

***MARITAL RELATIONSHIPS AFTER STROKE: A THEMATIC ANALYSIS OF
WIVES' PERCEPTIONS***

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By

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DECLARATION

This thesis is an original piece of work submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology. No part of it has been submitted for any other academic award.

MARITAL RELATIONSHIPS AFTER STROKE: A THEMATIC ANALYSIS OF WIVES' PERCEPTIONS

THESIS ABSTRACT

Background: Many partners of stroke survivors assume the role of informal caregiver. Little is known about how this informal care-giving role impacts on the partnership relationship.

Method: A systematic literature review evaluated the evidence of fourteen studies, ten quantitative and four qualitative, looking at the psychological impact of informal caregiving on the partnership relationship. Evidence from the wider informal caregiving population suggested that caregivers experience high levels of depression, reduced psychological functioning and deterioration in interpersonal relationships however this review found a paucity of clear and robust evidence for the spousal caregiver as distinct from other familial caregivers. To address this gap within the literature, a qualitative study was conducted using semi-structured interviews to investigate the lived experience of six female spousal caregivers whose husbands had survived a stroke. The transcribed interviews were analysed using a process of thematic analysis as described by Braun and Clarke (2006).

Results: Spouses of stroke survivors experienced a dramatic change in their relationship after their partner's stroke. Primary and secondary loss, increased responsibility, adaptation, evaluation and acceptance themes were developed into a dynamic thematic map. The loss of aspects of both their husband's traditional role and the reflexive nature of the relationship impacted on the quality of the relationship as a whole. The processes of evaluation and adaptation both used talking as an important strategy.

Conclusions: Little is known about the caregiving trajectory for spousal partners of stroke survivors. The current study makes a significant contribution to the evidence base and suggests that the changing nature of the partnership's interpersonal dynamics may underpin some of the negative outcomes for spousal caregivers and that a greater understanding of these underlying processes may help services to provide appropriate and timely support to this population.

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I dedicate this work to my late father and to my mother who cared for him both before and after his numerous strokes.

STRUCTURE AND WORD COUNT

	Main text only	Inclusive of References
Part 1: Literature Review	6,333	8,023
Part 2: Research Report	12,763	13,955
Part 3: Critical Appraisal	3,700	3,831
Appendices		
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Addendum – Interview Transcripts		

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PART 1:

LITERATURE REVIEW

**The psychological impact of caring for a partner who has survived a
Stroke:
A review of the evidence**

Prepared for submission to the British Journal of Health Psychology (Appendix A)

THE PSYCHOLOGICAL IMPACT OF CARING FOR A PARTNER WHO HAS SURVIVED A STROKE: a REVIEW OF THE EVIDENCE

Abstract

Purpose. Stroke is a life changing event both for the individual and those closest to them. Partners often find themselves in the role of informal caregiver. The current review aimed to evaluate the evidence for psychological impact on caregivers of caring for their partner post-stroke.

Methods. Fourteen studies examining psychological change in co-habiting care-giving partners of stroke survivors were evaluated, ten were quantitative and four qualitative. The methodological rigour and quality of the evidence was discussed together with implications for practice, set within a wider professional and political context.

Results. Poor sampling strategies, low up-take and high attrition rates resulted in poor quality studies. Tentative conclusions suggested that caregivers experience high levels of depression, reduced psychological functioning and deterioration in interpersonal relationships.

Conclusions. Factors influencing outcomes for caregiving partners of stroke survivors are complex and multi-factorial. The current review highlighted a paucity of clear and robust evidence for this specific population, particularly in regard to Clinical or Health Psychology. Good quality research, making distinctions between relationships and looking at both long term outcomes and how cultural, religious and ethnic differences may impact on the experience of care-giving is needed.

Introduction

Stroke is one of the major causes of death and disability in the UK and worldwide. In the UK 150,000 people every year have their first stroke and of these, more than a third will sustain a degree of disability that requires ongoing care (The Office of National Statistics, 2001).

Many survivors of stroke, after a period of hospital rehabilitation, return home to be cared for by a close family member or spouse. Informal caregiving has long been known to have a detrimental effect on the caregiver (Han & Haley, 1999; Visser-Meily et al., 2008) although some studies have pointed out the possible positive outcomes gained by the fulfilling nature of the caregiving role for some individuals (King & Semik, 2006). Potentially detrimental effects on caregivers range from an increase in accidents (Hartke et al., 2006), poorer general health (Frazen-Dahlin et al., 2007), reduced quality of life (Fatoye et al., 2006) and reduced employment (Ko et al., 2007) to the more psychological concepts of caregiver strain or burden (Cumming et al., 2008; Ilse et al., 2008), anxiety (Wilz and Kalytta, 2008) and depression. (Cameron et al. Fatoye et al., 2006; Taylor et al., 2008) together with psychiatric morbidity (Draper and Brocklehurst, 2007). Research has however identified increasing age (Franzen-Dahlin et al., 2007; Smith et al., 2008), a sense of coherence (Pierce et al., 2001; Chumbler et al., 2008; Van Puymbroeck et al., 2008) as well as employing effective coping strategies (Qiu and Li, 2008) as potentially protecting or mediating factors.

Stroke has been widely researched but significant gaps in the evidence base still remain (Department of Health, 2008). Alongside research into the care for stroke survivors, a considerable evidence base has emerged that looks at the health, well-being and experience of the informal, often familial, caregiver. The importance of

understanding and improving the lot for informal caregivers is threefold: 1) Improved caregiver wellbeing is associated with improved care-recipient outcomes (Perrin et al., 2008); 2) Caregivers are themselves consumers of health services and poorer outcomes place additional burden on services; and 3) The contribution of informal caregivers is immense and the economic equivalence immeasurable but considerable (Dewey et al., 2002) such that social and health services would be unable to replicate the care provided.

The literature shows informal care-giving to be a world-wide phenomenon. Whilst the phenomena may be global, the likely relationship between stroke survivor and caregiver appears to differ according to culture. In western cultures, the most frequent informal caregiver was a partner or spouse of the care recipient (Ohman & Soderberg, 2004). Studies in Thailand (Jullamate et al., 2006) and Korea (Park et al., 2006) however report that the most frequent informal caregiver was a daughter followed by a niece of the care recipient.

Research, and services, have tended to group all informal caregivers together regardless of their prior relationship to the stroke survivor. Very few studies have focused on the experience of caregiving to a partner as opposed to a parent, sibling or friend. Although many studies detail the stress and burden and sometimes subsequent depression of the informal caregiving role, little attention is given to the relationship they shared prior to the Stroke. Some studies have touched on related issues with measures such as: 'the patient has changed' (Franzen-Dahlin, 2006) and some studies have found a gender difference in caregiver outcomes with women's outcomes being poorer than men (Larson et al., 2008; Wyller et al., 2003) whilst others have found no difference (Taylor et al., 2008; Tiegs et al., 2006).

Previous reviews

Several reviews in recent years have attempted to draw together interventions that aim to improve the experience and outcomes for family caregivers. In 2009, Smith et al. conducted a Meta-analysis of 17 Random Controlled Trials (RCTs) (N=1058) where the provision of information was compared with either another therapy or 'care as usual'. They concluded that the provision of information alone could improve carer satisfaction and produce a reduction, albeit small, in depression scores.

Lee et al. (2007) conducted a meta-analysis to look at the efficacy of interventions that aimed to improve the mental health of caregivers. Rigorous selection methods resulted in four RCTs (N=718), all with the SF-36 Health Survey Questionnaire (Brazier et al., 1992), being used for the Meta-analysis. The interventions were either educational or provision of support. The quality of the studies was assessed and mean weighted effect sizes calculated. For the four studies, Lee et al. were able to conclude that overall, interventions were beneficial for caregivers mental health.

A review by Brereton et al. (2007) attempted to move beyond interventions that merely used an information giving or educational format. The seven studies included (N=1037) used very different interventions and therefore Meta-analysis was not conducted. The review concluded that the trials were of poor quality and whilst some interventions improved the caregiver's outcome, the evidence was insufficient to support any particular intervention.

Lui et al. (2005) reviewed the evidence for problem solving interventions. They reviewed eleven studies including six RCTs, one correlational study, one case study, one descriptive study and two qualitative studies. All of the studies employed some kind

of problem solving technique although these varied widely. The interventions were also delivered by different health professionals, in different settings and at different time points post stroke ranging from 2-12 months, making comparisons particularly difficult. Some of the studies looked primarily at caregivers but some sampled care recipients as well. Three RCTs found that the trialled intervention improved caregivers' problem solving skills and general knowledge about stroke care. Two RCTs found that the interventions improved rates of depression, preparedness, vitality and the ability to cope with the care recipient's emotions. The interventions though did not reduce stress, burden or improve physical health. The review was unable to draw any reliable conclusions due to the variable nature of the trials included.

A review by Eldred et al. (2008) systematically analysed seven RCTs that targeted psycho-social interventions for the caregivers of stroke survivors. Studies covered a variety of interventions based upon different theoretical models. The small sample sizes and high attrition rates were problematic. Effect sizes could only be calculated for three of the studies and the effect sizes were small to medium at best.

A more extensive but narrative review by Visser-Meily et al. (2005) examined twenty two studies (N=2435): 18 RCT's (n=2086), two uncontrolled studies (n=118) and two non-randomised comparative studies (n=231) where pre and post intervention measures were included. Most studies sampled both caregiver and care recipient. Only six studies focussed exclusively on the caregivers. Caregivers were reported to be a mixture of adult children and partners although some studies did not disclose characteristics of the caregivers. Interventions were categorised into counselling, peer support, specialist interventions to facilitate discharge and psycho-education interventions. No difference in outcome was found for peer support as an intervention,

however, facilitated discharge showed significant improvements for the caregiver in four of the twelve studies. Psycho-education produced caregiver improvements in four of the six studies and counselling in three of the four studies. Although Visser-Meily et al. (2005) concluded that counselling produced the most positive outcomes, the quality of the evidence was not evaluated. These recent reviews present rather a mixed view of the efficacy of interventions for caregivers. No robust conclusions could be drawn due to the poor quality of the studies and the variability of intervention and measures employed.

A lot of research studies over the last decade have focused on interventions for caregivers without looking further into the experience of caregiving for stroke survivors. Prior to reviews published in 2010, Gaugler (2010); Greenwood & Mackenzie (2010) and Sabin et al. (2010), the most recent review that had focused on the effects of caregiving on the family caregiver was by Han et al. in 1999.

Han et al. (1999) reviewed twenty two studies that included two controlled trials (n=430) and 18 cross-sectional surveys (n=1634). Han and colleagues found the studies to be of poor quality with small sample sizes, simplistic analysis as opposed to multi-variate analysis, a lack of proper controls and a wide variety of outcome measures, some of which were considered to be of dubious validity. Although the studies looked at various factors, sufficient attention was not given to factors of ethnicity, time since stroke, positive aspects of caregiving and specific difficulties resulting from stroke e.g. communication.

Sabin et al. (2010) reviewed twenty four studies focusing on stress and physical health in caregivers. Half of the studies were cross-sectional or descriptive and half were prospective. No characteristics or numbers of participants were given. The studies

were very varied in what they were measuring and the time points of measurement. The authors used a newly developed theoretical model, the adapted Pittsburgh Mind Body centre model (Matthews, 2008), to guide their interpretation of the literature. They concluded that a better understanding of the caregiving trajectory was required to enable vulnerable time periods to be identified.

Gaugler (2010) rose to the challenge of reviewing longitudinal studies with a view to examining how the outcomes for stroke caregivers may change over time. In this complex and thorough systematic review, 117 studies (N=9899) were reviewed, the majority of which were of a longitudinal design (63 studies) with the inclusion of some cross-sectional studies where a timing variable was stated in the title or abstract (22 studies) and some qualitative studies (33 studies), one of which included both qualitative and quantitative data and so was included in two categories for the purpose of review. No characteristic of the caregiver was required other than them being of eighteen years or older. The studies were very variable and the average age of caregiver ranged from 41.2 years to 76 years. The synthesised results were not able to demonstrate any consistent change over time, with differing studies showing results in both directions. Gaugler concluded that the qualitative studies suggest that the process of change over the illness trajectory is a dynamic and complex one that may only be understood in the context of the relationship between caregiver and care recipient. He suggested that, in order to further the state of the art in this area of research, more specific measurement tools and more sophisticated methods of research design and analysis are required.

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 using a method proposed by Noblit and Hare (1988) that utilised both induction and interpretation. They identified 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.

Whilst research into care-giving for stroke survivors is extensive much of the literature does not make the distinction between partner or spousal caregivers and other familial caregivers.

Aims

The aims of the current literature review were to evaluate the recent evidence for psychological impact on partners and spouses caring for their partner post stroke and to set this within a wider context of family caregiving. A secondary aim was to understand what factors, both external and internal contributed to the psychological experience and outcomes for this population.

Method

Inclusion Criteria

Participants

Participants were to be over eighteen years old and either a co-habiting partner or spouse of a stroke survivor.

Setting

A community or home setting where the partners were still living together.

Study design

Any study design that looked at change over time, both qualitative and quantitative

Outcomes

Any outcome measure looking at psychological or emotional change.

Exclusion Criteria

Participants

Caregivers to patients with co-morbidities such as dementia or chronic physical illness or disability not due to stroke. Carers that had either no relationship to the stroke survivor or a relationship other than husband, wife or partner.

Study design

Any study with a primary focus on testing an instrument or intervention and any study with a primary focus on gender differences.

Search Strategy

A search of electronic databases was conducted using the search terms: stroke, cerebrovascular accident and caregivers, caregivers, carers, spouse, spousal, partner, informal, family, psychological and emotional. The databases used were: Psychinfo, Medline, Web of Knowledge and Ovid Embase. Restrictions to the search were: Published in English 2004-2011 in an adult human population. The timeframe was broadened to see if this would generate more specific UK Clinical, Health or Rehabilitation Psychology papers for consideration but was unsuccessful in doing so.

Initial searches were supplemented by identifying key researchers and viewing their publishing records together with searching relevant reference lists and citations. Titles and abstracts that potentially fulfilled inclusion criteria were identified.

The effectiveness of this search strategy was validated by cross checking recent published reviews (Brereton et al., 2007; Eldred et al., 2008 Gaugler et al., 2010, Green et al., 2007, Greenwood & Mackenzie, 2010, Lee et al., 2007; Lui et al., 2005; Ostwald et al., 2008, Sabin et al., 2010, Smith et al., 2009 and Visser-Meily et al., 2005). This search strategy had successfully identified all the recent papers reported in these reviews.

The available abstracts were read and studies that focused solely on methodological issues or on the testing or validating of measures and tools were excluded. Papers focusing primarily on service issues were also excluded.

The full text papers were obtained for the remaining studies and reviews. A four phase strategy was employed in accessing full text articles. Initially they were sought through the University of Leicester's library E-link facility. Where this was unsuccessful, further searches were conducted through the NHS Electronic Library and through an open access internet search. Finally, papers unable to be accessed through the first three methods were acquired from the British Library through the University of Leicester's inter-library loan facility. Most of the papers were not of UK origin and very few were within the psychological literature, most being in specialist nursing and rehabilitation journals.

Results

Identification of studies

The initial database searches produced 128 papers. After the initial exclusions described above, 63 full-text papers (Appendix B) were read and then categorised into reviews, both quantitative and qualitative and then further into those that dealt with psychological impact (N=8) or intervention (N=6). Studies were categorised into qualitative (N=12), those that dealt with the psychological effects of caregiving (N=19), those that focused on wider quality of life measures (N=13) and those that dealt with developing interventions (N=5). It was often not clear until this detailed scrutiny of the studies what the prior relationships between care recipients and participants, variably referred to as informal caregivers, caregivers or family carers, were.

Some papers did not comment on the relational status between care recipient and caregiver at all whilst others included other relations and friends together with partner caregivers. There was no mention in any of the studies of either same sex partnerships or co-habiting unmarried partnerships, which may be due partly to this information not being routinely collected. Many studies allowed the stroke survivor to identify their closest carer but did not record what the prior relationship status had been (Tiegs et al., 2006; Wyller et al., 2003). Some studies used terms such as ‘significant other’ (Franzen Dahlin et al., 2006) that might be thought of as synonymous to partner, but closer examination revealed that 21% of ‘significant others’ were adult children of the stroke survivors. Studies were rejected if they were not explicit in stating that their participants were the spouses or partners of the stroke survivors. This left 14 studies for review, 10 quantitative and four qualitative.

Data Extraction

Data was extracted from each of the 14 studies (Appendix C). The authors, source and date of publication, together with sample size, characteristics of partner care provider, study design, the measures used as well as outcomes were extracted. Studies were then categorised into quantitative or qualitative for the purposes of review.

Data Synthesis of Quantitative Studies

Methodological Critique

Comparisons between the studies were difficult and statistical synthesis not possible due to the heterogeneity of variables including: participants, approaches, measures (Appendix D), timings of measures (Appendix E) and outcomes. None of the studies was randomised due to the nature of the population and no control groups were employed in the study designs. Where information was available to calculate effect sizes the effect sizes, were small. Low uptake rates and high attrition rates were both symptomatic of the predominantly elderly and ill populations but also served to bias the available data. It was hard to predict how this bias might work but could possibly bias towards participants that were higher functioning or more engaged with services. Alternatively, it may well be that potential participants who were busy and coping well, dropped out due to lack of interest in the studies.

Sample

Sample size varied from 44 (Draper, 2007) to 187 (Visser-Meily, 2005). Nine of the 10 quantitative studies gave information on the age of caregivers; the mean age ranged from 54years (Visser-Meily, 2005) to 69.2 years (Rochette, 2007) with an across studies mean of 61.34 years.

Measures

A wide array of measures were used that measured disability in the care recipient and various measures of distress, function, life satisfaction and psychopathology in the caregiver (Appendix D).

Measurement points

In addition to the wide variety of measures used, the timing of the measurements varied widely (Appendix E). Most studies had a baseline measure that was between the stroke event and a month post discharge from rehabilitation. Because of the lack of information about how long a period of rehabilitation was, even the baseline measures were subject to wide variability between and possibly even within studies.

Reviewed Quantitative Studies

Overview

Nine of the 10 quantitative papers looked at a variety of psycho-social functioning and quality of life indicators such as caregiver strain, burden, life satisfaction, anxiety (Wilz et al., 2008) and depression, whilst the tenth paper (Rochette et al., 2007) took a slightly different approach looking at coping strategies and appraisal as well as depression.

Some studies focused on age bands, either younger or older care givers whilst others paid closer attention to gender.

Predictors of stress and psychopathology in partner caregivers

Understanding what causes increased stress, sense of burden and reduced psychological wellbeing forms the main thrust of the reviewed quantitative studies.

Post-stroke disability

Blake et al. (2003), Draper and Brocklehurst (2007), Ostwald (2009), Visser-Meily et al. (2008) and Wilz et al. (2008) all looked at the relationship between disability in the stroke survivor and stress, burden and psychological well-being of the carer. Both Blake et al. (2003) and Ostwald et al. (2009) reported an association between decreased functioning in the care recipient (CR) and increased strain on the care providing partner (CG). Visser Meily (2008) also found a significant association between the level of impairment in the CR and psychosocial functioning in the CG and Wilz et al. (2008) found that greater disability was associated with increased levels of anxiety in the CG. Draper and Brocklehurst (2007) however, reported that greater impairment in the recipient of care was not associated with increased strain for the caregiver, but that it was more specifically language impairment that was associated with elevated levels of strain in the caregiver.

The measures used varied between studies, making comparison difficult. Draper and Brocklehurst (2007), Visser-Meily et al. (2005; 2008) and Wilz et al. (2008) used the Barthel Index (Mahoney & Barthel, 1965) to measure disability, whilst Blake used the Extended Activities of Daily Living Scale (EADL) (Nouri & Lincoln, 1987) and Ostwald et al. (2009), the Functional Independence Measure (FIM) (Dodds et al., 1993). Similarly, Blake et al. (2003), Draper et al., (2007) and Visser-Meily et al. (2005, 2008) used the Caregiver Strain Index (CSI) (Robinson, 1983) whilst Ostwald et al. (2009) used the Perceived Stress Scale (PSS) (Cohen et al. 1983) to measure strain in the caregivers.

Age of caregiver partner

The age of the caregiver has been associated with poorer outcomes. Franzen Dahlin et al. (2007) identified age as a positive predictor of psychological health, with older partners having better psychological health than younger ones. This finding was replicated in the study by Ostwald et al. (2009). It is not clear why this might be, but possibly this association could be explained by people developing improved coping strategies over time or might be linked to expectations around normal developmental trajectories, illness and caring at different ages.

Gender of caregiver partner

Both Ostwald et al. (2009) and Wilz et al. (2008) found that female caregivers experienced more stress and higher levels of anxiety prevalence and intensity. Franzen Dahlin et al. (2007) found that women's psychological health was more negatively affected at the six month point than was the men's. Because all of the samples were heterosexual couples, it was unclear whether this was because partners caring for men experience increased stress and anxiety or whether it was that female caregiver partners experienced this regardless of the gender of care recipient. In other words, it is unclear whether there was an association with some characteristic of the male care recipient or whether it was in response to the caregiving role. Blake et al. (2003) found no gender difference in outcomes within their sample.

Physical health of caregiver

Reduced physical health in the caregiver was found to be positively correlated with increased stress (Blake et al., 2003 and Ostwald et al., 2009) and reduced psychological

wellbeing (Franzen Dahlin, 2007). Draper and Brocklehurst (2007) also found that physical health was poorer in CGs than in matched norms.

Coping style and strategies of caregiving partner

Rochette et al., 2007 found that appraisal and coping style two weeks post the stroke event (T1) was associated with depression at six months post stroke (T3) and that coping styles did not change much over time. A passive coping style was correlated with higher levels of stress (Ostwald et al., 2009) and reduced life satisfaction and increased burden and depression (Visser-Meily et al., 2005).

