

A thesis submitted in partial fulfilment for the degree of
Clinical Psychology Doctorate.

VOLUME I

RESEARCH COMPONENT.

Literature Review and Research Paper

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Overview

This thesis is submitted in partial fulfilment for the degree of Clin.Psy.D from the School of Psychology, the University of Birmingham.

Volume I contains the research component of the thesis, which is made up of a literature review, an empirical paper, and an executive summary; the two main papers focus on the lived experiences of family caregivers of those with stroke. The first presents a narrative synthesis of the qualitative literature on the lived experience of family caregivers for those with stroke. The second, the empirical paper, uses qualitative methods to explore how caregivers reconcile the demands of care giving with their own life goals and the impact of this on their psychological well-being. It is intended that both pieces of work will be submitted to 'Disability and Rehabilitation' for publication (see appendix 1 for publication guidelines).

Volume II contains five clinical practice reports (CPRs) completed throughout the training course. CPR1 presents the formulation of a feeding behaviour difficulty in a two-year-old girl from both a behavioural and systemic perspective. CPR2 reports a small scale service evaluation of the inclusion of two new psycho-education modules into 'WATCH IT,' a childhood obesity prevention program. CPR3 presents a single-case experimental design of an analogue assessment of self-stimulation and self-injurious behaviours in a child with profound learning disabilities. CPR4 describes the case study of an 83 year old woman with depressive symptoms. Finally, CPR5, is represented in the form of an abstract outlining the case study of a women with low mood, low self-confidence and relationship difficulties.

For my ever supportive parents.

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**A NARRATIVE SYNTHESIS OF THE QUALITATIVE
LITERATURE ON THE LIVED EXPERIENCE OF FAMILY
CARERGIVERS FOR THOSE WITH STROKE.**

LITERATURE REVIEW

Abstract

This paper presents a narrative synthesis of the qualitative literature, published from 2004 to 2010, focussing on the experience of individuals' caregiving for those with stroke. The aim of the review was to 'pull together' (Noblit & Hare, 1988) the experiences of informal caregivers to provide a better understanding of the psychological issues they face, in an effort to improve the quality of life for both carers and patients. The review indentified a number of shared themes in the experiences of caregivers. These were separated into: 'on becoming a carer', 'being a carer', 'acknowledging what was lost', 'managing the caring role', and stroke providing 'an added element'. The review highlighted the continuing impact of the stroke event on caregivers and the iterative process of adjustment that caregivers appeared to move through in managing the significant changes brought about by stroke. The similarities between the findings of the current review and the findings from other caregiving groups are also discussed, for example, caregivers' descriptions of feelings of loss and uncertainty. The review highlights that whilst all individuals cope with caregiving in their own way there may be fundamental aspects common to the caregiving process.

Keywords: Qualitative, Review, Informal carers, Stroke.

Stroke is the third leading cause of mortality in the UK and the leading cause of complex disability, with over 300,000 individuals left with moderate to severe disabilities following stroke (Adamson, Beswick, & Ebrahim, 2004). Following discharge from hospital, those who have suffered a stroke can be left with significant cognitive and physical impairments and may require long-term care and support. This support is commonly provided by spouses and family members, who become informal carers¹ offering full-time care within the family home. Therefore, stroke not only impacts upon the individual but also on their immediate and extended families. The typically sudden onset of stroke means that families can suddenly find themselves in a caring role. The associated profound lifestyle changes have been shown to place carers at increased risk of psychological and emotional problems. As such, perceived caregiver burden has received a great deal of research attention (Anderson, Linto, & Stewart-Wynne, 1995; Forsberg-Wärleby, Möller, & Blomstrand, 2001; Han & Haley, 1999; Low, Payne, & Roderick, 1999; Wade, Legh-Smith, Langton, & Hewer, 1986). Research in this area has consistently found that family carers have a higher incidence of depression (Anderson et al., 1995; Carnwath & Johnson, 1987; Han & Haley, 1999) and anxiety (Macnamara, Gummoq, Goka, & Gregg, 1990; Wade et al., 1986) compared to the general population. Other factors predictive of caregiver burden and emotional distress have also been explored. Stroke severity and patient age, as well as perceived caregiving burden were found to be associated with depression in caregivers (Berg et al. 2005; Schulz, Tompkins, & Rau, 1988). Additionally stress, caregiver burden, quality of life, survivor functioning and social relationships have all been identified as predictors of caregiver emotional well-being (Draper & Brockelhurst, 2005; Franzen-Dahlin, Larson, Murray, Wredling & Billing, 2007; Han & Haley, 1999; Low et al., 1999; Ostwald, Bernal, Cron, & Godwin 2009; Rigby,

¹ 'Informal carers' refers to non-paid spouses, cohabiting partners, relatives and friends with primary responsibility for the caring needs of those who had suffered a stroke.

Gubitz, & Phillips, 2009; Schulz et al., 1988; Visser-Meilly, Post, van de Port, Mass, Forstberg-Warleby, & Lindeman, 2009).

To date, research investigating family carers in stroke has tended to primarily focus on levels of distress related to caregivers' objective and subjective burden. The relatively narrow focus of such research has led some authors to argue that a broader understanding of caregiver experience is needed (Low et al., 1999). Qualitative research is concerned with understanding social interactions, and the meanings of these for individuals through exploring the language used to describe them (Smith, 2004, p. 40). It therefore offers researchers the ability to gain an in-depth account of the experiences of individuals and examine these within the context in which they occurred (Crossley, 2000, p.46). Qualitative methods are well suited to add a 'rich and deeper' perspective to quantitative methods (Davis, 1991; Geertz, 1973, as cited in Smith, 2003, p.1) and for these reasons we will now turn our attention to qualitative research.

Qualitative research in stroke initially concentrated upon the experiences of those living with stroke, but has recently begun to pay increased attention to the experiences of family caregivers. However, despite the growing body research in this area, there remains little synthesis of these findings. Several authors (e.g. Booth, 2001; Sandelowski, Docherty & Emden, 1997) have suggested that a greater focus upon amalgamating qualitative research is needed. Syntheses are increasingly being used in clinical based decision making, as they can produce accessible overviews of the research in one area (Booth, 2001; Popay et al., 2005).

McKevitt, Redfern, Mold, and Wolfe (2003) conducted a review of qualitative literature on stroke, examining 95 articles, 11 of which dealt specifically with caregivers' experiences. Although carers were not primarily discussed, the research found that carers often feel under-prepared for the role and become isolated, with major changes to their previous lifestyles

(McKevitt et al., 2003). This was supported by Smith, Lawrence, Kerr, and Lees (2004) who found that caregivers did not feel adequately prepared to provide care. They also discussed ongoing anxieties, for example anxieties of stroke reoccurrence and their ability to provide long-term care. O'Connell and Baker (2004) found uncertainty to be a major theme of caregivers' experience.

Greenwood, Mackenzie, Cloud and Wilson (2008) produced a systematic review, examining the informal experiences of caregivers. The paper provided a brief summary of studies which examined solely caregiver experiences, and was a sister paper to an earlier qualitative review of stroke survivors experiences. The review included 17 articles from 1996-2006, and provided a systematic account of the qualitative research up to 2004. The findings highlighted the emotional and psychological impact of care giving. The main challenges identified by caregivers were the need for information and training (specific to their survivors' needs), as well as information on financial rights and health information. Emotional challenges were also highlighted, specifically, caregiver distress, the need for support, and feelings of being undervalued, trapped, and the impact of the ongoing survivors' dependence on the caregiver. In addition to the findings of previous quantitative reviews, the paper also highlighted major role and relationship changes, such as having to leave paid employment, the process of adjustment to the care giving role and taking on domestic roles previously shared with their partner. Caregiver coping strategies were also identified such as taking one- day at a time. Few satisfactions were spontaneously discussed by participants. Where positive changes were identified, these included relationship growth, and reassessing what was important. The authors acknowledged that the review did not provide an exhaustive account of the findings from the papers, instead providing an overview of those felt most relevant.

This review was the first to bring together qualitative research focussing solely on the experience of caregivers of stroke. Since this paper was published there have been a series of qualitative studies which have added to this expanding literature. In particular there has been a growth in the use of different methodologies e.g. Interpretative Phenomenological Analysis (IPA) and this has impacted upon the levels of authors' engagement with the data. In addition there has also been a shift towards a more positive focus on caregiver coping, with increasing numbers of studies examining caregiver difference.

Rationale

Therefore, the aim of the current review is to build on the previous qualitative review of Greenwood et al. (2008), including research from 2004-2010. to produce a narrative account of the experiences of those care giving for those with stroke. It is hoped that bringing together the qualitative research will provide a broader understanding of the psychological issues faced by carers in an effort to improve the quality of life for both carers and patients. Such work may also be useful to professionals in guiding service development and facilitating relevant and considered care decisions. Additionally, incorporating these qualitative findings into an already extensive quantitative body of research may suggest worthwhile avenues for future research.

Method

Synthesising Qualitative Literature

One of the possible reasons for the modest number of papers synthesising qualitative research is that methods on how to integrate qualitative data are still emerging. Two major barriers to the integration of qualitative studies are the practical difficulties in combining different philosophical methodologies and epistemologies (Murphy, 1998, Popay et al., 1998). The most common method of reviewing qualitative research is meta-synthesis, also known as meta-ethnography (Noblit & Hare, 1988). An alternative approach is narrative synthesis, which can be used to integrate both quantitative and qualitative research. There have been a growing number of examples of both of these approaches (e.g. Arai et al., 2007; Atkins et al., 2008). However, because narrative synthesis is becoming increasingly used for policy development, formal guidelines have now been produced (Popay et al., 2006; Rogers et al., 2009). Meta-synthesis differs from a narrative synthesis in that it develops a new interpretation of the data by engaging with the data from the primary studies. In comparison, a narrative synthesis does not move beyond the extraction and reconstruction of the initial concepts (Fingeld, 2003). Collins and Fauser (2005) suggest that narrative syntheses are best suited to cover comprehensive topics as they can theoretically handle larger sets of data, bringing together the similarities and differences from the main findings of work (Sandelowski, Docherty, Emden, 1997). In contrast meta-syntheses are typically conducted with small numbers of studies (below 10) (Sandelowski & Barraso, 2003). It was therefore decided to conduct a narrative synthesis of the qualitative research, to produce a coherent narrative of qualitative work thus far.

The synthesis followed guidelines set out by the Economic and Social Research Council (Popay et al., 2005). Popay et al. (2006) emphasised that it is the author's duty to provide a

detailed outline of this process; therefore a step by step account will be given. It is hoped that by giving a clear account of the process the reader can then judge for themselves the credibility of the claims being made (Collins & Fauser, 2005, p. 103).

Search strategy

A thorough search of the literature, using the following on-line data-bases was made: - PsycINFO, Medline, CINAHL, EMBASE. The search was limited to journal articles from the period 2004 to 2010, building upon the previous review by Greenwood et al. (2008). Each data-base was searched independently, to allow for differences in indexing, using the keywords: 'caregiver', 'stroke', and 'qualitative research.' Terms were initially mapped to the thesaurus to maximise the scope of the search. However, in order to allow for omissions, synonyms of the key terms were also searched (for example, using free text searchers e.g. caregiver*, carer*, informal carer* etc) as advocated by Dixon-Wood et al. (2006). Articles were only included if English language translations were available.

