think we'd do it any other way. (NWU2: P1)

Involving the family was also seen as a way of demonstrating to the family carer techniques to help the stroke survivor and continue therapy when they are back home:

And I know in terms of speech and language therapy we do do impairment based therapy but then we also do the functional side of the therapy as well, so rather than us just working with the patient on the therapy, it's about giving the family the strategies and demonstrating that on how they can assist their communication difficulties and helps them see them develop and gain as much speech as they can. (NWU1: ST)

However, a couple or family based approach to treatment was mostly seen as a process which advanced and continued the care of the stroke survivor through the use of the family carer as an extension of service provision, rather than assessing the needs of the couple or spouse:

... the patient obviously comes first and I'll always ask if they're happy to work with ... along with their family too...(SEU1: N)

We treat the spouse as one of the team really...if you want to change their behaviour then it's better to see them with their spouse so they can change together (SEU2: N²)

As discussed in CMO² above the service had to manage the needs of the family carer, at least in part to enable them to provide treatment and therapy to the stroke survivor. But health professionals recognised there was a conflict between being the main family carer and being the spouse or partner to the stroke survivor, and this abrupt change in the relationship had an effect:

...you know the dynamics and their relationship so that's gonna change the day to day running of their life, the impact on the wider family, you know how they'll manage with grandkids, how they'll manage with pets, it's a huge effect on relationships... (NWU1: P1)

I think even the word carer is always an issue for me as well because, you know, my husband is my husband, I don't particularly want him to be my carer because that's a whole different relationship isn't it for a start and that's a bit, but some people take on, almost become too professional in caring don't they and lose the relationship side of it and other people are clearer from the beginning that they don't want to be a carer (SEU1: N1)

I think on the flipside of that as you say if people don't want to take on that carer role we then think, 'why not, why won't the husband do that?' (SEU1: P)

'I think although we recognise that you know what the carer's needs are and there's a lot of burden placed on them, we do expect them and we do put a lot on them as well, you know it's just... 'well for better for worse, sickness and in health'' (NWU1: N)

The health professionals reverted to societal expectancies that spouses ought to care for one another as an obligation based on marriage or long term commitment to each other. Further, it was recognised that the health system and the way it was culturally configured, to provide individualised patient care around physical treatments meant that the relationship between spouses and

the way they interacted together leads to a service that ignores the relationship between the couple.

'I also think the system is quite cruel because there's a huge expectation...you know being expected to being in that carer role the package of care if there's gonna be one is set around what that patient can do and then the package of care is around that, the spouse becomes the main carer and suddenly they're like, 'oh my god, how did that happen, I'm here and I'm the main carer apparently', it's that label again and I think the system helps that happen and then they find themselves in the situation a few months later, they're 'oh my god, I didn't know it'd be like this, I didn't know to expect that I'm not his partner anymore but the carer', and I do think that is the system, not that anyone does anything wrong but it's just how the system is' (SEU1: N)

7.8.3: Findings from the RELATE focus group on CMO⁴

The RELATE counsellors used couple counselling as the main method of resolving issues associated with relationships. The basis of RELATE counselling is to explore openly how the couple reached this stage in their relationship and using insights about how the partners influence each other's feelings and behaviours during the dyadic counselling sessions, and so develop different patterns of responding to their partner:

We see them as couples but we may also see them individually...but ultimately you have to deal with them as a couple with a history behind them that brings them to this point and you need to look at how they interact with each other...how they maintain the relationship...(C2)

...and they react as a couple not individuals, especially if they have been in the relationship a long time (C1)

Counselling family carers of some stroke or dementia clients who had cognitive or functional problems forced the counsellors to see the family carer alone but it was not considered an optimal way to assist couples:

We do see some spouses individually as our sessions are always held on RELATE premises...some stroke clients cannot come to us or unable to contribute because of their language problems or those with severe dementia...so we see the caring spouse individually but it's not perfect that as you only get one view of the relationship...it takes two to tango...(C2)

However, individual counselling of stroke survivor spouses was a way of reducing the stress of caring, through focusing on the needs of the spouse, particularly if they had been carers for a long time. The counselling also included looking at how their identity as a person and as a couple had changed since the stroke:

You know the stress they are under and coming for some counselling relieves some of the stress for them...like releasing a valve and letting the build of pressure ease off...so that they can carry on a little more...(C3)

And sometimes we identify needs for them that they don't even realise they have any more since they've been in this caring mode for so long...A lot of the couple work that I do is going 'Well, how's intimacy? How are your other needs being met?', rather than just essentially the caring and looking after

yourself. Because we look at the person in more of a holistic sense... But it's almost reworking their identities, what ... what's my identity, who am I now, who was I before? Who are we now? It's like a child relearning life...because they need to know who they are in this changed relationship (C1)

The counsellors commented that they also tried to change the ways the spouse responded to the situations that produced the most stress for them. This approach was around looking at the strengths they acquired throughout their lives and their experiences of the family carer role reiterating the value of their contribution:

Yeah again, follow on from what you've said, and thinking about what happens to the couple...you've got to build up their confidence...I think coming to us is a last resort most have been caring for a long time so you got to say to them as you said previously 'you've your doing a great job look how you've managed up until now'...we try and build on their strengths as people...(C2)

...because you've been a partner, a husband, a wife, a daughter, whatever...you take on that role out of love, but then there is no recognition and no value put on that by...I mean I'm...I'm sure that's probably a huge exaggeration on my part, but I know that the clients that I've worked with haven't felt valued for what they're doing (C3)

When commenting on how health and social care professionals could help stroke couples manage the effects of the stroke and its impact on the relationship, it centered around facilitating communication through listening to what the couple were articulating and giving time for them to express their needs. However, there was a cautionary note in that health professionals

should not 'counsel' the couples as there maybe underlying issues that could inflame the situation:

And listening, just listening skills. Just listening skills, because they're...they're just massive, and nobody's taught them unless you go for counselling training, it's just not a package that's ever taught anywhere for health and social workers...(C3)

The only rider I would put in there if your not trained is if the relationship was very poor in the past...and if, for example, the...the cared for spouse was either unfaithful or abusive or...and then bringing back those memories may actually be very, very difficult for the carer. It may be that okay, I'm dealing with this at the moment, I don't want to remember...and, you know, if...if that door can be closed and left closed I can deal with the moment, but I can't keep going back there. So I don't know whether that would just be...you know, an area to be wary of, where there's been an abusive history and now you're left caring for this person that's been horrible to you. Do you...do you want those memories? I don't know (C1)

7.8.4: Summary of CMO⁴

The suddenness of a stroke changes the dynamic between stroke couples through a realignment of roles and responsibilities that modifies the way the relationship is perceived. For the couples in this study responsibilities had changed for the spousal carer, as they had to take on more of the tasks that their spouse did pre-stroke. The exception was Martha who cared for her husband whose worsening dementia increased rather than lessened her burden. There was a perception that the stroke had brought two of the closer

together, through recognition of what they meant to each other by being together over a long period of time. This enhancement in the quality of the relationship was not universal as the emotional changes due to the stroke created uncertainty through altered stroke survivor personality. The health professionals recognised the importance of the spouse and family in the rehabilitation process. The family were a means of extending therapy, as assistants to the staff in promoting stroke survivor functionality, as the focus of the health care team was on individualised patient care rather than the couple. However, health professionals needed to manage the emotionality created by the effects of the stroke as it impeded their ability to deliver the therapeutic regime. There was an expectation that a spouse should care for their partner, as an obligation of being in a long-term commitment, but there was also a recognition that the health and social care system was partly to blame for such a perspective. The RELATE counsellors preferred to use dyadic approaches for their counselling, but due to the physical and mental restrictions experienced by stroke survivors, this was not always possible. The counsellors attempted to use a strength-based approach in their therapy, getting the stroke carer to re-shape their thinking and to value their efforts in caring for their spouse through identifying their needs in a changed relationship.

7.9: Conclusion

This chapter presented findings from three different perspectives involved in the long-term management of stroke, their purpose being to refine the initial four CMOs developed from the realist synthesis and initial couple interviews. The first perspective came from the longitudinal interviews with the three couples. The second perspective came from health care professionals from four stroke units, two based in Wales and two in South East England. The final perspective of stroke carer support was the focus group with RELATE, who specialise in couple relationship counselling.

CHAPTER EIGHT: Discussion and Recommendations

8.1: Introduction

This chapter discusses the findings and draws conclusions through an analysis of theories associated with married couple relationships, whilst also revisiting theories that were the basis of the initial programme theory. The overall contribution of this thesis to new knowledge is through refashioning the way long-term marital partnerships should be perceived by health and social care professionals, so they are better able to support couples adapting to life following a stroke. The centrality of the couple relationship and the emergent mechanisms that sustain couple-hood through the experience of stroke are key for supporting activities. The overarching objective for this study was to throw light on why interventions targeting stroke family carers and stroke survivors have limited effectiveness in reducing their stress and perceived burden. A realist evaluation approach was utilised to articulate the contexts and mechanisms that could underpin 'what works, for whom and in what context'. The study's results are considered against the wider field of theory leading to a clearer understanding of the significance of the findings (Pawson & Tilley, 1997). The findings are discussed in the context of the initial programme theory uncovered in the realist review (chapter three), initial couple interviews (chapter four) and the critical review of the literature (chapter one). Finally, in this chapter, the revised programme theories from the findings are presented, in the form of guidance which can be developed and refined to support policy and practice.

8.2: Coalescence of the CMOs

According to Pawson and Tilley (1997), it is 'cumulation' that produces middle-range theories that can be utilised in other contexts but not too abstract as to lose their ability to test interventions. How 'cumulation' is enacted within realist evaluation is through abstraction, where theories bind data rather than similarities in data: "The process works through the development of a body of

theory which provides an *organising framework* which ‘abstracts’ from a programme a set of essential conditions which make sense of one case after another” (p.120: italic in original) (Pawson & Tilley, 1997). From the findings, the four identified CMOs are interconnected but coalesce around CMO⁴, the relationship between the couple and factors that enable health and social care professionals maintain couple-hood, as represented by figure 8.1 below:

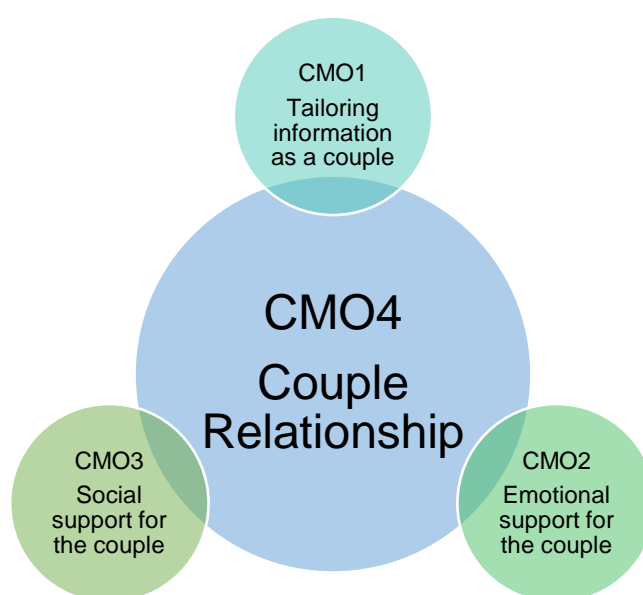


Figure 8.1: Coalescence of the CMOs

It is important to discuss the findings from this study within the wider literature on couple relationships and how they are affected by a stroke. Additionally, this study focused on elderly married couples who have been in their relationship for more than 40 years, these contextual features need to be considered by health and social care professionals in their management of stroke in the longer-term.

8.3: Couple relationships

From the health professional focus groups, it was evident that the management of stroke survivors and their family carer is driven by an individualistic approach to care. This individualism is derived from health and social care professionals’ cultural values supported by organisational policies, in that patient or person-

centred care helps eliminate task orientation in clinical practice, so improving the quality of service (Willetts & Clarke, 2014). This patient-centred approach principally applied to the stroke survivor but also extended to the family carer if stress and burden were problematic. However, all individuals live within a social system that affects their capacity to adapt and change to circumstances. The most intimate of adult social systems is that between partners or couples within long-term relationships, which frame their attitudes and behaviours (Clark-Polner & Clark, 2014).

The positive and negative effects of long term partner relationships have been evident over the past 25 years (Kiecolt-Glaser & Wilson, 2017). Intimate partners can influence each other in positive or negative ways that have a lasting impact on their physical and mental health. For example, the shared resources hypothesis (Meyler, Stimpson, & Peek, 2007) postulates that partners choose each other from a restrictive pool based on their compatibility. Also, partners live in similar environments, including housing, diet, exercise and social networks that can have beneficial or deleterious to health on both partners. (Hoppmann, Gerstorf, & Hibbert, 2012) showed in a longitudinal study of older couples the marital relationship shaped each partner's functional and mental health, to the extent that they concluded that health professionals "...need to extend individual-focused models of health and aging towards an inclusion of the social dynamics that characterize close relationships such as marriages" (p.9). Further, Barefoot, Mortensen, Helms, Avlund, and Schroll, (2001) in a thirty-year longitudinal survey of depression in married couples showed men increased in their depressive symptoms from age 60 to 80, but women did not, although they were higher than men at age 50 years. These findings point to a lessening of gender differences in both physical and psychological experiences within long term partnerships and indicate that there is a need to go beyond an individualised assessment of spousal associations, towards an examination of the underlying relationship-specific mechanisms. Essentially, a couple in a long-term relationship are more than the sum of two individuals living in close proximity, but become an 'operational unit' of analysis (Berg & Upchurch, 2007; Berscheid, 1994).

8.4: Relationship theory and CMO¹

Targeting information and problem solving strategies to the needs of the family carer and stroke survivor, has evidenced some efficacy in supporting stroke families (Bakas et al., 2014; Cheng et al., 2014). Indeed, teaching family carers problem solving and coping skills, rather than passive psychoeducational instruction was shown to be effective in the first few months following the stroke incident, in that it reduced stress and perceived burden. However, in the longer-term (>12 months), differences between family carers who received such training and those who did not was not sustained (Cameron et al., 2014; Creasy, Lutz, Young, & Stacciarini, 2015; Gaugler, 2010).

From the couple interviews it was apparent that they were not well informed as to the psychological changes that may be present resulting from the stroke. From a functional perspective, the stroke couples were satisfied with the interventions they had received, but changes in personality, however slight persisted over the long term, and the couples did not always link them to the effects of the stroke. This lack of knowledge impacted on the couple relationship, and may be a factor in the limited benefits of coping and problem-solving skills training on long-term stress perception. In the short term, providing practical ways of dealing with the stroke survivors particular physical problems are beneficial in helping family carers, but once functional abilities have plateaued the emotional and psychological issues remain, affecting the couple's ability to re-frame their relationship.