Satisfaction with life and relationship

Compared with matched norms for healthy couples, both care givers and receivers were less satisfied with their life situation (Carlsson et al., 2007). Although there were differences across domains, dissatisfaction with leisure time and sex life were the areas of greatest dissatisfaction for both CRs and CGs. This was a similar finding to Visser-Meily et al. (2005) who found that only 50% of caregivers were satisfied with their life as a whole, with only 45% happy with their leisure time and only 32% with their sex lives. When these participants were followed up two years later (Visser-Meily et al., 2008; 2009), their levels of satisfaction with life, social relationships and harmony in the relationship had all deteriorated further despite a reduction in care giver burden. Ostwald et al., (2009) found that a high level of mutuality in a relationship was associated with lower levels of stress for the care giver, but not to a statistically significant level.

Trajectory of change

Nine of the 10 quantitative studies were longitudinal in design. As mentioned earlier, there were many different time points for measurement (Appendix E) and with the exception of Visser-Meily (2008;2009), the trajectory of change and adjustment was only followed in the first year post stroke which does not appear to allow for as much change, as is seen after the one year point. It is quite difficult to make comparisons in time points, but the studies as a whole seem to demonstrate a shifting and adjustment process that shows ongoing impaired quality of life and increased rates of depression and anxiety with reduced levels of stress and burden as time progresses. The real ongoing trajectory seems to become apparent in the time frame between the first year and the third year post stroke when all aspects of psychosocial functioning and quality of life deteriorate with the exceptions of depression, which remained fairly constant (52-50%) over time, and care giver burden which diminished between one year and three years' post stroke.

Summary

The 10 quantitative papers in the current review varied widely in terms of measures and measurement points making comparisons difficult. They predominantly looked at predictors of stress and psychopathology in partner caregivers and suggested that female caregivers, younger caregivers and carers in poor physical health experienced poorer outcomes. The trajectory of change suggests that whilst levels of stress and burden for the caregiver reduced over time, their psychosocial functioning and quality of life deteriorated.

Reviewed Qualitative Studies

Only four of the qualitative studies remained after applying all exclusion criteria. The most common reason for exclusion was that either the relationship between the care provider and care recipient was not made explicit or that a proportion of the caregivers included in the study had a relationship to the care recipient other than spouse or partner.

All of the included four studies offered differing perspectives in terms of age or age range of participants and time points since the stroke event. Two of the studies were European, one Swedish (Backstrom, 2010) and one British (Buschenfeld, 2009) and two were North American, one from the USA (Brann, 2010) and one Canadian (Coombs, 2007). With the exception of Backstrom who sampled only middle-aged women, all sampled both male and female care-giving partners. Backstrom and Buschenfeld sampled working age populations whilst Coombs sampled over 55year olds and Brann had a broad age range of between 21 and 93 years of age. The time of duration since stroke varied between studies. Backstrom interviewed participants at three time points within the first year post stroke; all other participants were interviewed once. Time since stroke varied between one month to two years (Brann, 2010), three to seven years (Buschenfeld, 2009) and over one year (Coombs, 2007). Characteristics of participants and methods of data collection and analysis are summarised in Appendix F.

Themes

An iterative and interpretive approach as suggested by Noblit and Hare (1988) was used to analyse the qualitative themes across the qualitative studies. This process sometimes referred to as meta-synthesis or meta-ethnography uses the constant comparative

method of analysis (Glaser & Strauss, 1968) in order to identify common themes and meanings across studies. It enables qualitative studies to be systematically analysed to form a coherent understanding of the evidence base in a comparable method to that of meta-analysis in quantitative research. A criticism of the method is that it is reductionist and therefore, as well as losing some of the richness inherent in qualitative data, it may also lose important concepts. The process of meta-ethnography is somewhat of a trade off between this risk and the advantages of being able to include qualitative studies in synthesised presentations of literature.

Four main themes were identified that were represented in all four studies with a further three themes identified within at least two of the four studies (Appendix G). Some of the themes were quite broad and there was a considerable amount of overlap between one theme and another.

Loss and grief

Loss and grief were identified in all of the studies. Loss covered many things from loss of identity and previous role as spouse, to loss of freedom, choice and leisure time.

Participants talked of a loss of intimacy and affection within the relationship as well as a loss of the support, both physically and emotionally, that they were used to from their partner prior to the stroke event.

Fear of the future

A persistent theme was that of 'fear of the future' and of what might happen. This theme overlapped with the responsibility theme, partners worried that left unattended, their spouses may fall or have a further stroke. Overlapping with the theme of loss, spouses feared that something would happen that would cause them to 'lose' their

partner, either through death or more severe impairment. Backstrom (2010) was alone in reporting the fear that the care giving wife had that they might not be able to endure the relationship, which overlapped with the theme of responsibility.

A sense of duty and responsibility for everything

This for many partners, particularly female partners, was experienced as an ‘overwhelming feeling of responsibility and obligation’ to the stroke survivor to meet their every need and be a constant, or near constant, companion. Participants spoke of feeling guilty if they left their partners to go out (Coombs, 2007), even if for a short time. A belief in lifelong fidelity (Backstrom, 2010) could leave them feeling ‘trapped’ in an unwanted relationship.

Coping

Coping was a theme that ran through all studies and people talked of trying to find space for themselves within the relationship (Backstrom, 2010), gathering information (Brann, 2010), retaining a sense of humour, maintaining hope and optimism (Brann, 2010; Coombs, 2007) and seeking help from family and friends (Buschenfeld, 2009; Coombs, 2007).

Adaptation and adjustment

Adaptation and adjustment to new roles was talked about in three studies (Backstrom, 2010; Buschenfeld, 2009 and Coombs, 2007). This appeared to have two quite distinct components, one that might be perceived as increased burden as partners talked of taking on new roles of domestic responsibility in addition to those for which they already had responsibility. The other part of adaptation overlapped with the theme of loss and related to the adaptation from spousal partner to carer or even maternal figure.

This in turn had some overlap with the theme of ‘sense of duty and responsibility for everything’.

Comparisons

The theme of comparisons partly overlapped with the coping theme as participants talked of the merit of comparing their partner with others in worse situations (Buschenfeld, 2009) and counting their blessings (Coombs, 2007). Comparisons also worked in the opposite direction though as partners compared past to present and others with improved recovery and believed their current situation to be worse. Care givers compared themselves to their peers and this highlighted the negative aspects of their situation. Backstrom (2010) spoke of comparing the roles of sexual partner and carer and finding the two to be incompatible.

Expression of emotion/ suppression of emotion

Buschenfeld (2009) and Brann (2010) both identified a theme of trying to suppress or contain expressions of emotion, focusing on pragmatic coping styles and feeling the need to appear calm and strong, particularly in front of the care recipient. This theme had an overlapping aspect with the coping theme as this can be viewed as a ‘maintaining a stiff upper lip’ type of coping style.

Summary

The four qualitative studies included in the current review were varied and analysed interviews with partner caregivers between the ages of 21 and 93 years of age and at time points between one month and seven years after the stroke event. A meta-synthesis of the data produced themes of loss and grief, fear of the future, a sense of duty and

responsibility for everything, coping, adaptation and adjustment, comparisons and expression/ suppression of emotion.

Discussion

The current literature review aimed to evaluate the evidence for psychological impact on spousal or partner caregivers to stroke survivors within the context of family caregiving. A literature search produced 128 papers of which 14 remained after the exclusion criteria was applied. Of the 14 papers, 10 were quantitative and four were qualitative. Statistical synthesis of the quantitative data was not possible due to the heterogeneity of variables. The quantitative studies reviewed suggested that female caregivers, younger caregivers and carers in poor physical health experienced poorer outcomes over a number of measure and that whilst levels of stress and burden for the caregiver reduced over time, their psychosocial functioning and quality of life deteriorated. A meta-synthesis of the qualitative data produced themes of loss and grief, fear of the future, a sense of duty and responsibility for everything, coping, adaptation and adjustment, comparisons and expression/ suppression of emotion.

Limitations of the current review

This review was not without limitations. A single reviewer searched and selected papers for review, therefore reliability was not cross-checked. It is possible that key papers were missed or that details from reviewed papers were missed or misinterpreted. Whilst unpublished material was sought, it may still be possible that a publication bias may exist. Whilst marital and equivalent relationships are built upon an intention of longevity, the vast majority of these studies were looking at a very small snapshot of time in the immediate aftermath of the stroke event. Although the work by Visser-Meily

suggested that after the one year time point, many aspects of psychosocial and relationship functioning deteriorates, this is in a younger cohort and at three years post stroke, this is still a relatively small time frame in what might be expected to be a 20, 30 or 50 year relationship.

The Visser-Meily (2008; 2009) studies provided useful evidence about the experience for the spouse caregiver up to three years post stroke. Attrition rates were lower in this study than in others, although the take-up rate was not reported. It is however worth noting that the sample in these Visser-Meily et al. studies was significantly younger (mean = 53-54years) than in many others and so may not generalise out to an older population. Many of the couples had childcare responsibilities and employment issues that were unlikely to be present in studies where couples were retired and children grown up.

What the studies highlighted was the variation within the carer samples over the time span. Differences varied according to various aspects of psychosocial functioning, one to three years post stroke. It is not clear why there is such a decline in some areas of functioning. Possible reasons may only be speculated: It may be that the maximum amount of rehabilitation had been achieved by this point and that the couple had begun to realise that what initially was thought to be a plateau in improvement was actually how things would remain; finances may have become tighter and the initial flurry of social support may have diminished resulting in a reality check and a realisation of what was now not achievable in terms of life goals. However, because of a lack of research investigating the trajectory after the three year point, it is not known what happens after this point.

The varied nature of the studies made systematic review impossible and synthesis difficult. This lack of systematic analysis is the key weaknesses of this review.

The reviewed evidence suggests that understanding and attending to the psychological needs of spousal and family caregivers of stroke survivors is a complex and only partially understood task. The plethora of studies evaluating psycho-social outcomes and interventions for this population were characterised by their heterogeneity of both methods and theoretical frameworks. Previous reviews have been thwarted in their attempts to compare and meta-analyse because of lack of randomised sampling, lack of control groups, low participant numbers, high attrition rates and the vast array of methods, measures and differential variables.

Brereton et al. (2007) conducted a systematic review of interventions for family caregivers and found that half the interventions had no theoretic framework and that the other half used a stress-coping conceptual foundation. Much of the research in this area has focused on predicting which caregivers will experience negative outcomes, both physically and psychologically, so as to be able to target interventions appropriately (Visser-Meily et al., 2005). Whilst this is understandable in terms of service provision it fails to acknowledge that for some people the caregiving role may produce positive outcomes and personal and inter-personal growth (Buschenfeld et al., 2009, Palmer & Glass, 2001).

There is no clear understanding of how the stroke survivor's needs, and subsequently the caregiver's needs, change in the long-term (Smith et al., 2008). The longest time frame the current review covered was three years post stroke, by which time psycho-social functioning in the caregiver was deteriorating. Whether this

deterioration continues or whether a plateau or even an improvement is reached for some people is not known.

This inconclusive evidence base suggests that factors influencing the outcomes for family caregivers and spousal or partner caregivers are complex and multi-factorial. The current review highlighted a paucity of clear and robust evidence in this area, particularly in regard to Clinical and Health Psychology, and emphasised the need for a clearer understanding of the nature of the relationship between care recipient and caregiver. By treating family caregivers as a largely homogenous group, a key variable and predictor of outcomes may have been missed. Qualitative studies may be able to shed light on this area and increase understanding of how the pre-morbid relationship impacts on the post stroke caregiving experience.

Distinctions need to be made between partner and non-partner caregivers together with greater attention being given to caregiver and recipient characteristics to facilitate a better understanding of how family belief systems, cultural, religious and ethnic differences may impact on the caregiving experience. More high quality research is also needed to understand long-term outcomes.

Clinical Implications

The current review has highlighted the need for clinicians to develop a greater understanding of the prior co-habiting relationship together with an understanding of how family belief systems, cultural, religious and ethnic differences may impact on the experience of caregiving. This may enable health and social service care and support together with psychologically informed interventions to be better tailored to the needs of each family.

Conclusion

Informal caregivers to stroke survivors are an invaluable resource whose contribution could not easily be replaced. There is good evidence to show they experience a considerable psychological impact, although this is variable and some studies have shown that the care-giving role can bring about positive inter-personal changes.

The main body of the literature to date does not lie in the clinical or health psychology area but within the nursing and disability rehabilitation literature. It tends therefore to be medical rehabilitation focused and rather short term, the exception to this being the work by Visser-Meily and colleagues and the qualitative contributions. More and better quality research is required to enable a coherent picture to emerge and enable services to be effectively mapped. Creating tailored interventions that are both culturally sensitive and psychologically informed may require services to adopt a flexible framework responsive to the varied, changing and subjective needs of what amounts to a largely conscripted workforce.

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PART 2:

RESEARCH REPORT

**Analysis of wives' perceptions of the changing nature
of the spousal relationship post stroke.**

ABSTRACT

Objective

To examine the nature of relationship change in spousal caregivers to survivors of stroke.

Design

Qualitative Study

Method

Six participants were interviewed and the interview data was recorded, transcribed and then analysed using a process of Thematic Analysis described by Braun and Clarke (2006).

Results

Spouses experienced a dramatic change in their relationship post their partner's stroke. Categories of primary and secondary loss encompassed themes of the loss of certain aspects of the partner, loss of the traditional role and a loss of the reciprocal, dance like, balance within the relationship. This precipitated a process of evaluation and adaptation which for some led to acceptance of the altered life situation and relationship.

Conclusions

The results are discussed with the aid of relevant psychological theory and within the context of the existing literature. Clinical implications are discussed together with suggestions for future research

1. INTRODUCTION

Background

Stroke is one of the major causes of death and disability in the UK and worldwide. Many survivors of stroke, after a period of acute care and rehabilitation will return home to be cared for by their partners or other close family member. Despite stroke being widely researched, significant gaps in the evidence base still remain (Department of Health, 2008).

The evidence base strongly suggests that informal or familial caregivers are subject to negative outcomes ranging from reduced physical health (Franzen-Dahlin et al., 2007) and employment (Ko et al., 2007) to increased anxiety (Wilz & Kalytta, 2008), depression (Cameron et al., 2006; Fatoye et al., 2006; Taylor et al., 2008) and psychiatric morbidity (Draper & Brocklehurst, 2007). The use of terms such as caregiver strain and caregiver burden are often used to draw these together (Cumming et al., 2008).

Generally, both research and services have not made a distinction between partner caregivers and other familial caregivers such as siblings or adult children. By treating family caregivers as a largely homogenous group, a key variable and predictor of outcomes may have been missed. Studies that have focused on the experience of care-giving for a partner and how this may impact on the relationship are rare. The most notable is the longitudinal work conducted in The Netherlands by Visser-Meilly et al. in 2008 and 2009. The 2009 study was also one of the only studies to look at the post stroke care-giving trajectory beyond one year, examining the psychosocial functioning of couples three years post stroke.

Quantitative studies in this area have used a wide variety of measures and have taken measures at differing time points but have tended to concentrate their efforts on the first year post discharge and have not looked at longer term outcomes. Recent reviews (Gaugler, 2010; Saban et al., 2010) identified this lack of understanding about the trajectory of post stroke care-giving as a serious flaw within the evidence base.

The concentration of studies focusing on this narrow time frame may in part be due to reliance of recruiting through the National Health Service (NHS), in the U.K. and through the health services in other countries. Visser-Meily et al. (2008; 2009) recruited couples into a longitudinal research programme in order to look at outcomes later in the trajectory, but it has to be borne in mind that the very involvement in such research will make these participants different to those who have no contact or minimal contact with services. The focus of research has understandably been closely tied to the medical and rehabilitation process but to understand fully what happens longer term for this population, it is necessary to understand what happens when the support of services has receded.

Recent qualitative studies have begun to examine the experiences of spousal caregivers past the one year after discharge point (Buschenfeld et al., 2009; Coombs, 2007), although some qualitative studies either still concentrate on the first year (Backstrom et al., 2007) or don't record the time period since stroke (Brann et al., 2010). Whilst these studies are beginning to shed light on the longer term outcomes, more good quality qualitative research is required to enable us to fully understand the complex and multi-factorial nature of how partnership relationships change both in response to the care-giving responsibility and to the altered nature of the relationship itself.

The ability of qualitative research to provide rich accounts of individuals' lived experiences is invaluable and through processes such as meta-ethnography, these small scale studies can be synthesised to enable improved understanding of the population as a whole. Because a meta-ethnographical synthesis brings together the work of many individual researchers and research teams from varying backgrounds it provides robust reliable evidence on which to build both theories and possible interventions.

Aims

- To gain an understanding of the changing nature of the relationship post stroke as perceived by the wives of stroke survivors.
- To better understand how wives feel that the relationship before the stroke relates to the relationship post-stroke.
- To improve understanding of how family belief systems, cultural, religious and ethnic differences may impact on the care-giving experience.
- To consider the relevance of findings to the population.

2. METHOD

2.1 The Research Questions

1. How does a stroke event affect the partnership relationship?
2. What changes occur within the relationship?
3. How do wives experience this change?

2.2 Research Design

The study was qualitative in nature, using semi structured interviews. Although answers to some prescribed questions were sought, these were supplemented in response to information elicited and changed as the study progressed. The interviews were recorded and transcribed. Thematic analysis as described by Braun and Clarke (2006) was used to analyse the emerging data.

2.2.1 Thematic Analysis

Thematic analysis was chosen as the method of qualitative analysis because it has a clear methodological structure as presented in Braun and Clarke (2006). Thematic analysis has previously been seen by some as merely a tool for qualitative research rather than a method in its own right. Braun and Clarke (2006) however argue for its conceptualisation as a foundation method from which all qualitative research skills and methods can be built. This makes the method especially useful for the novice qualitative researcher. Braun and Clarke (2006) advocated that researchers make explicit the epistemological and theoretical assumptions underlying the various methodological choices taken within the research and analytic process (Appendix H). Because the method itself is free of overarching theoretical or epistemological assumptions, it

offered the maximum amount of flexibility of all the qualitative approaches and yet provided a framework that ensured that the captured data was analysed in a systematic and rigorous way. It enabled the study to be firmly grounded within the data and allowed for previously unforeseen themes to emerge, be analysed and shape the direction of study.

2.2 Participants

Participants were partners of people who had experienced their first stroke and survived. It excluded other relatives or friends and also partners where the stroke was not a first stroke. It also excluded individuals whose partnership relationship did not precede the stroke event. Six participants were recruited. All participants were white British women and all were wives of stroke survivors. The participants were aged between 53 and 73 years old and their husbands were aged between 52 and 75 years. The length of relationships ranged from 12-56 years and the time since stroke from eight months to 14 years. Four of the relationships were second marriages and two were first marriages (Appendix I)

2.3 Materials

A research interview schedule (Appendix J) was used as a guide during interviews. The schedule contained open questions designed to open up dialogue around the subject of the relationship and relationship change post stroke. This enabled the interviews to remain focused and grounded in the individuals' lived experience.

2.4 Procedure

The research procedure can be viewed as a chronological process in Appendix K.

2.4.1 Ethical Considerations

All participants were recruited independently of the NHS and made contact with the researcher in response to preliminary study information provided through newspaper editorials, a stroke group presentation or posters displayed in libraries and other community venues. Their participation was therefore entirely voluntary. Full information was provided to all potential participants to ensure that any consent to participation in the study was fully informed. Their identities were protected with the use of aliases and the changing of any identifying details within the write up. As an additional safeguard, all recordings and subsequent transcriptions and analysis were kept in a secure place to the same standard required for NHS ethically approved studies. Participants were made aware of their right to withdraw from the study at any point and to withdraw any or all of their data as they saw fit. They were offered an opportunity to read transcripts of their interviews with identifying details removed before their inclusion in the study. Participants were also made aware that the study was not connected to the NHS and that their participation would in no way affect their NHS treatment either now or in the future.

Participants were advised in their initial study consent discussion that the material they would discuss may cause them distress. They were also advised that although the sessions would be in a research rather than a therapeutic format, there was evidence (Pennebaker, 1997; Ward, Tedstone-Doherty & Moran, 2007) to suggest that talking through distressing material could be of benefit. They were informed of their right to pause or terminate the interview and told that time would be given at the end of each interview to allow for de-briefing before leaving. Each participant was also given a brief leaflet containing details of support available locally (Appendix L).

2.4.2 Ethical Approval

Ethical approval was sought and gained through the University of Leicester's ethics committee (Appendix M).

2.4.3 Recruitment of Participants

An opportune sample of participants was recruited through a variety of methods. The first method was through editorial requests for participants in four local newspapers (Appendix N). This method produced the first four participants. The second method of recruitment was through a presentation (Appendix O) to a local stroke group which produced a further one participant. The third method of recruitment was through a request on an online forum for carers and fourth method was the posting of recruitment posters (Appendix P) in sixty community areas. Although these last two methods produced some responses, they only provided one further participant after exclusion criteria was applied. Although the initial aim had been to recruit eight to twelve participants, because of severe recruitment difficulties and the limited time frame the study proceeded with the available six participants.

Potential participants had the study explained to them over the telephone together with issues of confidentiality and their right to withdraw without consequence. This information was also sent to them in writing as a Research Information Sheet (Appendix Q) and Consent Sheet (Appendix R). Participants were then asked to contact the researcher, by telephone or email, if they wished to proceed or had further questions about the study. Twelve potential participants made contact with the researcher but of these, four were excluded due to not being in a partnership relationship with a stroke survivor. Of the remaining eight participants, six decided that they wanted to proceed

after receiving the full participant information. They were then interviewed at a time and place convenient to them; in each case the participants chose to be interviewed in their own homes.

2.4.4 Data Collection

A semi structured interview (Appendix J) technique was used for data collection with the interviews being digitally recorded for later transcription. Prior to the recordings, participants were given time to talk about both the stroke event and their personal history to enable the researcher to build up a rapport with the participant and to enable the research interview to concentrate on the research aims without too much deviation. Notes and memos were made by the researcher during these informal conversations, which were later fed into the analysis process. The total interview time varied between 60-90 minutes, with the recorded sections lasting between 45-70 minutes.