Inclusion Criteria

As the review aimed to synthesise the current qualitative literature, studies were included if they were i) peer reviewed, ii) available in English, iii) dealt exclusively with data from informal caregivers, iv) included carers' own words and an interpretation of the meaning of these experiences was presented. Papers using quantitative methods, or focusing on caregiver intervention, physical measures and service development were omitted. Of the 250 papers identified a total of 28 met the inclusion criteria (see table two). A further review of the abstracts excluded a further 7, and therefore a total of 21 articles were included.

Study	N.	Aim of study	Epistemological position	Participants	Setting and Methods	Themes found
Cao et al., 2010 (Canada)	10	Explore perspectives f caregivers of persons with stroke with respect to their own physical activity 1)ways caring affects own activity 2)preferences, needs and interests	Epistemological position: Not given Data analysis: Constant comparative method	Consecutive Primary carers 10 women 45-73 years, (majority 60-70yrs) 2-12 years caring role All wives	Past or present attendee of a stroke exercise class rehabilitation unit Semi-structured Interviews ~ 1 hour	Change in role Change in activity Barriers to activity and health Change in Meaning of activity
Strudwick & Morris, 2010 (UK)		To explore the experiences of African-Caribbean informal stroke carers in the UK	Epistemological position: Not given Data analysis: Thematic analysis (Braun & Clarke, 2006)	African-Caribbean Carers Principal carer min 6 months 1 man, 8 women 30-72 years (mean=62) spouse, 1 partner, 2 daughter 1 niece	Non-statutory organisations Semi-structured Interviews conducted in participants' homes 40-80 mins.	Trauma, Quality of care, Support , Physical Understanding indiv. needs, Battle, Independence from services, Faith in God, Family Ties, Avoiding institutional care.
Greenwood at al. 2009 (UK)	31	To explore the experiences of informal stroke carers discharge to 3 months	Epistemological position: "Draws on ethnography and identification of recurrent themes" Data analysis: Ongoing analysis resulting in themes	Purposive sample Informal carers No gender information 77% > 66 years 58% White British 71% cohabiting	Acute and Stroke Rehab wards. Open-ended Interviews conducted at Discharge, 1 and 3 mnth. Initial interview in hospital side room/ subsequent interviews at home. 30-90mins	Reduced control and unpredictability Reduced Autonomy, Choice and control Strategies for increasing autonomy (optimisation, selection, compensation, help from others, negotiation), benefits of reliance on others
Backstrom & Sundin, 2009 (Sweden)	9	To explore the experiences of being a middle-aged close relative of a person who has suffered a stroke	Epistemological position: Not given Data analysis: Thematic latent content analysis (Patton, 2002)	Consecutive sample Middle-aged relatives First time stroke 2 men, 7 women 41-65 years (mean 55 years) Spouse, 1 non-cohabiting partner, 2 mothers 7 employed, 1 retired, 1 job seeker	Rehabilitation Clinic Narrative Interviews were conducted 1, 3, 12 months post-discharge. 50-80 mins.	Intertwined and conflict turning point Inevitability of altered future Adjusting
Green & King 2009 (Canada)	26	Male patients with minor stroke and their wife-caregivers perceptions of factors affecting quality of life and caregiver strain first year post stroke.	Epistemological position: Not given Data analysis: Content analysis	Minor stroke 26 Married patient-wife dyads Carers 39-63 years (mean=63.9) Average year married 1-55 (mean=29.7 years)	Part of larger descriptive study 1 month post-discharge assessment 2 Semi-structured Telephone Interviews were conducted 1,2,3,6,9 and 12 months	Being vulnerable, hyper-vigilance Realization, loss and changing self and relationships

Study	N.	Aim of study	Epistemological position	Participants	Setting and Methods	Themes found
Greenwood et al. 2009 (UK)	31	To investigate the experiences of informal carers of stroke survivors over time.	Epistemological position: Not given Data analysis: Ongoing analysis resulting in themes	Purposive sample Informal carers 9 men, 22 women 26% >65 58% White British 16 spouse, 13 child, 2 sibling	Acute and Stroke Rehab wards. Open-ended Interviews conducted at Discharge, 1 and 3mth. Initial interview in hospital side room/ subsequent interviews at home. 30-90mins	Central Theme of uncertainty: Adopting routines and strategies Absolute and relative positives Questioning the future
Buschenfeld et al. 2009 (UK)	7	To explore the experiences of partners of young stroke survivors (under 60 years)	Epistemological position: Not given Data analysis: Interpretative Phenomenological Analysis	Purposive sample Informal Young carers (<60) 4 men, 3 women 49-62 years (Mean=58.8) All white British and partners Relationship length 13-35 years Care recipient hospitalised 2-8 months 2-7 years post-stroke	Community stroke organisations Semi-structured Interviews were conducted in participants' homes ~ 90 mins.	Adjustment – changed lives Enduring effects on self Coping
Johansson & Johansson, 2009 (Sweden)	9	To describe relatives experiences of their next of kins eating and swallowing disorders	Epistemological position: Not given Data analysis: A constant comparative analysis approach was used to indentify themes	Snowball sampling 1 male, 8 women 57-79 years (mean=64.1) 7 spouse, 2 parent Length of time caring 2.5-15yrs	Community centre for caregivers Semi-structured Interviews were conducted at community centre or participant's home. 45-90 mins	Provider for health and well-being Sensitive attitudes about next of kin's changed appearance Adaptation to the new situation
Smith et al., 2008 (Canada)	9	To learn about family experiences and support needs during the rehabilitation process to inform program development	Epistemological position: Not given Data analysis: Content analysis	Consecutive sample Informal family caregivers young carers (<55 yrs) Mean age=45.6 years 2 men, 3 women 4 older carers (>55 yrs) Mean age=68.8 years 1 male, 3 women spouse, 2 children, 1 sibling 9 weeks – 3 months since stroke	Inpatient and Outpatient Clinics Rehabilitation Unit Semi-structured Interviews were conducted in private room at hospital. ~40-60 mins.	Age-related themes Younger carers: Informational support and training needs Criticism of health care system and staff Older carers: A positive outlook Common themes: Concern re: further stroke Rehabilitation was positive and motivating for carers Role of family and friends – support
Pierce et al, 2008 (USA)	36	Not given	Epistemological position: Not given Data analysis: Secondary content analysis of emails for narrative content of spirituality	Those taking part in e-mail discussion group during first year of caring for stroke survivor 31-80 years, (30.6% 51-60yrs) 69.4% women 86.1% Caucasian 56% employed	Rehabilitation programmes Informal carers using 'Caretalk' email discussion group connects caregivers with other caregivers and nurse 24 hours a day	Feeling the presence of a greater power Practicing rituals (routines) Being one with nature Interacting with family and friends

Study	N.	Aim of study	Epistemological position	Participants	Setting and Methods	Themes found
Wallengren et al., 2008 (Sweden)	16	To explore the meaning of going from being just a relative to gradually becoming a relative of stroke in first few weeks post-stroke	Epistemological position: Phenomenological Hermeneutic (Ricoeur, 1976) Data analysis: Phenomenological Hermeneutic Lindseth & Norberg, 2001	Caring for First time stroke First 4 weeks post stroke 13 men, 3 women 30-79 years (Mean=58) spouse, 8 daughter, 1 daughter in law, 1 friend 6 retired, 7 employed, 3 other	2 stroke centres Open-ended interviews were conducted. 10 in hospital, 6 at their home. 30-90 mins.	Being in chaos Searching for order in the chaos Turning point, linked to own strengths, stability
Bocchi & Angelo, 2008, (Brazil)	10	To understand the experiences of family caregivers for CVA patients with regard to social support during their rehabilitation process at home	Epistemological position: Symbolic interactionism Data analysis: Grounded Theory	Informal caregiver 1 male, 9 women 36-69 years 3 months to 5 years caring spouse, 2 daughter, 2 mothers	University Teaching Hospitals Physical Therapy Service Open ended Interviews conducted at participants' home	Assuming care with support Assuming care without support
Brittain & Shaw, 2007 (UK)	20	To examine the notion of 'dirty work' and 'unbound' bodies in the role of informal carers	Epistemological position: Not given Data analysis: Constant comparative method and deviant case analysis (Glaser, 1965)	Informal carers 7 male, 13 women 51-86 years 7 months-18 years caring	Stroke Association Family Support Officer & Medical Research Incontinence study Semi-structured Interviews conducted in participant's home 45-90mins	Acceptably continent Dealing with bodywork and dirty work Changing geography of care/home environment
Coombs 2007 (Canada)	8	To explore what it is like for older caregivers to care for a spouse who has survived a stroke.	Epistemological position: Phenomenological approach (van Manen, 1997). Data analysis: Saturation of emerging themes used to guide analysis	Caregiving Spouses Minimum 50 years old Caring for minimum one year 3 men, 5 female 57-81 years (mean=65.5yrs) 1.5 to 5yrs caring (mean=3.4yrs)	2 Rehabilitation units Semi-structured Interviews 7 interviews conducted at participant's home, one alternative location. 60-120 minutes	Experiencing a profound sense of loss Adjusting to a new relationship with a spouse Taking on new responsibilities Feeling the demands of caregiving Having to depend on the support of others Maintaining hope and optimism
White et al., 2007 (Canada)	14	To explore caregivers perceptions regarding barriers and facilitators to undertaking the post-stroke caregiving role	Epistemological position: Qualitative thematic study Data analysis: Content analysis procedure	Informal caregiver 7 men, 7 women Majority over 50 years Less than 6-12 months caring	University Teaching Hospitals Focus groups (4-6 carers per group) Conference room outside hospital 2-2hrs 30 mins.	Lack of collaboration vs. Coordination of care Intensity of caregiving vs. Progress to normalcy Negative impact on the caregiver vs. mastery Lack of community support vs. Accessible resources
Silva- Smith, 2007, (USA)	12	To described the process associated with preparing for and beginning a new caregiving role following a family members stroke	Epistemological position: Grounded theory study Data analysis: Constant comparative method Nvivo qualitative analysis software programme	Carer for First time stroke Purposive, consecutive sample 3 men, 9 women 38 to 78 (mean 58) years African American 6 Caucasian 4 wives, 3 husbands, 2 sisters, one mother, daughter, fiancée	3 Inpatient Rehabilitation Unit Open ended Interviews were conducted pre discharge and 4 weeks post discharge Interviews NO info on interview length /setting	Restructuring Life: Managing multiple roles Relationships with stroke survivors Future hopes and plans Time to self