8.4.1: Tailoring information

Considering the relatively short-term, but important benefits of skill building interventions for family stroke stress reduction, there is a requirement to tailor information at different stages in the stroke trajectory (Cameron et al., 2015). A National Institute for Health Research (NIHR) themed review for stroke recovery (NIHR, 2017) outlined research over the stroke pathway: prevention of stroke, hyper-acute care (thrombolysis), acute care (early discharge), rehabilitation (first six months), and long-term care (maintenance). There was

a paucity of research on the longer-term aspects of stroke rehabilitation, but a recognition that this aspect of stroke care should be addressed. McKeivitt et al., (2011) in a survey of stroke families at one to five-years post-stroke highlighted many issues that remained problematic, including emotional and informational needs. In qualitative longitudinal studies of stroke families the relationship between the couples was a factor in the spousal carer well-being, with couples having unresolved issues with their marital relationship with patterns of communication having changed for the worse (Gaugler, 2010).

Couple relationship literature has identified beneficial and problematic ways that relationships develop. Coyne and Smith, (1991) outlined three styles of couple relationship communication: 'active engagement' that involves both partners discussing the situation they find themselves in and engaging in constructive problem-solving. The second style is 'protective buffering' where the spouse hides their concerns, denying worries, and avoid disagreements. The third mode is 'overprotection' that limits the stroke survivor's capabilities, resulting in attempts to limit activities. Protective buffering and overprotection may be considered positive in the short term as a means of coping, but become destructive to the relationship in the long term. In a recent study by Radcliffe, Lowton, and Morgan, (2013) using joint biographical narrative interviews with 13 stroke couples aged between 75 and 85 years showed three styles of interaction: The 'united couple', who collaborated with one another in a way that re-affirmed their pre-stroke relationship; the 'positive' focus couples who showed collaboration in their attempts to re-frame their marriage, and thirdly, 'frustrated' couples who focussed on the difficulties they experienced witnessed by conflict between the couples. Within this study, there were echoes of these categories as a 'united couple' with Mary/John and Martha/Jim dyads, whereas Dennis and Helen were a 'frustrated couple' with overprotection as a communication strategy.

8.4.2: Tailoring as a concept

According to (Rimer & Kreuter, 2006) tailoring is the generation of communication patterns where information about a person is used to determine what specific content he or she will receive, the contexts surrounding the content, who will transmit the information and how will it be delivered, e.g., face-to-face or on-line. Tailoring information is a way to make the targeted person engage with the material to improve or change their behaviour. (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008) Kreuter and Holt, (2001) outlined four ways tailoring is thought to influence behaviour: attention, personal relevance, emotionality, and self-reference. For information to be acted upon, then it must reach the attention and consciousness of the intended target so that they understand what is required. Individualising information for couples may be difficult since many long-term partnerships think as 'we' rather than 'I' when processing information (Badr & Acitelli, 2005). The couple may attend to the information if they see it as beneficial for both, viewing rehabilitation as a shared problem rather than just affecting the stroke survivor or spouse individually. From the present study tailoring information would require the health care professionals to frame the communication as couple related. Similarly, personal relevance which attempts to frame the communication so it fits into the person's schema or ways of thinking would become couple relevance. Here the idea is that the less effortful the processing of the information is, and the more the information fits into habitual behaviours then there is greater likelihood of adoption (Spunt, 2015). As couples in long-term partnerships are more likely to operate as a dyad, then presenting information that reinforces the dyad are better received.

Emotionality is the presentation of information that is positive rather than negative as this is less effortful to comprehend (Forgas, 1998). Emotionality also attends to the non-verbal elements of the communication in that tailoring will register with the target that 'the sender understands me', so providing a positive space in which to frame the interactions. As discussed above couples think as 'we' rather than 'I' so framing communication that reinforces the importance of the dyad in the process of stroke rehabilitation will enhance engagement. Likewise, health care professionals did indicate that transmitting

'hope' to the couples was important for motivation in the rehabilitation process, so that the stroke survivor can reach their potential however disabled they were. The last feature in tailoring of information is self-reference (Symons & Johnson, 1997), where the receiver focus on their own context and how the information links into their lifestyle.

8.4.3: Self-efficacy or dyadic-efficacy

Self-efficacy is the confidence that a person must have to complete a task, as an established concept it is fundamental to successful functioning (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011). Dyadic efficacy as defined by Sterba et al., (2007.) "...is concerned with partner beliefs about the dyad's efficacy rather than an individual's contribution to the couple's efficacy" (p295). Sterba et al., (2007) tested dyadic efficacy on couples where one partner was living with rheumatoid arthritis, their findings suggest that couples seeing the arthritis as affecting both partners worked as a 'team' to overcome problems. Dyadic efficacy correlated well with marital satisfaction and co-operative communication, whereas couples who managed the arthritis poorly had divergent efficacy scores. Conceptually, dyadic efficacy works by engendering confidence in the couple that they can work together in tandem, so health care professionals need to cultivate confidence in their ability as a stroke couple to engage and succeed with the rehabilitation process.

8.4.4: Hope as a concept

According to Soundy, Liles, Stubbs, and Roskell, (2014) one of the best definitions of hope is provided by Snyder, et al., (1991) as: "...a positive motivational state that is based on an interactively derived sense of successful agency (goal-directed energy) and pathways (planning to meet goals)" (p.287). Hope is linked to resilience and self-efficacy in that it strengthens the emotional connection between partners (Johnson, 2004), allows skills to be built (Christenson & Jacobson, 1996), and permits couples to apply existing skills during times of need (de Shazer, 1988). In a meta-synthesis of qualitative

research looking at hope in older people living with a chronic illness (Peacock et al., 2017) and Duggleby et al., (2012) produced a framework that envisaged hope as incorporating positive reappraisal and transcendence. An important feature of positive reappraisal is the combination of personal or inward searching for meaning, together with an outward or relational search for meaning that connects with family and friends. Without experiencing hope in a spouse or partner then the positive reappraisal for the person living with a chronic condition is limited, reducing feelings of hopefulness for the future. Hope as a concept for older adults is sustained through relationships with family, particularly the spouse, friends, health care professionals, and religious faith. Consequently, the assessment of hope by health care professionals should include both partners and sustained through a relational focus (Soundy et al., 2014).

8.5: Relationship theory and CMO²

In CMO² the contextual feature was on emotional support for the stroke couple by health care professionals linked to a strength-based approach. The emphasis on the positive aspects of the couple's life together rather than the negative connects with aspects of CMO¹ in that it incorporates hope and dyadic self-efficacy between the couples as important mechanisms that sustain couple-hood. Emotional support has been investigated by Cutrona, (1996) and showed that it is more important for couples than instrumental or tangible support, which is the most likely support offered by health care professionals.

8.5.1: Couple emotional support

Ekstam, Johansson, Guidetti, Eriksson, and Ytterberg, (2015) in a mixed-methods study with stroke dyads identified that at 12-months post-stroke approximately 30% of couples were not satisfied with the rehabilitation process. The survey was linked to the 'Sense of Coherence' (SoC) (Antonovsky & Sourani, 1988) construct that people need to have meaning and comprehensibility in their lives. Dissatisfaction revolved around relationship and

emotional issues still present at 12-months and discordance was related to the individuals in the dyad being at different stages in their adaptation to the stroke. Ekstam et al., (2015) recommend that rehabilitation input should continue with these couples through providing psychological interventions that address the couples' need for understanding the changes brought about by the stroke. As the findings in this thesis has identified, there is a shift in long-term rehabilitation from functional to relationship issues, and unless resolved can create difficulties within the marriage. Information then needs to change from function orientated content to greater attention on couple dynamics including emotional support that attempts to reframe the relationship in the context of stroke.

8.5.2: Resilience and sense of coherence as dyadic concepts

A limited number of studies have investigated resilience following a stroke with none looking at couple resilience (Sadler, Wolfe, Jones, & McKeivitt, 2017). According to Smith and Hayslip, (2012) resilience in elderly adults is "...a dynamic process embedded within multiple systems of interactions and not view it as an individual trait" (p.22). They also acknowledge that resilience is a multifaceted and complex concept, involving a biopsychosocial perspective that create challenges for researchers and policymakers. Resilience has been variously defined as a trait, process or outcome, but some consensus is emerging on viewing resilience as a process (Windle, 2010). Positive adaptation and risk are two important constructs in conceptualisations of resilience. For there to be positive adaptation then a Sense of Coherence that bestows comprehensibility and meaning to life following stroke are important considerations. One means of achieving meaning to couples following stroke is through a strength-based approach that highlights everyday successes, with the principles of 'mindfulness' a possibly useful approach for stroke couples. (Kabat-Zinn, 2003) described mindfulness as "the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment" (p.145). Mindfulness-based stress reduction (MBSR) is a structured group program that uses mindfulness meditation to improve well-being. The MBSR has been

adapted for couples (O’Kelly & Collard, 2014) with chronic conditions (Merkes, 2010), and stroke survivors (Lawrence, Booth, Mercer, & Crawford, 2013). Lawrence et al., (2013) in a systematic review found four studies with a total of 160 stroke survivors (no spouses), which delivered MBSR training in group sessions and one-to-one. Findings from the review showed overall positive results both psychologically, (anxiety/depression) and physically, (blood pressure) with no evidence of harm. Interestingly, in a very small sample of stroke survivors (n=4) Merriman, Walker-Bircham, Easton, and Maddicks, (2015) using Mindfulness Based Cognitive Therapy (MBCT) showed positive results for anxiety and depression, but in follow-up qualitative interviews, participants reacted negatively to mindfulness’s requirement to be ‘accepting’ and ‘non-striving’ as they had needed these traits to motivate them to overcome their stroke disabilities.

In a systematic review of resilience in the elderly, (van Kessel, 2013) reached a consensus from the papers’ reviewed that saw resilience: ‘...as the ability to bounce back and recover physical and psychological health in the face of adversity. According to Connolly, (2005): “Resilience, or protecting against stressors and rebounding from adversity, is an important relational process for all couples” and it “...is a central factor in couples’ ability to maximize relational strengths, mitigate external challenges, and manoeuvre successfully in the relationship” (p.267). In Bodenmann and Randall, (2012) ‘stress-coping cascade’, there are three forms of coping that follow: individual coping, dyadic coping, and obtaining support from a wider social network, such as family and health professionals. If the individual lacks internal resources or the stressor is overwhelming, then dyadic and social coping become important. Testing of the stress-coping cascade with couples recovering from breast cancer (Lim, 2014) showed there was interplay between the spouses, individual coping was affected by the level of each partner’s resilience scores, which supports a relational intervention strategy for increasing resilience among couples coping with long-term conditions. In one of the few studies to investigate resilience training with stroke survivors but not spouses Sadler et al., (2017) used a scoping review, stroke survivors, family members and stroke health professional interviews probing the meaning of resilience. From this data, they

followed UK Medical Research Council (UKMRC) framework for the development and evaluation of complex interventions, and piloted a six-week group-based peer support intervention to promote resilience after stroke. Eleven older stroke survivors participated, the results showed six participants having slightly increased and four slightly decreased scores on the Brief Resilience Scale, there was no change in mean activity levels or depression scores, a small increase in mean quality of life scores, but a slight increase in mean anxiety scores, given the sample size and short follow-up, the results were not surprising. In the follow-up qualitative interviews the stroke survivors said the course was useful and the peer guide was an important role model. If resilience and coping in stroke couples within long-term relationships has a dyadic component then studies should address this in their interventions.

8.6: Relationship theory and CMO³

In CMO³ social support is the key theoretical perspective with perceived social support being highly related to quality of life and wellbeing (Cohen & Wills 1985). Social support is thought to affect mental and physical health through its influence on emotions, cognitions, and behaviours. Two models of social support have been developed: 'the stress buffering' model proposes that social support helps when a person is under stress, while the 'main effect' or direct model proposes that social support or perceived social support, regardless of stress, is beneficial to the individual (Cohen & Willis 1985). Additionally, there are different types of social support that people need to draw upon, and include (Wills & Shinar, 2000):

- Emotional support: open discussion of feelings and empathy that can reduce anxiety and enhance self-esteem
- Instrumental or tangible support: provision of practical or material items such as money or assistance with cooking that can increase time for other activities

- Informational support: provide advice and information that can lead to better coping skills
- Companionship support: this can be between couples or wider networks that produces more positive affect (p.89)

Each type of support function can be provided by many different people from the partner to health and social care professionals, however, emotional support in long-term couple relationships is predominantly provided by the partners.

8.6.1: Social support and stroke

The effects of social support on stroke survivors has been investigated through impact on physical and psychological functioning. Equating social support with improved physical outcomes is problematic, but a study by Glass, Matchar, Belyea, and Feussner, (1993) found improved functioning in 46 stroke survivors at six-months post-stroke. Stroke survivors who could marshal greater social support showed better functioning. Paradoxically, stroke survivors who had a mild stroke appeared to fare worse because they received less support as their functioning was considered satisfactory. It is the psychological outcomes of social support that has drawn a greater number of studies in stroke recovery. In a literature review of social support interventions for stroke survivors, Salter et al., (2010) identified ten studies that provided professional and lay support. Findings showed only one study (Claiborne, 2006) with statistically significant results on stroke survivor mood and depression (no data on family carer mood), the other nine studies did not show an effect. Salter et al., (2010), attributed the success of the one study to early commencement, number of contacts that were initiated by the health professional, with assessment and screening for depression, and provision of counselling if indicated. Claiborne's (2006) study utilised a care co-ordination model for her intervention that integrated services for the stroke survivors. Maintaining contact with the stroke family reassured them that they were being supported through information provision but also signposted for appropriate specialist care. Professional social support can

provide the stroke couple with a sense of security, which is especially important for as relationship issues persist long-term.

8.6.2: Social support in couples

Social support relations between couples has been expressed as: "...responsiveness to another's needs and, more specifically as acts that communicate caring; that validate each other's worth..." (Cutrona, 1996, p.10). According to Cutrona (1996) 'responsiveness' is a key component and is developed through attachments made during infancy with the mother (Bowlby, 1969). These then develop into relational schemas that feed into the longer-term perception of a partner's social support behaviour. If one partner demonstrates emotional support pre-stroke then there is reassurance that this will continue in future, particularly in adverse circumstances. However, if there have only been intermittent displays of support the schema would be one of lacking trust that the partner will be supportive in a future stressful situation that then can be destructive to the relationship (Evans et al., 1992). The types of social support provided between couples includes emotional, instrumental, informational and companionship, but when a partner has a stroke that limits cognitive, speech and functionality there are limits for a reciprocal relationship. Interestingly, Cutrona and Russell, (1987) found that there is a discrepancy between the type of support given and that desired. If comfort and reassurance is wanted by a partner and instrumental support given, support is evaluated negatively, but if tangible assistance is wanted and emotional support given there is little negativity expressed. Expressions of caring and concern are more highly regarded by couples than other kinds of supportive functions. In summary, research has found that perceived emotional responsiveness is a key component in the quality of interpersonal interactions (Laurenceau, Feldman Barrett, & Pietromonaco, 1998) as well as the maintenance of intimacy within a couple relationship and perceptions of their partners' emotional responsiveness may be more important in maintaining the relationship than their partners' actual behaviours (Laurenceau, Barrett, & Rovine, 2005).