At the end of the interview participants were thanked for their participation and reminded of their right to withdraw without reason or consequence. It was explained how their data would be anonymised and stored and they were given a sources of support sheet (Appendix L) and asked whether they would like a copy of their transcript for approval and or an end summary of the research (Appendix S).

2.4.5 Transcription

Transcription and initial analysis by the researcher took place as soon as was practicable after each interview to help shape the direction of future questioning. At this point, names and identifying details were changed to ensure that participants' anonymity was preserved. Full anonymised transcripts of the interviews have been included as an Addendum to this thesis.

2.4.6 Data Analysis

Transcripts were initially analysed using line by line coding, applying descriptive labels to each line of the transcript. This ensured that the analysis was firmly grounded in the data and enabled the researcher to become immersed within the dataset. From these initial codes, meaningful ‘chunks’ of data were gathered. Meaningful ‘chunks’ of data would be extracts from the data that seemed to be pertinent to the research question. Theoretical categories and themes began to emerge as these ‘chunks’ of data were grouped together. Notes and memos were written throughout the process from initial interviews to final analysis. As the initial themes emerged, the researcher used a recursive, back and forth process similar to the constant comparative approach as detailed by Glaser and Strauss (1968), going to and fro comparing ‘incidents’ within the data set. As the themes became refined, the transcripts were read and re-read looking for further examples as well as for disconfirming data. As a minimum standard, themes were to be prevalent in at least two of the six accounts to exclude the possibility of them being something particular to one individual. In reality, most themes were present in five out of six accounts. The themes and sub-themes were clustered and arranged into a thematic explanatory framework which was compared back against the data to see if it provided an explanatory framework for each case. This constant comparative process resulted in various versions of the thematic map being developed (Figures 1 to 5, Appendix T) and then refined until a model of ‘best fit’ was developed (Appendix U).

2.5 Quality Issues

Various measures were employed to ensure methodological quality. The reliability of the study was ensured by being transparent and explicit about methodological procedure to enable replication. To improve validity, sections of transcript were independently

coded by three peer researchers with no prior knowledge of the research aims or questions as well as by the research supervisor. Cross coding agreement was >90%.

Whilst the study makes no claim to have achieved theoretical saturation by the fifth participant, no further themes emerged. This is consistent with studies that have suggested that a high level of saturation may be achieved with relatively few participants. Guest et al. (2006) claimed that virtual saturation (>90%) was achieved with 12 participants and Romney et al. (1986) found that sampling four people provided a consensus (>99%) of data providing that the participants were experts in the subject matter they were interviewed about.

3. RESULTS

Although there were considerable differences within the lived experiences of the women interviewed, there were themes that emerged across all of the dataset. There were also some themes that were more evident in some accounts than others.

The theme of Loss was by far the biggest overarching theme that came out of the data. The loss can be thought of as ‘primary loss’ and ‘secondary loss’. Primary loss was the immediate and practical reduction or alteration in functioning in the stroke survivor post stroke that included both cognitive and physical ability as well as altered personality and traits. Secondary losses were less directly rooted in the physical and cognitive changes post stroke, but nevertheless stemmed from the primary losses and the changes that subsequently occurred. Secondary loss referred more to the loss in the inter-relational functioning of the couple as well as the loss of certain ideas about the future and the past. These secondary losses, whilst being directly linked to the primary losses, were mediated by other external and internal factors such as values and expectations.

3.1. Primary Loss

Participants spoke of the primary losses such as loss of certain aspects of their partner’s cognitive functioning or personality, particularly a loss of tolerance towards, and empathy for others.

He didn’t used to be like that. He used to not give a toss what anybody else were doing....nothing at all bothered him, he never raised his voice, nothing annoyed him.

June from line 121

But now he just...he sees he’s got his problems and he doesn’t see why anybody else’s problems (matter). Kath from line 117

The next most common thing that the women spoke of was that their partners had lost the ability to plan and manage their day-to-day tasks and now lacked the ability to make decisions or hold, retain and manipulate complex information.

“ no, no it’s gone...because he can’t reason...so if I try to involve him, which I do try to involve him in a ...decision making, he can’t. He can’t be given options...he very much wants me to say ‘this is what we are going to do ’” Jane from line 523

He just can’t...work out how to prioritise it and so un so it...it is very much that he’d sort of seeing along tramlines if you like and (pause) the sort of flexibility in looking at things just isn’t there at all. Kath from line 394

Their partners struggled to remember things and wives frequently found themselves having to instigate, organise and cajole their partners to do things that they would have done independently before.

“And you feel you’re nagging, Jonnie do so and so, Jonnie put your feet up and sometimes it’s...he’ll fall asleep before he’s taken his tablet and you have to wake him up...Jonnie you haven’t taken your tablets....he needs reminding, I mean really he shouldn’t need reminding...the stool’s at the side of him...so that’s frustrating...actually on his back and nagging him.” Joan from line 944

Commonly wives also reported in their partners a loss of motivation or agency even to fully take part in their own rehabilitation and recovery

But now I get frustrated with him because he won’t try....he won’t walk straight. I’ll be at the side to try and make him but he won’t. Jennifer, from line 207

Wives were sometimes surprised at their husband's response to their own disability and reduced opportunities; feeling that prior to the stroke their partner would have been far more frustrated and annoyed with such limitations. This was spoken of as an unexpected positive side to the apathy and reduction in drive that was described by all the women, but also seen as further confirmation of personality change.

*And that was his main hobby so not being able to drive is like...well he's had to give his license up obviously....and actually he's fine...he's accepted it much more easily than I thought he would. I'm surprised he's not a lot more frustrated than he is...he's quite accepting...this is what is surprising and I would have really thought that if you said [to him] you can't drive and you can't do this and that and the other...if he was mentally as he was before it would have driven him mad.. **Jane from lines 250 and 541***

Physically many of the stroke survivors had a degree of disability, weakness or fatigued easily, meaning that they were no longer able to drive or do hard manual tasks.

*Just simple things like clearing the snow...I was out clearing (it).....but what can you do? He can't **Jane from line 536***

Speech was affected in some participants but it was not spoken of as a significant problem. Wives complained about their husbands being reluctant to make phone-calls or ask for things in shops but this was generally conceptualised by the participants as a problem of apathy rather than of reluctance due to inability or stemming from embarrassment.

*He keeps saying he can't talk but he can really...he often says he's not talking properly but he is...well she gave him a test you see **Jillian from line 536***

3.2. Secondary Loss

Women spoke about various losses that came about as secondary to the stroke event. These were the loss of their role as a wife in the dyadic traditionally gender divided partnership. Because of having to care for their more vulnerable partners, they felt less like a wife and more like a mother or carer for their husband. It seemed as though there was a tension between trying to retain the role of wife whilst feeling that one's role was now closer to that of mother. The relationship appeared to be out of balance and wives mourned this loss of balance, equality and shared burden within the relationship. Wives spoke of a loss of their own freedom brought about by the increased dependence of their partner and also of the grief for the loss of their imagined future. Wives had previously imagined that their lives would get easier as their lives progressed and yet now felt that the future would in fact be harder.

3.2.1. Loss of Traditional Masculine Role

Because of the loss of physical strength, men were often unable to work or undertake their traditional male tasks around the home. In all of the interviews, wives spoke of clearly demarked household tasks consistent with traditional male and female roles prior to the stroke event.

He always kept the cars you know, checked the oil and water and kept the cars running...he just did things like that. He sort of did all that side of things.... I've always took care of the bills and that...Yeah so it just all gelled together really how we did it. I mean I've...I've always been the one that's done (the cleaning and laundry)

*Mm..you know but we've just always each had us own little jobs, you know **June from lines 202 and 233***

Rarely had these ever been discussed between the couples; there was an implicit assumption around men undertaking the harder or 'dirtier' jobs with women taking care of cleaning, cooking and caring duties, be it for older relatives or children. Wives consequently felt a significant loss of a large part of their partner that they closely associated with the traditional masculine role. This loss of the role of husband, of someone to be strong, supportive and driven was the most keenly felt of the women. It wasn't that women couldn't manage to take on extra tasks or even so much the burden of doing so, but rather something deeper.

Yes I think that is the main thing, yes. He was always such a very capable person...such a gentle giant...but you knew that if something wanted doing...he would do it...yes, yes and not just the practical things ...as well he was always very sensitive and...you know....there to be there kind of ...he would always hold my hand or put his arm round and if we were sat together, he'd always have his arm around me...you know...that kind of thing **Jane from lines 360 and 406**

It was something more than needing to step out of the feminine role to take upon the heavier practical tasks, but a loss of their partner taking this traditional strong masculine role.

Jonnie was more the one in charge before his illness...but now it has to be me. **Joan from line 603**

It was as though the participants felt that they had lost a fundamental part of what they valued about their partner and it seemed as though, for some wives, witnessing their partner being vulnerable and weak had an impact on how they felt about their husband and their relationship.

*It's difficult to kind of verbalise I suppose...from being a very capable and independent man...erm...private kind of person you know...well when he came from hospital I had to do everything for him...I mean you know you are reduced, aren't you to a basic level in hospital...very much so when you've had a stroke....so we did have some trauma...some traumatic times in terms of what I had to do for him. **Jane from line 372***

Most of the women felt quite resentful about this change in role and particularly the women of working age resented the need for them to assume the role as main breadwinner, or perhaps more accurately, really disliked the idea of their husbands being at home whilst they were out at work and would do whatever they could to prevent this reversal of roles from happening.

*I know I've got to work yeah...Jules' slowed down...Yeah it's role reversal because I'd fully thought that when I got to fifty-five I would work a couple of days a week and spend, I'd love to have three or four days or even three days a week at home just pottering about being able to do things you knowall we've done in the last probably six months is argue because I sort of thought well I think Jules should be trying to go back to work full-time...I'm working eight or nine hours a day and thinking what, what you doing (at home) and thinking well you know he doesn't work half what I work. **June from lines 567 and 627***

*That's another factor with us you see because I'm, I was resentful towards Jules because he couldn't work full time and his income dropped. **June from line 1139***

*....and I was thinking my God, I'm going to end up being the one who's working...and dealing with the children and you're just going to sit at home sort of thing **Kath from line 200***

it just seemed an opportunity when they were laying people off that I, I'd take it and er in some ways it has made life easier and in some ways it hasn't but it, I'd thought it was better if (I did) it then he would know that he had to stay with the job **Kath from line 215**

3.2.2 Loss of the Relationship Dance (including sex): Reciprocity and Shared burden

This loss of a partner taking the traditionally masculine role together with needing to maintain the feminine role resulted in a loss of what could be described as the 'partnership dance': a loss of the interplay between the partners and their complementary roles. This resulting imbalance of the reciprocal dyadic feminine, masculine partnership led wives to describe feeling less like wives and more like mothers, carers or organisers of their partners.

I don't feel so much as Jules' wife now as his, somebody that looks after him, that makes decisions for him (and) that sorts things out for him cos he's rubbish now at talking to people on the phone or you know if he needed to make a dentist appointment...I feel I'm not so much Jules' wife as more somebody that just lives with him and looks after him. **June from line 456**

He's still very much, he's still very...childlike in a lot of (ways)...and this is not James at all you know but things like...I leave him, he can dress himself now and because he has struggled to do it with one hand. But even now, like I said to him this morning....pop these trousers on for a change...I usually just leave him to it but because we were going out then I went in and said ..what about if you put that on...it'd be easier...and he kinda looks at me and says, oh right...kind of as I say it's almost like as you might with a

child...kind of watching over him...I try to give him as much independence obviously to decide things...but.... **Jane from line 335**

Adding to this uncomfortable shift in the relationship dynamics, none of the couples resumed a sexual relationship approximating to what they had enjoyed prior to the stroke event. For half the couples the stroke event marked the cessation of sexual activity.

I think it was about two months after and we partly had sex but not properly...and nothing since....the stroke...you know that's the only time so it's nearly fourteen years ain't it since. **Joan from line 477**

The renegotiating of the sexual relationship after the stroke event was fraught with difficulty both practically and emotionally and none of the participants remembered receiving any information or guidance on what to expect.

There was a distinct lack of clarity around why sex was problematic. Some women found it embarrassing to talk about and did not wish to raise the subject with their partners or professionals. Despite all women acknowledging this as a significant loss, there was a tendency for some to minimise it or devalue it.

It does make me feel unloved but I don't consider it to be the be all and end all **June from 1012**

Oh well, I mean (laughing) I had more to worry about really than that....I feel as though that was the least of my worries, quite honestly **Jillian from line 263**

Women talked instead about being thankful that their husbands were still alive as though expecting to have a sex life as well would have been expecting too much.

*Yes...well what you've never had you never miss.....I mean he's still here isn't he...that's what people say to me...well you've still got him haven't you? **Jennifer from lines 18 and 26***

It was almost as though they had little interest in changing the situation and possibly the situation may have been convenient if they found their partner less attractive due to them not fulfilling the masculine role or if they felt over tired with their additional duties.

Women also talked about how their husband's behaviour towards them had changed in regard to initiating sexual activity. Women described having to always be the one who initiated closeness now whereas before the stroke, their partner had often, or usually, been the one who instigated closeness and intimacy.

*He was a very sensitive and sensuous (man) in many respects even. He would always hold my hand or put his arm around me....but now it's I tend to be holding his hand and I have to say "can I have a kiss?", Let's have a cuddle...so I do have to instigate things **Jane from line 403***

*It has to come from me...yeah, I mean you know they love you still, don't get me wrong...you know that they still love you but it's...it's as though they can't show that love. **Joan from line 542***

Women spoke of having their sexual advances rejected by their partners in a way that sometimes made them feel bad and also see their partner as less masculine.

Jules will now say now "Oh I don't, I've got a headache" which is like a woman's thing to say isn't it? or you know, "I don't feel like it, I'm tired"...before..he'd have been up

there, all for it sort of thing as men normally [are] but now he'll say "oh I feel tired".

*Makes me feel sulky and mardy **June from line 507***

Reasons given for the lack of resumption in their sex lives after the stroke were various and ranged from their own fear of harming their partner to his lack of mobility,

So we haven't had sex since he came outa hospital because...well it's his blood pressure isn't it?...Because it does effect it doesn't it? Well I think it's more me than him

*but...well he can't roll over...you know what I mean...he's there **Jennifer from line 1***

*....and you see now anyway, I think his heart wouldn't stand it (laughs) not that we'd go mad (laughs). **Joan from line 530***

to the effects of the medication and their partners reluctance to be touched.

*It's affected; it affects your sex life and everything. That alters because of the medication. I mean for a long time Jules didn't want that sort of relationship with me or anything. **June from line 465***

*He doesn't like to be touched any more...I can't kiss him or even touch him, he says "don't touch me" **Jillian from line 237***

Some women had managed to adapt and resume some kind of sex life but for half of the couples, after initial difficulties, they had accepted that they would have a sexless future. All women described this as a significant loss but most felt that it wasn't the 'be all and end all' of a relationship and that they should just accept it. Some women spoke about the impact the loss had had on their mood.

I've put a lot of weight on as well and I think that's because I, I've been quite depressed last few, last eighteen months. It's started to really affect me.....I think you lose your

*closeness as a couple as well. I mean we still sleep together and we have a cuddle and we do make love and that now but it's not like it was. **June from lines 473 and 483.***

One of the women, who said that it was a difficult topic to raise with their partner, explained how they managed to retain some of the 'relationship play' despite not feeling able to have or discuss sex.

*I mean we laugh about it when we go to bed. I do his injection of...he needs creams on and then I get his duvet and I put it either side and I'm sort of larking about, holding it down and kissing him you see cos he can't move can he? He'll say "go on you silly apeth", you know but it's that closeness. **Joan from line 455***

The loss of this partnership dance included the loss of working together towards shared goals, both practical and otherwise, whether it be decorating a room or raising the children.

*Well little jobs like that...Jeff and me we'd have done between us....we've even gone over to Billy's when they've been on holiday and done it between us you see, where Jeff's left handed and I'm right handed...like what was awkward to me[was]easy for Jeff, and vice versa...Oh yes we worked well...really well... **Jennifer from line 130***

*The kids were looking to me a lot of the time for (pause)...I don't know, parenting if you likeand he was engaging with them less [and] less...whenever there's an issue it's me that sort of has to confront it....I mean it helps if there's two of you (laughs) whereas [now] in a sense I kind of find that he works against it...it all seems just a kind of muddle. **Kath from lines 283 and 299***

3.2.3 The Loss of an Idealised Past and an Imagined Future

The stroke event was disruptive in the course of life events for the women. It presumably required them to alter the life narrative that they'd held and reconstruct it to take account of what had happened. When most of the women spoke about their partners and the relationship that they'd shared prior to the stroke, they tended to talk in idealised terms and struggled to think about any negative aspects to their partners or the relationship prior to the stroke event.

And I'd be at the kitchen window and I can see it now; he'd be down the garden doing gardening and the kids would be playing on the swing with their friends...and I used to be so content because that to me is how a family should be...it's just a perfect scene.

Joan from line 701

They generally spoke of how well suited they were for each other and how they 'just clicked'.

Everything about us...we were totally compatible as a couple. You couldn't have got a couple that were more, as a couple than we were. Everything was perfect. We were happy. ***June from line 158***

This seemed to imply that for many of the couples, they never really negotiated their reciprocal roles within the relationship but rather used templates from their childhood of how relationships worked. When pressed, some women could identify some traits in their partner that they were unhappy with now that had existed prior to the stroke event but in a less intense or problematic form. Women also spoke about how they had imagined the future would be for them, and the difficulty of accepting an alternative future to the one that had been imagined or planned.

3.2.4 The Loss of Certainty: Fear of Further Loss

A significant realisation for the women was that they had little, if any, control over what happened in the future. A realisation that a lifetime of planning could all be swept away in an event that was unpredicted and largely unpredictable. This loss of certainty about the future also brought with it a sense of fear and worry about what could happen.

Wives worried that their partners would suffer further strokes and that they would result in further loss of their partners either through increased disability or through death.

*You still love him just the same. You worry about them more because you are frightened of them having another stroke erm...and it being fatal. **Joan from line 983***

I don't want to be without him....if anything happened to him it would devastate me.

June from line 694

They worried about what might happen to them when they left them alone and often felt the need to be with them in case anything happened.

*Well I used to [go out] but I was always ever so worried about him. **Jillian from line 358***

3.3 Increased Responsibility

The stroke event caused an immediate need for care and increased responsibility. Wives sometimes thought that as the rehabilitation phase progressed they would lose this extra responsibility as their husbands recovered and took on more responsibility and became more independent. All of the wives talked about having to be responsible for 'everything' and bemoaned the apathy, lack of drive and cognitive flexibility in their husbands. Although many tried to encourage, cajole and even nag their partners to do

more, they felt that they now needed to 'manage' the household and were not able to lean on or trust their partners to take any responsibility anymore.

*I said Jules you've got to do stuff, I can't keep working the hours I work and then come home and start again. **June from line 543***

*well he needed me to do everything. **Jillian from line 249***

*I've had to take over, all that over as well from Jonnie... er ...so I see to all the money...but as I say, now everything I do [everything. **Joan from line 122 and 132***

He's very dependent on me...at first he wouldn't let me out of his sight....I've got to spend the time...and obviously I have to do everything so I'm cooking, cleaning, well when it gets cleaned (laughs) so yes everything....as I say he doesn't [do anything].

Jane from lines 273, 312 and 321

For most of the women interviewed the increased responsibility was a negative experience. However one woman told how some aspects of the increased responsibility, particularly the need to advocate for her husband, had a positive impact on her life.

*Well you've had to do more you've had to speak for him...erm going to the carers' classes and meetings we go to, that's done me lot of good and it's amazing how it gives you more confidence...because we've gone to meetings and where at one bit I wouldn't say anything and my daughter's exactly the same. Now we do, we join in...[before] I wouldn't have spoken up....which now I find I can. **Joan from lines 843 and 906***

For some women, they welcomed the chance to be in control.

*I do like...well I do like to be in control I suppose...I do like it and I think when things work, you see it's just when things don't work. **Jillian from line 414***

3.4 Evaluation (of the Present and Possible Future)

As the dust settled after the stroke event and the rehabilitation phase had come to end, women began a process of evaluation of their new and altered lives. Evaluation in this context was a ‘weighing up’ process and an essential aspect of progression, along with adaptation. There appeared to be two sub-themes or main processes of evaluation that came out of the women’s dialogues, ‘making comparisons’ and ‘talking things through’.

3.4.1 Making Comparisons

Making comparisons was a key feature of most of the interviews with participants making a variety of comparisons with a variety of outcomes. Comparisons were made with the past and the present.

*We always did things together...we still do but I find everything’s more traumatic now...and everything’s altered because of the stroke...life has altered so so much. **June from lines 101 and 572***

*The relationship has changed completely because he drove everywhere...it’s one of his great loves...and [now] I have to drive him everywhere...there are still moments when I get a bit uptight...so I’m the driver now. **Jane from lines 244 and 251***

*It’s when I think back to what he was like (tearfully)... **Jennifer from line 383***

Sometimes comparisons were made with an imagined alternative future that facilitated a grieving response.

*I know I wouldn’t be able to live without him, not having anyone to talk to again at night. **June from line 712***

Comparisons were made with each other both in terms of workload.

*I guess I'm kind of resentful that....in a sense...I know I had the boys just as much as he did but it seems that I'm getting a larger part of the work ...I've given up a lot in a way for the relationship if you like. **Kath from line 449***

Most of the women imagining their roles reversed with themselves as the stroke survivor and their partner as the carer. When they did this they concluded that the general situation would have been much worse had the roles been reversed and it therefore produced a kind of thankful response.

*I kid him on...I said it's a good job it was you and not me [that had the stroke] because he couldn't have done...he wouldn't have pushed like I do..I mean I (laughing) had sciatica years ago and he couldn't even get me tights on. **Jennifer from line 481***

*I thought, God I'd rather be the one that's in charge and not the one who's not able to do anything and be bossed around...but he wouldn't have been able to...he'd have been pretty helpless I think ...I can't imagine what I'd have been like...I don't think I'd have been so demanding. **Jillian from lines 509 and 520***

Comparisons with other people's lives and opportunities and the realisation of one's now reduced life opportunities led to the women feeling sad and envious.