Study	N.	Aim of study	Epistemological position	Participants	Setting and Methods	Themes found
Pierce et al., 2007 (USA)	73	This descriptive study examined problems and successes of carers in first year of caring	Epistemological position: Not given Data analysis: Content analysis QSRN5-27 qualitative analysis software programme	Informal carers 18 men, 55 women Average age 55 years 34 wives, 13 husbands, 13 daughters, 1 son and 9 relatives	Rehabilitation Units Interviews conducted over 12 month Bi-monthly telephone interviews Each call lasted ~20 mins. 2,455 problems 2,687 successes	Being frustrated in day to day situations Feeling inadequate and turning to others for help Struggling and Looking for normal Making it through and striving for independence Doing things together and seeing accomplishments Reaching a new sense of normal and finding balance
Pierce et al., 2006 (USA)	9	Analysis of qualitative data from the intervention project that used rigorous protocol to examine 68 problems	Epistemological position: Not given Data analysis: Content analysis	Informal carers men, 4 women 51-68 years (Mean=60) 89% White Husbands, Wives and Adult Children Numbers not given	Rehabilitation Units Pilot study for 'CareWeb' Interviews conducted over 3 months Bi-monthly telephone interviews Each call lasted ~20 mins.	No problem response 20.93% responses Having independence issues Dealing with emotions Living with physical limitations Managing comorbid conditions Balancing it all Participating in therapy Having sleep issues
King & Semik, 2006, (USA)	93	To identify the most difficult times, unmet needs and advice of caregivers during the first 2 years of caregiving. *Mixed Methods	Epistemological position: Not given Data analysis: Content analysis	Consecutive sample First stroke cares Women (64%) Average age 56.7 years White (75%) Married (89%)	Rehabilitation Units Semi-structured questions No further information	Uncertainty, new responsibilities, impairments Lack of confidence, information and skills Unmet needs, preparing for caregiving, enhancing the survivors emotional and physical functioning, sustaining the self and the family
Pettersson et al., 2005 (Sweden)	12	To explore how spouses of persons with disability following stroke described their experiences regarding assistive devices in everyday life	Epistemological position: Phenomenological 'lifeworld' Approach Data analysis: Phenomenological approach (van Manen, 1997).	Spouse of persons with stroke 2 men, 10 women 36-80 years (mean = 75 yrs) 10 retired	Recruited from previous study (n=22) One year post stroke Semi-structured Interviews conducted at participants' home. ~ 1 hr.	Lived body Lived space Lived Time Lived Human Relation
Hunt & Smith, 2004 (UK)	4	To explore the experiences of members of families who are involved as carers of stroke survivors before patients return home	Epistemological position: Phenomenological 'lifeworld' Approach Data analysis: Interpretative Phenomenological analysis	Criterion sample Carer of individuals with stroke still on rehabilitation ward 1 man, 3 women 38-68 years (mean = 46yrs) 2 spouses, 2 daughters	Rehabilitation ward Semi-structured Interviews were conducted in a private area on the ward. ~45 mins.	Uncertainty Personal Impact Strength in Relationships

	<u>PsychInfo</u>	<u>Medline</u>	<u>EMBASE</u>	<u>CINAHL</u>	<u>TOTAL</u>
Hits from database	58	119	116	149	442
Limits					
Publication Year 2003-2010, Peer reviewed, English	29	84	59	78	250
Exclusions					
Duplicates between databases		15	36	63	114
Not focused on caregiver's experience	5	8	4	2	19
Quantitative	3	21	5	2	31
Mixed methods		2			2
Physical Health Interventions	3	8	9		20
Intervention/service related	8	11	1	5	25
Failure to meet inclusion criteria for other criteria	1	5	3	2	11
Total Papers remaining	9	14	1	4	28

Table 2: Literature Database Search Result

There was some deliberation over what constituted 'true' qualitative research. However, Sandelowski and Barroso (2003) argued that removing papers may exclude potentially important findings. Therefore it was decided to use an inclusive policy, whereby papers that had made effort to analyse and interpret caregivers' experiences were included in the review. Papers that contributed to the scope of the review were also retained. These included one paper that interviewed carers and stroke survivor dyads where the data from each was discussed separately (Green & King, 2009). Other papers included: one paper exploring caregiver experiences and issues of ethnicity (Strudwick & Morris, 2009) and three that focused on specific health-related topics; incontinence, eating difficulties and assistive devices (Brittain & Shaw, 2007; Johansson & Johansson, 2009; Pettersson, Berndtsson, Appelros, & Ahlstrom, 2005). To help the reader to determine the quality of the review a broad assessment of the quality of the papers was conducted.

Quality appraisal

The quality of the papers was assessed using criteria set out by Mays and Pope (2000) and Popay et al. (2006). These criteria were decided upon due to their transparency and ability to be applied to a wide range of qualitative methods. The credibility of papers was rated according to

whether : i) they provided a clear account of their data collection, ii) it was clear how the analysis was conducted and conclusions were drawn iii) if authors had acknowledged their influence in the process of interpretation, iv) if deviant cases and exceptions were discussed. The relevance of the included papers was acknowledged if authors had included adequate information about the participants and setting of the data. This does not refer to their direct transferability to other populations and settings but instead findings in the context of the existing research.

Study	Credibility:				Relevance			Score
	Data collection	Reflexivity	Negative cases	Analysis	Fair dealing	Transfer-ability	General-isability	
Cao et al., 2010 (Canada)	*	*			*	*	*	5/7
Strudwick & Morris, 2010 (UK)	*	*	*	*	*	*	*	7/7
Greenwood et al, 2009 (UK)	*	*		*		*	*	5/7
Backstrom & Sudin, 2009 (Sweden) +	*	*				*	*	4/7
Green & King, 2009 (Canada) +	*	*			*	*	*	5/7
Greenwood et al., 2009 (UK)	*	*	*	*	*	*	*	7/7
Buschenfeld et al., 2009 (UK)	*	*		*	*	*	*	6/7
Johansson & Johnansson, 2009(Sweden)	*	*	*			*	*	5/7
Smith et al, 2008 (Canada) +	*	*			*	*	*	5/7
Pierce et al., 2008 (USA) +	*	*			*	*	*	5/7
Wallengren et al.2008 (Sweden)	*	*		*		*	*	5/7
Bocchi & Angelo, 2008 (Brazil)	*					*	*	4/7
Brittain & Shaw, 2007 (UK)	*	*		*		*	*	5/7
Coombs, 2007 (Canada)	*	*				*	*	4/7
White et al.,2007 (Canada)	*	*				*	*	4/7
Silva-Smith, 2007 (USA)	*	*		*	*	*	*	6/7
Pierce at al. 2007 (USA) +	*	*					*	3/7
Pierce at al., 2006 (USA) +	*	*					*	3/7
King & Semik, 2006 (USA) +	*	*				*	*	4/7
Pettersson et al., 2005 (Sweden)	*	*	*	*	*	*	*	7/7
Hunt & Smith, 2004 (UK)	*	*	*	*	*	*	*	7/7

Table 3: Quality Appraisal (+ indicates those studies using content analysis)

The above table (Table 4) summarizes the ratings of credibility and relevance for the reviewed papers. The quality of the studies varied widely with only four of the 21 studies fulfilling all criteria and seven meeting four of the measures or below. Those studies which scored less well were those which engaged less closely with the data, for example, those using content analysis. These papers emphasised the commonalities rather than the contradictions among themes, therefore making deviant cases less apparent, and are indicated in Table 3. However, these studies were retained with the aim of producing a comprehensive review.

Data synthesis

A preliminary summary table was produced collating the findings from each study. The table consisted of four columns; 1) the final themes, 2) the supporting quotes alongside these, 3) any related author's discussion points from the original paper and 4) a space for the main researcher to record additional things of interest (for worked example see Table 5). An entry was included for each of the papers; however, this information was not available for all cases therefore producing sparser accounts for some studies (see appendix 2 for the preliminary synthesis table for all studies).

Study	Primary Themes	Quote	Authors Notes	Notes expansion
Backstrom & Sundin, 2009 (Sweden)	Becoming reconciled to a changed way of life: Adjusting to changed way of life	"In some way, I'm doing well. At the same time it's almost just as tough. Because the more..the time passes, and the more you realise that thing won't, you're being forced to realize that things will not be the waythey were. No matter how much you wish they were"	Coming to terms with a new way of living, adjustment, security, emotional balance and sense of relief, no control, accept, learn and integrate, forced into adaption and restructuring. Abandoned idea and everything could go back to the way life had been.	Adjusting to changed way of life Coming to terms with a new way of living, adjustment, security, emotional balance and sense of relief, no control, accept, learn and integrate, forced into adaption and restructuring.

Table 4: Preliminary synthesis – (extract from appendix 2)

The main author then began a process of engaging with the data through reading and re-reading the initial themes. The final themes were examined for any fundamental similarities to provide a higher level of abstraction. Key concepts were noted and grouped together (e.g. ‘adjusting to changed way of life’ (Backstrom & Sundin, 2009) and ‘realisation’ (Green & King 2009). A list of similar and deviant themes across the studies was produced and over-arching concepts were developed into sub-ordinate and super-ordinate themes. Where appropriate the terminology described by each of the studies was used in developing over-arching terms to describe the concepts discussed in the papers. This process shares similarities with grounded theory techniques, specifically coding the data and identifying shared concepts (Glasser, 1992). Papers discussing similar themes were then grouped together as evidence for that particular, an excerpt from this table is presented, see Table 6 below (for full table see appendix 3).

Super-ordinate themes	Studies supporting themes
Adjusting/redefining goals hopes and plans	Backstrom, Silva- Smith, Green & King Buschenfeld, Pettersson, Coombs, Wallengren

Table 5: Table of supporting studies –(extract from appendix 3)

The synthesis was further developed using a ‘working map’ to develop a plausible account of caregivers’ experiences. This involved re-ordering the concepts to develop a line of best fit. The credibility of these emergent themes was discussed at each stage with my project supervisor to improve the trustworthiness of the conclusions found. Themes were also discussed with peers who were familiar with qualitative research methodology. To enable the reader to assess the credibility of the process, the final themes will be presented alongside verbatim quotations taken from the original papers.

Results

The majority of papers explored how individuals responded to the challenge of becoming a carer and managing the demands of care giving. The themes generated by the synthesis are presented in four time-points of the caregivers' experiences. These were; on becoming a carer, being a carer, acknowledging what was lost and finding a way forward. Each theme had a number of related sub-themes, (see Table 7 for identified themes). The final presented themes were common across a range of studies and therefore likely to be representative and reflect the reality of the experiences of caregivers for those with stroke population. Further details of which themes were based on which studies are provided in appendix 3.

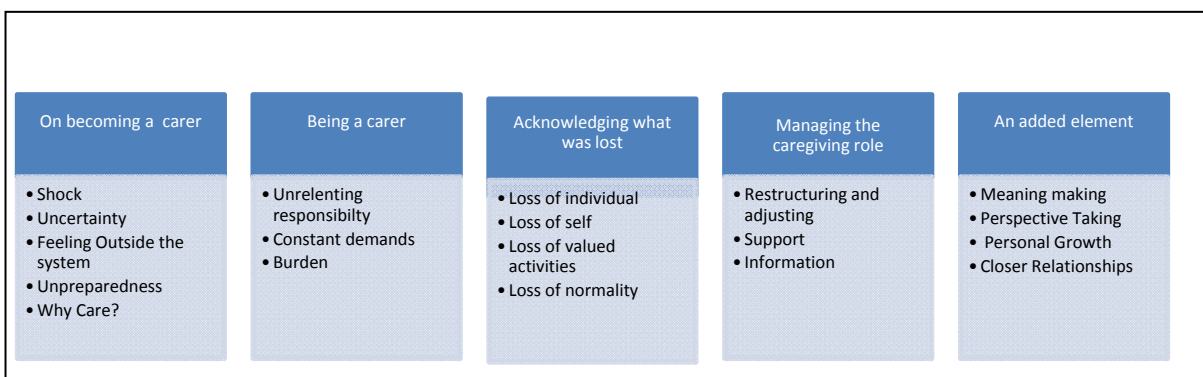


Diagram 1: Emergent Themes

On becoming a carer

Shock

A number of the studies discussed caregivers' shock around the stroke itself (Buschenfeld, Morris, & Lockwood, 2009; Hunt & Smith, 2004; Johansson & Johansson, 2009; Wallengren, Friberg, & Segesten, 2008). This appeared to be linked to the suddenness and dramatic nature of stroke (Hunt & Smith, 2004) and the sudden and significant changes stroke had on individuals' lives (Buschenfeld et al., 2009). Wallengren et al. (2008) likened this to being

thrown into chaos. It was notable that caregivers who had been caring for 7 years preferred not to “talk about those first few days so much anymore” possibly because the memories surrounding the stroke still had the same intensity: “...when I think back to that time, it’s the shock of still seeing him as he was” (Buschenfeld et al., 2009).