8.6.3: Professional support and technology

The possibility of maintaining and extending professional support to stroke couples over a longer time frame is considered unfeasible in the current financial climate (Robertson, Wenzel, Thompson, & Charles, 2017). Information and Communication Technologies (ICT) is seen as a way to alleviate the problem, and is being implemented in many chronic illness self-management programmes (Wildevuur & Simonse, 2015). Within stroke family interventions there have been several studies which have used ICT as a means of supporting carers, and have shown some efficacy on psychological outcomes. One such study by Grant et al., (2002) using telephone to deliver a social problem support package to stroke carers, began with a three-hour face-to-face session with a nurse while their spouse was in hospital. Once discharged, telephone contact was continued weekly and biweekly for 12-weeks and results showed better carer problem-solving, social functioning, mental health, less emotional problems and greater satisfaction with the service as compared to a control and sham telephone groups. The telephone intervention was tailored to each couple's needs, and was arranged in a flexible manner to fit in with the carer's daily activities. The 12-week time frame for the intervention enabled the health professional and carer to develop a trusting relationship that would enhance perceived social support. In another telephone intervention (group teleconferencing) to support 88 stroke carers, Hartke and King, (2003) used the stress and coping model as the theoretical backdrop to the intervention programme. Unlike the Grant et al., (2002) study where the intervention was administered in the first six-months following the stroke, Hartke and King's (2003) participants were more than two-years post-stroke. Findings showed a statistically significant reduction in stress, but none for depression, burden or loneliness, with the control group showing a marked increase in burden scores, whereas the intervention participants remained constant. The relative success of these two studies, and others such as Bakas et al., (2009) and Kim et al., (2012), using telephone support contrasts with those utilising face-to-face individual or group based interventions which mostly prove inconclusive (see chapter three). The focus in the telephone interventions remains on individual

stress perceptions not the dyadic interaction between partners. In a Cochrane systematic review by (Lins et al., 2014) evaluating the use of telephone only counselling (from trained counsellors) for family carers of people living with dementia found nine RCTs and two qualitative studies. Overall the primary outcome of depression showed some improvement as did perceived carer burden, there were increases in self-efficacy and social support scores but were statistically non-significant. The authors of the review concluded there was scope to develop telephone counselling as a way of providing support to family carers. From the evidence to date there could be scope for health professionals to proffer social support through regular telephone contact. Within this study, it was evident that contact with the primary care team was appreciated by the three couples, even though these may have been for other functional reasons than stroke.

8.7: Relationships for CMO⁴

Based on extensive evidence, caregiving in stroke is burdensome and stressful for family carers (Bakas et al., 2014). Many statistically significant stroke caregiving interventions have focused on training spouses in practical care tasks and problem-solving coping skills (Quinn et al., 2014). However, while reviews confirm that caregiver task training reduces stress and burden in the short term (three to six months), in the longer term there have been few differences between caregivers who receive skills training and those who do not (Cameron et al. 2014; Gaugler 2010; Lutz & Young 2009). In a review of longitudinal caregiving studies, Gaugler (2010) found that most stroke caregivers learned care skills, and suggested the dyad relationship had been a neglected area as a source of stress, the results from this thesis supports this assertion. This study has developed four CMOs that considers the relationship between couples following stroke as a central theme in their rehabilitation process. How intimate relationships are maintained in elderly married couples and how they are affected by a stroke will be discussed and linked to the four CMOs. To underpin the four CMOs a model of social support for intimate

partners will be described and linked to the context-mechanisms of the programme theory. The Relationship Enhancement Model of social support (figure 8.2) was developed by Cutrona, Russell, and Gardner, (2005) and its central tenet is increasing a sense of trust between the partners, and so establishing relationship satisfaction and stability.

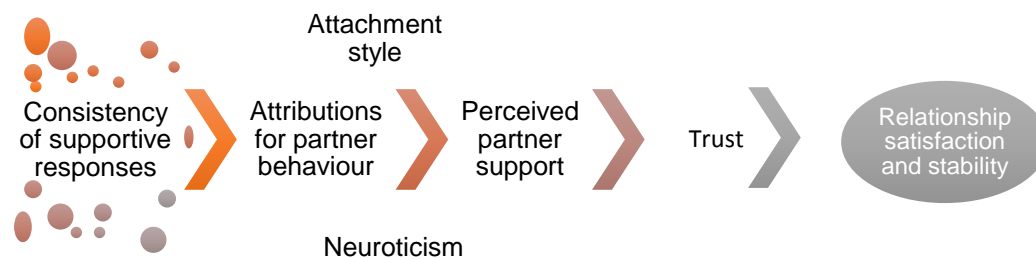


Figure 8.2: Relationship enhancement model of social support (Cutrona et al., 2005, p.74)

8.7.1: Formation and maintenance of intimate relationships

The relationship enhancement model begins with responsive supportive behaviours between the couple, as discussed in CMO³ the way a partner views the reason for giving support is important: "...responsiveness describes how partners attend to and support each other's needs and goals" (Reis & Gable, 2015, p.67). If the partner sees support as an enduring trait that has been consistently given in the past then it reinforces the perception that there will be support in future crisis. There are two personality influences that affect partner attributions and therefore, perceived social support: attachment style and neuroticism.

8.7.1.1: Attachment

Intimate relationships satisfy many important needs from companionship to sexual intimacy, but attachment theory suggests that it is the need for security, to feel loved and valued by a responsive partner that is fundamental (Feeney & Collins, 2015). Attachment theory is a mental model for understanding close relationships that links subjective experience with behaviour incorporating both conscious and unconsciously held beliefs. Attachment models have been the topic of much research, beginning with how infants develop cognitive representations of close relationships. These representations guide the infant's patterns of care-seeking and maintaining attachment to caregivers who are essential to the child's physical survival and psychological development (Ainsworth, 1985). In adult life, secure attachment to intimate partners has been linked with health, stress management, and emotional wellbeing (Mikulincer & Shaver, 2007; Waldinger, Cohen, Schulz, & Crowell, 2015). Attachment behaviour begins with the infant-parent bond that is formed through three behavioural systems: attachment, exploration and caring (Bowlby, 1980). Attachment for Bowlby was not limited to infancy but was instigated across the life-span, however most research on attachment theory has focused on child-parent and young/middle-aged relationships rather than older generations (Mikulincer & Shaver, 2007). Attachment becomes important for the adult whenever there is a perceived threatening event and so will seek proximity to their attachment figure. Exploration is the urge to explore the environment and pursue personal goals. However, exploration is antithetical to attachment, so that to explore the environment a person should deactivate themselves from their attachment bond. For this process to succeed good attachment bonds are essential for exploration, the person needs to feel secure enough that if there is a threat they can re-establish attachment, as a sense of felt security is necessary for productive exploration (Bowlby, 1980). The final behavioural system is caregiving that enables the person to reduce harm to a close other, and alerts the person to the needs of others so they can help them through the threatening situation. Again, the attachment system and the caring system are antithetical in that caregiving can only happen when the carer has their own attachments needs met. So, when the support provider feels secure, they will

be able to devote resources to the needs of others but if the caregiver's own security is threatened, and their own attachment system is activated then their ability to support is impaired leading to poorer support, depression and anxiety (Bowlby, 1980).

Based on repeated interactions with caregivers, children develop scripts that shape expectations about and behaviour in close relationships. These scripts guide children to behave in ways that help them maintain proximity to caregivers. Reliable, responsive caregiving is thought to enable children to develop secure attachment scripts characterized by comfort with closeness and the willingness to depend on others. By contrast, unresponsive or inconsistent caregiving is thought to foster insecure attachment, manifested in 'anxiety about abandonment or 'avoidance' of closeness (Bowlby, 1969). The resulting schemas are relatively enduring persist into adulthood (Waters, Merrick, Treboux, Crowell, & Albersheim, 2000), and shape expectations, experience and behaviour in romantic partnerships. Secure attachment in intimate adult relationships is associated with greater relationship satisfaction a stronger sense of intimacy. However, for those adults who experience 'anxious-ambivalent' attachment styles want closeness to their partner, but are unsure if their partner truly cares for them. In the 'avoidance' attachment schema fear or mistrust closeness and so have a tendency to stay emotionally distant (Mikulincer & Shaver, 2007).

8.7.1.2: Neuroticism

Neuroticism is one of the 'Big Five' personality traits developed by (Goldberg, 1993) and includes: openness, conscientiousness, extraversion, agreeableness and neuroticism. Neuroticism is the inclination to experience negative emotions, such as anxiety and depression. In terms of social support, people who score highly on neuroticism perceive lower expectations from social support interventions (Cutrona & Russell, 2017). This negativity ascribed to partners who try to be supportive lowers their trust and credit motivations for the support to external influences rather than to the altruism of the partner.

Insecure attachment schemas and high neuroticism are reasonably stable traits so are difficult to alter without specialist counselling.

8.7.1.3: Trust

Trust is not a behaviour or a one-off decision it is an underlying psychological state, which is informed by both emotions and cognitive processes and shares two features: trust implies a willingness of the trusting individual to be vulnerable and trust involves holding positive expectations in the individual being trusted (Wade & Robison, 2012). Trust is the most important component of close relationships in that beliefs about the partner's availability in times of need is central to an evaluation of relationship quality (Murray & Holmes, 2015). According to the Relationship Enhancement model when people are vulnerable they experience the greatest need for reassurance and demonstrations of the partner's support are most critical. Social support behaviours on the part of the partner incorporate two elements: self-sacrifice and accommodation (Cutrona, Russell & Gardner, 2005). Self-sacrifice involves the well partner putting the needs of their spouse first through taking on additional tasks. Accommodation is the process of accepting partner behaviour that may be considered unreasonable and still providing support. Through these processes partner responsiveness is shown that builds a trusting relationship (Cutrona & Russell, 2017)

8.8: Programme theory and couple relationship

Interventions to help family carers following a stroke have shown only limited success despite there being 14 systematic reviews evaluating the effectiveness of such interventions since the year 2000. Eleven of the reviews were included in the realist synthesis (chapter three), but the reviews that followed the cut-off date for the synthesis did not show any marked developments. Bakas et al (2014) in a systematic review for the American Heart Association and Stroke Association outlined reasons for limited effectiveness, including the fidelity of

the interventions and their applicability in real clinical contexts, heterogeneity of participants, who is the target of the intervention (stroke survivor, family carer or both), and lack of longitudinal studies. What is missing from Bakas et al., (2014) review and others is a recognition that interventions to lessen the psychological impact of stroke negated the way spouses operate as a couple when faced with a threat which affects them both. As Murray and Holmes (2015) state couples in close relationships have 'interdependent minds'. The reliance on the strength of the dyadic relationship, if not recognised by stroke researchers, then it is by couples themselves. Two recent polls found that 83% of older people and 93% of adults thought that having strong personal relationships with partner and family was the most important factor for them (Relate/Ipsos MORI, 2013; YouGov, 2013). Within the interviews for this study relationship between the spouses and close family were extremely important for the couples, and indeed recognised by the health care professionals.

A further reason commented upon in many of the systematic reviews analysed in the synthesis was the lack of theoretical frameworks to guide the interventions. When frameworks were made explicit, the most prominent being stress/coping (Lazarus, 1993b), and social problem-solving (Chang et al., 2004), however they were invariably used in an individualistic manner, either targeting the stroke survivor or family carer. Models of dyadic coping are available, and suggest that spouses share health stressors and actively engage in joint coping efforts (Berg & Upchurch, 2007; Bodenmann, 2005), and results in greater marital satisfaction (Falconier, Jackson, Hilpert, & Bodenmann, 2015).

8.8.1: Generalisability and realist evaluation

Before discussing the implications of the study for stroke couples, it is important to clarify how programme theories can be generalised, making them accessible in different contexts. Unlike, experimental interventions, generalisability in realist research focuses on the underlying generative mechanisms not the intervention itself, as discussed in chapter two. If mechanisms are triggered in

certain contexts then practitioners can be reasonably confident that the same mechanisms will be triggered in other similar contexts. For example, married couples who suffer from other long-term conditions, such as dementia or Parkinson's disease and cancer will also have improved outcomes if the couple are treated as a dyad with tailored information that meet the needs of the couple over time. Centring on the couple relationship enhances mutuality and trust, important mechanism that help support couples adapt to their condition. It is the CMOs that are transferred not the intervention, but because of differences between conditions then the programme theory needs to be further validated and refined with those couples.

8.9: The study's final programme theory and demi-regularities

The aims of this study were to determine what works to support married couples in their long-term adaptation to stroke. The use of a realist approach facilitated the articulation of context, mechanism, outcome configurations, and development of middle-range theories.

Couples in long-term relationships need to be understood as a dyad, whose reactions and behaviours affect each other in numerous and subtle ways. Treating a stroke survivor or their partner individualistically limits the value of the support provided by practitioners. To achieve a more couple-centric response to stroke and chronic illness management more generally, health care organisations need to enable health and social care professionals to engage in dyadic support

Table 8.1: Final programme theory

The study's findings have uncovered four demi-regularities, which demonstrate how support of stroke couples can be successfully implemented. The demi-regularities coalesced around *couple relationship* where the HCPs perceive and manage the couple as interconnected dyads rather than two people living together.

The first demi-regularity was *tailoring and timing* of information. HCPs need to recognise changes in informational needs as the couple adapt to the stroke in the longer term. Once the functional status of the stroke survivor is established, then the couple need to re-establish couple-hood affiliation rather than a carer – patient relationship. It is through social interaction especially the long-term relational ties between partners that self-identity and self-efficacy develops. Informational needs should be tailored to the continuing emotional needs of the couple who co-manage their lives with a stroke. Couples need to be made aware of the longer term psychological and behavioural changes that may result from the stroke, so that there is understanding that changes are not ‘personal’ but directly linked to physiological changes.

The second demi-regularity was *emotional support*, linked to empowering or encouraging the couple to focus on day-to-day activities that they perform together. Through adapting their routines and social patterns as a couple, they co-construct positive meaning that provides a ‘new normality’ leading to greater life satisfaction.

‘Maintaining contact’, is the third demi-regularity particularly with the assistance of technology. Professional support is still valued by stroke spouses as their needs change, particularly elderly couples, many of whom have other co-morbidities they need to manage with the stroke. Using communication technology is a way of achieving longer-term contact that does not rely on the stroke couple initiating the exchange.

The final demi-regularity is *‘coupleness’*, in that the spousal couple should be treated by HCP as a ‘unit’ acting as one, rather than two individuals living together. Within long-term partnerships coping with stress is a dyadic process in that the partners cooperate to overcome difficulties. Through emphasising and appreciating the way the couple support each other mutuality is reinforced in day-to-day shared activities.