*She can just say I'll go, oh we're going so and so tomorrow...she's just been on holiday with the girls...she said to me come with us. I says I can't leave Jonnie...but she can with her mother because she's got a husband at home [that] sees to her mother when she's not there... You know she'll go out shopping every day...I do envy her. **Joan from lines 1096 and 1107***

Comparisons were made with others who had had strokes and other ill health. When the comparison was with someone in a better position or with improved recovery, it had a

negative effect and when it was with others in similar or worse positions, it provided comfort in the similarity with others.

Like a chap down the road he's had a stroke...about eight weeks ago but nowhere near as bad...and I said to [Jeff], Rob is undressing himself you know. Undressing himself and Jeff can't. Sometimes he will pull his sweater off but that's it.

*There were eight of us, we've whittled down to five now...all the men, Conrad had cancer, Bob got leukaemia and he died, Trevor had a bad heart attack, he died and the paramedic brought him back round and Jeff had a stroke. **Jennifer from lines 335 and 153***

Comparisons were also made with how things could have been worse, which was the most common comparison made across the dataset and led to a feeling of being thankful that things had not been worse than they were. Wives compared their current emotions with how they would feel if they were to have lost their partner altogether and took some comfort from the fact that they still had them.

*I know I wouldn't be able to live without him; not having anyone to talk to again at night. **June from line 710***

3.4.2 Talking Things Through

The other way that the wives both evaluated their situation and also processed some of their emotions was through talking. Participants talked about how they selected who they would speak to.

When I go to my carers group we have a talk there because there are other carers so you can...talk with some of them, you can open up...with some of them you can't

*because their husbands have got Alzheimers, that's worse than anything. **Joan from line 082***

They described how they carefully sorted out who they could get certain types of emotional or practical support from. All of the participants found some outlet in talking through their difficulties with family, friends, neighbours or health professionals, but all also talked about a vast array of people who they could not talk to and of a need to find people who understood, were non-judgemental and respected confidentiality.

*Can't talk to Adam because I don't want to worry him, I don't want to talk to my daughter about it cos I'd frighten her ... you feel as though you are being disloyal don't you? But you need to be able to talk to someone about it definitely... [and know] that she's not going to make a joke or tell other people about it. **Joan from line 157 and 259***

*You need somebody that is in the same boat cos I've got other friends erm good friends, close friends but because they've not experienced it they don't know what it is like to live with somebody that's had an illness like this. **June from line 812***

*Well I've talked to everybody...I've talked to all my friends and said...and some people are more sympathetic and some people I think, "Oh God I'd better shut up", you know because they are fed up with this. **Jillian from line 378***

What other people said had a direct impact on the wives, sometimes negatively and sometimes positively. Things other people said that were intended to be helpful often were not.

But erm loads of people say "oh well ignore it" you (laughing)..I don't find that easy or possible and then of course other people say "Oh you ought to stand up to him"...so many people say "Oh for goodness sake, leave him" you know, it's terrible...but I quite

*like my friend who says “poor man it must be awful for him”, I quite like it that she says that. **Jillian from lines 336 and 476***

*One of my closest friends and we’re really close, but her partner died about three years ago...Sian’s put him on a pedestal as happens when someone dies and she’ll..if I moaned about Jules to her she’d say ‘yeah but you’ve still got him here...so I don’t then **June from line 817***

3.5. Adaptation and Coping

The couples made many practical adaptations. Wives had to make psychological adaptations and find ways of coping with the new imposed situation. When asked what was helpful now, wives spoke of the importance of trying to find time for themselves away from their partner and also of being able to talk to people candidly.

*I’ll often have a walk down to Patricia’s and we’ll sit and have a drink of wine... in her garden and just the two of us and have a natter...or I’ll just ring her up and she’ll say “Is he getting on your nerves?” or she’ll say “Basil is driving me up the wall today” and we’ll just have a laugh and a joke about the pair of them and then it’s over and it’s good. **June from line 803***

Whilst Talking Things Through has been categorised under the Evaluation theme, Talking Things Through is also present within the Adaptation, coping and respite themes. The Adaptation and Evaluation themes can be conceptualised as a process occurring in a loop (see thematic model, Appendix U) helping individuals to move towards a resolution whether that be a termination of the relationship or an eventual acceptance of the altered state of the relationship.

3.5.1. Respite and forms of escape

Participants talked of understanding the importance of, and of striving to carve out time and activities away from their partner with varied level of success.

I get very little respite so we are together 24/7 his daughter takes him maybe once a week...so I get that kind of two or three hours...Jane from line 531

They spoke about the effort and planning that was required to ensure that they could take time away,

But what I do is..he's had the shower and everything..he's sat here with the TV and we work out the programme and so he's sat here happily and he's sorted. I've been out to the theatre with my sister..so have actually left him for a good three hours on a few occasions but not often. Jane from line 300

And how hard it was to do this because of the competing demands on their time.

You do tend to neglect yourself when you're caring because it's like...oh I haven't time to do this...I haven't time to do that. Joan from line 281

Women also described how even when they were able to take time away, it never felt like quite enough.

I went for a swim in the afternoon...so I did have some time but...but there's whole chunks of the day that are gone. Jane from line 319

3.6. Acceptance

The process of adapting through talking and taking time out together with the process of evaluation through comparisons and more talking seemed to enable the women to

process the experience and a move towards a point of acceptance. For some, this was an acceptance of an altered life but one they wanted to live with their partner. For others it was an acceptance that their lives and their relationship had changed irrevocably to the point of their relationship being no longer viable.

*The fact that I've still got him, that he's still here...we've got one another. And we don't...my expectations of life are quite simple and we'll get back to...I'm sure we'll get back even if he can't drive or we have to have an adapted car or whatever.... We can still I'm taking him on holiday middle of January...and so we might not be able to do the long haul holidays that we would have done before or the motorhome to the south of Spain that we did ..but we'll do...we'll do what we can do. **Jane from line 583***

*We still have a good life...I'd just like Jules to be able to do things for himself...just move about on his own...But if it isn't it isn't is it? **Jennifer from line 242***

*Sometimes when the weather is better...he forgets all his miseries and I think "thank goodness we've had a nice half hour." **Jillian from line 44***

4. DISCUSSION

The current study aimed to improve understanding about the changing nature of partnership relationships post stroke. An inductive thematic analysis was used to examine wives' accounts of their changing marital relationship after their husbands' strokes. Wives spoke of increased responsibility and various losses, most notably that of the loss of a dance like, reciprocal relationship with someone taking a strong masculine role. They also spoke of adapting, evaluating and eventually adapting to the altered life. Some women also spoke of positive benefits arising from the change.

4.1 Discussion of the results

This section discusses the results of the current study in relation to the existing literature in this area and explains how it makes an important and unique contribution to the evidence base. The clinical implications of these findings together with suggestions for future research are also discussed.

The vast body of literature examining informal or familial caregivers presents an array of negative outcomes for the informal caregiver (Han & Haley 1999, Visser-Meily et al., 2008). Some studies (Buschenfeld et al., 2009; Palmer & Glass 2001) however, have identified positive outcomes for people who take on a familial caregiving role. Palmer and Glass (2001), in their review of family functioning and Stroke recovery, used a family systems framework and found positive changes in terms of family functioning that included improved communications and emotional closeness. Buschenfeld et al. (2009), discovered that some partners perceived that the experience had brought about personal and interpersonal growth.

What has largely been neglected in the literature and what the current study has begun to explore, was how this care-giving impacts on the marital or equivalent partnership relationship. Inductive thematic analysis allowed an exploration of the lived experience of wives post their partner's stroke. It enabled the focus of the research to be on what was important for the participants and hopefully, their stories are very evident within the Results.

4.2 Discussions of the themes and thematic model

The themes are presented as existing within a dynamic thematic framework (Appendix U), and as such, are interchangeably discussed as both themes and stages. The use of the word 'stage' does not intend to imply a distinct period as there is no direct linear transition between stages. All or most of the themes may co-exist at any one time point but the general psychological trend may be to move focus as time progresses from a focus on the primary losses, during hospitalisation, through a period of adaptation and evaluation and finally towards a focus on acceptance. Although this structure was developed from the ground up, using an inductive process as explained earlier, it bears a striking similarity to that of the World Health Organisation's 1980 International Classification of Impairments, Disabilities and Handicaps model (ICIDH, World Health Organisation, 1980). This was a model to categorise impairment, disability and handicap. It has been superseded by a new model called the International Classification of Functioning, Disability and Health (ICF, World Health Organisation, 2001). The new model embodies a more positive style of thinking in terms of abilities and health rather than in terms of impairment and recognises the psychological power of language. It is therefore interesting that the current study showed that the language of the participants is that of the earlier model.

4.2.1 Primary loss

Participants talked of their frustration at their partner's impaired functioning in a variety of areas that were perceived, by them, as being a direct result of the stroke event. These were the loss of the ability to plan and prioritise day to day tasks, difficulties with making decisions, memory difficulties and changes in personality, most noticeably loss of drive, enthusiasm and increased irritability. Whilst these were grouped together under the heading of Primary Loss, it is important to consider what the underlying mechanisms may be behind these changes and what the implications may then be for the relationship.

It is possible that many of these 'symptoms' or deficits in the stroke survivor's functioning have an organic basis resulting from the damage caused by the stroke. It is also possible however that a portion, at least, of what is being witnessed could be attributable to depression in the stroke survivor as a reaction to the stroke event and subsequent lifestyle changes. How these two possibilities may be teased apart is an issue outside the remit of this discussion, but the fact that there are two possible explanations for the witnessed changes in the stroke survivor's functioning, and that both may exist together, is important. They are important for two main reasons: the first being the possibility for change and improvement and the second being the potentially differing reaction that each possibility may produce in the partner. If the changes are viewed as being organic and therefore largely irreversible, then the wife may feel grief for the lost aspect of her partner but also may feel a degree of sympathy and understanding. She may however feel a degree of futility at their situation. How the wife perceives the changeability of their partner's behaviour and their shared situation may affect her transition towards acceptance and ultimately affect the outcome of the

relationship. So by contrast, if her husband's symptoms were viewed to be largely a depressive reaction in response to the stroke event or subsequent life changes, then there would be the possibility both for improvement and the potential for a quite different evaluation of the situation. It is perhaps important to note that a partner realising that her husband's deficits were not primarily of an organic nature but had a more functional component would not necessarily provide an improved outcome for the relationship despite the potential for improvement. In the accounts examined in the current study participants tended to be more sympathetic to what they perceived as organically derived symptoms rather than to those they considered to be symptoms of mood disturbance.

Evidence is mixed as to whether there is a positive correlation between degree of disability in the stroke survivor and poorer psychosocial functioning in the care giver. Whilst several studies (Blake et al., 2003; Ostwald, 2009, Visser-Meily et al., 2008 and Wilz & Kalytta, 2008) suggest there is, Draper et al. (2007) argue that it is specifically language impairment in the care-recipient that is associated with poorer outcomes for the caregiver.

These primary losses are often not explicitly identified in the themes of the four qualitative studies reviewed earlier (Backstrom et al., 2010; Brann et al., 2010; Buschenfeld et al., 2009 and Coombs, 2007) but underpin some of the other themes in those studies, such as 'profound sense of loss (Coombs, 2007) and 'changed lives' and 'changes in intimacy' (Buschenfeld, 2009).

4.2.2 Secondary Loss

Secondary losses were in effect wrapped within the reactions of the wives to their husband's altered state. Two of these, Loss of Certainty and Loss of an Imagined Future were very much about disturbances or fractures in the normal developmental trajectory of the relationship. It required a re-assessing of life plans and expectations and a reflection back, often idealistically, on what had gone before. In models of life development stages, these types of reflections and dilemmas are characteristic of mid-life transition periods (Smelser & Erikson, 1980; Levinson, 1979). The difference here is that these reflections were not part of a gradual normal developmental process but were rather transitions in reaction to changes thrust upon the couple suddenly. The current findings confirm Buschenfeld's (2009) findings of loss of familiarity, intimacy and spontaneity in the relationship; these are encompassed within the current study in the 'Loss of the relationship dance' theme. Brann et al. (2010) referred also to the lack of equity in the relationship as part of their partner orientation/self-orientation dialectical tension.

The current findings confirm earlier studies that identified loss of roles, changes in roles and loss of the marital relationship (Backstrom, 2010), loss of familiarity and changes in intimacy (Buschenfeld, 2009) as important themes in the experience of care giving partners. The current study went one step further by illustrating how these losses and changes in relation to the previous partnership norms as well as the loss of the dynamic reciprocity and reflexivity within the relationship contribute to spousal caregiver distress, suggesting that this may be a major factor underpinning the difficult adjustment process.

The 'Loss of the traditional masculine role' theme and the 'Loss of the relationship dance' theme very much required wives to re-evaluate their lives in terms of the roles they played within the relationship. As mentioned earlier, these roles were often never discussed, they were assumed, they were cultural and they formed a very powerful part of the working dynamics of the relationship. These templates for life allowed a degree of comfort and security within a familiarity that was most probably rooted within their own experiences of their birth family. That is not to suggest that couples simply re-played the relationships of their parents, but rather that they drew heavily on those relationships and the surrounding experiences of their socio-economic, ethnic, geographical and generational peers in establishing their relationship norms. Stepping out of these roles for extended periods of time caused distress and frustration for the wives. They had very clear ideas about how men 'should' behave and how women 'should' behave. Despite the additional caring responsibilities fitting within their stereotypical female role, because their husbands were not, or could not, reciprocate by playing their stereotypical male role, the women felt that they were caring in a mother role rather than as a wife. It seemed that to feel like a wife, one's husband had to behave like a husband and for the large part, that meant performing a traditional masculine role.

Backstrom et al. (2010) reported the beginnings of this fracture within the relationship as soon as one month post-discharge and by one year post discharge, the themes emerging within that study were around grief for the loss of the marital relationship and a feeling of being trapped within that relationship. Feeling trapped within the relationship was not a theme that emerged within the current study and because of the small sample sizes in both studies, it is hard to say why this might be. Backstrom's sample was the most similar in participant characteristics to the current study, being

exclusively middle aged women, but the time frame of sampling was very different. It could be that Backstrom picked up on a mood prevalent in the first year of adjustment or it may have been that there was something particular about those individuals' responses to their situation.

4.2.3 Increased Responsibility

This theme was probably the least surprising theme to emerge from the current study given that much of the existing research, both qualitative and quantitative, had focused on the burden of care-giving. Whilst burden must not be seen as synonymous to 'Increased Responsibility', many studies measuring burden may have actually been recording the increased responsibility that is almost inevitable after the stroke event. Burden however implies a negative response to this additional responsibility and for the most part, that may be true, but it is not always true (King & Semik, 2006). Nor is it necessarily a directly related concept in that perceiving the additional caregiving as a burden may be in response to the lack of the reciprocal relationship as much as to the additional work itself. Interestingly, the current participant wives tended to refer more to the share of the work they had to do rather than to the amount of work itself. Buschenfeld et al. (2009) talked of the 'centrality of the caregiver role' and the sometimes overwhelming nature of the increased responsibility. Buschenfeld's participants were younger and even within the current study, somewhat counter intuitively; it was the youngest of the wives who perceived the greater burden of the increased responsibility. This appears to confirm earlier findings (Franzen-Dahlin, 2007; Smith, 2008) that increasing age was a protective or mediating factor. Whether this is due to different expectations at different ages either as a developmental factor or a generational factor is not known.

4.2.4 Adaptation

Adaptation as a theme referred to the coping strategies employed by the participating women to manage their new reality. This encompassed both the cognitive protective adaptations and the more practically based strategies, such as Talking Things Through and Respite and Forms of Escape: Finding Time for the Self amidst the caring responsibilities. These were the two key sub-themes that emerged in the current study. There are semantic problems with the use of the terms ‘coping’ and ‘coping strategy’ as it is used differently by different authors (Donnellan et al., 2006; Greenwood & MacKenzie, 2010). Because of this, some other studies (Silva Smith, 2007) have conceptualised what is labelled here as Adaptation as a coping theme. How the same phenomena is categorised varies widely between studies. Brann et al. (2010) referred to a partner orientation/self-orientation tension and for the women in the current study, the balance seemed to err heavily towards the partner orientation. Part of their coping, how they adapted to cope with this imbalance was to find some time for themselves, a shifting towards the ‘self-orientation’ even if for just short periods of time. Backstrom et al. (2010) saw this as a need to find ‘breathing space’ from within a stifling relationship. The current study’s findings that Talking Things Through’ was an important part of Adaption as well as Evaluation adds weight to Visser-Meily et al.’s (2005) conclusion that counselling as an intervention produced the most positive outcomes.

4.2.5 Evaluation

The Evaluation theme was where many of the themes come together. The participating women thought and talked through their losses and their increased responsibilities, they evaluated the adaptations that they had made and they ‘weighed up’ their current

situations in comparison to the past, the imagined future and other people both in worse and in better situations. They compared their workload to that of their partners and they imagined how things might have been had the roles been reversed and it had been them who had had the stroke. The current findings concur with Brann et al.'s (2010) findings on aspects of past/present, present/future and past/future. Whilst Brann viewed these as aspects of a realism/idealism dialectical tension the current study viewed them as polarities for comparison as part of an underlying mechanism of the evaluation process.

Undertaking this evaluation process through making comparisons and through talking can be thought of as an attempt to re-write their personal life narrative and evaluate what the future could be. Social comparisons can be seen as a way of understanding both the self and its relative position within society. Research building upon Festinger's (1954) social comparison theory has shown how social comparisons have a significant impact on how individuals feel about both themselves and their relative situation (Guimond, 2006). This process of evaluation has the potential to be an important lever in mediating outcomes.

There have been suggestions that higher status groups within western society value traits of individualisation, independence and autonomy more than lower status groups (Fiske, 1998) and thus comparisons with the past self and with socio-economic peers for higher status wives, where these values have been compromised, may be expected to produce worse outcomes. This seemed to be the case within the current study but for any conclusions to be drawn a larger sample size would be required.

In interdependency models of relationship maintenance, those that stress different types of commitment such as personal, constraint and moral (Stanley, 1992) might suggest that wives from lower socio-economic groups may stay in less satisfying partnerships

because they have higher level of constraint commitment due to poorer access to financial resources and greater reliance on the resources of, and therefore the approval of, the wider family. Other investment models (Rusbult & Buunk, 1993) would suggest that wives face a multifaceted commitment decision whereby they take into account the size of their investment in the relationship (time, children etc) as well as their satisfaction levels together with the quality of their perceived alternatives. In this scenario, greater investment in terms of shared children would help bind some couples together whereas the awareness of high quality alternatives, that might be more available to women from higher socioeconomic groups, may present a strain on the relationship. The model also suggests that once the commitment has been made then a variety of cognitive and behavioural mechanisms are used to sustain the belief in the value of the relationship.

4.2.6 Acceptance

The Acceptance theme covered the aspects of the women's accounts that have drawn conclusions from the cycle of Adaptation and Evaluation. It was not just the acceptance of the stroke event and the subsequent practical considerations, although that may form a large part of it. It was an acceptance of the legacy of the stroke for the relationship. In some cases, this was a realisation that the relationship did not have a future and for others, it was an acceptance of the changed relationship where the result of the evaluation stage was that the relationship was still of value to them despite its altered state. Brann et al.(2010) talked of a dialectic tension between uncertainty/acceptance that appeared to incorporate what in the current thematic model (Appendix U) was conceptualised both as part of the Loss theme, that of loss of certainty and of part of the Acceptance theme. This highlights the dynamic nature of the process illustrated in the

Thematic Model (Appendix U). Acceptance was very closely linked to the outcomes of the evaluation and comparative process. In the current study, some women fared much better than others in their acceptance of the altered relationship. Reasons for this were unclear, although it did appear that those in first marriages with shared grown up children living nearby were more accepting of their altered relationship, possibly for the reasons discussed above.

4.3 Methodological Critique

Whilst the current sample was adequate to enable themes to emerge, it was not sufficient to reach theoretical saturation. Further theoretical sampling may have been able to achieve that goal. The current study aimed to explore the experiences of caregivers to their spousal or equivalent partners. Due to recruitment difficulties and time limitations, all the participants were white British middle-aged wives of male stroke survivors, a population that has been sampled before. This has however been a strength of the study as it has made it possible to focus on the experience of wives and compare the findings, and add weight to, those found independently by other small scale studies. A central tenet of the findings was cultural definitions of role, it therefore needs to be borne in mind that, whilst some of the underlying principles may be common to all committed relationships, the findings overall may well not be generalisable beyond this specific population. Although no attempt was made to recruit a representative sample, it needs to be considered that individuals who volunteered to be interviewed may have had considerably different experiences to those who chose not to respond to recruitment. Requests for participation were widely and repeatedly distributed through community notice boards and the press and yet, uptake was incredibly low which meant that those who did participate were different from the norm in at least this aspect of

their motivation. The recruitment strategy is however a strength of the study in that it sampled mostly participants who were not linked into any kind of support group and were not still in contact with the rehabilitation services. This is a strength because most studies rely on these two avenues for recruitment and therefore potentially bias their findings towards people who are adept at accessing support. The transparency of the research process together with the systematic application of method as suggested by Braun and Clarke (2006) is also a strength.

4.4 Clinical Implications of the results

Participants felt that they were not supported by the health system and were not given information on what to expect. Providing timely information about the initial difficulties couples might expect on their return home and other problems that might occur later would help to normalise some of the experiences and perhaps reduce some of the trauma of entering into an unknown altered life-style. Helping wives to understand what would be helpful practically as well as how to go about re-initiating sexual intimacy, how to recognise depression and understand what has helped others together with when and where to seek help, participants thought would be useful. The women in the current study believed that being prepared for some of the negative emotions and understanding where and how to access help would have been invaluable despite studies (Lui,2007) suggesting that interventions to improve preparedness did not reduce stress or negative psychological outcomes.