Uncertainty/Anxiety

Alongside this upheaval, carers also experienced being thrown into limbo, waiting for signs of improvement or to hear the prognosis. Carers frequently discussed ongoing health concerns, for example, anxieties about future stroke (Smith, Gignac, Richardson, & Cameron, 2008; Johansson & Johansson, 2009). As the length of time in the caregiving role progressed, uncertainty appeared to generalise from anxieties about prognosis to anxieties about the future, such as being able to provide care in the long-term (Greenwood, Mackenzie, Wilson, & Cloud, 2009; Wallengren et al., 2008).

Being outside the system

Caregivers also described feeling ‘outside’ the care giving system, in an unfamiliar environment. Carers described feeling invisible and ignored and not included (Wallengren et al., 2008). They wished they had received more support themselves “... [I didn’t know] how to deal with him on a different level. I wish they paid more attention to me.” In addition, caregivers felt they had limited control over formal support (Buschenfeld et al., 2009; Coombs, 2007; Green & King, 2009; Greenwood, Mackenzie, Wilson, et al., 2009; Hunt & Smith, 2004; King & Semik, 2006; White et al., 2007). Caregivers receiving paid care described anxiety over carers entering their home and did not perceive themselves as having control over these visits. It was suggested

that these experiences added to caregivers' feelings of chaos and uncertainty (Greenwood, Mackenzie, Wilson, et al., 2009).

Unpreparedness

Caregivers reported feeling unprepared to meet the demands of the caregiving role (Buschenfeld et al., 2009; Hunt & Smith, 2004; Johansson & Johansson, 2009; Wallengren et al., 2008). Many reported feeling overwhelmed by the new role (Cao, Chung, Ferreira, Nelken, & Brook, 2010; Coombs, 2007; Green & King, 2009; Greenwood, Mackenzie, Wilson, et al., 2009; White et al., 2007) and unprepared for the unfamiliar responsibilities that now fell to them (King & Semik, 2006; Pierce, Steiner, Govoni, Cervantez Thompson, & Friedemann, 2007; Silva-Smith, 2007; White et al., 2007). White et al. (2007) discussed the limited time that caregivers felt was available to them to adjust to their new role. One caregiver discussed the risk associated with this saying "they sent my father home too quickly and we did not have the capacity to care for him so they were sending him home to an environment that was not safe for him" (White et al., 2007). King and Semik (2006) described that caregivers "knew what to expect intellectually but not emotionally", highlighting the ongoing process of psychological adjustment, not only to the stroke but also to care giving.

Why care? Feelings about care giving.

From the minute an individual was admitted into hospital with a stroke, the spouse or family member were often assumed to be the carer (Silva-Smith, 2007). This perhaps added to the expectation that family members should take up management of care following discharge. Caregivers described multiple reasons for taking up the role. The predominant appeared to be a

societal and moral expectation that spouses and relatives would automatically or contractually (through marriage) provide support, and this was discussed in a number of the papers (Backstrom & Sundin, 2009; Bocchi & Angelo, 2008; Cao et al., 2010; Coombs, 2007; Hunt & Smith, 2004). Family members and care- recipients themselves, also reinforced this idea preferring not to have outside support (Bocchi & Angelo, 2008; Coombs, 2007;) again affixing responsibility to the relatives or spouse.

Being a carer

Unrelenting responsibility and ‘burden’

A predominant theme arising from the synthesis was caregivers’ descriptions of holding complete responsibility for the care recipient. The number of tasks caregivers named was extensive, from taking responsibility for individual’s health and well-being (Backstrom & Sundin, 2009; Green & King, 2009; Johansson & Johansson, 2009; White et al., 2007) to their psychological well-being (Buschenfeld, et al., 2009; Coombs, 2007; Johansson & Johansson, 2009; White et al., 2007). This responsibility appeared to be influenced by the caregiver’s perception of the fragility and vulnerability of the care-recipient, and led to hyper-vigilance and monitoring behaviours from carers (Green & King, 2009). Carers frequently described anxiety at leaving patients alone for more than short periods, often linking any time out to domestic errands or caregiver related activities (Bocchi & Angelo, 2008; Silva-Smith, 2007; Wallengren et al., 2008). One carer stated that, “my husband accuses me of babying him, but my over protectiveness is automatic because I am afraid of letting him go”. Caregivers also alluded to “being on guard”, watching for progress or physical improvement (Silva-Smith, 2007; Smith et

al., 2008; Wallengren et al., 2008) as well as signs of deterioration. This unrelenting responsibility also extended to medical equipment and devices (Pettersson et al., 2005).

Caregivers described becoming protectors for the individual with stroke (Buschenfeld et al., 2009; Wallengren et al., 2008). Pettersson et al. (2005) described a carer defending her husband from the stigma of other peoples' reactions to him being in a wheelchair. This sense of protection also appeared when caregivers took on the role of advocates for their relatives by 'fighting the system' (Backstrom & Sundin, 2009; Smith, et al., 2008; Strudwick & Morris, 2010; White, et al., 2007). Bocchi and Angelo (2008) suggested that the weight of this responsibility increased when carers felt isolated in the role and had no-one to turn to. Increased patient dependence on the caregiver added to this (Greenwood, MacKenzie, Cloud, & Wilson, 2009; Hunt & Smith, 2004).

Caregivers described these ongoing demands and responsibilities as "working a 24 hour day" (Cao et al., 2010; Coombs, 2007; Hunt & Smith, 2004; King & Semik, 2006). They talked about taking on multiple roles (Backstrom & Sundin, 2009; Pierce et al., 2007) and roles previously held by their partner (Buschenfeld et al., 2009; Cao et al., 2010; Coombs, 2007; Green & King, 2009; Hunt & Smith, 2004; Pierce et al., 2007; Silva-Smith, 2007). The distress associated with these ongoing demands was highlighted by a number of papers (Buschenfeld et al., 2009; Greenwood, MacKenzie, Cloud et al., 2009; Hunt & Smith, 2004) and caregivers discussed the impact on their energy of responding to the demands of the role (Cao et al., 2010; Coombs, 2007; King & Semik, 2006; Pierce et al., 2007; Silva-Smith, 2007). The impact upon sleep was frequently mentioned by carers (Backstrom & Sundin, 2009; Cao et al., 2010; Coombs, 2007; Green & King, 2009; Johansson & Johansson, 2009; Pierce et al., 2007; Silva-Smith, 2007). Such demands impacted upon the time and energy that caregivers were able to direct to

non-care-related activities (Backstrom & Sudin, 2009; Greenwood et al. 2009; Pierce et al. 2007; Silva- Smith, 2007; Pettersson, 2009).

Acknowledging what was lost.

Loss of the individual – Altered Relationships

One of the main shared points of change for caregivers was witnessing the impact of stroke on the person affected (Hunt & Smith, 2004). It was difficult for caregivers to witness “such physical change” in the individuals they knew (Wallengren et al., 2008). Wallengren et al. (2008) also suggested that carers experience feelings of ‘abandonment by the sick one’ in the early days. These changes had a significant impact on caregivers and survivor relationships (Backstrom & Sundin, 2009; Buschenfeld et al., 2009; Coombs, 2007; Green & King, 2009; Hunt & Smith, 2004; Johansson & Johansson, 2009; Pierce et al., 2007). Carers described the physical and personal change in those with stroke and talked of no longer recognising the individual as their past selves anymore (Wallengren et al., 2008), for example, Coombs et al. (2007) said “I haven’t had a conversation with him for the last 4 or 5 years...I’m going on like, maybe sometimes like I’m with a stranger.” Brittain and Shaw (2007) suggested that some physical consequences of stroke impacted on caregivers perceptions of stroke survivors’ adult status. The research also highlighted issues of the social ‘acceptability’ around these changes, such as, odours (Brittain & Shaw, 2007), sounds whilst swallowing and eating (Johansson & Johansson, 2009) or visibility of physical aids such as wheelchairs (Pettersson, 2005). Changed personalities and behaviours also affected relationships: one caregiver stated “I have to treat her like a child...she cries so much. It is just different. It is overwhelming to me somewhat because I (knew) her one way and now she is this other way” (Silva-Smith, 2007). The physical limitations of

stroke survivors also appeared to have a significant impact on shared interactions: “I’ve lost my man. [] There was no intimacy, there was nothing...you there, me there, that was it. So we were complete and utter strangers” (Buschenfeld et al. 2009). Carers also discussed difficulties balancing the nursing role and the role of partner: “After all he is my husband and I have to insert and remove an object into and out of his body” (Johansson & Johansson, 2009).

A small number of the studies identified positive aspects, such as growth and strength in relationships: “Whilst he relies on me, I rely on him, works both ways, I think the bond has got stronger, it definitely has got stronger” (Buschenfeld et al., 2009). Coombs (2007) argued that, for some carers, the fundamental strength in the relationship was still evident. For example, caregivers described their commitment to providing care, saying “I’ve always stuck with me mum [] a mother and daughter relationship [] I’ll do anything for her” (Hunt & Smith, 2004); and “You want to be there, still, it’s almost as we’re together as best friends, we’re not much more than are good friends and buddies living under the same roof” (Backstrom & Sudin, 2009).

Loss of self/prioritising others

Many of the changes also had an impact on the caregivers themselves. Once caregivers had taken on the role of caregiving, it was often described as all-consuming and they defined themselves primarily as a ‘carer’. One carer indicated what this meant for him stating that “life revolves around my wife [] I have no real individuality”; another said “you become less important” (Buschenfeld et al., 2009). For some carers, continuing work can provide some respite from the caring role and working appeared to be one way that carers were able to maintain a sense of autonomy; however, this was linked to how much caregivers’ valued the job (Buschenfeld et al., 2009). For the majority of caregivers caring appeared to reduce their

autonomy (Green & King, 2009; Greenwood, MacKenzie, Cloud et al., 2009) with stroke survivors needs coming first (Cao et al., 2010; Hunt & Smith, 2004; Johansson & Johansson, 2009). Johansson and Johansson, (2009) described caregivers prioritising their relative's meal over eating themselves. Wallengren et al. (2008) highlighted the potential for carers to feel isolated because of the attention given to the survivor: "...so there was sort of no [family member] who really asked me how I felt".