8.10: Realist evaluation as a methodological approach

This study's design was realist in nature and as such had a different epistemological and ontological dimension than those research approaches seen in stroke support interventions. The rationale for proceeding with realist understandings of the social world was to overcome some of the criticisms levelled at studies that have investigated stroke family support, namely lack of theoretical frameworks that can direct the interventions, which have only delivered limited efficacy. Realist evaluation through investigating the triggering of generative mechanism in certain contexts develops programme theories that can help practitioners and researchers better identify why and for whom certain interventions may work. A key component of realist evaluation is stakeholder engagement within the process that tests out the programme theories at a practical level that can then feed back into practice.

8.11: Limitations and strengths

As with all research this study has its limitations. Since stakeholder engagement is important for realist evaluation, there were limitations in the couples who participated, particularly in the longitudinal phase of the study. It was regrettable that the younger couples did not continue with the study as this would have broadened the CMOs. Also, all the couples were heterogeneous with no single-sex partners participating, but this is a limitation of almost all stroke family support studies (Burgio, Gaugler, & Hilgeman, 2016). The participants were all spousal couples, so the findings are limited to such cohorts, this leaves out daughters and sons who become the main family carer for their stroke parent. These cohorts operate with different family relationship issues that would impact on effective relationship support, requiring other realist studies to establish further programme theories. Also, the couples were all white British, so the results could have limited application to other cultures and ethnic groups.

The couples were interviewed together, as discussed in chapter four for which there are advantages and disadvantages. One limitation is how 'truthful' the stroke survivor and spousal carers were in their discussion, some participants

may have provided answers that did not reflect their feelings to avoid conflict or upsetting their partner. Truth telling with any form of interview is problematic in terms of social desirability (Braun & Clarke, 2013), but throughout the longitudinal interviews trust was built up between the couples and the interviewer, and being in my mid-fifties with a nursing background may also have been beneficial.

A further limitation was the composition of the practitioner focus groups, in that the overwhelming majority cared for families in the acute phase of stroke, and up to six-months post-stroke, few practitioners saw families past this point. However, there is only limited provision in the UK for long-term management of stroke couples, even though the evidence does underscore the long-term emotional effects resulting from a stroke (Wolfe et al., 2011a). The refined programme theories need to be re-tested in other contexts, such as younger married couples with children, same-sex couples, and the different relationship patterns of daughters or sons as the main carer for their stroke parent.

Strengths of this thesis, include the realist approach with its emphasis on theory development that can lead to usable frameworks as a basis of empirical testing through RCTs. A further strength, are the longitudinal dyadic interviews, longitudinal research in stroke and other chronic conditions are not the norm, most being cross-sectional, and as a result only consider one time frame that is limiting in couple relationship research.

8.12: Recommendations for practice, research and policy

The results from this study outline several areas for developing practice, research and policy that may impact on the longer-term rehabilitation of stroke couples.

8.12.1: Recommendations for practice

Health and social care practitioners need to recast their rehabilitation management of stroke couples from an individualistic or patient-centred approach towards one that incorporates the dyad as a unit who affect each other's emotional and psychological status. In supporting stroke couples, rehabilitation should include the spouse in the decisions that are made through all phases of stroke recovery. There should be an emphasis on how the couples relate to each other following the stroke, particularly when the stroke survivor returns home and the months following the acute phase. Re-establishing couple-hood, rather than caregiver and care-receiver relationship should be as important as regaining functionality for the stroke survivor. This change in emphasis from individual co-production between HCP and stroke survivor or spousal carer to co-production between the HCP and the couple as a dyad, would be further enhanced if HCPs (at medical appointments as well as at interventions) are sensitive to labels during their communication with couples, so that being the caregiver or care-receiver are not their primary roles but husband and wife. If HCPs can develop couple-centeredness when managing the consequences of a stroke, particularly in the longer-term through use of communication technology, they can provide increased support and that could sustain couple-hood. In a small pilot RCT, Robinson-Smith et al., (2016) showed that a support package provided by nurses, that concentrated on positive reframing, in which role and marriage relationship changes post-stroke were discussed resulted in positive didactic coping with less depression.

This transformation will be difficult to achieve without organisational changes in the way stroke teams work, with most staff requiring additional education in relationship development. Most stroke services offer assessments of stroke survivors at six-weeks and at six-months post-stroke. The assessments should include instruments such as the Family Assessment Device (FAD) scale (Ryan, Epstein, Keitner, Miller, & Bishop, 2005) that monitor relationship quality between couples, and if there are burgeoning issues can then be signposted to family psychologists or RELATE. A further way that HCPs can help stroke couples is through relationship maintenance by suggesting shared tasks which

engage both partners. Sharing tasks such as housework and treatment routines bring the couple closer together, preserving communication between the two.

8.12.2: Recommendations for research

The use of the realist approach to analyse stroke family support has proved constructive in delineating programme theories that can be tested. Research to date on stroke carer support interventions have had limited success (Bakas et al., 2014). Many systematic reviews on stroke carer support interventions have commented on the lack of theoretical frameworks underpinning interventions. The realist approach, which is theory-driven can provide practical frameworks to be used and tested further. Carer support interventions occur within complex settings, not least partner relationships, which limits the impact of simple interventions (White et al., 2015). To understand how support interventions work then they should be encased around a relationship model such as Berg and Upchurch, (2007) 'developmental-contextual model of couple coping' or the relationship enhancement model of social support (Cutrona et al., 2005). These models would attempt to explain how the support interventions influence and are modified by the dyad's reasoning.

Future research in stroke spousal support should also provide interventions targeting longer-term issues where relationship stress surpasses concerns related to functionality. Support needs to be relationship centred in which the couples' resilience and communication skills are enhanced. Additional research is needed on how marriages following a stroke are reconstituted, identifying couples who remain together and couples who separate or divorce.

8.12.3: Recommendations for policy

Policies and guidelines for stroke management should focus more on the longer-term concerns resulting from the stroke, rather than the first six-months post-stroke. With better clinical management in the acute phase of stroke with techniques such as thrombolysis and endarterectomy results in more patients surviving a stroke that impacts on the spouse and family. Adapting and

maintaining couple-hood has shown health benefits for married couples, (Kiecolt-Glaser & Wilson, 2017), so reducing the need for institutional care, providing significant savings for health and social care services. Investment in HCPs education and initial training in family and couple-based care would improve the management of chronic illnesses in the community. However, there are few models for how long-term stroke should be managed by primary care teams (Aziz, 2010). Further, there is limited information on what stroke families require or need from primary care services to support them long-term, from this thesis, relationships between stroke survivors and their family carer should be part of management in the community (Aziz, Pindus, Mullis, Walter, & Mant, 2016).

8.13: Reflections on the process

The process of realist synthesis and evaluation is complex, requiring me to re-orientate my thinking in terms of the scientific process, and this took a great deal of time to 'switch' the way I viewed the social world. Having familiarity with positivist and interpretive research approaches in the past, realist inquiry did make intuitive sense for a way to provide some pragmatic solutions that could be used by health practitioners. This pragmatism, through developing programme theories that can be utilised in practice, for me, answered the problems that are inherent in RCTs and qualitative research for a practice discipline. RCTs and resultant systematic reviews are limited for social interventions as they underplay the complexity of social interaction, whereas, qualitative research being descriptive was limited due to their lack of generalisability. Realist evaluation, because it infers theories that can be transferable identify on just if an intervention works but tries to explain for whom and in what context, which becomes more usable for practitioners and researchers.

The most gratifying part of the thesis were the couple interviews, I learnt a great deal about the long-term effects, even seemingly a 'mild' stroke can have. It

was surprising how open the couples were about their relationship and the changes they had to make, showing courage and resilience.

8.14: Concluding remarks

This thesis has detailed the outcomes of research that investigated couple support following a stroke through a theory-driven process to find out what works, in which contexts? For long-term partnerships, it is the centrality of the relationship between them and the generative mechanisms that are triggered to enhance their couple-hood that would then augment the effectiveness of supportive interventions. This is the main contribution to knowledge from the thesis that has advanced the body of evidence in the rehabilitation of stroke couples. Because long-term partnerships operate as a 'unit' whose identities interweave together, resources in the form of professional support need to be tailored to the couple's relationship experiences as they adapt to the effects of the stroke. Introducing interventions that do not take account of couple-hood limits their impact.

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APPENDICES

Appendix 4.1: Participant information sheet – stroke survivor



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Project title: Sources of Support After Stroke

Participant Information Sheet – Part 1

Invitation to participate

You are being invited to take part in a research study into how people cope after stroke. Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact Dr Christopher Burton at Bangor University (his details are above and at the end of this document) if there is anything that is not clear to you or if you would like more information.

- Part 1 tells you the purpose of the study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

What is the purpose of the study?

Every year, over 130,000 people in the UK have a stroke. Relatively little is known about what sources of support people use after stroke, and why. These can include formal health and social care services, but may include other sources of support such as friends and family, voluntary groups, leisure facilities, and transport schemes. This information will help us to improve how we organise our stroke service.

Why have I been chosen?

Because you have had a stroke and have received care from the stroke service at Ysbyty Gwynedd, North West Wales NHS Trust, we are asking you take part in this study. 12 patients will be included in this study. You are also being contacted because you already gave consent when you agreed to the first assessment interview with the Stroke Research Nurse.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form, a copy of which you can also keep. If you decide to take part, you can withdraw at any time and without giving a reason. If you do decide to withdraw, you can do so by contacting Dr. Christopher Burton from the research team (01248 382556), and all the information you have provided will be destroyed. A decision to withdraw at any time, or a decision not to take part, will not affect the care you receive.

What will happen if I take part?

If you agree to take part in this follow-up study, you will be asked to participate in an interview with a Nurse Teacher from Bangor University. In the follow-up interview we would talk about the impact your stroke has had on family relationships. This interview will be an informal chat, lasting approximately one hour, where questions will focus on identities, roles, and relationships following the stroke. This interview can take place in your own home or another place in the community such as the house of family member if you prefer. Again you will be given the choice of conducting the interview in English or Welsh.

If you agree, the interview will be audio-recorded. Once the interview is completed all audio-tapes will be treated in strictest confidence with only the interviewer knowing who took part. All information from the audio-tapes will be anonymised and no person will be identified.

The interview will be conducted with you and your main family carer together and they will be asked to sign a consent form to say that they are happy to take part in the interview. Both you and your family carer need to consent to being interviewed as a pair. You will be asked to sign a consent form to say that you are happy to take part in this follow-up study.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks from taking part in the follow-up interview. You may feel tired during the interview, in which case we can stop the interview, and arrange for it to be completed at a later date. However, we do recognise that some issues may be sensitive and we would terminate the interview if any distress was felt by you or your partner.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get might help improve the care of people with stroke in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

If you have a problem, please telephone the research team on 01248 382556. Any questions about the care you are receiving or concerns about your health, should be directed to the relevant doctor such as your General Practitioner (GP).

If during the follow-up interview, you or your partner feels distressed, details of a local counselling service will be provided at the end of the interview.

Will my taking part in this study be confidential?

Yes. All the information about your participation in the study will be kept confidential. The details are included in Part 2.

Contact details

Dr. Christopher Burton
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Bangor University
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Tel: 01248 382556
Email: c.burton@bangor.ac.uk

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before you make your decision.

Project title: Sources of Support After Stroke

Patient Information Sheet – Part 2

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

You can withdraw from the study at any time and without giving a reason. If you do decide to withdraw, all your data will be destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers, who will do their best to answer your questions. The contact telephone number is 01248 382556.

If you remain unhappy, or if you have any complaints about the way the researchers carry out the study, you may contact the Head of School, School of Healthcare Sciences as follows:

Mr. Ruhi Behi
Head of School, School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF
Tel: 01248 383117

Will my taking part in this study be kept confidential?

Yes. If you consent to be part of this study, all information that is collected about you during the course of the research will be kept strictly confidential. However we will send a summary of your participation in the study to your General Practitioner (GP) Where the researcher is concerned for your partner's health and well-being, they may contact the GP to inform them of their concern. Concerns that they may act on include fire and other hazards in the home, severe mental health problems such as risk of suicide, or where there is evidence of potential abuse. In these extreme circumstances, confidentiality will be broken as the researcher will discuss them with your GP.

Any information about you and your relative which leaves the hospital will have all names and addresses removed so that no-one can be recognised from it. Only members of the research team on hospital premises will have access to actual data or information that identifies you. All documents about your involvement in this study will be kept in locked filing cabinets or on password protected computers and will not be disclosed in any reports. The data from this study will be kept for ten years and then disposed of securely. After ensuring that any identifiable data has been removed, we may also use the data we collect for teaching purposes.

What will happen to the results of the study?

We will be making a report of the study to the North Wales Clinical School. We will also publish some of the findings in academic journals and present findings at conferences. No one will be named in any report or publication. On the Consent Form you will be asked to sign, you can ask for a summary of the results to be sent to you.

Who is funding the study?

This research study is being funded by the North Wales Clinical School, and **Rcbcwales – First into Research Awards.**

Who is undertaking the study?

A research team led by Dr Christopher Burton (Bangor University) is working together on the study. Other members are Dr Salah Elghenzai (Consultant Physician, Ysbyty Gwynedd), Rhian Owen (Stroke Nurse Specialist, Ysbyty Gwynedd) and Peter Jones, Nurse Teacher (Bangor University).

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by the North West Wales Local Research Ethics Committee.

Thank you for taking time to read this information sheet.

Appendix 4.2: Participant information sheet – family carer



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Project title: Sources of Support After Stroke

Family Member Information Sheet – Part 1 Supplementary Interview

Invitation to participate

You are being invited to take part in a follow-up research interview into how people cope after stroke. Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact Dr Christopher Burton at Bangor University (his details are above and at the end of this document) if there is anything that is not clear to you or if you would like more information.

- Part 1 tells you the purpose of the study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

What is the purpose of the study?

Every year, over 130,000 people in the UK have a stroke. Relatively little is known about what sources of support people use after stroke, and this includes social and emotional issues that may arise. This interview will try and explore what sources of support families' turn to for help with the emotional issues that may be experienced following a stroke.

Why have I been chosen?

Because you are the partner of a stroke patient of the stroke service at Ysbyty Gwynedd, North West Wales NHS Trust, we are asking you take part in this study

You have already contributed to this study by completing the interview with the Stroke Research Nurse a few weeks ago, and you also agreed to be contacted again for this supplementary interview.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form, a copy of which you can also keep. If you decide to take part, you can withdraw at any time and without giving a reason. If you do decide to withdraw, you can do so by contact Dr Christopher Burton from the research team (01248 382556), and all the information you have supplied will be destroyed. A decision to withdraw at any time, or a decision not to take part, will not affect the care your relative receives.

What will happen if I take part?

If you agree to take part in this follow-up study, you will be asked to participate in an interview with a Nurse Teacher from Bangor University. In the follow-up interview we would talk about the impact your partner's stroke has had on family relationships. This interview will be an informal chat, lasting approximately one hour, where questions will focus on identities, roles, and relationships following the stroke. This interview can take place in your own home or another place in the community such as the house of family member if you prefer. Again you will be given the choice of conducting the interview in English or Welsh.