Suggesting the provision of information is of course not new (Smith et al.,2008), although the participants for the current study reported receiving none. The particular focus of the information and the intended outcomes may differ slightly from those suggested in earlier studies in that the current study suggested a focus on supporting the

relationship and understanding the relationship hurdles and dilemmas. The current study suggests that this support is sorely needed and, although an informal network of support exists through the Stroke Association stroke groups, this was not always perceived as accessible or appropriate for all partners. Increasing the awareness of GPs and primary care staff to the likely process of change that couples may undergo and the importance of supporting relationships through the difficult transition post-stroke might go some way towards mitigating some of the negative physical and psychological health outcomes for both partners. This might be about initiating or encouraging an open dialogue and explicitly providing information on how to re-initiate a sexual relationship and the importance of attempting to maintain some fun within the relationship rather than allowing the relationship to be reduced to a mere care-giving/ care-recipient dynamic. It might be around making sure that appropriate relationship therapy is provided at a primary care level and that therapeutic staff understand the particular impact that this type of life event has on the relationship. During the current economic climate, it is perhaps important to stress that most of these recommendations could be achieved within the current Continuing Professional Development systems without the need for additional funds. If additional funds were available, then providing discharge packs with information and sources of support leaflets would be a prudent use of limited resources.

In recent years alongside the positive psychology movement there has been considerable interest in the area of post traumatic growth (Linley & Joseph, 2004); Zoellner & Maercker, 2006). Researchers have attempted to look at trait and personality correlates of post traumatic growth in order to better understand the mechanisms that underlie the ability in some individuals to find benefit out of adverse

or traumatic events (Helgeson et al., 2006). The idea of positive growth emerging from adversity presents an exciting possibility for developing clinical interventions and, whilst many studies have looked at post traumatic growth in individuals who themselves have a life altering diagnosis, some studies have begun to examine what role this may have for the informal caregiver (Bacon, 2009; Haley et al. 2009). Clinicians working with caregivers may find that interventions that encourage mindfulness elements within a cognitive behaviour framework will enable partners to harness the potential of perceived benefits of caregiving.

4.5 Future Research

It would be helpful to recruit a larger sample and see if the emergent themes would be replicated. In addition, a survey based piece of research could test out how generalisable these were to a much wider population. Efforts should be made to recruit participants to studies from same sex couples and from an ethnic and cultural mix that is broadly representative of Britain today. Developing a better understanding of both the commonalities and the diversity between and within these minority groups will go some way to ensuring that the findings from studies, and ultimately interventions derived from the research base, are appropriate and applicable to the whole population.

Further research is required to help us better understand the underlying factors as to why some couples fare better than others. Investigating the role of attachment styles on post stroke relationships may help to shed some light on why there is such variation between couples and may help professionals to understand and assess which couples would be most vulnerable. In addition, multi-factorial and longitudinal research could identify both risk and protective factors for relationship outcomes and thus enable services to effectively target stepped level interventions. Factors to be considered would

be: length of relationship, socio economic status, close family members both geographical and emotional, marriage with shared children or not, attachment styles and degree of prior relationship enmeshment.

4.6 Conclusions

Historically, there has been very little research that has addressed the particular concerns of marital or equivalent partnerships post stroke. There is now a small but growing body of predominantly qualitative research in this area. The current research adds to this emerging evidence base by examining how the care-giving spouse experienced the changes in their relationships after the stroke event. The findings of the current study supported earlier findings about loss of role, grieving for the relationship and coping strategies. Recent reviews (Sabin et al., 2010, Gaugler; 2010) identified lack of knowledge about the care giving trajectory as a flaw within the evidence base. It was concluded that the trajectory was complex and needed to be understood within the context of the relationship. The findings of the current study suggest that the changing nature of the partnership's interpersonal dynamics may underpin earlier findings about wives' reduced satisfaction with their relationship and potentially other negative outcomes experienced by female spousal caregivers. It also suggests that couples generally are not well supported after the rehabilitation stage of stroke care and experience a difficult process of relationship transition that they navigate largely alone and unguided. It is hoped that the findings of the current study will lead to greater consideration of the impact the stroke event has on the marital relationship in both clinical and research settings.

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PART THREE:

CRITICAL APPRAISAL

Reflecting on the Process

1. Personal reflections on my choice of research topic

Prior to undertaking my clinical doctorate I did not have a clear idea of a research area that I wanted to investigate. My first placement was in physical health which I was enjoying immensely and so when my supervisor presented at the research fair suggesting a study in the area of stroke caregivers, I was immediately drawn to the idea. It also had personal interest to me as I had family experience of stroke through my father, but at the time of choosing my topic this felt very secondary.

2. Planning the research

I conducted an initial literature review of the area of informal familial caregivers to stroke survivors to inform my research proposal. For a number of weeks, I was overwhelmed by the sheer amount of research around caregiver strain and burden and factors leading to a negative outcome for the caregiver. Despite there being a few threads of positivity, the general thrust was of an impaired quality of life for the caregiver as well as the cared for person. I spent a considerable amount of time reading through papers in full to enable me to better understand the area. What struck me was that the accounts were somewhat extracted from the reality of the experience so that I did not get a true sense of what was going on for people. Obviously, this is what is required of quantitative studies and so I looked for the qualitative accounts to help me to better understand the processes that were happening. It was through doing this that I realised there was a noticeable absence of the stories of couples. It seemed an odd omission to me, although in most studies it was not that couples were omitted, but rather that their specific voice had been lost within the caregiver role. Because the focus of

research was on their role of caring, they had been grouped with other carers, often daughters. It seemed to me that the experience for a wife would be a very different one to that of a daughter, even if the caring requirements were the same. I began to think about how it would be for me now if I had a parent to care for post stroke and contrast this to what I imagined it would be like if it were my partner who had had a stroke and needed caring for. I decided that this would be a very useful niche that I could explore within this huge corpus of literature. At this point, I think I also started to form ideas that would be significant in the direction and progress of my recruitment strategies. I was aware that most participants were recruited through the health system responsible for treating and rehabilitating the stroke survivor. It was as though the caregivers had this link, this umbilical cord, to the services that provided care. I wondered what happened when the stroke survivor was cut adrift from these services, when there was no further contact, not even to be asked to take part in research. What happens then? I knew that there were such things as Stroke clubs, but I wondered what was happening to the people who were not linked into some form of support like this. I really wanted to hear the voices of these people rather than people who were well linked to some kind of support or service. It was clear from the literature review that much of the assessment and research took place within the first year post stroke. I could understand that this was because it was medically and rehabilitation focused and that it might become harder to recruit people further down the line when it was not easy to send out letters from the rehabilitation service. This informed my recruitment process, which I knew from the outset would be harder than recruiting through NHS services, but I had no idea how hard to reach people would actually be once no longer linked up to services.

I wanted to know how people were feeling five years, ten years, twenty years later. How had the Stroke event shaped their lives? It seemed to me that it was important to understand this process as it may shed light on what would be helpful for services to provide and at what time point. Without having an understanding of this long view, something vital may be missed. A longitudinal study of a cohort of partners, as Visser-Meily et al. (2008;2009) appears to be doing in the Netherlands will provide really valuable insights, but I wondered how valid and or generalisable the data produced will be. I wondered what the effect of knowing that you are a part of the study would have on how you experience the process. The participants in the Visser-Meily studies are being asked to reflect on the process at regular intervals over time in a way that other people are not. This in itself alters the experience and could be seen as an intervention in itself.

4. Ethics and Research Governance

As part of the learning experience I had completed all the forms for NHS ethical approval as well as undertaking the ethical approval process through the University. In previous years, these forms had been submitted to the local NHS Ethics Committees (LRECs) and trainees had gained approval, in principal, even for studies where recruitment was not going to be through the NHS. The local LRECs had recently decided that these proposals would no longer be dealt with as they caused unnecessary work for the committees and delays for researchers needing to gain approval before their recruitment could start. So for the current study, the NHS ethics forms remained in a box file. Had I made explicit a phase four recruitment strategy that required NHS ethical approval and had submitted the forms, then it is fair to assume that the recruitment phase overall would have been completed earlier and more successfully. To

enable more participants to be recruited other than through the NHS would have required a much longer period of time than was available for the current research project. Unfortunately this was not apparent at the outset.

3. Recruitment

I had developed a multi-phase strategy of recruitment. It seems unthinkable now but at the time, I was really concerned that I might attract more potential participants than I could realistically interview. I wanted to minimise this as I felt it would be unethical to partially recruit and then reject people who may have few contacts and may have relished the opportunity to talk to someone. My first phase was to start in one geographical area and get a small article printed in the local newspapers requesting participants for the study. In the area I chose, there were two newspapers that served different audiences: a daily tabloid newspaper that focused on a working class audience and a weekly higher brow paper that focused on a more middle class audience. I was pleased to be able to get a small piece published in both papers. Unfortunately the publication coincided with the worst snow the area had seen for many years and so I managed to persuade both papers to republish the appeal for participants three weeks later. I was surprised that these articles produced only four participants but decided to use the same strategy in papers in neighbouring counties. I particularly sought out a newspaper covering a large rural community as well as one covering ex-mining communities as I knew from my clinical work in these areas that many people lived isolated lives. Negotiating these inclusions in the papers took time and unfortunately, produced no new participants. I moved on to my second phase of recruitment by sending posters out to every library within a fifteen mile radius with a covering letter to the librarian hopefully encouraging them to display the poster prominently. Just over

sixty posters were sent. As I waited for responses and repeatedly checked my email and research phone for responses that did not come I decided that I would now have to move onto phase three of my recruitment strategy which was through the stroke clubs. I negotiated access to a number of stroke clubs but I had to wait until they could fit me in with their schedule, which was four months hence. I tried to gain access to stroke groups in a different county area but was told by the Stroke Association co-ordinator that they were 'protecting' their groups from researchers as too many people wanted to recruit people from the groups that it was impacting on the groups' primary function as a supportive structure and environment. I was finally allowed access to one group that she felt was 'robust enough' to cope with a visit. I had an enjoyable evening with this group and was able to recruit one further participant. As the time approached for my visits to the Stroke clubs in my original area, I rang to confirm the details only to be told that there had been a mix up and that the research slot was now filled by a senior researcher from the local University who they felt they should give priority to because he was local and his research had a large grant attached to it.

At this point I was somewhat despairing as to how to gain any more participants without going through the NHS. I sent out 60 more posters to community centres and libraries and settled down to analyse my work with just five participants. I received a call from my sixth participant just as I had given up hope. She had seen a poster in the library a few months back and had written down the number and then lost it. When she returned to the library several weeks later, the poster was still there and she noted down the number again and telephoned me the same week.

5. Data Collection

Interviewing the six participants was, for me, the most rewarding part of the research process. The generosity of people who opened up and shared with me their stories, recounted difficult personal and emotionally distressing events, never ceased to amaze me. The level of altruistic involvement in research made me feel humbled and I felt a deep responsibility and concern for the participants I spoke to. As my questioning probed areas that were psychologically sensitive it at times felt hard not to slip into a clinician role. I had been clear from the outset that this was a research interview and not a therapeutic session. I was aware that the participants had consented to that arrangement, nothing more, and nothing less. I was however aware of the impact of asking people to stop and reflect on their experiences. After each interview it felt necessary to spend a few minutes bringing the emotional climate back onto an even keel before leaving. Although my experience as a clinician made me aware of the unmet need within some participants, which was difficult at times for me to deal with, it also was helpful in that I had the skills to wrap up the interviews in a way that felt both respectful and safe.

6. Data Analysis

I had been keen to transcribe and begin analysis as soon as I had completed the first interview. In reality, the processes overlapped for the first four participants. I then had a considerable amount of time to immerse myself in these four stories before the final two participants presented themselves. I tried to have a parallel process going on whereby I immersed myself in the stories, complete with the embedded emotion and wrote memos whilst systematically coding the text in the manner suggested by Braun and Clarke (2006). The immersion in the four first stories initially felt somewhat overwhelming and

whilst I was able to write descriptive codes, the move from this to thematic codes and categories did not happen for some time. Without a doubt, the anxious process of continually looking for participants was unhelpful in the overall process. The formulating of a diagrammatical structure in which to test against the evidence proved to be the most effective way of moving forward. It soon became clear when bits did not fit and it felt like a similar process to that of clinical formulation and reformulation but without a therapeutic model to guide you. When a final diagram came together, it felt quite rewarding to finally be making sense of this wealth of disparate data. Finding succinct and inclusive labels for categories and themes was difficult and I felt the result was imperfect. I decided however that it was probably impossible to find suitable labels that would in one blow explain the complexities and intricacies of all that a theme or category contained and concluded that a ‘best fit’ and utility approach was required.

7. Quality issues

Thematic analysis has been subject to much criticism in the past about the lack of clarity of process and quality measures. Qualitative research by nature is subjective and interpretive. Whilst I strove to ground my research firmly within the data and use an inductive method to work from the ground up, I do not propose to claim that my analysis be free from bias. To ensure the reliability of my coding, I employed three other peer qualitative researchers to code sections of transcripts independently. I shared my developing themes and categories with my research supervisor and demonstrated the line of deduction back to the transcript data to validate my themes. Whilst the independent coding concurred with mine, it was interesting to note how the data threw up different questions for different people and the subsequent direction of travel may have been different for different researchers presented with the same initial data set.

8. The writing up process

The writing up process for me was both the hardest and the most helpful part of the whole research process. Whilst there was a fear of being unable to convert the thoughts in my head into a coherent linear narrative, the process of doing so enabled new thoughts, ideas and explanations to emerge. As a clinician, this should not have come as any surprise to me it is a technique that we employ with our clients on a daily basis, but for some reason this did surprise me. My supervisor spent a lot of time encouraging me to 'just write it' and yet there was some considerable resistance on my part to doing just that. I spent an inordinate amount of time tinkering around with my themes and codes whilst not feeling able to write. When I finally sat down to write I found the process almost cathartic in its ability to relieve the tension built up and certainly constructive in the process of fine tuning the analysis.

9. Reflections

At the start of the research process I acknowledged that the topic had personal salience to me as my late father had suffered a number of strokes during his lifetime. I did not feel that it would be a particularly emotional topic for me because my memories of my father's strokes were not traumatic but were rather distant and vague. I certainly did not view them as an important part of my family story or as particularly relevant to my research. They were more of an incidental historical occurrence. My reason for undertaking the research was its relevance to physical health psychology and the wider understanding of how relationships change over time and in response to unexpected or traumatic events. As the research progressed however, particularly during the analysis period, I began to see the relevance of it to my own personal story.

10. Reflections on the emotional content of the research process

Undertaking this research involved witnessing the accounts and narratives of women who, although each individual's circumstances and experiences were unique, had trodden a similar path to that of my mother. It became impossible not to reflect back on my childhood, most notably my teenage years, and see a different perspective. As a teenager, it is part of the developmental process to become exasperated with your parents and to strive to become independent. Certainly as a teenager I can remember keenly counting down the days until I could leave school and home as my brother had done two years before me. I remember home as being a place of stress and aggravation in those final years and had no doubt that my parents were also counting down the days to my leaving. Having now read widely around the subject of informal care giving for stroke survivors as well as hearing the first-hand accounts of wives, I recognise some of the recurrent themes that were present in my family home during that time and afterwards.

My mother seemed grumpy most of the time. She seemed always to be nagging and berating us, telling us what to do, what not to do and Father seemed to bear the brunt of it. She no longer trusted my father to wear the correct clothes and would send him back upstairs to get redressed. She no longer trusted him to manage money and so he was put on to an allowance the same as my brother and I. She got exasperated with getting him to rise from the breakfast table each morning as he would quite cheerfully spend half the day or more topping up his tea whilst trying to solve the Daily Telegraph crossword. My brother and I viewed this as a lack of respect for our father but I now recognise it as the lived experience of my parents' relationship changing irrevocably after his stroke.

My father, fourteen years older than my mother, could no longer be the strong one in the relationship. My mother was forced to take on that role.

So my mother had to contend with the fear of being widowed and had to face the thought that she may have to bring up two children alone. Add to this, being in reduced financial circumstances, isolated away from family and friends and with no support system to speak of, then the whole situation becomes quite grim. This is very much the theme of loss that is woven through every narrative in this study. My father had lost his drive, his motivation and his ability to plan. My mother perhaps felt that she had an extra dependant rather than the support of a husband in a reciprocal partnership relationship. My mother clearly felt that she had to 'do everything', a phrase often used in the narratives. I do not know what she used as a coping strategy. If she had anyone to talk to then we as children certainly were not aware of it.

Five years after the stroke event, both my brother and I had fled the nest which would in itself have brought further developmental change to their relationship. Seven to eight years post the stroke event and after twenty four years of marriage, my parents were teetering on the brink of divorce. Help for them came in the form of involvement with a local church which developed into a joint interest and then a shared faith. My mother decided (despite it meaning she lost her attendance allowance) to take a part time teaching post which perhaps gave her the 'escape' that made her life more tolerable and slowly, a catastrophic relationship breakdown was averted. They adapted and finally, I believe my mother probably reached a point of acceptance. Interestingly, in the current study faith was not a theme that came up, although people who seemed to reach an acceptance spoke in almost spiritual terms.

I had not thought when I started this research that it would result in me completely re-evaluating and analysing a part of my own family history in the light of the evidence I came across. In some ways I feel pleased that I did not have this understanding of the process before embarking on the research because I feel my naivety was a necessary and essential part of the inductive process. I think, as a developing clinician, it has been an invaluable lesson in the reflexivity between our personal life and experiences and the subject matter of our working world and the lives of those we have the privilege to venture into. It has been a lesson about the multiplicity of truths and differing perspectives as well.

11. Learning Outcomes

As a novice researcher I have been able to learn how to plan a substantial piece of research from inception to completion. Whilst the journey has been at times extremely challenging, I feel that it has been good preparation for future research. I have learnt about how difficult it can be to recruit people to a research study and how difficult it can be to keep to a time-frame or schedule when factors are outside of the researcher's control. More specifically I feel that I have learnt some invaluable skills in qualitative analysis, learning core skills of transcription and analysis using constant comparative methods. In the process of literature review, I have learnt about the process of meta-ethnographic synthesis which I feel will be a particularly useful tool to have in my possession. I feel that after the submission of this thesis, the learning will continue as I prepare papers for submission to journals and a poster for presentation at conferences. On a clinical level, I feel that I have a better insight into the dilemmas and difficulties faced by couples post-stroke.

If I was designing this project again I would design an additional wave of recruitment through the NHS, thereby allowing me to apply for NHS ethical approval even if the intention was not to use it. Then, should there be recruitment difficulties through the initial methods, a back-up source of potential participants could be accessed without delay. I would also set an absolute cast iron date whereby recruitment shifted to the next level if sufficient participants had not been recruited to ensure that sufficient time was available for analysis and the project could be completed within the appropriate time frame.

12. References

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APPENDICES

Appendix A: Journal submission guidelines

Appendix A: Notes for contributors

British Journal of Health Psychology (BJHP)

Notes for Contributors

The aim of the **British Journal of Health Psychology** is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- Methodological papers dealing with methodological issues of particular relevance to health psychology.

Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

Manuscript requirement

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They

should be placed at the end of the manuscript with their approximate locations indicated in the text.

- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. Please see the document below for further details:

 [British Journal of Health Psychology - Structured Abstracts Information](#)

Appendix B:

Full-text papers considered for Literature Review

Appendix B: Categorisation Table of full-text papers

Category	First Authors and year	Title	Notes on country and ethnicity of sample and/or publication	Notes	Fits criteria for inclusion Y/N
Reviews of interventions (all quantitative)	Brereton et al 2007	Interventions for adult family carers of people who have had a stroke: a systematic review	UK - Sheffield	6 studies – non info giving interventions - narrative	
	Eldred et al 2008	Psychosocial interventions for carers of survivors of stroke: A systematic review of interventions based on psychological principles and theoretical frameworks	UK - London	7 RCTs	
	Lee et al 2007	A Meta-analysis of Interventions for Informal Caregivers	USA - Baltimore	4 studies – meta-analysis	
	Lui et al 2007	Supporting family caregivers in stroke care: a review of the evidence for problem solving	Hong Kong	11 studies	
	Smith et al 2008	Information provision for stroke patients and their caregivers	UK – West Yorkshire	17 studies – meta-analysis	
	Visser-Meilly et al 2005	Intervention Studies for caregivers of stroke survivors: a critical review	The Netherlands	22 studies (18 RCT) narrative	

Reviews of effects of stroke care-giving on caregiver	Gaugler, 2010	The Longitudinal Ramifications of Stroke Caregiving: A Systematic Review	USA - Minnesota	117 studies – synthesized data – systematic review	
	Green & King 2007	The trajectory of minor stroke recovery for men and female caregivers – a literature review	Canada - Calgary	34 papers, 1990-2006 – narrative review	
	Greenwood et al 2008	Informal primary carers of stroke survivors living at home – challenges, satisfactions and coping: A systematic review of qualitative studies	UK - London	Summarising studies from past decade. Not limited to spouses and with no synthesis	
	Greenwood and Mackenzie (2010)	Informal caring for stroke survivors: Meta-ethnographic review of qualitative literature	UK - London	Qualitative: Seven studies of informal caregiver studies between 2006-2009. Synthesised data - predominantly but not exclusively spousal	
	Han et al 1999	Family Care-giving for patients with Stroke: Review and analysis	USA - Florida	12 years old	
	McKevitt et al 2004	Qualitative Studies of Stroke: Systematic Review	UK - London	Very broad covering patient, carer, professional and service but no specific to patient and partner dyad	
	Ostwald 2008	Predictors of life satisfaction amongst stroke survivors and spousal caregivers: a narrative review	USA – Texas	Narrative review of literature on life satisfaction – does not state no of studies reviewed	

	Sabin et al.2010	Measures of Psychological Stress and Physical Health in Family Caregivers of Stroke Survivors: A Literature Review	USA - Chicago	24 studies – narrative review	
Psychological effects of care-giving	Alexander and Wilz 2010	Family caregivers: Gender differences in Adjustment to Stroke Survivors' mental changes	German	97 spousal dyads looking at differences by gender in adjustment to changes in partner	N?
	Berg et al 2005	Depression Among Caregivers of Stroke Survivors	Finland - Helsinki	Closest contact not spouse. Prevalence and predictors of depression.	N
	Cameron et al 2011	Stroke survivor depressive symptoms are associated with family caregiver depression during the first 2 years post stroke.	Canada - Toronto	Focusing on the unique contribution of stroke survivor behavioural and psychological symptoms to caregiver depression. Not exclusively spousal	N
	Chumber et al 2008	Associations in sense of coherence and depression in caregivers of stroke survivors across two years	UK - Edinburgh	Longitudinal study to detect the relationship between 'sense of coherence' which is an active coping response. 115 veterans and their informal caregivers	N
	Dennis et al 1998	A Quantitative study of the Emotional Outcome of People Caring for Stoke Survivors	UK - Hull	Study is thirteen years old. Caregiver not spouse or partner. Describing outcomes and identifying predicting factors	N

	Draper & Brocklehurst 2007	The impact of stroke on the well-being of the patient's spouse: an exploratory study	Sweden - Stockholm	44 spousal dyads – found increase psychiatric morbidity and stress in spousal caregivers	Y
	Franzen Dahlin et al 2006	Post stroke depression – effect of the situation of the significant other	Sweden - Stockholm	71 dyads of patients diagnosed with post-stroke depression and their 'significant other'. Found greater depression in those with limited physical deficits.	Y
	Franzen Dahlin et al 2007	Predictors of Psychological health in spouses of persons affected by stroke	USA - Chicago	Spouses 1) Identifying predictors of psychological health over time 2) Looking at gender	Y
	King 2010	Patterns of relationships between background characteristics, coping, and stroke caregiver outcomes	Sweden - Stockholm	253 dyads – caregivers defined as co-resident but no relationship details given	N
	Larson et al 2008	The impact of gender regarding psychological well-being and general life situation among spouses of stroke patients in the first year post stroke - A longitudinal study	USA - Texas	Same study as Franzin- Dahlin et al 2007. Differences by gender in psychological well-being - spousal	N ? but key paper
	McKenzie et al 2007	Family carers of stroke survivors: needs, knowledge , satisfaction and competences	USA - Florida	159 dyads tested for stress every three months post discharge for the first 12 months. Spousal or equivalent co-habiting couples.	Y?