Loss of valued roles and activities

It is worth considering the impact of this lost autonomy upon carer self-identity. One carer discussed the importance of getting back to "looking after me" (Cao et al. 2010) but this was difficult for many caregivers. Carers experienced social restrictions and isolation (Bocchi & Angelo, 2008; Brittain & Shaw, 2007; Buschenfeld et al., 2009; Coombs, 2007; White et al., 2007) with activities becoming restricted, serving a purpose rather than recreational: "I only go biking if it's a destination I have to go pick up a prescription [] it's not pleasure biking like it used to be" (Cao et al., 2010). Carers also appeared to lament opportunities to be spontaneous (Backstrom & Sundin, 2009; Greenwood, Mackenzie, Cloud et al., 2009). One study suggested this was exacerbated by restrictions with formal care, for example having to 'wait in' for health care (Greenwood, Mackenzie, Cloud et al., 2009).

Caregivers found it difficult to ring-fence time for themselves (Backstrom & Sundin, 2009; Greenwood, Mackenzie, Cloud et al., 2009; Pettersson et al., 2005; Silva-Smith, 2007) for example, "You have to give yourself up to everything else. I don't participate in anything anymore [] I only live for my mother and my husband here at home and don't do anything else." Other barriers included guilt in leaving their relatives whilst pursuing activities for themselves (Backstrom & Sundin, 2009; Cao et al., 2010; Coombs, 2007; Hunt & Smith, 2004; Johansson &

Johansson, 2009; Wallengren et al., 2008). One carer mentioned that pursuing activities that they had previously done with their partner emphasised what they had lost in their relationship “You feel wrong doing it, because he can’t do it and you know he’s thinking about you out there doing it and wanting to be there” (Cao et al., 2010).

Loss of ‘normality’

As discussed above, caregivers’ lives were significantly disrupted by stroke, with their daily lives suddenly become unfamiliar (Buschenfeld, 2009; Johnsson & Johnsson, 2009; Silva-Smith, 2007; Wallengren et al., 2008) and the loss of normal everyday things (Brittain & Shaw, 2007; Buschenfeld et al., 2009; Cao, et al., 2010; Green & King, 2009; Pettersson et al., 2005; Silva-Smith, 2007; Wallengren et al., 2008). Loss of normality extended to the caregiver’s home environment (Brittain & Shaw, 2007; Pettersson et al., 2005; Wallengren et al., 2008; White et al., 2007). Carers described their homes as no longer feeling like theirs, instead being taken up with medical equipment (Brittain & Shaw, 2007; Pettersson et al., 2005). Carers described changing their living arrangements to cater for the physical difficulties: “Well, my home is not how I like it because everything is rearranged. I have the bed in the living room, all my carpets are rolled up..it’s just a mess..I mean it’s just not my home!” (White et al., 2007).

Stroke affected previously made plans (Backstrom & Sundin, 2009; Coombs, 2007; Green & King, 2009; Greenwood, MacKenzie, Cloud et al., 2009; Pettersson et al., 2005; Silva-Smith, 2007) with continued uncertainty impeding caregivers from making plans for their future. The majority of caregivers described attempting to get back to life as it was prior to the stroke, finding some ‘normality’, possibly as a way of managing the uncertainty about the future (Backstrom & Sundin, 2009; Coombs, 2007; Pierce et al., 2007; Wallengren et al., 2008; White et

al., 2007). Two of the papers suggested that when caregivers realised the practical difficulties associated with this there appeared to be a process of readjustment putting the others' priorities before their own (Backstrom & Sudin, 2009; Bocchi & Angelo, 2008).

Managing the Care giving role and Finding a way forward

Restructuring life and adjusting/taking each day as it comes

Finding a way forward appeared to be dependent on caregivers accepting an altered path and adjusting to the changes by redefining their goals and altering their activities (Backstrom & Sundin, 2009; Buschenfeld et al., 2009; Coombs, 2007; Green & King, 2009; Pettersson et al., 2005; Silva-Smith, 2007; Wallengren et al., 2008). Caregivers gave examples of altering ways of interacting with friends; for example, one carer caring for an individual with feeding difficulties, changed the couple's interactions so that they no longer involved food or drink (Johansson & Johansson, 2009). Caregivers also described selecting more personally valued activities above others to optimise energy levels. The studies also highlighted other strategies that carers employed to restructure their daily lives in order to deal more effectively with the challenges of the stroke, such as having routines and planning activities (Backstrom & Sundin, 2009; Brittain & Shaw, 2007; Greenwood, MacKenzie, Cloud et al., 2009; Greenwood, Mackenzie, Wilson et al., 2009; Johansson & Johansson, 2009; King & Semik, 2006; Pettersson et al., 2005).

Approaching things on a day-to-day basis was another theme repeated throughout the reviewed papers. Carers appeared to avoid thinking about the future (Buschenfeld et al., 2009; Greenwood, Mackenzie, Wilson et al., 2009; Wallengren et al., 2008). It was unclear whether this was because the immediate future i.e. coping day-to-day, presented too many demands itself or whether this served a more protective function due to restrictions around the future.

Feeling supported

The majority of studies included in the review cited support as a significant factor in carers' ability to cope (Backstrom & Sundin, 2009; Bocchi & Angelo, 2008; Buschenfeld et al., 2009; Cao et al., 2010; Coombs, 2007; Greenwood, MacKenzie, Cloud et al., 2009; Greenwood, Mackenzie, Wilson et al., 2009; Johansson & Johansson, 2009; King & Semik, 2006; Pierce et al., 2007; Pierce, Steiner, Havens, & Tormoehlen, 2008; Smith et al., 2008; Strudwick & Morris, 2010; White et al., 2007). Caregivers acknowledged their dependence on others (Bocchi & Angelo, 2008; Coombs, 2007; Greenwood, MacKenzie, Cloud et al., 2009; Hunt & Smith, 2004; Wallengren et al., 2008; White et al., 2007). This included dependence on others to provide respite (Backstrom & Sundin, 2009; Cao et al., 2010; Coombs, 2007; Greenwood, MacKenzie, Cloud et al., 2009; Hunt & Smith, 2004; Pierce et al., 2007; Silva-Smith, 2007). However, carers described difficulty trusting others to provide care. Consequently family support was the most discussed, with care often falling to family members.

Caregivers expressed awareness of the impact of the situation upon other family members: "Our son helps lift her on the bed and will change her and all sorts. I guess it was a big adjustment for himI feel like he hasn't had a life as such" (Buschenfeld et al. 2009). Some carers were protective of involving family members in care: "They would love to, but it's impossible [] I can't just expect them to leave their jobs every five minutes and come down" (Strudwick & Morris, 2009). Other studies suggested that carer expectations of family support did not always match what family members were able or prepared to give, potentially causing increased stress for the primary caregiver (Bocchi et al., 2008; Greenwood, MacKenzie, Cloud et al., 2009; Strudwick & Morris, 2009).

Dependence on formal support was also acknowledged (Hunt & Smith, 2004; Smith et al., 2008; Wallengren et al., 2008; White et al., 2007). Some carers described the benefits of formal support (Greenwood, MacKenzie, Cloud et al., 2009; Smith et al., 2008; Wallengren et al., 2008) but others authors highlighted their unreliability (Greenwood, Mackenzie, Cloud et al., 2009; Greenwood, Mackenzie, Wilson et al., 2009). Greenwood, Mackenzie, Cloud et al., (2009) suggested that carers felt better supported when they paid for private care, potentially placing them in control of the service they received. Smith et al. (2008) examined differences in the experiences of young and older caregivers and found younger carers were more critical of formal care, whilst older cares felt more positive towards outside help. In addition carers' with past experiences of care giving described this minimising the impact of the stroke (Greenwood, Mackenzie, Cloud et al., 2009; Smith et al., 2008).

Having Information

As found in other research, having adequate information was cited in a number of studies as important to carers. This information included details on the demands of care giving and having questions answered. It appeared that having information on medical issues and prognosis reduced caregiver guilt (Johannsson & Johnsson, 2009) and gave caregivers increased confidence in dealing with care-recipients' needs: "I needed somebody to answer questions during the first few months at home... to make me feel more confident" (King & Semik, 2006). Interestingly, Smith et al. (2008) highlighted differences between younger and older carers, suggesting that younger caregivers wanted more information and training, whilst older caregivers reported finding the information overwhelming. In addition younger carers appeared motivated to seek information for themselves.

“The professional information given by the doctors was fairly clear. The information coming forth from the nurses wasn’t as clear. It relied more on symptoms. So what I did was I went on the internet and I researched the symptoms, the ailment, possible side effects of medication and I sort of made myself aware of what has happened.” (quote from a young carer, cited in Smith et al., 2008,)

An Added Element

Meaning-Making and Providing an Altered Perspective

A number of studies discussed the process of meaning-making as a way to come to terms with the events of stroke (Hunt & Smith, 2004; Silva-Smith, 2007; Wallengren et al., 2008). From the point of diagnosis, there appeared to be a need for carers to try to make sense of what had happened. They talked about unfairness of the stroke, and asked ‘why me?’ (Hunt & Smith, 2004). Meaning-making also involved a process of making comparisons to people in situations perceived to be worse off (Backstrom & Sundin, 2009; Bocchi & Angelo, 2008; Buschenfeld et al., 2009; Coombs, 2007; Green & King, 2009; Greenwood, Mackenzie, Wilson et al., 2009, Wallengren et al., 2008). One caregiver stated: “It means it does make you appreciate what you have got, and also make you look at other people and think ‘My God I am lucky’ we are a hell of a lot luckier than some people” (Greenwood, Mackenzie, Wilson et al., 2009). Other examples of meaning-making included frequently looking to the positives and attempting to maintain a level of optimism (Backstrom & Sundin, 2009; Cao et al., 2010; Coombs, 2007; Greenwood, MacKenzie, Cloud et al., 2009; Greenwood, Mackenzie, Wilson et al., 2009; Johansson & Johansson, 2009; Pierce et al., 2007; Smith et al., 2008). Carers also described using humour to keep both their and the stroke survivor’s spirits up (Buschenfeld et al., 2009; Greenwood, Mackenzie, Wilson et al., 2009). Three of the studies discussed the role of faith, highlighting its importance to some carers in terms of understanding the meaning of events, for example having

“faith in a higher power” (Pierce et al., 2007) and knowing ‘someone else was in control’ (Coombs, 2007; Pierce et al., 2008; Strudwick & Morris, 2010).

Care giving appeared to provide some caregivers with a renewed outlook on life, enabling them to focus on the positives and appreciate the small things: “When you’ve nearly lost someone and you’ve still got them after all these years you just appreciate different things” (Greenwood, Mackenzie, Wilson et al. 2009). In some cases, stroke appeared to enable caregivers to see additional value in relationships with spouses and friends. One caregiver said “Although I cannot say that I’m glad for the stroke, we have truly seen the blessings that we have been given” (Pierce et al., 2007). Stroke appeared to facilitate perspective taking for some caregivers and act as a catalyst for change. For example, one participant stated:

“I value my partner more and other relationships more; I have stopped worrying about the little things. The stroke has put my life in perspective. Talk more openly, share more, greater appreciation of each other and the roles we play in the family” (Green & King, 2009).