If you agree, the interview will be audio-recorded. Once the interview is completed all audio-tapes will be treated in strictest confidence with only the interviewer knowing who took part. All information from the audio-tapes will be anonymised and no person will be identified.

The interview will be conducted with you and your relative who has had the stroke together and they will be asked to sign a consent form to say that they are happy to take part in the interview. Both you and your family carer need to consent to being interviewed as a pair. You will be asked to sign a consent form to say that you are happy to take part in this follow-up study.

You will be asked to sign a consent form to say that you are happy to take part in the follow-up interview.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks from taking part in the follow-up interview. You may feel tired during the interview, in which case we can stop the interview, and arrange for it to be completed at a later date. However, we do recognise that some issues may be sensitive and we would terminate the interview if any distress was felt by you or your partner.

What are the possible benefits of taking part?

We cannot promise the study will help you or the patient, but the information we get might help improve the care of people affected by stroke in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

If you have a problem, please telephone the research team on 01248 382556. Any questions about the care the patient is receiving or concerns about their health, should be directed to the relevant doctor such as their General Practitioner (GP).

If after the follow-up interview, you or your partner feels distressed, details of a local counselling service will be provided at the end of the interview.

Will my taking part in this study be confidential?

Yes. All the information about your participation in the study will be kept confidential. The details are included in Part 2.

Contact details

Dr. Christopher Burton
Centre for Health Related Research
Bangor University
Bangor LL57 2EF
Tel: 01248 382556
Email: c.burton@bangor.ac.uk

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before you make your decision.

Project title: Sources of Support After Stroke

Patient Information Sheet – Part 2

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

You can withdraw from the study at any time and without giving a reason by informing the research team. If you do decide to withdraw, all your data will be destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers, who will do their best to answer your questions. The contact telephone number is 01248 382556.

If you remain unhappy, or if you have any complaints about the way the researchers carry out the study, you may contact the Head of School, School of Healthcare Sciences as follows:

Mr. Ruhi Behi
Head of School, School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF
Tel: 01248 383117

Will my taking part in this study be kept confidential?

Yes. If you consent to be part of this study, all information that is collected about you or the patient during the course of the research will be kept strictly confidential. However where the Nurse Teacher is concerned for your partner's health and well-being, they may contact the patient's GP to inform them of their concern. Concerns that they may act on include fire and other hazards in the home, severe mental health problems such as risk of suicide, or where there is evidence of potential abuse. In these extreme circumstances, confidentiality will be broken as the Nurse Teacher will discuss the patient with their GP.

Any information about you and the patient which leaves the hospital will have all names and addresses removed so that no-one can be recognised from it. Only members of the research team will have access to actual data or information that identifies you. All other details will be kept in locked filing cabinets or on password protected computers and will not be disclosed in any reports. The data from this study will be kept for ten years and then disposed of securely. After ensuring that any identifiable data has been removed, we may also use the data we collect for teaching purposes.

What will happen to the results of the study?

We will be making a report of the study to the North Wales Clinical School. We will also publish some of the findings in academic journals and present findings at conferences. No one will be named in any report or publication.

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This research study is being funded by the North Wales Clinical School, and RcbcWales – First into Research Awards.

Who is undertaking the study?

A research team led by Dr Christopher Burton (Bangor University) is working together on the study. Other members are Dr Salah Elghenzai (Consultant Physician, Ysbyty Gwynedd), Rhian Owen (Stroke Nurse Specialist, Ysbyty Gwynedd), and Peter Jones, Nurse Teacher (Bangor University).

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by the North West Wales Local Research Ethics Committee.

Thank you for taking time to read this information sheet.

Appendix 4.3: Interview consent form - stroke survivor



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WRITTEN CONSENT FORM FOR PATIENTS

Title of study: Sources of Support after Stroke – Follow-up Interview

Name of Principal Investigator: Dr Christopher Burton

Participant Information Number:

**Please initial the
appropriate box**

YES

NO

1 I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3 I agree to:

Complete the follow-up interview.

Allow the interview to be audio-recorded and the information I supply to be used anonymously in reports, publications or for teaching purposes.

Allow my nominated carer () to participate in the assessment.

Allow research staff to contact my General Practitioner about concerns for my health and well-being, as described in the Patient Information Sheet

5 I would like a summary of the results of the study when it is completed.

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix 4.4: Interview consent form – family member



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WRITTEN CONSENT FORM FOR FAMILY MEMBERS: Supplementary Interview

Title of study: Sources of Support after Stroke – Follow-up Interview
 Name of Principal Investigator: Dr Christopher Burton
 Participant Information Number:

Please initial the appropriate box

YES NO

1 I confirm that I have read and understood the information sheet for the above study, dated 20th May 2009 (version 2). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

--	--

2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without the medical care or legal rights of being affected.

--	--

3 I agree to:
 Participate in the follow-up interview.

--	--

Allow the interview to be audio-recorded and the information I supply to be used anonymously in reports, publications or for teaching purposes.

--	--

4. I would like a summary of the results of the entire study when it is completed.

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix 4.5: Family Assessment Device (FAD)

1. Planning family activities together is difficult because we misunderstand each other.

-----SA -----A -----D -----SD

2. In times of crisis we can turn to each other for support.

-----SA -----A -----D -----SD

3. We cannot talk to each other about the sadness we feel.

-----SA -----A -----D -----SD

4. Individuals are accepted for what they are.

-----SA -----A -----D -----SD

5. We avoid discussing our fears and concerns.

-----SA -----A -----D -----SD

6. We can express feelings to each other.

-----SA -----A -----D -----SD

7. There are lots of bad feelings in the family.

-----SA -----A -----D -----SD

8. We feel accepted for what we are.

-----SA -----A -----D -----SD

9. Making decisions is a problem for our family.

-----SA -----A -----D -----SD

10. We are able to make decisions about how to solve problems.

-----SA -----A -----D -----SD

11. We don't get along well together.

-----SA -----A -----D -----SD

12. We confide in each other.

-----SA -----A -----D -----SD

Appendix 4.6: Interview schedule – initial couple interviews

Interview Guide

Pre-amble

- Introduce self and background of study
- Aims of study and confidential nature of the research interview
- Reaffirm consent procedure
- Reaffirm consent to record interview
- Right to stop the interview and withdraw at any time

1. Relationship before stroke

I would like to start by asking you a few questions about your relationship together a few months **before** the stroke.

1. How did you make decisions about important issues that affected the household? (e.g. bringing up your children OR household budget)
2. If there was a family problem how would you try and resolve it? (e.g., financial priorities OR disciplining the children)
3. What were your usual feelings when dealing with stressful household issues?
4. Before the stroke how much of your leisure time did you spend doing things together (e.g., hobbies or trips out together)?
5. Did you or your partner find it difficult to express feelings to each other or other family members about important family issues before the stroke?

(probe: as a couple did you feel the need to be physically close to one another? Did you like to be held or cuddled in times of stress?)

6. Before the stroke how much time did you spend with your friends and relatives? – did you spend this time as a couple or separately?

2. Relationship after the stroke

I would like to ask you a few questions about your relationship together now that you **have had** your stroke

1. Has your relationship changed since (Name) has had the stroke? (in what ways has it changed?, can you give some specific examples – prompt with replies to section 1 above)
2. Do you think the stroke has brought you closer together as a couple? (how?, and if not – why? Has the amount and nature of your physical relationship changed since the stroke?)
3. Have family roles and responsibilities changed since the stroke?
4. Have you changed your hobbies and leisure activities since the stroke?
5. Do you still see the same friends as you did before the stroke?

3. Support following stroke

I would like to ask you about the support you have had since the stroke

1. Who have you used for information and support since the stroke? (from whom? – e.g., voluntary services, professionals, extended family, friends)

2. What type of support have you received from each of these? (Probe for emotional/psychological support Probe: has this support been valuable?)
3. Do you feel you had enough support related to your relationship as a couple?
4. How easy was information about 'relationships following a stroke' been to find? (would you like more information about relationship issues?)
5. What type of information would you have found useful that you did not receive?
6. In what ways has the experience of stroke affected your view of the future? (as a couple and family?)

4. Additional Issues

1. Are there any ideas or issues we have not discussed so far?
2. Is there anything we have discussed you would like to talk about some more?

Thank the person/couple for their time and contribution

Leave a leaflet of contact numbers for RELATE/local counselling services

Appendix 4.7: Codes for initial couple interviews

FAD Dimensions	Couple 1* Mary/John	Couple 2 Ian/Katie	Couple 3 Martha/Jim	Couple 4 Maggie/David	Couple 5 Dennis/Helen	Couple 6 Mark/Sally
Problem Solving: FAD - Ability to resolve instrumental and affective problems	<p>John: Well anticipating what you're going to be asking next, I'm not sure there's a great deal of difference now to what there was two or three years ago.</p> <p>Mary: I think I'm...yeah, no, I don't think.</p> <p>John: If there is a vital decision to be made, and we don't seem to have many of those, then we would sit down and talk things through but very often we seem to come together and I</p>	<p>Ian: So just little things, simple daily tasks that everyone takes for granted.</p> <p>Katie: And cooking, if you put the cooker on and you go to the toilet you might forget you've put it on.</p> <p>-----</p> <p>Katie But I think about things from day to day and I don't see it as week to week because that's how I cope better, I see it from day to day, if we can just do it today, do this today and do this today, I organise things like that and then I cope fine then. But it's overwhelming, it was at the beginning when I was suddenly faced with this, this and this, you know.</p>	<p>Martha: Well my concern when I was in the hospital was, oh who's going to look after Jim's tablets, who's going to look after Jim, you know.</p> <p>-----</p> <p>Martha: Jim puts things off doing like as I said about the ceiling, I kept saying to him, phone the builder, I don't like pushing on him all the time</p>	<p>Maggie: I just said, I want to pay for a house outright with the money and then I've not got that worry and whatever. And then I said, I'm perfectly alright to do a job and hopefully it'll never happen again... I'm just absolutely focused now into thinking, got to pay the mortgage, got to do this, got to get this sorted, I feel like I need to tidy all my, not myself but my, I don't know, all my finances, get everything sorted, so if it ever happened again and anything did go worse, I need to be ready</p>	<p>Dennis: See there's a thing with this, I don't worry about everything, she does worry, and makes decisions, I just carry on.</p> <p>Interviewer: when you were making decisions about sort of household issues with the children or this sort of thing, how did you make those decisions between you?</p> <p>Dennis: Well she made a decision, I said yes.</p> <p>Helen: Yes, we had, we'd made the decisions, about the bungalow even didn't we after the stroke? We said...</p>	<p>Interviewer: So how do you make decisions now between you or solve family issues or problems?</p> <p>Mark: Well I guess Sally does more of the decision making now as I can't always remember as well</p> <p>Sally: Actually it's only the minor decisions I don't talk to him about I guess I just don't want to bother him with trivialities</p> <p>Mark: Yeah [laughs], but that's not a bad thing</p>

	<p>may well say to Mary, 'Is it alright if' and she will say, 'Yes, you go ahead and do it', and vice versa.</p>			<p>----- -- David: Yeah, basically while she was in hospital, it was my decision, every decision I made while she was in hospital proved to be wrong [all laugh], we knew that was going to happen, you know, why have you done this and why have you done that. But she didn't realise just how chaotic it is. But yeah, it came to me and I thought, oh I don't like this at all and it's always been like a joint sort of venture anyway.</p>	<p>Dennis: Yes, you told me what you'd... Helen: That would be for my daughter if anything happened to us and it is my daughter's bungalow while we're alive and as long as we keep it, that's all we've done, that. She cannot turn us away or anything.</p>	<p>Sally: No, it's not but on big problems we talk together and think them through don't we Mark: Yes we do. Sally: No, but I suppose I should talk to you about everything like I always did... Mark: know, it's that you well I am not as interested in the basic things.</p>
<p>Problem-solving</p> <ul style="list-style-type: none"> • Problem solving processes altered for all couples, some more than others • Gender differences in that the female spouse even as the stroke survivor continued to undertake 'household' related decisions, such as purchases or maintaining social networks • All couples planned decisions as couples, especially the ones considered 'important' to the family 						
<p>Communication: FAD - Clear or masked</p>	<p>John: We always had to compromise, we've always done it, everything's been done</p>	<p>Katie: But I leave him on his own Thursday and Friday because I</p>	<p>Interviewer: Do you go to the local hospital at all, check-up...?</p>	<p>David: But yeah, she can be talked off which not normal and I didn't</p>	<p>Interviewer: Have you seen the consultant after you were</p>	<p>Mark: I had a pack from them (hospital)</p>