	Ostwald 2009	Stress experienced by stroke survivors and spousal caregivers during the first year after discharge from inpatient rehabilitation	Canada - Quebec	Not spousal. Looking at the interaction between psychological health of caregiver and patient – formulated as a feedback loop	
	Perrin et al 2008	Structural Equation modelling of the Relationship between Caregiver Psycho-social Variables and Functioning of Individuals with Stroke	USA - Florida	Spouses –Short longitudinal study looking at changes in coping over six month timeframe – measures of depression taken	N
	Rochette et al 2007	Adaptation process, participation and depression over six months in first-stroke individuals and spouses		Part of a larger study. Info on relationships of care givers not given	Y?
	Tiegs et al 2006	Coping by stroke caregivers: sex similarities and differences.			N
	Visser-Meily et al 2008	Psycho-social functioning of Spouses in the Chronic Phase after Stroke: Improvement or Deterioration between 1 and 3 years after Stroke.	The Netherlands	Spouses: Describes psychosocial functioning and identifies predictors of negative change	Y
	Visser-Meily et al 2009	Psycho-social functioning of spouses of patients with stroke from initial rehabilitation to three years post stroke	The Netherlands	211 couples examined at four time points and assessed for marital harmony as well as strain, problem solving ability and depression	Y

	Wilz et al 2008	Anxiety symptoms in spouses of stroke patients	Germany - Berlin	Longitudinal study to investigate prevalence and associated factors. 114 couples at admission for rehab and 1 year later.	Y?
	Wyller et al 2001	Emotional well-being of close relatives to stroke survivors	Norway - Oslo	Nearest relative well-being. Does not specify relationship or whether any care-giving responsibilities	N
Qualitative Studies	Backstrom et al 2010	The meaning of middle-aged female spouses lived experience of the relationship with a partner who has suffered a stroke, during the first year post discharge	Sweden/ Norway	4 spouses interviewed at three time points post stroke. Analysed using a phenomenological-hermeneutic framework	Y
	Brann et al 2010	Dialectical Tensions in Stroke Survivor Relationships	USA - Sampled from 3 mid Atlantic states	16 spouses of stroke survivors interviewed and analysed using a dialectics perspective.	Y
	Buschenfeld 2009	The experience of young stroke victims	UK – Bristol/ Cardiff	Interpretive phenomenological analysis of seven partners of stroke survivors under the age of 60 years. DClinPsy	Y
	Coombs 2007	Spousal care-giving for stroke survivors	Canada (east) Published in USA	A phenomenological study of eight spousal caregivers	Y
	Greenwood & McKenzie 2010	Loss of autonomy, control and independence when caring: a qualitative study of informal carers of stroke survivors in the	UK - London	31 informal carers interviewed just prior to discharge, one month and three months post discharge. Unknown relationship	N

		first three months after discharge			
	Hunt & Smith 2004	Personal experiences of carers of stroke survivors: an interpretive phenomenological analysis	Australia – Sydney	IPA analysis of four family caregivers – more detailed information about relationship not given.	N
	Masry et al 2010	Understanding the experiences of caring for someone after stroke: a qualitative study of caregivers and stroke survivors	Sweden	20 informal caregivers interviewed about their care-giving experiences – 15 spousal, 2 sibling and 3 child.	N
	Ohman and Soderberg 2004	The experiences of Close Relatives living with a person with serious chronic illness	USA – north Michigan	13 out of 14 participants were spouses. A range of chronic illnesses and 3 partners had died up to 3 years ago.	N
	Pierce et al 2007	Two sides to the care giving story	USA – Colorado	73 caregivers interviewed over the telephone about their experiences. 69% were spouses or equivalent	N
	Silva-Smith 2007	Preparing for and Beginning a New Care-giving Role	UK – Glasgow	Grounded theory analysis of the experiences of twelve primary family caregivers. Interviewed at discharge and one month after. No information given on caregiver relationship to stroke survivor.	N
	Smith et al 2004	Experience of Caring for stroke survivors	Canada - Toronto	Part of a larger study to develop an instrument. 90 caregivers of stroke survivors interviewed one year after the stroke event. No information on the relationship between survivor	N

	Smith et al 2008	Differences in the experiences and support needs of family caregivers to stroke survivors: does age matter?		and caregiver given. Part of a larger study to identify needs of caregivers. Nine caregivers, some family some friends. Not exclusively spousal	N
General Quality of Life studies and caregiver strain or burden	Blake 2003	Caregiver strain in spouses of stroke patients	UK – Nottingham	Testing logistical regression model ability to predict caregiver strain. 79 spouses	N?
	Bugge 1999	Stroke patients' informal caregivers; patient, caregiver and service factors that affect caregiver strain	UK – Glasgow / Aberdeen	Part of a larger study. Principal caregiver but no relationship identified. 110 dyads	N
	Carlsson 2007				
	Chow et al 2007	Coping and caring: Support for family caregivers of stroke survivors	China – Hong Kong	Examines the physical and emotional burden of caring for stroke survivors compared with patients with neurological disease. Not exclusively spousal	N
	Jonsson 2005	Determinants of quality of life in stroke survivors and their informal caregivers	Sweden – Lund	234 informal caregivers who had contact at least twice per week. Not exclusively spousal	N
	Mc Cullagh 2005	Determinants of caregiving burden and quality of life in caregivers of stroke patients	UK – London	Part of a larger RCT of caregiver training. 90% of caregivers familial but not necessarily spousal.	N
	McPherson 2010	The balance of give and take in caregiver-partner relationships:	Canada – Ottawa	A mail survey of 57 partnership dyads. From the viewpoint of the	

	Nelson 2008	An examination of self perceived burden, relationship equity, and quality of life from the perspective of care recipients following stroke	USA - Minnesota	care recipient but showing inequitable relationships produce significantly higher self-perceived burden	N
	Van Puymbroeck 2008	Declining patient functioning and caregiver burden/ health: The Minnesota stroke survey – quality of life after stroke study	USA – Florida and Puerto Rico	Part of a large ongoing study. 356 informal caregivers – relationship to stroke survivor was not recorded.	N
	Rigby 2009	Influence of sense of coherence on caregiver burden and depressive symptoms at 12 months post stroke	Canada - Halifax	Part of a much larger multi-site study. Caregivers defined as family or friend.	N
	Steiner 2008	Caring for stroke survivors: baseline and 1-year determinants of caregiver burden	USA – Toledo OH	Aiming to identify patient factors that contribute to higher levels of caregiver burden. Caregivers a mixture of spouses, daughters, daughters in law and other	N
	Van Exel 2004	Emotional support, physical help and health of caregivers of stroke survivors	The Netherlands – Rotterdam/ Amsterdam	Part of a large study to evaluate the effectiveness of an intervention. Of caregivers 69% had a spousal relationship to the stroke survivor	N
	Visser- Meily 2005	What really matters: an inquiry into the relative importance of dimensions of informal caregiver burden	The	Cross sectional study to identify the dimensions that caregivers say contributes to their caregiver burden. Pooled sample from stroke and arthritis studies.	N

		Spouses' quality of life 1 year after stroke: predictions at the start of clinical rehabilitation	Netherlands - Utrecht	Prospective study to identify early predictors of spouses' quality of life. 187 spousal participants	Y
Developing or testing Interventions	Franz in Dahlin 2008	RCT support and education for spouses of people			N
	King et al 2007	Prob solving intervention			N
	Louie et al 2009	Stress of caregivers in caring for people with stroke: implications for rehabilitation	China -Hong Kong	124 ethnically diverse primary informal home caregivers (relations not stated)	N
	Perrin et al 2009	Identifying at-risk, ethnically diverse stroke caregivers for counselling: A longitudinal study of mental health	USA –sample from Florida, Puerto Rico, South Georgia and Virgin Islands	Questionnaire and interview of 124 ethnically diverse dyads. Caregiver identified as nearest informal caregiver. No information given on relationship	N
	Robinson et al 2005	Caring for carers of people with Stroke: Developing a complex intervention following the Medical Research Council Framework	UK – Newcastle upon Tyne	Developing a Cognitive Behavioural intervention for carers of stroke survivors. Phase 1 was a qualitative modelling stage to identify carers needs. Carers not limited to spousal.	N

Appendix C:

Data extraction of reviewed papers

Appendix C: Data extraction from reviewed studies

First Author, year and country of origin	Care-giver sample size (m/f)	Characteristic s of Care-recipients (CR) and Caregivers (CG)	Data collection	Outcomes and measures	Key findings
Backstrom et al, 2010. Sweden	4	CG mean age = 52(40-58) Gender = all female.	Interviews at 1, 6 and 12 months post discharge. (T1,T2 and T3)	Semi structured interviews of 60-80 minutes. A phenomenological – hermeneutic interpretation of the narrative.	Two overarching themes emerged at T1: Theme 1. fearing to lose the relationship and Theme 2. Losing own identity. By T2 Themes were 1.being in a struggle to restore the marital relationship and 2. Feeling lonely together. By T3themes were 1. Grieving the loss of the marital relationship in silence, 2. Being trapped in a drained marital relationship and 3.searching for own space and well-being.
Blake et al 2003. United Kingdom	116 (28% male and 72% female)	Mean age = 66.35 (SD 10.8)	Postal survey at 3 months (T1) and 6 months (T2) post stroke	Caregiver Strain Index (CSI) and at T1 only: General Health Questionnaire (GHQ-12), Negative Affectivity Schedule (PANAS) and the Extended Activities of Daily Living Scale (EADL)	Depression (T1=39%, T2=40%) and Strain remained fairly constant between time points. Strain at T2 was positively correlated with GHQ-12 and patient EADL) and negatively correlated with negative affectivity. No gender differences found.
Brann et al., 2010. USA	16 Gender = 6 men, 10 women	Mean age not stated. Range 21-93 years	9 interviews face to face and 7 by telephone	Semi structured, open ended interviews. A dialectical tensions approach	Dialectical tensions: self-orientated/ partner orientated, realism/idealism, uncertainty/acceptance, emotional release/emotional reservation.

Buschenfeld 2009. U.K.	7 (3 female s, four males)	Mean age=54.6	7 interviews	Semi structured interviews of 90 minutes duration, analysed using Interpretive Phenomenological Analysis	Trauma of stroke event and aftermath persisted over years effecting relationship, domestic tasks, family roles, employment and social life. Both positive and negative effects on spousal caregiver were noted. Super-ordinate Themes were: Adjustment, which included sub-themes of changed lives and enduring effects on the self and Coping
Carlsson et al., 2007 Sweden	56	Median ages: CR =60 (38-74) interquartile range 50-67. CG=59 (34-79) IQ range 50-66 CR gender 70% male, 30% female. CG gender not stated.	Matched couples. CR assessed at one week post stroke (T1) and both CR and CG at one year post stroke(T2)	CR at T1 and T2: Scandinavian Stroke Scale (SSS), Mini mental state exam MMSE), Barthel Index CR at T2: Oxford Handicap Scale (OHS) and assessment for post stroke fatigue and depression to DSMIV criteria. CR and CG at T2: Life satisfaction (LiSat)	Compared with norms both CR and CG less satisfied with life. CG and GR differ in their satisfaction levels across life domains. Satisfaction with leisure time and sex life were the most affected for both CG and GR.
Coombs 2007. Canada	8	CG mean age=65.5 (57-81). Gender 5male, 3female CR mean age 68.5 (57 – 81)	1 year+ post stroke.	Phenomenological study - 2 semi-structured interviews of 60-120 minutes. Thematic analysis	Six inter-related themes emerged. A profound sense of loss, adjusting to a new relationship, taking on new responsibilities, feeling the demands of care-giving, having to depend on others, maintaining hope and optimism,
Draper & Brocklehurst	44 – 13	CG mean age=65 (27-	Home visit at 12+ after	The Barthel Index (CR only), General Health Questionnaire (GHQ),	Higher GHQ scores in spouses (CG) than in reference groups. No correlation found

2007. U.K.	male, 31 female	83). CR mean age=67 (26- 91)	stroke event	Caregiver Strain Index (CGSI).	between spousal distress or strain and level of CR disability but correlation between CR language impairment and CG distress.
Franzen Dahlin et al 2007 Sweden	100 20% male and 80% female	Mean age = 67 (no SD or range given)	Interview at baseline (T1), six months (T2) and twelve months (T3) post stroke	CPRS-S-A (measuring psychological health), Quality of Life (QOL), Bradley's short well-being questionnaire, an abbreviated Swedish version of the Interview Schedule for Social Interaction, the Life Situation Among Spouses after the stroke-event questionnaire (LISS), the short version of Antonovsky's Sense of Coherence questionnaire, a 'knowledge of stroke' questionnaire devised for this study, the Barthel Index (to assess patients functional capacity) and the EuroQol (to assess general health)	Clinically significant depression in 32% (T1), 26% (T2) and 37%. Womens' psychological health was more negatively affected than mens' at T2. The most consistent predictor of psychological health was self-estimated general well-being. Reduced physical health was a predictor of reduced psychological health and Age was a significant positive predictor with older spouses having better psychological health.
Ostwald et al., 2009. U.S.A.	159 – 119 male, 40 female	CG mean Age=62.5, CR mean age=66.4 74.8% CR were male	5 data collections points: at discharge and every 3 months thereafter until 12 months most discharge.	Perceived Stress scale (PSS), Self reported health status (1-5 excellent to poor scale), The FIM (measures independence in CR – 1-7 scale), Stroke Impact Scale (SIS), Medical Outcomes Study (MOS) Social Support Survey, Family Crisis orientated personal evaluation scale (F-COPES), the preparation for caregiving scale (PCS) and at baseline, 6m and 12 month only the Mutuality Scale	SG reported greater stress than CR and this decreased less over the year. Higher levels of CG and CR stress were associated with lower levels of functioning in the CR. Poor health, being younger and or female were predictors of higher stress for CG as were passive coping strategies. High mutuality was associated with low levels of stress but not to a statistically significant level (p=0.07) . Strong support networks were also associated with lower stress.
Rochette et al 2007 Canada	47 58% male	Mean age = 69.2 (SD	Measures of coping and appraisal	Stress Appraisal Measure (SAM), Revised Ways of Coping Questionnaire (RMCQ). At T3 only:	Spouses experienced an increased perception of the uncontrollability of the situation over time. Coping strategies were

	and 42% female	11.2)	taken at two weeks (T1), 3 months (T2) and 6months (T3)	Assessment of Life Habits (LIFE-H 3.0, short version) and Beck Depression Inventory (BDI)	not significantly changed. Appraisal and coping measures at T1 were associated with participation and depression scores at T3. Perceived threat and stress reduced over time.
Visser meily et al. 2005. The Netherlands	187 35% male, 65% female	Mean age=54 (median=54, IQ=15)	Measures at baseline (T1) and one year post stroke (T2)	T1 – depression measured with Goldberg depression scale (GDS). T2 - Burden measured with CSI, Life satisfaction with Lisat-9 and depression with GDS. Patient's ADL dependency was measured with BI, communication with Utrecht communication observation (UCO), Cognitive functioning with MMSE. Spouses' characteristics: Coping strategy was measured using the Utrecht coping list. Depressive symptoms with GDS, Harmony in relationship with Interactional problem solving inventory and social support with the social support list.	Spouses quality of life 1 year after the stroke event. A large proportion of caregivers perceive impaired quality of life at this point. 80% reported low quality of life on one or more of the measures, 52% reported depressive symptoms, and 54% significant strain. 70% reported changes in family adjustment, changes in personal plan (having to not go on holiday or take a job) and 'there have been other demands on my time'. 65% reported 'the upsetting feeling that the patient had changed from their former selves. 23% reported financial strain. 50% were satisfied with 'their life as a whole' 45% were happy with their leisure time and only 32% were happy with their sex lives. Passive coping strategies were the most predictive of burden, life satisfaction and depression.
Visser Meily et al 2008. The Netherlands	121 35% male, 65% female .	Mean age of caregiver = 55 (9), Mean age of care-recipient (56). 25% with children under	Interviews at one year post-stroke (T1) and three years post-stroke (T2).	Caregiver Strain Index (CSI), Life Satisfaction Checklist (LiSat-9), Goldberg Depression Scale (GDS), Interactional Problem Solving Inventory (IPSI) and the Social Support List (SSL). At T1 only the Passive Coping Strategy Subscale	Most aspects of psycho-social functioning deteriorated between one and three years post-stroke. The exception was Caregiver Burden which diminished over time. Depression rates fairly constant over time (52-50%). Life satisfaction, harmony in the relationship and social support all

		18 and 46% being employed for at least 20 hours a week.		from the Utrecht Coping List (UCL) was employed. Additionally at T1 the care-recipients were categorised into cognitively impaired and cognitively unimpaired.	significantly deteriorated. Care-recipient impairments associated with worse psychosocial functioning in the caregiver. Satisfaction with sexual life, partnership relations and family life all decreased as did harmony in the relationship.
Visser Meily et al., 2009 The Netherlands	121	Mean age of caregiver = 55 (9), Mean age of care-recipient (56). 25% with children under 18 and 46% being employed for at least 20 hours a week.	T1= hospital based, T2= 2months after discharge, T3= approximately 1 year post discharge and T4= 3years post discharge	Caregiver Strain Index (CSI), Life Satisfaction Checklist (LiSat-9), Goldberg Depression Scale (GDS), Interactional Problem Solving Inventory (IPSI) and the Social Support List (SSL). At T1 only the Passive Coping Strategy Subscale from the Utrecht Coping List (UCL) was employed. Additionally at T1 the care-recipients were categorised into cognitively impaired and cognitively unimpaired	Caregiver burden decreased significantly between T2 and T3 and between T3 and T4. Depressive symptoms decreased from T1 (68%) to T2 (53%) but showed no further significant decrease. There was a decreasing in the harmony in the relationship between T1 and T2 and between T3 and T4, the latter showing the biggest increase ($p<0.01$). Social relations decreased between T2 and T3 and declined further between T3 and T4. Patients functioning did not decrease significantly between T3 and T4.
Wilz & Kalytta, 2008. Germany.	114	CG mean age =58 (26-82) SD 11.4 CR mean age= 60 (30-83), SD 10.6. Gender: 28% male, 72% women	T1 = admission, T2 = 1 year post stroke	CG anxiety assessed using the Beck Anxiety Inventory (BAI). CR function assessed with Barthel Index and Patient competency rating scale (PCRS), CR depression with the Cornell Depression Scale (CDS)	Prevalence and average sum scores were similar at both time points. Gender correlated with anxiety at both points with women experiencing greater anxiety with greater prevalence. The mean level of anxiety at one year were 9.7 for women and 6.4 for men. Greater disability in CR was associated with greater CG anxiety. Prevalence of clinical levels of anxiety in CG is high (approximately a third) with 14% (T1) – 15.8% (T2) experiencing severe symptomology.