A small number of carers described growth in their relationships with those they were caring for, recognising positive movement forward: “You couldn’t return to where you were... people think that getting better is getting back to as you were. She got better but in a different way. We evolved our life in a different way.” (Buschenfeld et al., 2009). Some caregivers also identified growth in themselves, developing a new sense of identity and mastery as a caregiver (Wallengren et al. 2008; White et al., 2007) “You grow into a role, you get routines, it sort of starts to calm down” (Backstrom & Sudin, 2009).

Discussion

The aim of this review was to summarise qualitative research, from 2004 to 2010 focusing on the lived experience of family caregivers of those with stroke. The reviewed papers included a broad range of caregiver experience over a variety of time periods. A narrative framework was used to present the shared findings to produce an account of the process of: becoming a carer, being a carer, acknowledging what is lost, and finding a way forward. Despite the included papers covering a variety of time periods that caregivers had been in the role (from one month to over 7 years), a number of common themes were evident. Due to space limitations, the discussion will not re-iterate these themes but instead highlight specific areas of interest. Consideration will also be given to their place within the quantitative caregiver research.

It is perhaps unsurprising that, due to the unexpected nature of stroke, caregivers typically felt unprepared for the role. In addition, the reviewed papers alluded to the ongoing impact of the trauma, specifically the loss and changes resulting from stroke itself. The papers discussed the acceptance of the event as a continuing process that carers moved through. Many of the papers described a transitional period where caregivers moved from shock to acceptance and adjustment. This has some similarities with the stages identified by Cameron and Gignac's (2008) 'Timing it Right Framework'. However, this paper emphasises the iterative nature of this process, with caregivers returning to each of these phases, perhaps due to the continued anxiety, uncertainty and challenges they faced. This perhaps shows similarities to Kubler-Ross' (1969) Grief cycle model, moving through to acceptance of 'what was lost' and 'looking towards the future'. As discussed previously, unlike many other health conditions, families often have little time to adjust to the multiple changes that can arise from the occurrence of stroke (National Audit Office, 2005) and there are increasing demands as the care-recipient improves. Interestingly, the review also

highlighted caregivers' feelings of invisibility, for example, not being involved in care-making decisions and 'being outside the system'. The theme of invisibility has also been identified in other stroke caregiver research (Brereton & Nolan, 2000; McKevitt et al. 2008).

Positively, the synthesis identified a number of methods that caregivers used to manage the care giving experience, for example: social comparisons, taking one day at a time and remaining positive. The level of social support received by carers was also seen as integral to their coping; this was demonstrated by the high frequency with which 'feeling supported' was mentioned by caregivers. Another important issue raised by the papers concerned the difficulties some carers had in sharing care with others. This appeared to relate both to difficulties trusting others, as well as not wishing to burden them, and highlights the potential complexities that sharing care may present for some caregivers. A differentiation was also noted between formal and informal support, suggesting that not all caregivers felt able to rely on the care provided by outside agencies, preferring instead to depend on family. Strudwick and Morris (2010) discussed the role of cultural expectations in relation to this, with African-Caribbean carers describing a cultural responsibility to provide care at home.

Links with other quantitative and qualitative research

It was hoped that focusing solely on caregivers' experiences would offer a detailed insight into areas less accessible through quantitative methods, for example, the coping strategies caregivers use, the positive aspects of the caring role, and the significant role and relationship changes, all of which have been identified in previous qualitative reviews (Greenwood et al. 2008; McKevitt et al. 2003; Murray, Ashworth, Forster, & Young, 2003). The current review found that unfortunately, positive outcomes were not the main focus of investigation for the

majority of studies. However the satisfactions that were identified were similar to previous reviews, for example ‘meaning-making’ and ‘growth in relationships.’ These seemed to be linked to those found by Greenwood et al. (2008), ‘realising what was important’ and ‘feeling closer to the survivor’. In addition to these themes the current review builds on Greenwood et al.’s (2008) research, highlighting issues of ongoing uncertainty and anxiety for caregivers. O’Connell and Baker (2004) also discussed caregiver uncertainty, and in keeping with the findings of this review, described a number of methods caregivers used to manage the stress of caring, such as, keeping positive, comparing their situations to others, and taking each day as it comes.

The similarities with previous quantitative reviews are also notable, for example, the significant impact of care giving on individuals’ emotional well-being, and reduced quality of life (Anderson et al., 1995; Han & Hanley, 1999; Low et al., 1999). Other commonalities included requests for more information and training. It is well documented that first time carers value literature on prognosis and available support. The review also highlighted the importance of feeling supported, in addition to receiving tangible help. Although support is known as a protective factor for caregiver well-being (Carnwath, & Johnson, 1987; Grant, Elliot, Weaver, Glandon, Raper, & Giger, 2006; Schulz, & Tompkins, 1990) the review suggests that, due to the enduring impact of the changes brought about by stroke, the timing of this support is important. This was highlighted by Visser-Meily et al. (2009) who reported a significant negative effect of time on caregiver depression. Therefore, it may be helpful for caregivers to have the opportunity to access support as they require it, rather than focussing upon the time immediately after discharge. This review suggests that knowing this type of support is available may be helpful in itself. The review also offers some further insights into the potential psychological barriers caregivers may experience in making use of formal and informal respite, for example, anxiety,

guilt at leaving their relative and cultural, or societal expectations (e.g. Strudwick & Morris, 2010). It may be helpful to acknowledge these when planning care provision.

Links with carer research in other groups

A number of the findings from this review have also been described in care giving populations in other chronic conditions. Williamson, Simpson and Murray (2008) examined the experiences of care giving in spouses of those with Parkinson's disease with psychotic symptoms, and found that caregivers also described uncertainty, sought understanding, struggled with changed identities and used social comparisons in a process of adaption. This perhaps suggests a process of adjustment that caregivers work through in adapting to the role. There also appear to be core elements of uncertainty and anxiety that go along with this process, for example, Walker, Livingston, Cooper, Katona and Kitchen (2006) described anxieties about leaving the care-recipient, in caregivers for those with dementia. Neville (2003) conducting an integrative review of uncertainty in orthopaedic conditions, emphasised the psychological distress linked to uncertainty. The importance of social support has also been emphasised in other areas of care giving, for example multiple sclerosis (Krokavcova et al., 2008) dementia (Au, Lai, Pan, Lam, Thompson & Gallagher-Thompson, 2009) and in those with chronic illness (Sells et al., 2009).

Research with caregivers for those with dementia also describes the impact of the perceived loss of the care-recipient on the psychological well-being on the caregiver. Indeed relationship affinity between caregiver and care-recipient was shown to be important for carer well-being in spouses caring for those with dementia (Boss, Caron, Horbal, & Mortimer, 1990). Another similarity noted in the experiences of caregivers was shown by Walters, Oyebode, and

Riley (2010) who found that some female caregivers of spouses with dementia experienced a sense of loss from their partner and discontinuity between their previous and current relationship. Sanders, Ott, Kelber and Noonan (2008) examined grief in caregivers and suggested that grief is often overlooked in research, with a tendency to focus upon more apparent psychological aspects, e.g. depression. They found that caregivers for those with dementia also described loss, lost past, guilt, and isolation, all of which were similar to the issues identified in the current study. In addition the ‘added elements’ that caregivers described from the role, including satisfaction, boosts to self-esteem and meaning-making (enabling a shift in perspective) echoed positive concepts from more general caregiver research (Haley et al., 2009; Hunt, 2003). Whilst we should not assume that care giving experiences are the same for all people, the findings from this review support the idea that there are fundamental aspects common to the process of care giving and the methods by which individuals manage the demands of this role.

Methodological Considerations

The similarity with previous research in this area and research conducted with other caregiver groups lends support to the presented findings. However, the quality of the review is ultimately dependent on the papers included. Although intended to be inclusive, as with any database search, some relevant studies may have been omitted. In addition, although all included papers were identified as qualitative, the studies varied in their methodology and the level of detail given by the authors. However, due to the methods of synthesis those papers which produced less supporting information were given reduced weight. Of the 21 articles, only nine gave a clear account of the philosophical approach being taken, and this appeared to relate to the method of analysis, for example describing the approach taken as ‘an iterative approach to

determine codes and themes.’ The ability to generalise the findings of the research also depends on the representativeness of the sample. Although the included studies were based upon small sample sizes (relative to quantitative studies), the total number of caregivers were 479. Of these, the majority were female spouses, although this is likely to be representative of the care giving population in general. Six of the 21 studies were conducted in the UK, with five from the USA, five from Canada, four from Sweden and one from Brazil. Information on the ethnicity of participants was given for only seven of the included studies. All participants were self-selected, and this may have excluded those caregivers who were functioning less well. However this is also likely to be true of quantitative studies in this area.

The author’s influence upon the process of qualitative synthesis should also be considered. From my own experiences as a trainee clinical psychologist, and through working alongside family carers, I was drawn to thinking about the care giving process as a journey. It is likely that this narrative perspective was influenced by my interest in narrative approaches to therapeutic work. Crossley (2000, pp. 135-158) writing about narrative psychology, discussed adaptations to chronic illness in terms of a process of reconstruction. She also highlighted that there is also a story of loss, conversion and growth, and attempts made to return to normal. These themes show clear similarities to the process described in this review, including the active role which caregivers play in adjusting their lives to re-gain a sense of ‘normality’. To enhance the credibility of the review the themes were also discussed and re-organised through discussion with colleagues and evidenced through the quotations and author notes. However, these conclusions could have been further strengthened by using multiple methods of triangulation, for example, using multiple reviewers to code the literature.

Conclusions.

Finally, it is likely that the dominant narrative of loss and change reflects the reality of care giving for many. However, while counselling is recognised as good practice (Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005), it remains rare for it to be offered and can be difficult for carers to attend when it is. Clinicians need to consider how support is offered over the course of care giving rather than only at times of crisis and immediately following discharge. Perhaps through educating caregivers and clinicians about the ongoing psychological challenges associated with care giving, more appropriately timed support can be provided to enable caregivers to adapt improving their psychological well-being. Longer-term case management involving follow-up appointments may also be helpful to support carers in dealing with the ongoing process of adjustment and help them to feel supported and heard. It is hoped that by having a better understanding of the challenges that caregivers face, health professionals will be better equipped to support individuals through the care giving process, in turn benefiting care-recipients. One potential low cost intervention could include providing psycho-educational leaflets on sleep hygiene to caregivers, as a number of studies highlighted the inevitable impact of care giving upon energy levels and sleep.

Future Research

Future research could benefit from a better understanding of caregiver diversity. Even with an increased understanding of the general coping mechanisms which caregivers employ to manage the experiences of care giving, there remains a limited understanding of the individual protective factors which means caregivers are affected in different ways, for example, why some caregivers cope better than others? Few studies have examined the role of faith and cultural

expectations on caregiver coping, with the majority of faith studies being conducted in the USA. It would be interesting to see how these issues impact on caregivers in the UK. Finally, it is hoped that this attempt to 'bring together' the qualitative research on the experiences of caregivers for those with stroke will add to previous knowledge in the area and shift the focus from caregiver burden and emotional well-being to more positive aspects of the process, such as caregiver resiliency.