<p>Instrumental or affective Direct or indirect communication patterns, but also relating to health and social care staff</p>	<p>that way hasn't it, you've never been in charge of one thing and I'm in charge of anything, we've always sort of... animated discussion Mary: Yes ----- Mary: I've been left out, I think the hospital goes wrong by not saying, you might think you're over it, but it's tiredness, rest is important, I was told nothing like that by anybody coming out, you know I had the stroke nurse thing, yes, but nothing sort of explaining anything. Interviewer: What about yourself (John), were you ever involved in any, any information or anything at all in terms of this? John: I'm not immediately aware of having been involved in any of that sort of information that you're hinting at, but then on the other hand, this is a question of what's a person is content with. As a professional yourself and knowing what the</p>	<p>work, but you get so depressed because you've got nobody to talk to all day and I get home and I'm tired and I don't want to talk about anything because I've been in work all day, so that's a bit. Ian: So the quality of life has completely gone. ----- -- Interviewer: Right, so you've had no formal assessment in terms of anything. Katie: No Ian: No. Obviously, I mean the cardiologist has done his job fantastically in terms of putting me back and improving the condition of my heart and giving me the right medication, he's not interested in the stroke. My GP, you</p>	<p>Martha: He came with me, yes. Jim: Oh yes, I got, it was quite a little shock really because I just assumed they would accept us both, but they didn't include me so I thought, I'm only a chauffeur and not a... Martha: But it's too far and you see Jim isn't very reliable to say, oh I'll go out into P M for a couple of hours because he could forget where the place was, or, you know... ----- Martha: Yes, and people from other places, and they've come and talked to me and to you, they've spoken to you as well as to me. A lot of people have talked to both of us but not much about the stroke, nobody's talked much about the emotional side of anything...</p>	<p>like it at first when she came home because I've always looked to Maggie because she's always been like the lead and I'm not ashamed of saying that, you know, I obviously say I'm the man of the house but she's always led the house and when she came back I thought, oh, I don't want to be doing this. Maggie: But it's not that which is my main concern, my concern is I want somebody to say, oh that's normal, or yeah that's perfectly normal after having a stroke for that to happen, oh you know, this and that's normal and I think I want reassurance because I'm not</p>	<p>discharged from hospital? Helen: Yeah, we saw him once. Helen: We went back and we saw him. Dennis: Yeah, we saw him once and then that was it. Interviewer: How long afterwards was that? Dennis: I can't remember. Helen: A couple of weeks. Interviewer: But nothing since then? Helen: No. Interviewer: Not from the stroke association or anything? Helen: No.</p>	<p>Sally: Quite a big information pack. Mark: From yeah, the stroke nurse at the hospital and that gave me a few things... bits of information like one of these frequently asked questions things... So that was quite good. I don't know what was in it. Sally: You haven't read it though that's why. Mark: I did, I read some because I read it at the time because I said, part of what I was feeling would probably either be normal or should I go and see a doctor or whatever, so parts of it answered bits of questions I had, so -----</p>
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	<p>circumstances might be, I've no doubt you can think of a number of different aids that we might've asked for, might've been offered or something...</p>	<p>know, he's a fantastic. Katie: Fantastic, he's lovely. Ian: And he would do any referral to these things, but I don't know what's available and to be honest with you I think maybe he might be, you know, it's not up to him to do that, I mean how many minutes do they get with each patient, it's not fair for him to spend an hour with me going, you know, counselling me through these things. Interviewer: Has a stroke nurse been in touch with you, or physiotherapist related to the stroke or you had a Stroke Association, this lady from the Stroke Association. Katie: She came once Ian: Yeah.</p>		<p>getting this information I need</p>	<p>Mark: No, I think as well with the problem, when I first got out of hospital obviously, you know, still very confused and everything and I think the main job at that point was just to try and get me going, you know, to get this sorted, to learn about all this medication that I'm starting to take and I think the main priority, I start, you know, I need to know what help is there because so many questions that, you know, doctors and, you know, can't answer in terms of all these questions that I've got like about the confusion Sally: They're dismissing it aren't they?</p>
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		<p>Interviewer: Do you have a contact for her and so on, did she leave contact or just leave things open?</p> <p>Katie: She did, but we don't know what's available so we didn't know what to ask for.</p>				<p>Mark: Doesn't seem to be addressed, you know.</p> <p>Sally: It's not.</p> <p>Mark: And it's not because they're not doing their job, it's because I just don't think they're educated in that thing, so, you know, to see anything connected...</p>
Communication	<ul style="list-style-type: none"> • Communication patterns related to those seen between the couples and how the couples were communicated with by health and social car professionals • Communication styles altered to some extent after the stroke, linked to the latitude spouses gave to their partners' • Those couples (Ian/Katie and Maggie/David) who were of working age there was added potential conflict in communicating together, related to forced proximity. Whereas the older, long time retired couples were more settled in that they had adapted to retirement. • Communication by H&SC professionals, from information giving and support were not personalised to individual needs, with many aspects of the emotional impact of the stroke not being addressed. • Similarly the relationship between the couples was seldom confronted, with the GP being the main focus for information and support 					
Roles: FAD - Patterns of behaviour fulfilling family function	<p>Interviewer: As I say, you haven't sort of done a lot more in terms of roles that your wife used to take?</p> <p>John: We're very fortunate because Mary has made a fairly good recovery overall and we've just reverted to</p>	<p>Katie It's been stressful because you've been suffering with the stroke, I've been sorting out the financial side of things, I was just filling in a form this morning because</p>	<p>Martha: I think I've got a lot of stress so much as I've, the work sometimes I find a bit hard. You know, I'll stand at the sink and do the pots and things like that and stuff, and sometimes I just want to come and sit down</p>	<p>Maggie: Yeah, and because of how he (David) like goes, I don't like fuss and I don't like anything like that, and it's always been me that'd do the sorting, doing this, doing that and he</p>	<p>Interviewer: Right, okay. So it sounded as until your stroke both of you seemed quite independent in terms of what you were doing.</p>	<p>Sally: I now have to take more of a lead in the things Mark did, such as the house we had a leak in the flat roof a couple of months ago and I phoned around builders</p>

	<p>things as they were...I guess. Mary: I think so, yeah. Interviewer: Yeah, yeah? Mary: Yeah, and I'm doing most of the things that I did before, yeah. But we do do things...certainly we've got our own lives and we've always been very independent people I think is what we could honestly say so it's just carried on like that I think. And he hurts when he's not independent.</p>	<p>you haven't got a clue... Yeah, I've taken over because he hasn't got a clue of what's in the bank. ----- - Ian Which is quite weird, because I think she (daughter) sees Katie doing so much now and so she's lost that sort of where if I tell her to do something she won't until Katie says, you listen to your father, you do that and then she'll do it.</p>	<p>and I do tend to come and sit down, whereas at one time I'd have had my morning coffee, working in the kitchen and I wouldn't sit down, yes, I'm not as hardy as I was. ----- Interviewer: But at some points you do feel a bit? Martha: Oh yes, sometimes I am a bit weepy or a bit... Jim: Bit down. Martha: A bit down, yes, I am, I do get, yes. Jim: Yes. Especially when our daughter's in France. Martha: Yes, I do miss her terribly. Jim: Yes, she's a great help when she's here. Martha: Yeah.</p>	<p>can't, if he had to step forward, if it had been him that had had a stroke, I could run this place...right, with help, with their help, but he wouldn't be able to cope and that to me is another pressure I've got which I know sounds horrible and I'll say that. ----- - Maggie: I used to be absolutely meticulous with everything I did, whenever I cleaned a room and everything, now I've had to accept that I can't cope with keeping on doing it all, when we've no help and stuff and it's again and again and I might Hoover a floor, the bathroom floor instead of mopping,</p>	<p>Dennis: Oh very independent. Interviewer: Yeah, so you're doing your thing and you're doing your thing. Helen: Yes. Interviewer: Yeah, so that, is that because you can't do things now like going to B, do you find that a problem and issue? Dennis: Well it is a problem because my friends in B, so I haven't been able to go and see them. And everybody, they all keep asking about how's Dennis, where is he? Interviewer: Yeah. How do you find it now that your husband is not as mobile? Helen: Just have to put up with it</p>	<p>to see how it could be repaired, that was Mark's job... -----</p>
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				or something like that, whereas normally I'd be on my hands and knees and mopping in every corner. And I'll do little things but I appreciate I can't keep going on. But I don't really know.	really, it's very hard. Interviewer: Right, in what ways? Helen: On a Saturday because I like to clean my house right through and I just can't sometimes because, and I can't keep telling him, move out of the way and things, so he gets cross with me and I'm to blame as well aren't I? But I do like to keep the place clean if I can.	
Roles	<ul style="list-style-type: none"> • Role patterns changed for all couples from pre-stroke, again there were gender differences as described in the 'problem-solving' dimension above in that the female spouse continued to undertake 'household' related decisions, such as purchases or maintaining social networks, whereas the male stroke survivors relinquished their gender role stereotypes • For some couples (Maggie/David and Dennis/Helen) the disruption in role specific behaviours was problematic for their adaptation post-stroke. For these two couples it was for different reasons <ul style="list-style-type: none"> ○ Maggie and David ran a business and the change resulting from their usual decision-making roles caused major issues ○ Dennis and Helen had experienced relationship difficulties pre-stroke that had been 'resolved' through separate activities, since the stroke where Dennis was unable to act independently causing renewed tensions in the relationship. 					
Affective responsiveness:	Mary: And, you know, I'm very conscious that this is me different and I then	Katie And also if I did want to go out and	Martha: Well it's not me, it's the boss has given up on the sex	Maggie: David hates anything like that, talking about	Interviewer: Since you can drive, do you go	Mark: I can't say how much

<p>FAD - Capacity to respond emotionally</p>	<p>say I'm sorry, I lost my temper on that and I didn't intend to sort of thing, I don't know why I did and all this sort of thing so I think we've got it sorted out to a certain extent, well I hope so but we both are conscious of it and I know John's conscious of it.</p> <p>Interviewer: How do you feel about that, the change...</p> <p>John: Well it's a very sweet aspect of her nature which I hadn't anticipated, she's actually apologising for some of these outbursts now I know her sufficiently to allow it also, roll over and knowing that things will get better in time but yeah, it is a distressing feature which doesn't register in terms of medical treatment or anything.</p> <p>Interviewer: Right, so you find that the GP said oh, you know, passes it off really in a sense?</p> <p>Mary: No he didn't, he just said, 'Does he mind?' you see, this is some months</p>	<p>do something, like I say, each day that you stay in, your confidence goes a little bit more I think.</p> <p>-----</p> <p>-</p>	<p>side of everything and... well I don't mean he's given up...we don't cuddle much now do we?</p> <p>Jim: Not like we used to</p> <p>Martha: No, but we do still say I love you and get a kiss now and again</p> <p>Jim: Well, yeah, we still have affection for one another.</p> <p>Martha: Yeah but I think we're still very fond of one another.</p> <p>Jim: Of course.</p> <p>-----</p>	<p>your finances and yet I was alright about it and whereas now it's kind of like we don't say as much and we've got different things but I just have to keep it to myself, if I say one word about this, worrying about that and then it'd become his worry and his worry would feel like ten times more onto me.</p>	<p>out and sort of do shopping together, that sort of thing?</p> <p>Helen: No, no, no. Very seldom we do that unless my daughter is with us. No, because I would start saying you're too slow and I'd get irritated and that's no good, so we don't.</p> <p>-----</p> <p>--</p> <p>Helen: how I cope, well I'm tired sometimes, you know, because he gets me up at night and I get up and I do all this and then I get cross as well.</p> <p>-----</p> <p>--</p> <p>Helen: She lives in (Town)</p> <p>Interviewer: so not too far.</p>	<p>support Sally has been to me...</p> <p>Sally: It's what I want to do, we are a partnership</p>
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	<p>back and he just laughed, he said, 'Well does he mind?' and I think my reaction was you (John) just have to lump it at the time, something like that and he just laughed, you know, so I mean...but we're both...we are conscious of it and John can say that to me where I suspect that in some relationships perhaps you couldn't, I don't know.</p> <p>John: And I accept that it's a nervous laugh on the doctor's part, knowing that there's not a great deal he'll be able to do about it</p> <p>Mary: Or whether he could anyway</p>				<p>Helen: Not too far away, no, she's marvellous with us really, she's really really marvellous, I don't know what I'd do without her, she is. Yes, and she's got a very good husband as well and he doesn't, you know, he's very good I must say so.</p> <p>Interviewer: Yes, yeah.</p> <p>Helen: You know she can handle him...</p>	
<p>Affective Response</p>	<ul style="list-style-type: none"> • Couples emotional responses were strained following the stroke. • All the spouses (except 'Helen') provided a degree of latitude to their partner to accommodate changes in emotional responses • Helen's negative responses linked to Dennis's sometime aggressive behaviour post-stroke. Helen relied a great deal on her daughter to mediate and relive the situation. • The stroke survivors' appreciated the support provided by their partner and acknowledged that circumstances would be a great deal worse if relationships were not positive pre-stroke. 					
<p>Affective Involvement: FAD - Involvement in each</p>	<p>Mary: I think because we do talk to each other about things, we have at least sort of made the comment about it, as we</p>	<p>Katie: Although you're not quite the person you were before, you still</p>	<p>Martha: We have had a strong relationship all our lives...supporting</p>	<p>David: Sorry, I tend to ask probably more times in a day, you know, do you feel alright, you</p>	<p>Helen: He's had this freezing episodes where he can't move and I can't shift</p>	<p>Interviewer: Did anybody there talk to you again about your moods might</p>

<p>member of the family</p> <p>How couples' view themselves as a unit (we Vs 'I')</p>	<p>say we haven't sat down and had a big discussion about it as John has been just a wonderful husband, he always has been and, you know...</p>	<p>resemble the Ian I knew. Ian: Yeah, so. Interviewer: How is he not quite the person he was before, what's changed there? Ian: More fearful I think. Katie: Very fearful, more needy. Ian: Yeah.</p>	<p>each other and doing things for the family Jim: I do as I am told!... Martha: No...but if the bedrock was not there then I think it would be very hard for them after the stroke...</p>	<p>know, I'll ask, I don't know, it could be ten times a day, are you alright but I used to say, are you alright anyway, but I'm asking now to make sure she's always. Maggie: Too much. David: And she gets so annoyed with me...but it's just concern, I mean that's all, you know, and I try my best not to ask. Maggie: Over protective and it just irritates me then. David: I think I do get very overprotective.</p>	<p>him, afraid he'll fall over so I get (daughter) here to sort him out. Helen: he got a temper on him sometimes... Dennis: I'm afraid so... Helen: So I keep out of his way</p>	<p>change or that sort of thing? Sally: No. Interviewer: To either of you. Sally: Nobody spoke about that at all. Interviewer: Nothing at all. Sally: No, nothing at all. Interviewer: Would that have been useful to you in terms of talking these things through? Mark: Yes, I think so? Sally: The hardest part of it as the moods really. Mark: So we had a time of it. Sally: Yeah.</p>
<p>Affective Involvement</p>	<ul style="list-style-type: none"> • The couples' did revert to 'we' frequently during the interview demonstrating dyadic closeness • Spouses acknowledged that the emotional and mood changes in their partners' were very problematic to deal with. Reliance on family in the main to help deal with these change 					
<p>Behavioural control: FAD - Rules the family adopts. Repetitive</p>	<p>Martha: We do, we always sit down for a meal, yeah, always sit down, we don't sit in front of the television</p>	<p>Ian: What's happened also is the fact that, like I said, all these things, but you're</p>	<p>Martha: Yes, but you are the same in the morning aren't you, you'll get up in the morning, he doesn't</p>	<p>Maggie: Yeah, because like now if the bookings for August didn't come in, I just think oh my</p>	<p>Helen: He used to go on his own, he used to go on, you know, and</p>	<p>Sally: Even when you were in hospital, I shouldn't be here, I'm not sick,</p>