Appendix D:

Measures

	Care Giver Strain Index (CSI)	Stress Appraisal Measure (SAM)	Depression to DSMIV criteria	Beck Depression Inventory (BDI)	Goldberg Depression Scale (GDS)	Cornell Depression Scale (CDS)	Negative Affectivity Schedule (PANAS)	Beck Anxiety Inventory (BAI)	CPRS –S-A (psychological well-being)	Life situation among spouses (LISS)	Perceived Stress scale (PSS)	Life Satisfaction (Li-Sat-9)	Family Crisis orientated personal evaluation scale (F-COPES)	Mutuality Scale
Blake et al 2003	T1 only						X							
Carlsso n 2007			X							X				
Draper 2007	X													
Franzen Dahlin 2007									X	X				
Ostwald 2009											X		X	X
Rochette 2007		X		X										
Visser Meily 2005	X				X							X		
Visser Meily 2008	X				X							X		
Visser Meily 2009						X								
Wilz 2008								X						

Appendix D: measures of psychological health and wellbeing in the caregiver

Appendix E:

Timings of measures

Author and date	Baseline – 1 week post stroke to 1 month post discharge	2 months after discharge	3 months	6 months	9 months	12months	3 years
Backstrom 2010	1 month post discharge			T2		T3	
Blake et al 2003	No baseline within this time frame		Baseline T1	T2			
Carlsson 2007	1 week post stroke					T2	
Draper 2007	Not longitudinal					Single time point data collection	
Franzen Dahlin 2007	T1			T2		T3	
Ostwald 2009	At discharge		T2	T3	T4	T5	
Rochette 2007	At 2 weeks post ?		T2	T3			
Visser Meily 2005	baseline					T2	
Visser Meily 2008						T1	T2
Visser Meily 2009	Hospital based	T2				T3	T4
Wilz 2008	On admission to rehab					T2	

Comparison of time points for measurements taken across studies.

Appendix F:

Characteristics of participants

First Author, year and country of origin	Care giver sample size	female	Male	Ages of care givers	Time point post stroke	Data collection method	Analysis	Key findings
Backstrom et al, 2010. Sweden	4	4	0	mean age = 52(40-58)	1, 6 and 12 months post discharge. (T1,T2 and T3)	Interviews at Semi structured interviews of 60-80 minutes	A phenomenological – hermeneutic interpretation of the narrative.	Two overarching themes emerged at T1: Theme 1. fearing to lose the relationship and Theme 2. Losing own identity. By T2 Themes were 1.being in a struggle to restore the marital relationship and 2. Feeling lonely together. By T3themes were 1. Grieving the loss of the marital relationship in silence, 2. Being trapped in a drained marital relationship and 3.searching for own space and well-being.
Brann et al., 2010. USA	16	10	6	Range 21-93 years	1 month – 2 years	9 Semi structured, open ended interviews face to face and 7 by telephone	A dialectical tensions approach	Dialectical tensions: self orientated/ partner orientated, realism/idealism, uncertainty/acceptance, emotional release/emotional reservation.
Buschenfeld 2009. U.K.	7	3	4	Mean age =54.6	3-7 years	Semi structured interviews of 90 minutes duration	Interpretive Phenomenological Analysis	Trauma of stroke event and aftermath persisted over years effecting relationship, domestic tasks, family roles, employment and social life. Both positive and negative effects on spousal caregiver were noted. Super-ordinate Themes were: Adjustment, which

								included sub-themes of changed lives and enduring effects on the self and Coping
Coombs 2007. Canada	8	5	3	mean age =65.5 (57-81).	1 year+	1 year+ post stroke. 2 semi-structured interviews of 60-120 minutes.	Phenomenological study - Thematic analysis	Six inter-related themes emerged. A profound sense of loss, adjusting to a new relationship, taking on new responsibilities, feeling the demands of care-giving, having to depend on others, maintaining hope and optimism,

Appendix G:

Meta-ethnographic themes

Themes	Backstrom	Brann	Buschenfeld	Coombs
Loss and grief:	Loss of own identity, role as spouse, reciprocity in the relationship, feelings of estrangement, loss of choice, loss of sexual and emotional closeness	Loss of freedom, of own life, of independence, support of a partner, closeness in relationship, partnership equity	Loss of familiarity, intimacy, difficult to maintain other roles and relationships, employment, income, time to self, social life, individuality, devaluation of self, spontaneity,	Loss of leisure time, loss of freedom and loss of marital partner, loss of physical and emotional support, loss of partnership
Fear	Feared loss of relationship by death, of not being able to endure changed relationship	Of another stroke, of the uncertainty of the future	That something will happen,	Fear of something happening to partner, particularly if left unattended,
Sense of duty and responsibility for everything	Felt obligated to respond to and take responsibility for spouse without thought for self, self denial, being forced into an unwanted relationship, belief in lifelong fidelity	Whole life centres around partner and meeting their needs	Protective and responsible for partners well-being. Responsible for all or most domestic tasks and personal care of partner	Female caregivers felt an overwhelming sense of responsibility, obliged to be at home with them, guilt if away, 'no choice'
Coping	Finding space for self within the relationship, remembered the partner as was before the stroke	Maintain optimism, being thankful, gathering information,	Use humour to cope, comparisons with those in a worse situation, problem solved, sought support from friends and family.	Counted blessings, maintained optimism and hope, sought help from family and friends.
Comparisons	Incompatibility between carer and sexual partner roles	Between realism and idealism, comparing past to present and present to future, comparing reality to what might have been (worse)	Feel different to peers, comparisons with past and other caregivers and receivers	

Adjustment and adaptation: changing roles	Taking role of mother or carer rather than spouse,		Taking on new tasks, accepting a changed life path, reassessment of priorities	Moving from spousal relationship to carer relationship, taking on domestic role partner had in addition to own.
Expression of emotion/ suppression of emotion		Attempting to contain emotion, frustration particularly in front of care recipient, need to appear calm and strong	Focus on task orientated, pragmatic coping, suppress emotion	

Appendix H:

Epistemological position

Statement of Epistemological Position

Braun and Clarke (2006) make clear the importance of clearly stating the epistemological underpinnings of any thematic analysis research endeavour. The researcher took a critical realist position which allowed both the possibility of reflecting reality whilst also acknowledging the wider socio-economic and historical context that influenced that very reality.

This position stands between the extremes of constructionalism and essentialism and can be thought of as contextualist in flavour. This essentially means that knowledge is valid within a particular context. This epistemological position very much fits within a post modern Clinical Psychology framework whereby the intra personal and inter personal nestle within and interact with a broader contextual world.

Appendix I:

Characteristics of Research Participants

Pseudonym name of Participant	Age at time of interview	Age of partner at time of interview	Time since stroke	Length of relationship at time of interview	1 st marriage or 2 nd Marriage	Children of the partnership or of previous relationships	Occupation of participant caregiver
Jane Partner: :Jack	65	66	8 months	7 years co-habiting, 18 years total	2 nd marriage	Two grown up children each from previous marriage – never involved in this marriage	Retired teacher
Jennifer Partner: Jeff	65	66	6 years	42 years	1 st Marriage	Adult married son living nearby	Retired clerical assistant
Jillian Partner: Jim	73	75	8 years	28 years	2 nd marriage	Grown up children from previous relationship never involved in this marriage	Retired teacher
Joan Partner: Jonnie	73	78	14 years	56 years together, married 53 years	1 st marriage	Two adult daughters living nearby	Retired part- time cashier
June Partner: Jules	53	52	5 years	12 years together, cohabiting /married 11 years.	2 nd marriage	No children from either marriage, no step children	Clerical worker
Kath Partner: Karl	54	53	4 years	18 years, 15 cohabiting /married	2 nd marriage	2 school aged children of marriage and one young adult child of previous relationship – living at home	Professional grade civil servant

Appendix J:

Research Interview Schedule

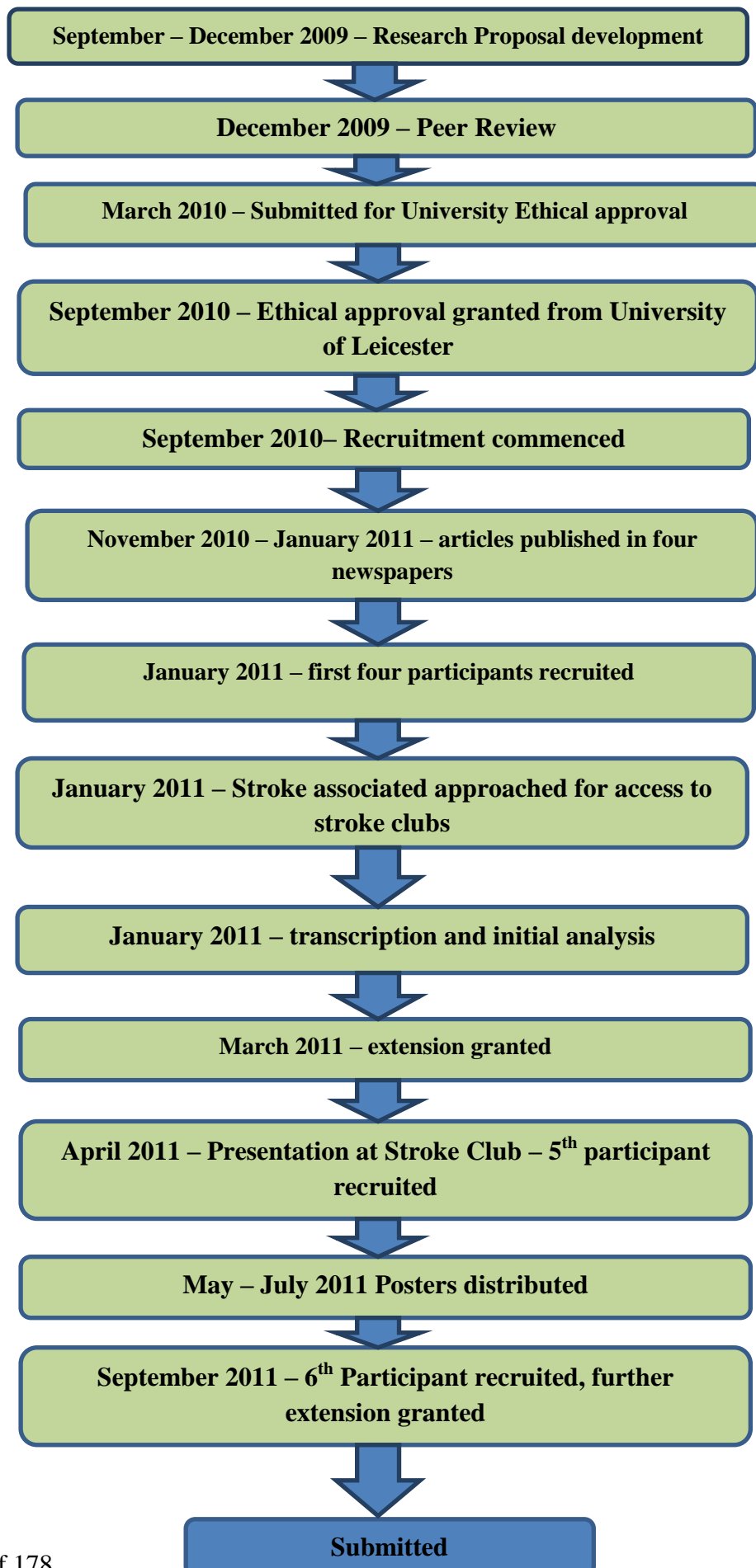
Interview Schedule

1. Can you tell me a little bit about you two as a couple?
 - a) How did you get together?
 - b) What did you enjoy about being together?
 - c) Did you spend much time apart?
 - d) How did you arrange who was responsible for different things in your relationship? E.g. finances, arranging holidays, cleaning, cooking, decorating, maintenance jobs.
 - e) Would you say that one of you was 'in charge' more than the other?
 - f) How close would you say you were as a couple?
 - g) How intimate do you feel you were together before the Stoke?
 - h) Can you tell me a lit bit about the type of personalities you feel you are? Are you very similar/different?
2. What was life generally like for you two before the Stroke?
 - a) Did you ever have times when your marriage/partnership was under a lot of strain?
 - b) Have you ever come close to separating?
3. How has your life changed sincehad his/her stroke
 - a) How has your life as a couple changed?
 - b) How close do you feel you are now? Has that changed?
 - c) In what ways has that changed?
 - d) Are you as intimate with each other as before or has this changed?
In what way has it changed?
4. What used to frustrate you or annoy you before.....had his/her stroke?
5. What frustrates you or annoys you now?
6. How do you deal with pressures of caring for
7. Do you seedifferently now to before?
8. Ifwere here what would they tell me about you two as a couple?
9. What wouldsay has changed?
10. What support do you get from other people?

Appendix K:

Research Chronology

CHRONOLOGY



Appendix L

Sources of support sheet

Sources of support sheet

Your GP: Your own family doctor can offer support and will be able to refer you to an NHS counsellor for talking therapy if you both think that it would be helpful.

The Samaritans: Sometimes just having someone to listen to you can be helpful.

The Samaritans are there to listen, day or night. Their confidential helpline is charged at a local call rate. **Tel 0845 909090.**

The Stroke Association: Provide information about Strokes and can put you in touch with local services. **Tel 0845 3033100**

Online support groups: These may offer an additional source of support.

www.behindthegray.net - Online support group for those whose lives have been affected by a subarachnoid haemorrhage or stroke; with articles, message boards and more.

www.strokesupportgroup.org - On-line stroke support forum for stroke information, advice, message board and chat on-line for all stroke survivor and stroke carers advice and support.

NB. Please remember that information and advice from online forums may be unreliable. You are advised to consult your Doctor for advice.

Appendix M

Ethical Approval

To: **TABATHA KON**

Subject: Ethical Application Ref: **twhk1-1733**

(Please quote this ref on all correspondence)

09/09/2010 11:45:13

Psychology

Project Title: **Life after Stroke: A psychological examination of the partner relationship**

Thank you for submitting your application which has been considered.

This study has been given ethical approval, subject to any conditions quoted in the attached notes.

Any significant departure from the programme of research as outlined in the application for research ethics approval (such as changes in methodological approach, large delays in commencement of research, additional forms of data collection or major expansions in sample size) must be reported to your Departmental Research Ethics Officer.

Approval is given on the understanding that the University Research Ethics Code of Practice and other research ethics guidelines and protocols will be complied with

- <http://www2.le.ac.uk/institution/committees/research-ethics/code-of-practice>

Appendix N

Press release

Partners of stroke victims in the XXXX area are being asked to help a new research project.

The study aims to look at how the stroke affects the relationship between the person who has it and their wives, husbands or partners. Previous research has tended to group all carers together, regardless of their relationship to the stroke victim.

Now the idea is to focus on how the stroke impacts on marital or equivalent relationships.

Twelve volunteers are requested to make themselves available for confidential interviews.

The information will then be analysed and used to help improve understanding in this under researched area.

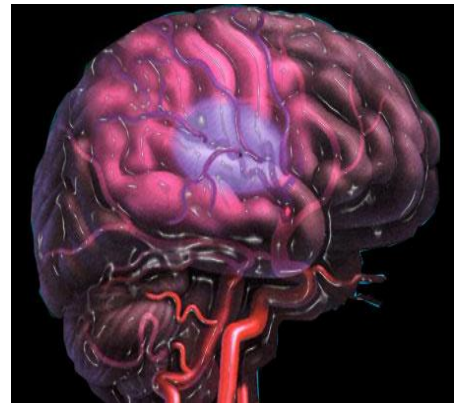
Strokes are one of the major causes of death and disability worldwide.

More than 150,000 people in the UK suffer their first stroke each year.

And of these, more than a third will sustain a degree of disability that requires ongoing care by a close family member or spouse.

Researcher Tabatha Kon, based in XXXX, said: "We hope people will come forward as this could help to shed light on the changing nature of the relationship between patients and their partners and give a greater understanding of the needs of carers."

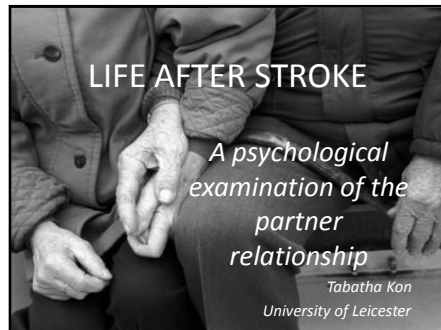
Volunteers are asked to call 0781 616 9457 in confidence



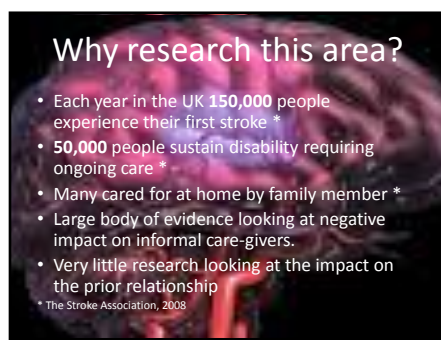
Appendix O:

Presentation slides

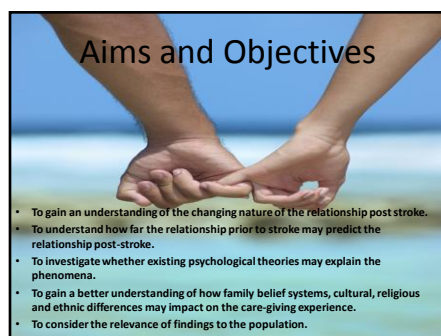
Slide 1



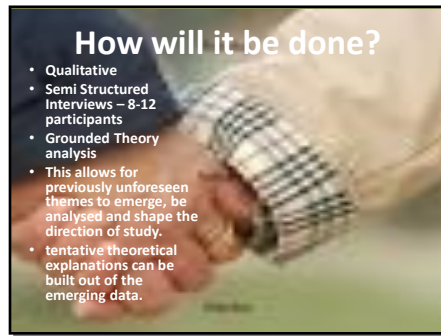
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Slide 3



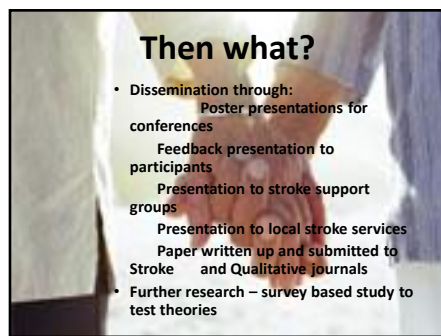
Slide 4



How will it be done?

- Qualitative
- Semi Structured Interviews – 8-12 participants
- Grounded Theory analysis
- This allows for previously unforeseen themes to emerge, be analysed and shape the direction of study.
- tentative theoretical explanations can be built out of the emerging data.

Slide 5



Then what?

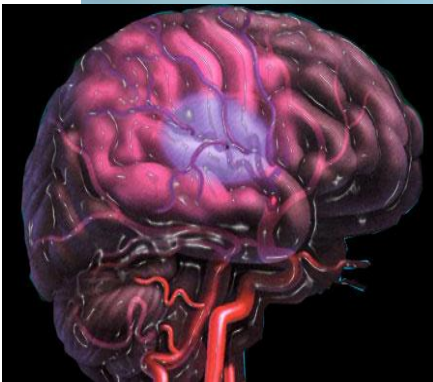
- Dissemination through:
 - Poster presentations for conferences
 - Feedback presentation to participants
 - Presentation to stroke support groups
 - Presentation to local stroke services
 - Paper written up and submitted to Stroke and Qualitative journals
- Further research – survey based study to test theories

Appendix P

Posters

Can you help with my research?

Research looking at the changing nature of partner relationships after one partner has a Stroke.



My name is Tabatha Kon. I am at the University of Leicester studying for a doctorate in clinical psychology. My studies include carrying out research and I am interested in finding out more about how relationships change when one partner has a stroke.

I would be very grateful if you would be willing to tell me about your experiences.

If you are interested in helping please call XXXXX or email twhk1@le.ac.uk for further information.

Appendix Q:

Participant Information

Participant Information Sheet

Life after Stroke: A psychological examination of the partner relationship

You are being invited to take part in a research study. Before you decide whether or not to take part you need to understand why the research is being done and what it will involve for you. Please take some time to read the following information carefully. You may wish to discuss the study with your partner or someone else before deciding to take part.

Why is this research important? Stroke is one of the major causes of death and disability in the UK and worldwide. In the UK 150,000 people each year will have their first stroke and of these more than a third will sustain a degree of disability that requires ongoing care (The Stroke Association, 2008). Many Survivors of Stroke, after a period in hospital will return home to be cared for by a close family member or spouse.

What does this research aim to do? This study aims to shed light on the changing relationship between partners post-stroke with a view to better understanding their needs.

Why have I been invited to take part? You have been asked to take part because your partner has experienced a stroke. Participation in this research is entirely voluntary.

What is involved in participating? The researcher, Tabatha Kon, will contact you to arrange a convenient time and place to visit you. She will want to ask you some questions about your experiences and hear your story. This will take approximately 60 minutes and will be audio recorded. After the interview the researcher will go away and transcribe the recording removing any identifiable details. You have the opportunity to see this transcript and comment on it if you like before it goes forward to be analysed.

What are the benefits of taking part? Taking part will help improve understanding about how relationships change after a partner has experienced a stroke. This knowledge may help professionals respond to the needs of couples post stroke more effectively. Talking through life events can be therapeutic even though the interview is not a therapy session. The researcher will also be able to offer advice on appropriate avenues of help and support if required.

What are the disadvantages of taking part? The only potential disadvantage envisaged is that talking about difficult events in your life may cause you to become upset. Despite this being unpleasant there is evidence that this talking through of difficult events can have a beneficial effect even when in a research interview. If you become distressed you can pause for a while or even stop the interview if you want to. The interviewer will be able to offer you contact details for sources of support.

What will happen to the information I give? Your personal information will be kept confidential and locked in a secure cabinet. The only people able to access this will be the researcher and her academic supervisor at The University of Leicester. You will have the opportunity to view the anonymised transcripts of your interview. To improve the quality of the research anonymised transcripts may be viewed by other qualitative researchers from within the Clinical Psychology department of The University of Leicester.

What happens if I change my mind about taking part? If you change your mind about taking part in the study you have the right to remove yourself and/or your data at any point during the research process without any negative consequence.

Who is funding this research? This research is funded by the University of Leicester.

Who should I contact if I want to find out more or want to make a complaint? Tabatha Kon is the lead researcher for this study. The easiest way to contact her is on **07816169457**. If you have any questions about the research but do not want to contact Tabatha Kon you can contact her academic supervisor, Mary O'Reilly. Contact details are as below.