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**AN EXPLORATIVE STUDY OF WHAT CAREGIVERS
UNDERSTAND THE RELATIONSHIP TO BE BETWEEN THEIR
OWN LIFE GOALS AND THEIR CARER-GIVING
COMMITMENTS**

EMPIRICAL PAPER

Abstract

Stroke is the third most common cause of disability in the UK. Stroke not only has a significant impact of those who suffer stroke but also upon family members who can find themselves in the caring role with little time to adjust. Despite the wealth of research carried out examining the impact of caregiving on individuals, little is known about the factors which mediate successful caregiver coping. Motivation and goal directed research has consistently shown the role of self-efficacy on psychological well-being. This study aimed to explore self-efficacy for life goals in relation to caregiver coping using an interpretative phenomenological approach (IPA). Eight participants, caring for those with stroke, took part in individual interviews concerning what they understood the relationship to be between their own life-goals and their care giving commitments. Five main themes emerged from the data: shock, loss and changed relationships, motivations to care, continuing fragility, and adapting as a team.

The study found that caregivers discussed fragility to their own life-lines, describing both anxiety and guilt at taking time for themselves. Indeed, participants in the study tended not to focus upon their own life goals, instead discussing shared activities and their reliance on improved care-recipient well-being in moving forward together. The omission of caregivers' own goals may perhaps reflect a generational shift from the 'I' to the 'we.' However, it may also highlight some of the potential barriers caregivers face in taking up respite opportunities or considering their lives moving forward alone. Interestingly, all participants discussed the importance of having time away from the responsibility of the role but this was not directly linked to time away from the care-recipient.

Keywords: Qualitative, Caregivers, Stroke, Goals.

Stroke is the most common cause of complex disability and the third highest cause of mortality in the UK today (National Audit Office, 2010). The World Health Organisation describes a stroke as a sudden change to the blood supply or the bursting of a blood vessel within the brain. It affects between 174 and 216 people per 100,000 in the population per year (National Clinical guidelines Royal College of Physicians, 2004) and can have a significant impact upon the lives of those affected, not only for the individuals who have suffered the stroke but also their immediate and wider families. In the UK in 2001 there were estimated to be over 6 million people providing unpaid care within home settings to individuals with a variety of difficulties (Office of National Statistics, 2001). The informal cost of this is estimated to be around £2.4 billion but this does not account for the indirect costs to those providing the care (National Audit Office 2005).

Research has consistently demonstrated that caregiving has significant effects upon the wellbeing of carers. Indeed it is well recognised that the activity of caregiving can lead to increased stress and poorer emotional and physical health outcomes compared to the general population (Hunt, 2003; Piquart & Sorensen, 2003; Schulz, Mittlemark, Burton, Hirsh, Jackson, 1997; Schulz & Beach, 1999). The 'Health Effects of caregiving study' (1997) found that just over half of those providing care reported high levels of strain, mental health problems and associated physical stress (Schulz et al., 1997). Following this Schulz and Beach (1999) conducted a prospective 4 year longitudinal study examining the association between caregiving and mortality. They found that carers who experienced high levels of strain had an increased risk of mortality compared to those with a disabled spouse but who were not providing care, and non-caregiving controls. The above research demonstrates that caregiving can be associated with significant health issues.

Whilst it is difficult to estimate the number of carers caring specifically for those with stroke, it is estimated that over 300,000 people are living with moderate to severe disabilities as a result of stroke in the UK (Adamson, Beswick, & Ebrahim, 2004). A significant proportion of these individuals will be cared for in the community by non-professional carers such as spouses and family relatives. Adamson et al. (2004) stated that due to the complex nature of the impact of stroke and the trajectory of recovery, stroke can affect families more broadly than many other chronic diseases. Stroke can constitute a major life event for spouses and relatives due to the sudden loss and changes to their lives and subsequent adjustment. Consequently, it is not surprising that research has consistently demonstrated higher incidences of mood disorders such as depression and anxiety in caregivers of those with stroke (Anderson, Linto, & Stewart-Wynne, 1995; Han & Hanley, 1999; Low, Payne, & Roderick, 1999; Wade, Leigh-Smith, Langton Hewer, 1986). The association, between caregiving and mental ill health, has been attributed to a number of factors, including caregiver burden, stroke severity, quality of life, physical health and stroke survivor emotional distress (Bugge, Alexander, & Hagen, 1999; Franzen-Dahlin, Larson, Murray, Wredling, Billing, 2007; Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1999).

Although caregiving for those with chronic conditions is associated with significant consequences for wellbeing, the primary focus of attention on those suffering from medical conditions means that caregivers as a population can be overlooked (Breton & Nolan, 2002). Positively, the important role which carers play in the treatment and rehabilitation of chronic conditions is increasingly being recognised. Public health policy is now beginning to acknowledge that caregiver well-being can impact on patient outcomes. In answer to this the UK government have produced legislation stating that the needs of caregivers should also be included

in care packages (DoH, 2007, National Stroke Strategy) building upon the ‘Carers Equal Opportunities Act, (2004). Although the impact of caregiving on both individuals and care-recipients is increasingly being recognised, the question remains as to how best to support caregivers in the role. One strategy being tried is to provide the opportunity for respite. However, the National Institute for Health Research found that the uptake of respite remains poor (Shaw et al., 2009). Consequently, understanding why some caregivers are better able to cope with the demand of caregiving whilst others struggle remains an important avenue of research and may lead to the development of more effective interventions for these groups.

In considering how some caregivers maintain their own psychological well-being better than others it seems clear that we need to gain a more thorough understanding of the links between caregivers strain (burden), depression, and the factors that influence coping. Previous research, as discussed above, has gone some way to answer this by identifying contributing factors to ‘caregiver burden’, such as, stroke severity (e.g. Rigby et al., 2009; Schulz, Tomkins, & Rau, 1988) and social support (e.g. Carnwath & Johnson, 1987; Ostwald, Bernal, Cron, Godwin, 2009). In addition, research on personality factors and coping has explored the contribution of these factors to individual coping. Pearlin, Mullan, Semple and Skaff (1990) presented a conceptual model of ‘Caregiving and the stress process.’ highlighting the varied ways in which individuals cope with similar situations. This seminal paper described stress as a consequence of the interplay between an individual’s characteristics and caregivers resources when faced with the challenge of caregiving. The model also shares some similarities with social cognitive theory (SCT) and self-efficacy (Bandura, 1977). Social cognitive theory posits that all humans are self-organising and self-regulating systems in the way we operate in the world. Self-efficacy is the individual’s belief that they have the capacity to meet the demands specific to an event. Based

upon this theory, Bandura, (1997) proposes that as individual agents we set our own goals and pursue our own motivations. Therefore those with higher self-efficacy are likely to pursue their goals more veraciously, increasing their own psychological well-being.

Research has also explored the role of self-efficacy in job satisfaction and found that workers experienced reduced stress if they valued their role and saw it to be purposeful (Knoop, 1994a). In addition Knoop (1994b) also found that if workers felt their job was valued by others, and that they were achieving something of worth, their satisfaction increased. In the context of caregiver research this would suggest that caregivers who value their role and perceive themselves to be valued should have higher self-efficacy and experience less distress. A number of health studies have examined the relationship between self-efficacy and depressive symptoms, for example with pain (Arnstein, Caudill, Mandle, Norris, and Beasley, 1999; Asghari, Julaeiha, & Godarsi, 2008). Ekwall and Halberg (2007) examined job satisfaction and self-efficacy in relation to caregiving and found positive activities buffered caregiver burden. Higher self-efficacy has also been found to be associated with lower levels of depressive symptoms in family carers of those with dementia (Gilliam and Steffen, 2006) and family carers of those with stroke (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). Van den Wijngaart, Vernooij-Dassen, & Felling (2007) examined the role of self-efficacy in caregivers of those with dementia and found mixed support for the influence of perceived self-efficacy on burden. However, interestingly the study found reduced burden with increased patient social functioning.

Research has also linked lower levels of leisure and recreational activities with poorer psychological outcomes. Pearlin et al.'s model (1990), 'Caregiving and the stress process,' identified the limits to social and recreational activities resulting from the demands of caregiving as additional stressors that caregivers face (Pearlin et al, 1990). The restrictions on caregiver time

can make it difficult for individuals to pursue activities outside of their caregiving role. The disruption of life activities as a result of caregiving also affects activities relating to caregiver self-concept, for example, working status and roles. Therefore it would seem probable that providing care to loved ones would also impact on caregiver life goals.

There has been a wealth of research documenting the restriction of caregiver activity. Reich and Zautra, (1981) found that positive life events led to improved well-being and decreased distress. Interestingly this effect was only significant at times of increased stress. Research examining activity levels in those with stroke found them to be predictive of patient satisfaction (Edwards, Hahn, Baum, Dromerick, 2006; Hartman-maeir, Soroker, Ring, Avni & Katz, 2007). A two-year longitudinal study of primary carers of those with stroke found that the incidence of depression in the first year of caring was affected by patient recovery, activity and mood (Wade, et al., 1986). The same was also found for those providing care (Nieboer, Schulz, Matthews, Shceier, Ormel & Lindenberg, 1998; Rochette, Desrosiers, Bravo, St-Cyr Tribble, Bourget, 2007). Nieboer et al. (1998) found that decreased activity participation had a direct effect on depressive symptoms in spousal caregivers, and suggested that activity had a mediating effect on well-being. Cao, Chung, Ferreira, Nelken, and Brook (2010) examined caregiver activity levels in wives caring for their husbands following stroke. They found that the changes brought about by stroke necessitated that caregiver activity be more purposeful, with caregivers re-focusing their time on their partner.

The evidence outlined above suggests that coping with the demands of being a carer may be easier for those people who are able to maintain and pursue some activities, particularly those activities that increase their feelings of self-efficacy and promote a positive self-concept. However, goals need to be not only realistic and achievable given the context of caring

commitments, but also meaningful to the carer. For these reasons, gaining a better understanding of how caregivers are able to reconcile the pursuit of activities with their ongoing care commitments may identify the role which pleasurable activities have as protective factors for caregiver well-being. There have been a number of calls for further research into the mediating role of self-efficacy on caregiver well-being (van den Wijngaart et al., 2007; Visser-Meily et al., 2009) .

In summary, caregiver well-being is an important clinical outcome to examine since it has implications not only for the mental health of individuals, but also for care-recipient rehabilitation. A great deal of progress has been made in understanding the experiences of caregivers of those with stroke. However, to date little research has examined whether the ability to pursue life goals in caring leads to increased well-being. It is hoped that an interpretative study examining the experiences of carers in relation to their own life goals may further our understanding of the mediating functions that these factors perform. To this end an interpretative phenomenological analysis (IPA) approach was employed to provide an in-depth and detailed study of caregivers' experiences. It was felt that IPA was well suited to answer the proposed question due to its commitment to make sense of lived experience within context (Smith, Flowers, Larkin, 2009). IPA uses purposive sampling to consider a small number of detailed cases. IPA also allows the researcher to analyse the transcripts both individually and collectively enabling detailed engagement with the participants' experiences.