<p>patterns of behaviour</p> <p>Adaptation to stroke</p>	<p>of eating a meal, we sit at the table.</p> <p>Interviewer: And that hasn't changed at all, that still continues?</p> <p>John: We always held on to that and...</p> <p>Interviewer; You feel that that's important?</p> <p>John: It's only much to her credit Mary is still able to plan ahead and to cook meals very effectively.</p> <p>Mary: But you can do it if you need to...No but I mean we are very sort of able to interchange jobs to a but I can't do heavy garden work at the moment and that has been a problem</p> <p>-----</p> <p>Mary: It's coming to terms with it, as I've said I've either got to come to terms that it is something like disabled, I mean I would kick the idea of a disabled badge for ages, I mean I was virtually disabled with a bad ankle for quite some time but I never went for a badge did I?</p>	<p>still here so you'll get that bit of relief as well that it could have always been worse.</p> <p>Katie: Or we could be facing something like terminal cancer.</p> <p>Ian: Yeah.</p> <p>Katie: That would be awful.</p> <p>Ian: So, you know, with this and that your house doesn't mean nothing does it.</p> <p>Katie: It's easier to cope if you think about it like that.</p>	<p>know what day it is, he'll say, is it Sunday, is it Monday, you know.</p> <p>Jim: Yes, I'm afraid that is true these days.</p> <p>Martha: You see I wake up and I know what day it is even after he stroke</p> <p>Jim: I have to work it out.</p> <p>Martha: But I don't know other things. And I'm going to a club now, it's at P M and that's the trouble, I knew it was P something but I couldn't remember what but it's stupid because I always knew these names, you know. And I'm going to a club at P M and when the young lady came and said, to interview me here, and she said, come but you only need to come once a fortnight because it is a long way, most of the other people live in P M area, you know.</p>	<p>god, my August diary is dire and everything and I don't know, things didn't pick up quite the same as they usually do, but then I don't know, things that everyone says, oh you shouldn't bother because I mean we always have an overdraft and you shouldn't bother with running into the overdraft, well it always worries me an overdraft anyway, but it's like ten times the worry now.</p> <p>-----</p> <p>---</p> <p>David: I'm sort of looking at (Date), we'll get past that, that's a big milestone, you know, because that's like an anniversary of it and things are just getting better and better and better.</p>	<p>meet other friends there.</p> <p>Dennis: I used to go there a couple of times a week.</p> <p>Helen: Yeah, and I used to kind of go and fetch him and he used to go on the bus from here, there and then I used to go and fetch him in the afternoon didn't I?</p> <p>Interviewer: And this stopped when you had the stroke?</p> <p>Dennis: I haven't been able to go since.</p> <p>Helen: But now I do go out and I go out every morning, go and see my friends and things like that and I can drive my car and he has the mornings for himself at home because I think that's better</p>	<p>they were your exact words. But these poor people that you were sat next to, you know, sat amongst who were paralysed and stuff like that, and you just couldn't get your head round it that you were sort of categorised in the same category as these who couldn't move. In fact you were waiting on them hand and foot weren't you?</p> <p>-----</p> <p>Mark: I mean it gave you information about a stroke club that was local who actually rang up as well, so there was quite a few little things, like back up for that, you always had that phone</p>
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	<p>John: I remember people said, 'In your condition you should ask for it'. Mary: Yes, this was two years, three years ago. John: We said no. Mary: No, I'm getting better, you know, I'm going to get better, I'm not having a badge. But I think this is what I'm saying, I've got to get now, in the next few months, I want to know...I want to know whether I've got to accept a certain situation and get everything that will help me with that or get better to be able to do a bit more and I'm the sort that wants to be active and use the, you know, do things to keep my body going which I think is the right thing for both pains that are - back pains that I can do nothing about and strokes.</p> <p>-----</p> <p>Mary: As he's just said, he feels more so that it's important that we keep going together but I feel I'm getting bothered about</p>			<p>But she's always been very very stubborn and she may or may not correct me when I say this, you know.</p>	<p>really. Without seeing my friends I couldn't cope with him.</p>	<p>number, if it wasn't on there, I wouldn't have done but perhaps if I'd have had more things I would have rang them up because I'm a great believer, I like to look up to see if things are right or if it's just a normal progression and I'd rather ring them than waste the doctors time and stuff like that.</p>
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	<p>it because I feel it's not fair on John because as I say we've had 40 odd years now and there's never been a problem, some people have had times...we've never had a problem I don't think.</p>					
<p>Behavioural Control</p>	<ul style="list-style-type: none"> • Couples demonstrated resilience and a belief that in the face of problems and issues resulting from the stroke they could overcome the impact of the stroke on their lives together • This resilience demonstrated in all age ranges (Ian/Katie and Maggie/David) who were younger couples • Resilience appeared to be a feature even though there were significant psychological problems that affected both partners • H&SC professionals had limited impact on psychological strains between the couples 					

Appendix 6.1: Ethics approval - longitudinal couple interviews

North Wales Research Ethics Committee- West

Bangor
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor
Gwynedd
LL57 2PW

Tel/Fax: 01248 -384.877

Mr Peter Reece Jones
School of Healthcare Sciences
Fron Heulog, Bangor University,
Bangor, Gwynedd
LL57 2EF

19 March 2011

Dear Mr Jones,

Study title: Sources of Support After Stroke: Informing the development of a locality-based integrated commissioning framework (Follow-up interview study)
REC reference: 10/WNo01/71

Thank you for your letter of 24 March 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Ethical review of research sites

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

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

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

Approved documents

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

Document	Version	Date
Covering Letter		03 March 2011
REC application - 76631/194104/1/685		07 March 2011
Protocol	5	01 February 2011
Participant Information Sheet: Follow-up interview patient information sheet	3	21 March 2011
Participant Information Sheet: Follow-up interview family member information sheet	3	21 March 2011
Participant Consent Form: Written consent form for patients	1	01 February 2011
Participant Consent Form: Follow-up interview written consent form for family members	1	01 February 2011
Letter of invitation to participant - Initial invitation letter	1	03 February 2011
Letter of invitation to participant - Reminder Invitation letter	1	01 February 2011
GP/Consultant Information Sheets - Letter to patient's GP	2	21 March 2011
Interview Schedules/Topic Guides - Follow-up interview guide	1	22 February 2011
Evidence of insurance or indemnity	UMAL	01 August 2010
Investigator CV (Mr Peter Reece Jones)		01 March 2011
CV of Academic Supervisor – (Dr Christopher Burton)		03 March 2011
CV of Academic Supervisor – (Professor Jo Rycroft-Malone)		01 March 2011
Response to Request for Further Information		24 March 2011

Statement of compliance

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

After ethical review

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

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

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

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


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

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

10/WNo01/71	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely


Mr David Owen
Chairman

Email: angela.filippi@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

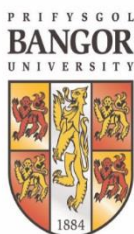
Copy to: Sponsor: Dr Malcolm Godwin, School of Healthcare Sciences, Bangor University
R&D Office: Betsi Cadwaladr University Health Board (Primary Care)

Appendix 6.2: Letter to stroke survivor general practitioner

Coleg Iechyd a Gwyddorau Ymddygiadol
Ysgol Gwyddorau Iechyd
Prifysgol Bangor

Fron Heulog, Ffordd Ffriddoedd
Bangor, Gwynedd LL57 2EF

Ffôn 01248 351151
Ffacs 01248 383114



College of Health and Behavioural Sciences
School of Healthcare Sciences
Bangor University

Fron Heulog Ffriddoedd Road
Bangor, Gwynedd LL57 2EF

Tel: 01248 351151
Fax: 01248 383114

Peter Reece Jones,
Lecturer,
School of Healthcare Sciences,
Fron Heulog,
Bangor University,
Bangor,
Gwynedd,
LL57 2EF

Tel: +44(0) 1248 xxxxxx
Fax: +44(0) 1248 xxxxxx
e-mail: p.jones@bangor.ac.uk

Dear Dr/ Practice Manager

Re: Stroke survivor name and address
Research project: Impact of stroke on family relationships and support – REC:
10/WNo01/71

I am a nurse teacher and researcher from Bangor University and I am writing to you to confirm the above patient's health status and their ability to participate in a research study. The research has had recent Health Board ethics approval in May 2011.

The patient has already been interviewed in 2010 in connection with another study 'sources of support after stroke'. We now wish to carry out further interviews with the patient and main family carer over the next 24 months to explore the impact of stroke on family relationships over an extended time period.

Recent reviews have suggested that patients with a stroke and their informal carer require diverse informational and support needs that change over time. This qualitative study is part of a PhD project that hopes to provide recommendations for service provision.

The information you provide will be confidential and is required so that there is no undue distress caused to the patient and their families because of a change in their circumstances. The patient and their family carer will be sent study information sheets and consent forms following satisfactory confirmation of their health status and prior to the interview.

If you require any further information on the study then please do not hesitate to contact me on 01248 xxxxxx, or if you prefer, contact my supervisor, Dr. Christopher Burton on 01248 xxxxxx.

May I thank you for your time in this matter.

Yours sincerely,

Peter Reece Jones
Nurse Lecturer

Health status for inclusion in these qualitative interviews

Name and address of patient

In your opinion do you think the above patient is well enough to be involved in a one hour interview carried out in their own home?

Yes

No....

Are there any further comments you wish to make on the patient's suitability to participate in this study?

Signature:

Date:

Could you please sign and date this reply slip and send back to me in the attached stamped addressed envelope. Thank you

Appendix 6.3: Participant information sheet - longitudinal couple interview



Peter Reece Jones
School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF

Tel 01248 383135
E-mail p.jones@bangor.ac.uk

Project title: Sources of support after stroke: Follow-up interviews

Participant information sheet

Invitation to participate

You are being invited to take part in two further follow-up interviews into how families cope after stroke. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me, Peter Jones at Bangor University (details above) if there is anything that is not clear to you or if you would like more information.

What is the study about?

Previous research has looked at how people cope with significant life events such as stroke. This study is designed to explore the way in which stroke survivors and their spouses cope with changes following a stroke, and how they adjust to the social and emotional issues that may arise. The two interviews that I would like to carry out with you and your spouse will build upon the previous interview I conducted with you both last year. The purpose of the two interviews is to gain a better understanding of the longer term issues that may affect family relationships following a stroke. The hope is that the information you and your spouse provide can be used by health and services to provide better focused interventions that meet some of the family needs.

Why have I been chosen?

You have already contributed to this study by kindly completing an interview with me in your home last year. I understand that you did not agree to any further interviews but your contribution was very important to the study. We would like to have two further interviews over the next 18 months in order to better understand family relationship issues and how they change over the longer time scale.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form, a copy of which you can also keep. If you decide to take part, you can withdraw at any time and without giving a reason. If you do decide to withdraw, you can do so by contacting myself, Peter Jones (01248 383135) or Dr Christopher Burton from the research team (01248 382556), and all the information you have supplied will be destroyed. A decision to withdraw at any time, or a decision not to take part, will not affect the care your relative receives.

What will happen next?

If you agree to take part in these interviews, you will again be interviewed by me, Peter Jones a nurse teacher from Bangor University. In the follow-up interviews we would talk again about the impact the stroke has had on family relationships. These interviews will be an informal chat lasting approximately one hour, where questions will focus on identities, roles, and relationships following the stroke. This interview can take place in your own home or another place in the community such as the house of family member if you prefer. Again you will be given the choice of conducting the interview in English or Welsh.

If you agree to take part in the first interview then you need to sign the consent form and post it to me in the stamped addressed envelope enclosed. When I receive your signed consent form from both of you, I will then contact you by phone to arrange a convenient date and time that I can come and talk to you and your spouse.

If you agree to this follow-up interview you do not automatically agree to the second interview. Before the second interview you will again be sent another participant information sheet and consent forms for you both to sign. You will still have the opportunity to withdraw from either interview at any time without prejudice.

If you agree, the interview will be audio-recorded. Once the interview is completed all audio-tapes will be treated in strictest confidence with only the interviewer knowing who took part. All information from the audio-tapes will be anonymised and no person will be identified.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks from taking part in the follow-up interview. You may feel tired during the interview, in which case we can stop the interview, and arrange for it to be completed at a later date. However,

we do recognise that some issues may be sensitive and we would terminate the interview if any distress was felt by you or your spouse.

What are the possible benefits of taking part?

We cannot promise the study will help you or the patient, but the information we get might help improve the care of people affected by stroke in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

If you have a problem or query, please telephone the researcher Peter Jones on 01248 383135. Any questions about the care you are receiving or health concerns should be directed to the relevant doctor such as their General Practitioner (GP).

If you have a concern about any aspect of the study, you can speak to the research supervisor, Dr Burton.

Contact details

Dr. Christopher Burton
Centre for Health Related Research
Bangor University
Bangor LL57 2EF
Tel: 01248 382556
Email: c.burton@bangor.ac.uk

If you remain unhappy, or if you have any complaints about the way the researchers carry out the study, you may contact the Head of School, School of Healthcare Sciences as follows:

Dr M Godwin
Head of School, School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF
Tel: 01248 383117

If following the interview, you or your spouse feel anxious the researcher will leave details of the local Stroke Association, who can help families affected by stroke in many ways. In addition, the researcher will leave details of the local RELATE relationship counselling service, that can provide experienced support in all matters affecting family communication.

Will my taking part in this study be kept confidential?

Yes. If you consent to be part of this study, all information that is collected about you or the patient during the course of the research will be kept strictly confidential. Where the researcher is concerned for you or spouse's health, safety or well-being, he may contact your GP to inform them of his concern. In

these unusual circumstances, confidentiality will be broken as the researcher will discuss issues with your GP.

All details will be kept in locked filing cabinets or on password protected computers and will not be disclosed in any reports. The data from this study will be kept for ten years and then disposed of securely. After ensuring that any identifiable data has been removed, we may also use the data we collect for teaching purposes.

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

You can withdraw from the study at any time and without giving a reason. If you do decide to withdraw, all your data will be destroyed.

What will happen to the results of the study?

We will be making a report of the study to the North Wales Clinical School. We will also publish some of the findings in academic journals and present findings at conferences. No one will be named in any report or publication. On the Consent Form you will be asked to sign, you can ask for a summary of the results to be sent to you.

Who is funding the study?

This research study is being funded by the North Wales Clinical School, and the Welsh Assembly Government Social Care Studentship Award

Who is undertaking the study?

A research team led by Dr Christopher Burton (Bangor University) is working together on the study. Other members are Dr Salah Elghenzai (Consultant Physician, Ysbyty Gwynedd and Peter Jones, Nurse Teacher (Bangor University) who will be conducting the interviews.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by the North West Wales Local Research Ethics Committee – West.

Thank you for taking time to read this information sheet.

Appendix 6.4: Consent form - longitudinal couple interview



Mr Peter Jones
 School of Healthcare Sciences
 College of Health & Behavioural Sciences
 Bangor University
 Gwynedd LL57 2EF

Tel 01248 383135
 E-mail p.jones@bangor.ac.uk

WRITTEN CONSENT FORM: 1st Longitudinal Interview

Title of study: Sources of Support after Stroke – Follow-up Interview
 Name of Principal Investigator: Mr Peter Jones
 Participant Information Number:

Please initial the appropriate box

YES- NO

1 I confirm that I have read and understood the information sheet for the above study, dated 20th May 2009 (version 2). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

--	--

2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without the medical care or legal rights of being affected.

--	--

3 I agree to:
 Participate in a further follow-up interview in the next few months (a further consent form and information sheet will be sent to you BEFORE the second interview)

--	--

Allow the interview to be audio-recorded and the information I supply to be used anonymously in reports, publications or for teaching purposes.

--	--

Allow my spouse () to participate in the interview

4. Allow research staff to contact my General Practitioner about concerns for my health and well-being, as described in the participant information sheet:

5. I would like a summary of the results of the entire study when it is completed.

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix 6.5: Participant information sheet - Health and social care professionals' focus group



Peter Reece Jones
Nurse Lecturer
School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF

Tel 01248 383135
E-mail p.jones@bangor.ac.uk

Project title: Supporting Families Affected by Stroke

Participant Information Sheet – Part 1

Invitation to participate

You are being invited to take part in this group discussion with your colleagues to clarify how interventions designed to improve stroke family carer stress and burden can best meet their needs and preferences. Before you decide it is important that you understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact Peter Jones at Bangor University (details are above) if there is anything that is not clear to you or if you would like more information.