Tabatha Kon Clinical Psychology Department University of Leicester 104 Regent Road Leicester LE1 7LT Tel: 0781 616 9457/ 0116 223 1639 Email: twhk1@leicester.ac.uk	Mary O' Reilly Clinical Psychologist/academic Tutor Clinical Psychology Department 104 Regent Road Leicester LE1 7LT Tel: 0116 223 1642 (private voicemail if not in) Email: mjo11@le.ac.uk
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Thank you for considering taking part in this study

Appendix R:

Consent form

Participant Consent Form

Title: Life after Stroke: A psychological examination of the partner relationship

Researcher: Tabatha Kon from the University of Leicester School of Psychology.

Purpose of data collection: To satisfy the research component of a DClinPsy

Details of Participation: This research aims to better understand how relationships change after one partner has a stroke.

Participants who agree to take part will be asked about their experiences in an interview conducted by the researcher. Interviews will last approximately an hour and can be conducted in the participant's home if the participant wishes.

All interviews will be audio recorded. The recording will then be transcribed removing identifying details before being analysed. Participants can request to view the anonymised transcripts to verify that they are both a true record of the conversation and that they are suitably anonymised before analysis.

All personal data will be securely stored and then destroyed after five years. Participants have the right to withdraw from the study at any time and may remove some or all of their data at any time without giving any reason. There will be no negative consequence of not taking part in or withdrawing from this study.

CONSENT STATEMENT

1. I understand that my participation is voluntary and that I may withdraw from the research at any time up until January 2011, without giving any reason.
2. I am aware of what my participation will involve.
3. My data are to be held confidentially and only Tabatha Kon and her supervisor Mary O'Reilly will have access to them.
4. My data will be kept in a locked filing cabinet for a period of five years after the appearance of any associated publications. Any personal information, e.g. names and contact details will be destroyed one year after completion of the study
5. In accordance with the requirements of some scientific journals and organisations, my coded data may be shared with other competent researchers. My coded data may also be used in other related studies. My name and other identifying details will not be shared with anyone.
6. The overall findings may be submitted for publication in a scientific journal, or presented at scientific conferences.
7. This study will take approximately fifteen months to complete.

8. I will be able to obtain general information about the results of this research by requesting a 'summary of research findings' on a separate form. I can also request to see a copy of my anonymised transcripts on the same form.

I am giving my consent for data to be used for the outlined purposes of the present study

All questions that I have about the research have been satisfactorily answered.

I agree to participate.

Participant's signature: _____

Participant's name (please print): _____

Date: _____

Please note that this form will be kept separately from your data

Appendix S:

Request form

Request Form

I would like the researcher to send me copies of my anonymised transcripts:

By email ☐ Please provide email.....OR

By post ☐ to the address we have for you.

I **do not** wish to receive copies of the transcribed interview ☐

At the end of the study a summary of the findings will be written. Would you like to be sent a copy?

Yes, to my email address.....☐ OR

Yes, to my postal address ☐ OR

No, I do not wish to receive a copy of the findings ☐

Participant's signature: _____

Participant's name (please print): _____

Date: _____

Please note that this form will be kept separately from your data

Appendix T:

Thematic map development

Fig. 1

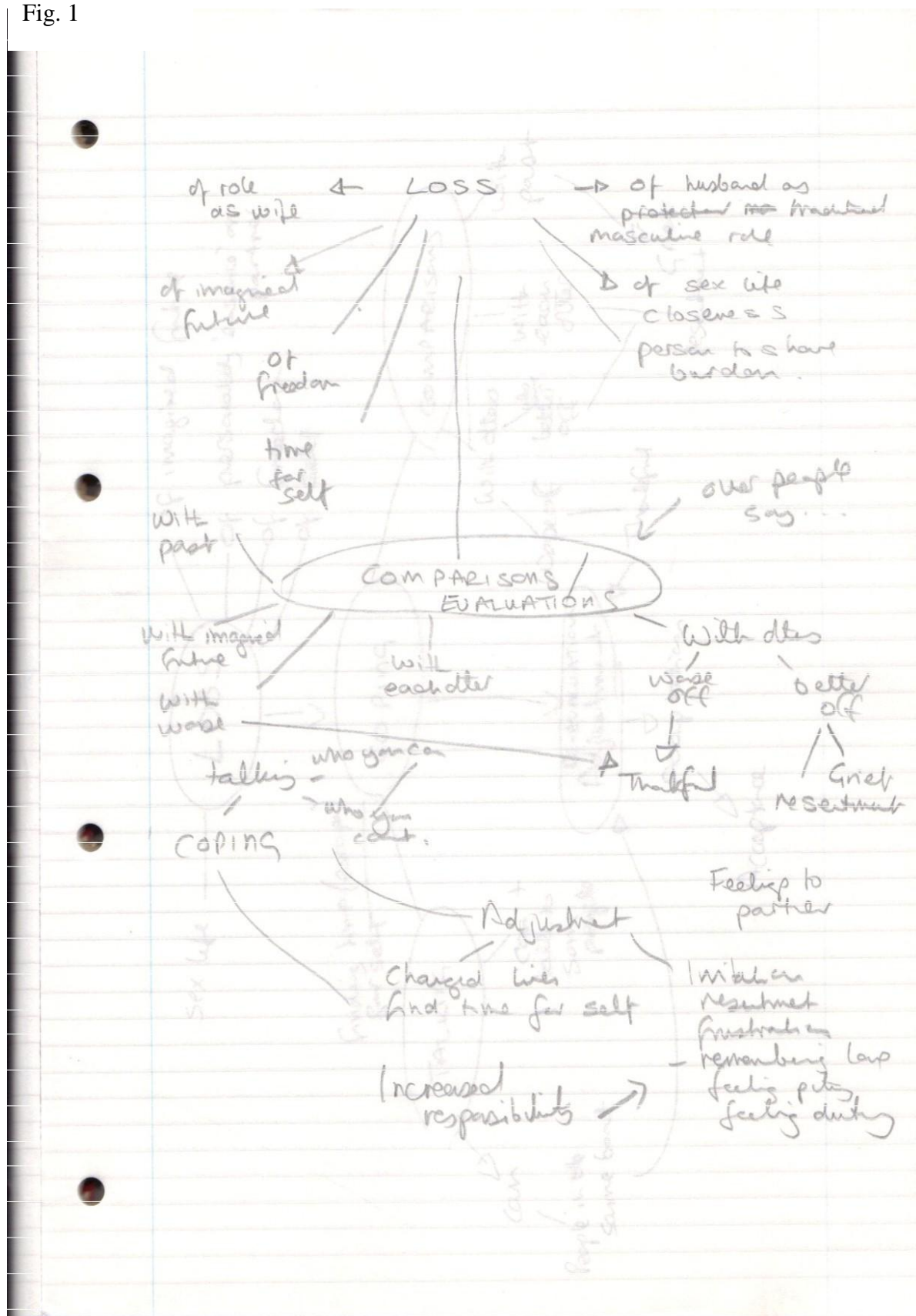


Fig. 2

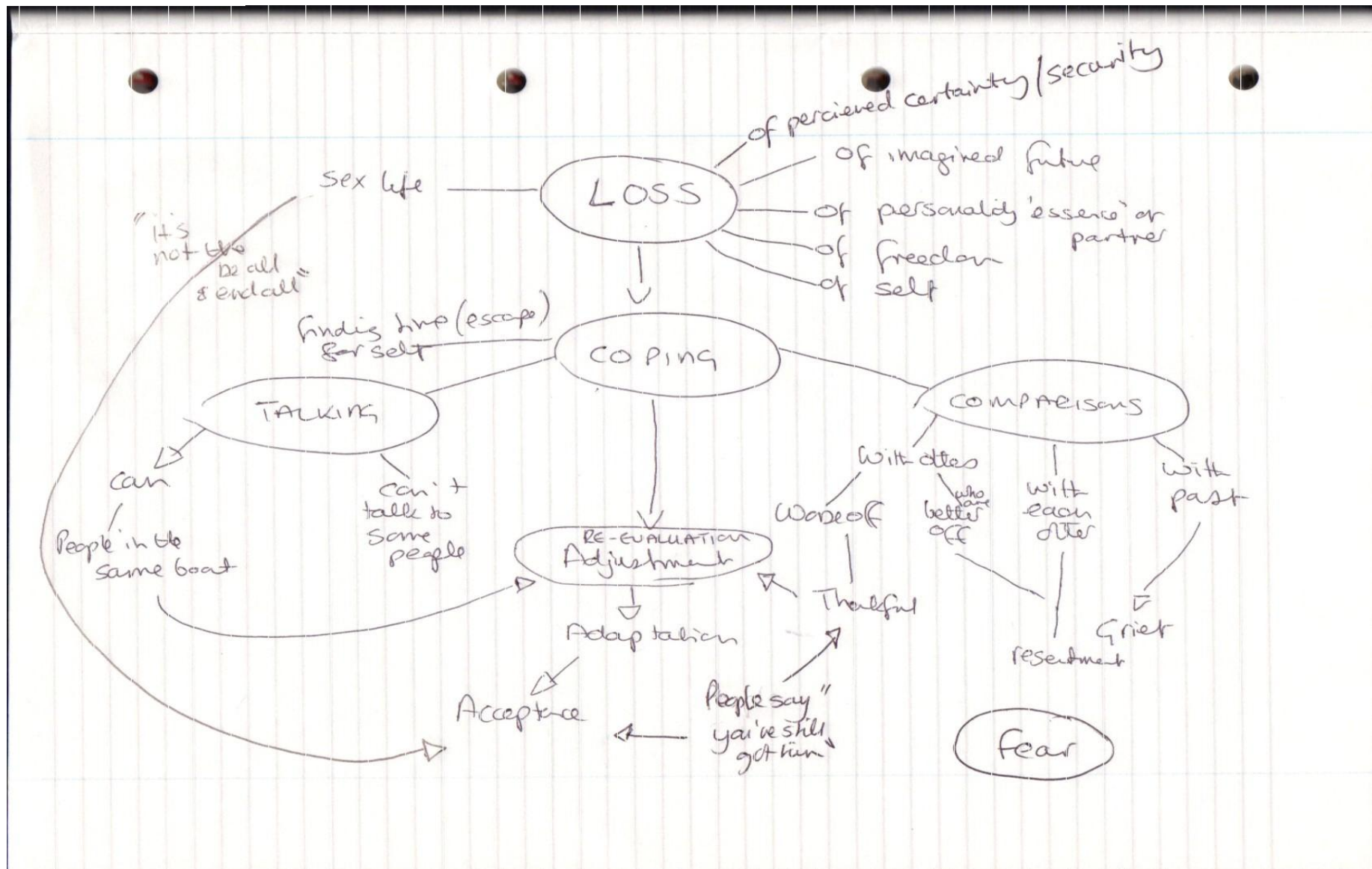


Fig. 3

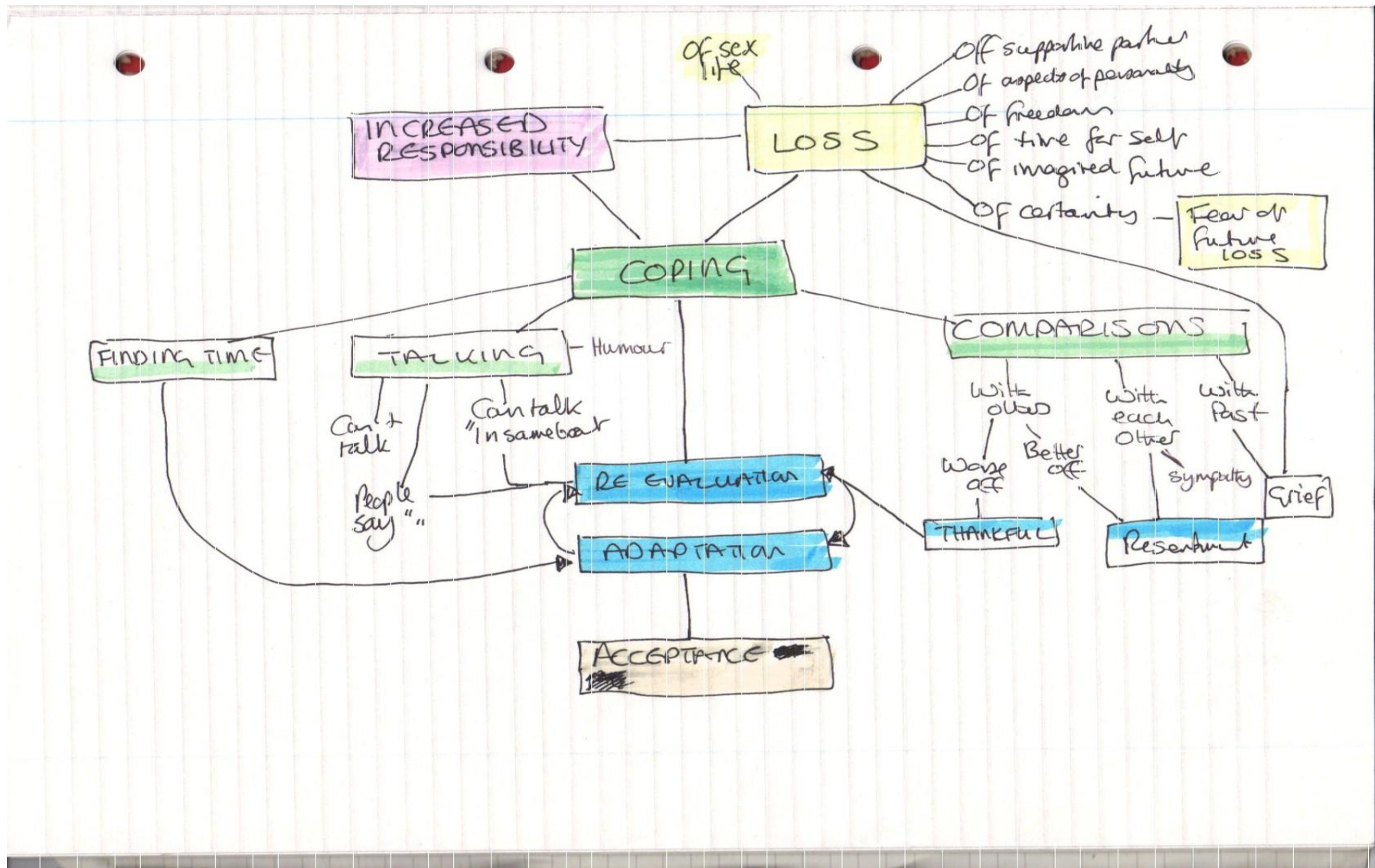


Fig. 4

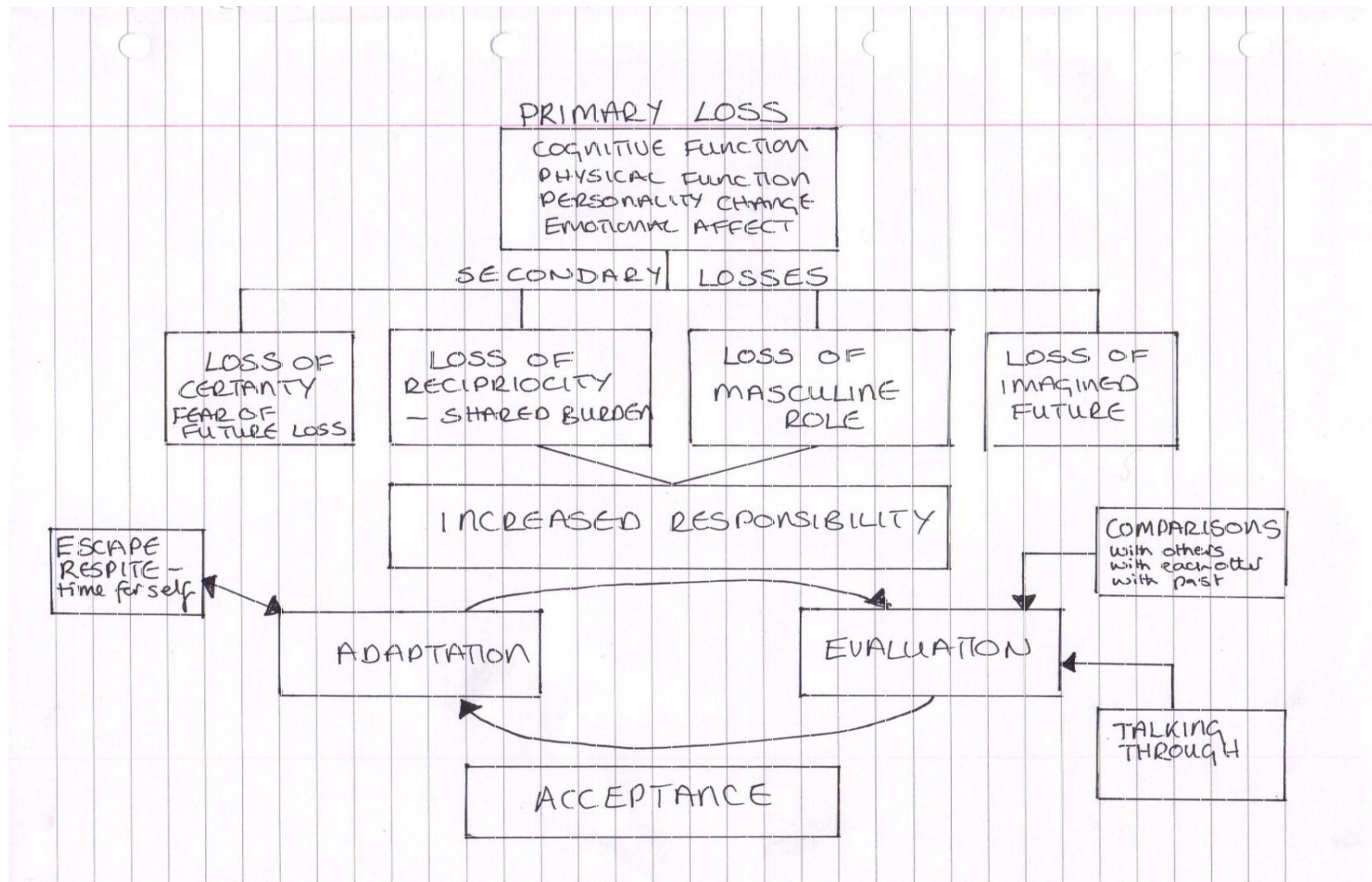
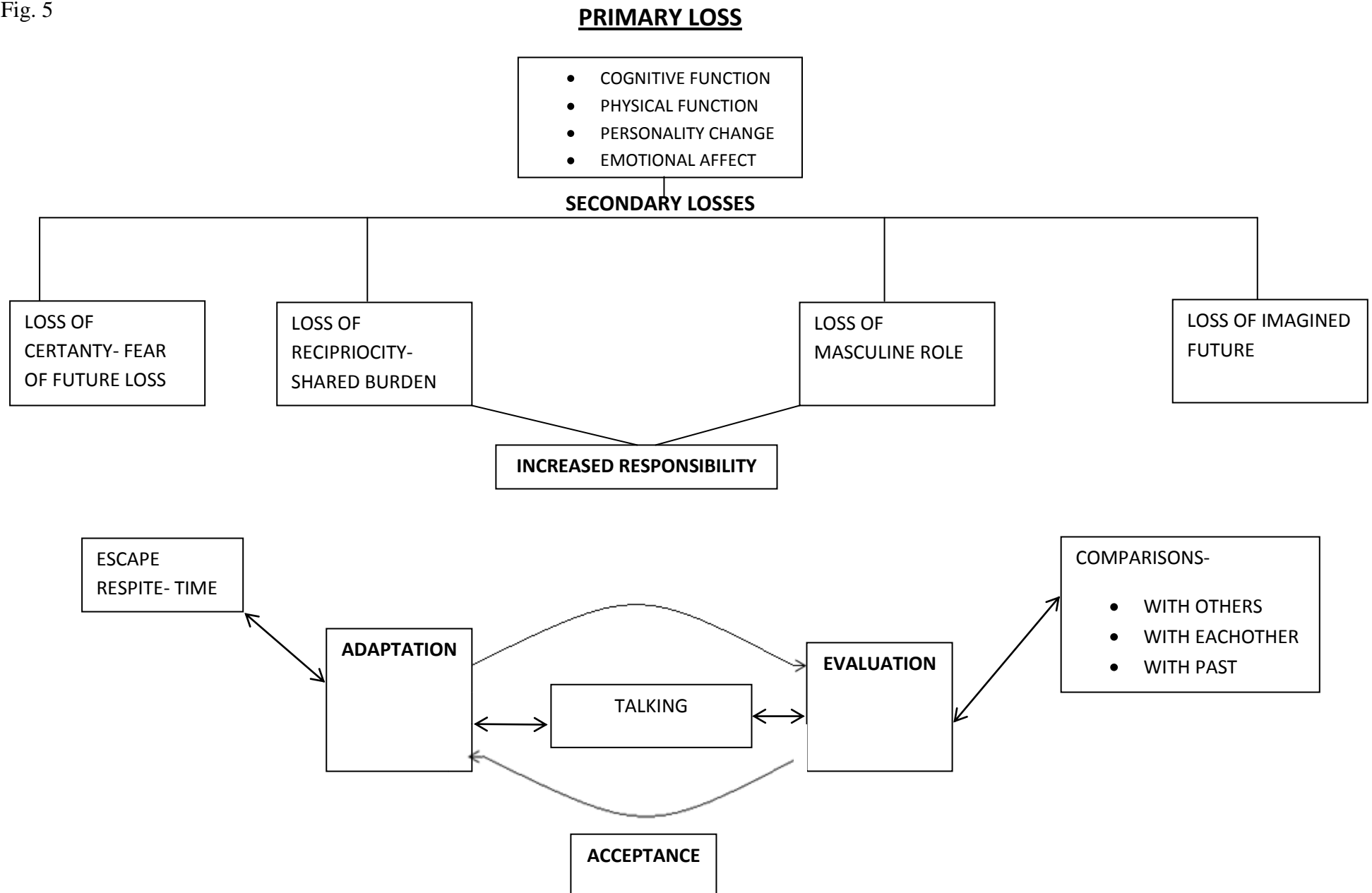


Fig. 5



Appendix U:

Dynamic Thematic Map

Fig. 6