- Part 1 tells you the purpose of the study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

What is the purpose of the study?

The purpose of this study is to gain new insights into how health care staff can better support patients and their partners affected by significant health problems such as stroke.

Stroke is a leading cause of disability and handicap in the UK. Stroke survivors experience significant functional limitations resulting from decreased mobility, cognitive impairment, depression, and personality changes. The substantial psycho-social impact of stroke extends to family members and other unpaid caregivers. Family caregivers play a crucial role in maintaining stroke survivors in the community but this often comes at a substantial personal cost. Many

caregivers experience a poorer quality of life and greater restraints in their social activities than non-carers as a result of caring for stroke survivors. Caregiving has been linked to higher rates of depression, anxiety, cardiovascular disease, and mortality. Given the negative effects of caring for a family member with stroke there is evidence that there are also positive aspects of the caring role such as being brought closer to other family members, appreciating their inner strength and taking better care of their own health. A key component that has not been widely researched in the stroke literature is the quality of carer – care recipient relationship. One in four stroke survivors experienced problems in his or her relationship with his or her partner. In addition, the evidence suggests that relationship satisfaction tends to diminish over time. The effects on spousal carers have been highlighted in a recent Stroke Association survey (Feeling Overwhelmed, 2013); in which 60% of carers reported difficulties in their personal relationships with their partner as a result of stroke. In addition the same survey showed that stroke families did not receive adequate assessment or support from health and social care staff in dealing with these relationship issues.

Why have I been chosen?

Because you are experts in stroke care and rehabilitation. It is your expertise with stroke survivors and their family carers that is needed to comment on the concepts that have been developed from the literature and talking to stroke couples.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form, a copy of which you can also keep. If you decide to take part, you can withdraw at any time and without giving a reason. If you do decide to withdraw, you can do so by contacting Peter Jones (01248 383135). A decision to withdraw at any time, or a decision not to take part, will not affect your personal or professional standing in any way.

What will happen if I take part?

If you agree to take part in this study, you will be asked to participate in a group discussion with your colleagues facilitated by Peter Jones from Bangor University. We would talk about the feasibility of supportive interventions developed from the literature and interviews with stroke couples. The group discussion will take place at the Queen Alexandra Hospital, Portsmouth, and will last about an hour. The discussion will be audio-recorded and transcribed by the researcher

Once the group discussion is completed the digital recording will be treated in strictest confidence with only the facilitator having access to the original recording. All information from the digital recording will be anonymised and no person will be identified.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks from taking part in the group discussion. However, if there are any issues the discussion would be terminated.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information might help improve the care of families who experience stroke or other long-term illnesses in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

If you have a problem, please telephone Peter Jones on 01248 383135.

Will my taking part in this study be confidential?

Yes. All the information about your participation in the study will be kept confidential. The details are included in Part 2.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before you make your decision.

Project title: Family Support After Stroke

Participant Information Sheet – Part 2

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

You can withdraw from the study at any time and without giving a reason.

What if there is a problem?

If you have a concern about any aspect of this study, then in the first instance contact Peter Jones, who will do his best to answer your questions. The contact telephone number is 01248 383135.

If you remain unhappy, or if you have any complaints about the way the researcher carried out the study, you may contact my supervisor or the Head of School, School of Healthcare Sciences as follows:

Dr Christopher R Burton
Centre for Health Related Research
School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF
Tel 01248 382556
E-mail c.burton@bangor.ac.uk

Dr Malcolm Godwin
Head of School, School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF
Tel: 01248 383117

Will my taking part in this study be kept confidential?

Yes. If you consent to be part of this study, all information that is collected about you during the course of the research will be kept strictly confidential. The digital recording will be transferred to the researcher's password protected work-based desktop computer that is kept in a locked office (the recording will be wiped from the digital voice recorder). Transcription of the recording will be completed by the researcher for his own use. No names will be identifiable on the transcription, only person 1, 2, etc. A paper version of the transcript will be kept in a locked filing cabinet in the same locked office. The only person who will see the anonymised transcript document (not the original recording) is the researcher's supervisor for inter-rater reliability purposes.

What will happen to the results of the study?

The group discussion is part of a PhD study funded by the National Institute for Social Care and Health Research Wales (NISCHR) for post-graduate qualification, so the anonymised information from the group discussion will be

incorporated into the thesis. Also we will publish some of the findings in academic journals and present findings at conferences. No one will be named in any report or publication. On the Consent Form you will be asked to sign, you can ask for a summary of the results to be sent to you. Portsmouth Hospitals NHS Trust will be acknowledged for their support with the study.

Who is funding the study?

National Institute for Social Care and Health Research Wales (NISCHR)

Who is undertaking the study?

Peter Jones, Nurse Teacher is the PhD student and is under the supervision of Dr Christopher Burton, both from the School of Healthcare Sciences, Bangor University.

Who has reviewed the study?

The larger PhD study was given a favourable ethical opinion for conduct in the NHS by the North West Wales Research Ethics Committee, Bangor. The group discussion was deemed to be a service evaluation on 5th July 2013, and R&D approval was not required

Thank you for taking time to read this information sheet.

Appendix 6.6: Consent form - Focus group



Peter Reece Jones
Nurse Lecturer
School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF

Tel 01248 383135
E-mail p.jones@bangor.ac.uk

WRITTEN CONSENT FORM FOR PARTICIPANTS

Title of study: Supporting Families Affected by Stroke – RELATE counsellor group discussion

Name of Principal Investigator: Peter Reece Jones

Participant Information Number:

Please initial the appropriate box
YES NO

1. I confirm that I have read and understood the information sheet for the above study, dated 10th June 2013 (version 1). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

--	--

2. I understand that my participation is voluntary and that I am free to withdraw at any time (during or after discussion) without giving any reason.

--	--

3. I agree to:
Complete the group discussion.

--	--

Allow the discussion to be digitally-recorded and the information I supply to be used anonymously in reports, publications

--	--

4. I would like a summary of the results of the study when it is completed.

--	--

Name of participant

Date

Signature

Name of researcher

Date

Signature

Please send back the completed form in the stamped addressed envelope provided

Appendix 6.7: Topic guide stroke units and RELATE

The H&SC professional focus group topic guide

A

Context – identified needs of family carers – Tailoring information and support

Outcome – improved life fulfilment (quality of life)

B

Context – stroke family carers - Recognition of needs, concerns and role

Outcome – increased resilience (spirit/bounce-back/bounce-forward)

C

Context – stroke rehabilitation – implementation of a family based service that focuses on the family relationship

Outcome – improves stroke survivor and carer outcomes

D

Context – interaction between carer and stroke survivor – facilitative or ‘counselling’ approach

Outcome – increases trust and reduces depression

E

Context – family carers - Increasing contact timeline

Outcome – buffers stress from carer role

F

Context – stroke survivor and family carer - Focus on family dynamics between carer and stroke survivor (patient specific stroke side-effects)

Outcome – improved emotional well-being

G

Context – stroke family carer gender – recognising gender differences in role responsibility

Outcome – different care-giving behaviours

H

Context – family carer – supporting/building upon resilience or fortitude

Outcome – improved well-being

I

Context – family carers – developing self-efficacy or beliefs in their capabilities

Outcome – improved mental health

J

Context – family carers – informal social networks

Outcome – better coping capabilities leading to improved life-satisfaction

Appendix 6.8: Ethics approval - RELATE

relate
the relationship people

Premier House
Carolina Court
Lakeside
Doncaster
DN4 5RA

T: 0300 100 1234
F: 01302 366287

E: enquiries@relate.org.uk
www.relate.org.uk

Peter Reece Jones
Lecturer in Nursing Studies,
NISCHR Scholarship 2010-2013,
Ysgol Gwyddorau Gofal Iechyd / School of Healthcare Sciences
Prifysgol Bangor University
Bangor
Gwynedd
LL57 2EF

10 July 2013

Dear Peter

Thank you for your application to conduct a research study in Relate.

I am pleased to inform you that your proposal meets the criteria set out in Relate's guidance for accepting requests to conduct research within Relate.

Please ensure that you notify me of any changes from the original design or conduct of the research so that the Relate Institute Research Ethics Committee can consider whether a new application for ethical approval will be required.

Yours sincerely,

Nick Turner

Nick Turner
Interim Head of Clinical Services

Appendix 6.9: Participant information sheet – RELATE counsellors



Peter Reece Jones
Nurse Lecturer
School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF

Tel 01248 383135
E-mail p.jones@bangor.ac.uk

Project title: Supporting Families Affected by Stroke

Participant Information Sheet – Part 1

Invitation to participate

You are being invited to take part in this group discussion with your colleagues to clarify how interventions designed to improve stroke family carer stress and burden can best meet their needs and preferences. Before you decide it is important that you understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact Peter Jones at Bangor University (details are above) if there is anything that is not clear to you or if you would like more information.

- Part 1 tells you the purpose of the study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

What is the purpose of the study?

The purpose of this study is to gain new insights into how health care staff can better support patients and their partners affected by significant health problems such as stroke.

Stroke is a leading cause of disability and handicap in the UK. Stroke survivors experience significant functional limitations resulting from decreased mobility, cognitive impairment, depression, and personality changes. The substantial psycho-social impact of stroke extends to family members and other unpaid caregivers. Family caregivers play a crucial role in maintaining stroke survivors in the community but this often comes at a substantial personal cost. Many

caregivers experience a poorer quality of life and greater restraints in their social activities than non-carers as a result of caring for stroke survivors. Caregiving has been linked to higher rates of depression, anxiety, cardiovascular disease, and mortality. Given the negative effects of caring for a family member with stroke there is evidence that there are also positive aspects of the caring role such as being brought closer to other family members, appreciating their inner strength and taking better care of their own health. A key component that has not been widely researched in the stroke literature is the quality of carer – care recipient relationship. One in four stroke survivors experienced problems in his or her relationship with his or her partner. In addition, the evidence suggests that relationship satisfaction tends to diminish over time. The effects on spousal carers have been highlighted in a recent Stroke Association survey (Feeling Overwhelmed, 2013); in which 60% of carers reported difficulties in their personal relationships with their partner as a result of stroke. In addition the same survey showed that stroke families did not receive adequate assessment or support from health and social care staff in dealing with these relationship issues.

Why have I been chosen?

Because you are experts in couple relationship counselling, with involvement in counselling families who are experiencing a long-term illness or disability. Even though this study targets stroke families, the literature does show similarities with relationship issues of families who have different long-term conditions, including dementia. It is your expertise in counselling family carers that is needed to comment on the concepts that have been developed from the literature and talking to stroke couples.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form, a copy of which you can also keep. If you decide to take part, you can withdraw at any time and without giving a reason. If you do decide to withdraw, you can do so by contacting Peter Jones (01248 383135). A decision to withdraw at any time, or a decision not to take part, will not affect your personal or professional standing in any way.

What will happen if I take part?

If you agree to take part in this study, you will be asked to participate in a group discussion with your colleagues facilitated by Peter Jones from Bangor University. We would talk about the feasibility of supportive interventions developed from the literature and interviews with stroke couples. The group discussion can take place at a suitably convenient RELATE site or another appropriate venue, and will last about an hour. The discussion will be audio-recorded and transcribed by the researcher

Once the group discussion is completed the digital recording will be treated in strictest confidence with only the facilitator having access to the original

recording. All information from the digital recording will be anonymised and no person will be identified.

What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risks from taking part in the group discussion. However, if there are any issues the discussion would be terminated.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information might help improve the care of families who experience stroke or other long-term illnesses in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

If you have a problem, please telephone Peter Jones on 01248 383135.

Will my taking part in this study be confidential?

Yes. All the information about your participation in the study will be kept confidential. The details are included in Part 2.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before you make your decision.

Project title: Family Support After Stroke

Participant Information Sheet – Part 2

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

You can withdraw from the study at any time and without giving a reason.

What if there is a problem?

If you have a concern about any aspect of this study, then in the first instance contact Peter Jones, who will do his best to answer your questions. The contact telephone number is 01248 383135.

If you remain unhappy, or if you have any complaints about the way the researcher carried out the study, you may contact my supervisor or the Head of School, School of Healthcare Sciences as follows:

Dr Christopher R Burton
Centre for Health Related Research
School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF
Tel 01248 382556
E-mail c.burton@bangor.ac.uk

Dr Malcolm Godwin
Head of School, School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF
Tel: 01248 383117

Will my taking part in this study be kept confidential?

Yes. If you consent to be part of this study, all information that is collected about you during the course of the research will be kept strictly confidential. The digital recording will be transferred to the researcher's password protected work-based desktop computer that is kept in a locked office (the recording will be wiped from the digital voice recorder). Transcription of the recording will be completed by the researcher for his own use. No names will be identifiable on the transcription, only counsellor 1, 2, etc. A paper version of the transcript will be kept in a locked filing cabinet in the same locked office. The only person who will see the anonymised transcript document (not the original recording) is the researcher's supervisor for inter-rater reliability purposes.

What will happen to the results of the study?

The group discussion is part of a PhD study funded by the National Institute for Social Care and Health Research Wales (NISCHR) for post-graduate qualification, so the anonymised information from the group discussion will be incorporated into the thesis. Also we will publish some of the findings in academic journals and present findings at conferences. No one will be named in any report or publication. On the Consent Form you will be asked to sign, you can ask for a summary of the results to be sent to you. RELATE as an organisation will be acknowledged for their support with the study.

Who is funding the study?

National Institute for Social Care and Health Research Wales (NISCHR)

Who is undertaking the study?

Peter Jones, Nurse Teacher is the PhD student and is under the supervision of Dr Christopher Burton, both from the School of Healthcare Sciences, Bangor University.

Who has reviewed the study?

The larger PhD study was given a favourable ethical opinion for conduct in the NHS by the North West Wales Research Ethics Committee, Bangor. The group discussion was given ethical approval by the Relate Institute Research Ethics Committee on

Thank you for taking time to read this information sheet.

Appendix 6.10: Consent form - RELATE counsellors



Peter Reece Jones
Nurse Lecturer
School of Healthcare Sciences
College of Health & Behavioural Sciences
Bangor University
Gwynedd LL57 2EF

Tel 01248 383135
E-mail p.jones@bangor.ac.uk

WRITTEN CONSENT FORM FOR PARTICIPANTS

Title of study: Supporting Families Affected by Stroke – RELATE counsellor group discussion

Name of Principal Investigator: Peter Reece Jones

Participant Information Number:

Please initial the appropriate box
YES NO

1. I confirm that I have read and understood the information sheet for the above study, dated 10th June 2013 (version 1). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

--	--

2. I understand that my participation is voluntary and that I am free to withdraw at any time (during or after discussion) without giving any reason.

--	--

3. I agree to:
Complete the group discussion.

--	--

Allow the discussion to be digitally-recorded and the information I supply to be used anonymously in reports, publications

--	--

4. I would like a summary of the results of the study when it is completed.

--	--

Name of participant

Date

Signature

Name of researcher

Date

Signature

Please send back the completed form in the stamped addressed envelope provided