Rationale

The aim of the present study is to investigate how carers make sense of their caring commitments, and how they appraise their own wellbeing, in the context of their individual life goals. In addition, the research also sought to examine whether caregivers are able to identify areas of satisfaction in their lives and explore this in relation to caregiver well-being. It is hoped that identifying the protective factors present in their everyday lives, will lead to a better understanding of how caregivers experience care giving and aid professionals in providing more effective support.

METHOD

Design

A qualitative research methodology was used to explore what caregivers understand the relationship to be between caregiving commitments and their own life goals. Face-to-face interviews were conducted and the transcripts from these were analysed using interpretative phenomenological analysis (IPA) (e.g. Smith, 2003; Smith, et al., 2009). IPA is concerned with the phenomena of lived experience and focuses on “exploring experience in its own terms” (p.106 Smith & Osborn, 2003). This is specifically related to the meaning and understanding that individuals attach to events.

Recruitment

Caregivers were indentified through a purposive sample from 3 local support groups. The lead co-ordinators from each group were informed about the research and asked if they would provide information about the study to their respective group members. Copies of the participant information, an invitation letter, and a recruitment poster were sent out to those groups expressing an interest in the research. The researcher attended each of these groups in person to answer any questions regarding the study. Individuals wishing to take part then contacted the researcher themselves or gave permission to be contacted directly to arrange a convenient time and place for the interview.

Ethics

All participants were provided with an information sheet outlining what the study would involve, its potential benefits, any potential risks. Written consent was sought from all participants after reading the information. The information sheet informed participants that they would be free to withdraw from the study at any time and that there would be no repercussions for them should they do so. Prior to their participation, participants were also reminded of their right to withdraw from the interview at any time. During a debriefing process participants were reminded that they could remove all or some of their data for up to a 2 week period after the interview, prior to data analysis.

The study received ethical approval from the University of Birmingham, Life and Health Sciences Ethical Review Ethics Committee, on 22nd January 2010 (see appendix 2). All patient invitation letters (see appendix 3), recruitment poster (see appendix 4), information sheets (see appendix 5) and consent forms (see appendix 6) were reviewed.

Participants

Eight caregivers were recruited and interviewed for the study. This is consistent with the suggested sample size of between 4-10 participants for similar projects (Smith 2003, p. 52). In order to be eligible for the study, participants were required to be (1) aged 18 years or over; (1) identified as the primary carer; (2) caring for someone who had experienced a stroke no less than 6 months prior to taking part; (4) were able to speak and understand English. Criteria 1 to 2 were included to identify suitable participants. Criteria 3 was added in order to minimise the impact any potential recovery effects likely to occur in the first 6 months after stroke, consequently examining the longer-term effects of caregiving on caregivers. Finally, due to the qualitative

nature of the project and limits regarding interpretation costs, participants were required to be able to speak English. Participants were not excluded on the grounds of gender, race, religion or sexual orientation.

Of those included in the study, three were male and five were female. Seven of these were spouses living with those with stroke, and one daughter living separately from her mother. The average age of the participants was 64 years (between 49 and 81 years). The average age of care-recipients was 69 years (between 60 and 89 years). Participants had been in the caregiving role an average of 2 ½ years (ranging between 1 and 4 years). All participants were white British, with English as their first language and all were self-selected participants, motivated to take in the research. Demographic information can be found in Table 1.

Participant Alias	Gender	Relationship to care-recipient	Caregiver Age (yrs)	Care-recipient Age (yrs)	Length of time caring (yrs)	Occupation	Ethnicity
Amanda	Female	Wife	68	65	2	Retired post-stroke	White British
Lynn	Female	Wife	67	70	3	Retired pre-stroke	White British
Sarah	Female	Daughter	57	89	3 ½	Retired post-stroke	White British
Daphne	Female	Wife	59	65	4	Retired post-stroke	White British
Harold*	Male	Husband	66	61	1 ½	Retired post-stroke	White British
Kate	Female	Wife	49	61	1	Full time work	White British
Brian*	Male	Husband	81	80	1 ¼	Retired post-stroke	White British
John	Male	Husband	64	60	2	Retired post-stroke	White British

Table 1: Participants' Demographic Information
(Carers who chose to have their partners present are indicated with *)

Data Collection

The main researcher conducted eight, in-depth, semi-structured, face to face interviews with participants. Brief introductions of participants are given in appendix 1. All interviews were audio-taped and participants gave written consent for this. The questioning followed a semi-structured schedule. Questions were open and non-leading. The interview schedule (see appendix 7 for schedule) focused on carers' daily commitments, activities, life satisfaction, and life goals. The questions were developed and revised through supervision with a researcher experienced in using qualitative methods. The questions were also piloted to assess for validity. The interview schedule was also reviewed following the first interview.

The interviews required participants to discuss their caregiving commitments and current day-to-day activities in detail. The schedule began with a general question introducing 'how the participant came to be a caregiver' to ease the participant into the interview. The remainder of the questions explored activities where carers gained satisfaction and how they were able to incorporate these into their lives. However, the schedule was not followed prescriptively and the discussion was led by participants. Answers were explored further using prompts such as "could you tell me more about that?" or "what is it that you mean by that?" Interviews lasted between 45 – 107 minutes. All, but one of the participants chose to be interviewed at home. One participant asked to be interviewed on NHS premises so they could talk in private. In addition, two of the caregivers preferred to have their spouses present (these carers have been indicated in the participant demographic table above).

On completion of the interview, each participant was given the opportunity to debrief and to discuss any issues raised for them and asked whether they were comfortable with the content discussed. The main researcher transcribed verbatim the audio-taped interviews, including length

of pauses, sighs, crying and laughter. Pauses of two seconds were indicated by (pause) anything longer was also highlighted, short pauses were indicated using dots.

Data Analysis

To facilitate the reader in their evaluation of the conclusions drawn, the main author has also attempted to give a clear account of the process. Transcripts were analysed using IPA methods as outlined by Smith et al. (2009) and set out below.

1. Reading and re-reading: all transcripts were read and re-read to allow the main researcher to engage with the text (multiple readings are encouraged to provide the opportunity for new insights to emerge). Particular attention was given to the main issues of concern for each participant.
2. Initial noting: each transcript was annotated with initial notes of key things of interest, for example, the use of language and metaphors; providing descriptive notes on participants experiences. Transcripts were explored at an interpretive level and key words were used to summarise the experience participants described.
3. Development of emergent themes: similar themes were indicated throughout each transcript and any contradictions noted.
4. Searching for connections: once this process had been completed for each participant a list of themes was generated with supporting with quotations from the transcripts.
5. Repetition across cases: the resulting themes were then compared across the participants for both similarities and differences.
6. Looking for patterns across cases: this process was facilitated by organising the themes using a word processing document and mapping the initial the themes using word processing documents and tables to develop a plausible line of argument from the emerging themes. Themes were also physically arranged using A3 paper to allow further consideration and re-ordering (see appendix 10-12 for excerpts from this process). The names of participants contributing to the themes were listed and

line numbers were noted where the theme was illustrated in the participant's transcript. All participants and their partners were given pseudonyms to maintain anonymity.

As the main author was new to IPA the guidelines were used in an iterative fashion to abstract the main emergent concepts. To enable deeper understanding of the text, transcripts were re-visited at each level throughout analysis. As IPA is an idiographic approach, each participants individual transcript was examined individually before considering the collective experiences (Smith & Osborn, 2003). The ideas were discussed with my research supervisor throughout the research process to explore their credibility. The themes were also discussed and re-organised through discussion with my supervisor and other colleagues familiar with IPA methods. To facilitate the author's re-engagement and consideration of the data a reflective diary was also kept from the beginning the process.

RESULTS

An Overview

Over arching theme	Sub-themes
1) Shock	<ul style="list-style-type: none"> a. You don't realise how your life can change in a few minutes b. Severity of stroke – instantaneous total devastation c. Gradient of adjustment – being on a journey d. Previous experience tempering the shock
2) Loss and changed relationships	<ul style="list-style-type: none"> a. Loss of life/ Loss of future – things I miss of our life before b. Loss of partner – isolation, inequality c. Acceptance of what life has become
3) Motivations to care?	<ul style="list-style-type: none"> a. Obligation (shoulds) – I'd better do it b. Commitment – part of your duty and love for someone c. Personal characteristics – part of who you are
4) Continuing Fragility	<ul style="list-style-type: none"> a. Fragility of partners well-being Well-being/fragility Vulnerability of partner Sex might 'break' her Seeing them as patient/child b. Fragility of carer's lifeline The importance of having a lifeline Contemplating making a life for oneself Caregivers life on hold c. Fragility of balancing demands of caring and coping Unrelenting responsibility Coming second Anxiety/Guilt leaving Living life through stroke
5) Adapting as a team	<ul style="list-style-type: none"> a. Importance of previous relationship context b. Importance of feeling supported c. Importance of feeling valued d. Seeing it as a job – keeping things separate e. Features of the role: <ul style="list-style-type: none"> a. Motivator b. Facilitator c. Advocate – fighter f. Learning to cope <ul style="list-style-type: none"> a. Self-realisation b. Remaining positive c. Living in the past d. Keeping life full

Table 2. Over-arching themes generated from the Analysis.

The five main over-arching themes that emerged from the analysis are presented in the table below (see table 2). Although not all participants contributed to all themes, this is not a requirement of IPA (Smith, 2003). Therefore the final themes were not selected solely for their prevalence but for the strength of the narrative within the accounts. To improve the credibility of the conclusions drawn, direct quotes were provided for readers to review their plausibility. The five themes outline a story concerning the ways in which participants attempt to adapt and move forward from the shock and loss of stroke, including the barriers caregivers described to ‘making a life for themselves’ and achieving their own life goals. These will now be discussed in more detail below. The alias of the participant is given next to each extract. A brief introduction to each individual is provided in appendix 1.

Theme 1: Shock

The theme, ‘shock’, alludes to the sudden and lasting impact of stroke and the ‘gradient’ of adjustment caregivers appeared to go through in adapting to the changes brought about by stroke.

a. You don’t realise how your life can change just in a few minutes

Caregivers described instant and fundamental changes that stroke had on their lives, the breadth of which were specific to each participant but had long-term consequences for all eight and their care-recipients. Kate, 12 months into the caring role, described only really being able to take in the full impact when later reflecting upon the event.

“Er following my husband having a severe stroke. Which came out the blue obviously. At quite a young age er. He was 60, when he had the stroke. So it’s, when you sit down afterwards you don’t realise how your life can change (Long pause) just in a few minutes. Completely (pause) it’s erm, it’s quite difficult, well very difficult.” (Kate)

Kate's description of the stroke, 'coming out of the blue' and her husband being 'at quite a young age' emphasises the unexpected nature of the stroke. Other caregivers stated that the stroke victims' good health was one of the reasons for the 'unpreparedness' and confusion they experienced coming to terms with the event of the stroke.

Most caregivers gave nuanced and detailed responses to the initial question, for example Lynn's extract below. Although initial accounts of how participants came to be caregivers were often factually based they were highly emotive, affecting both the participant and the interviewer.

"Yes... erm.... well (long pause) I sort of, I always get up early ...and I'd taken the dog for a walk...and I got back and it was about... oh, 7 o'clock in the morning and... I was just in the kitchen actually cleaning the fridge out, and Kevin came downstairs in his pyjamas and he looked straight through me, he didn't recognise me and I said 'Kevin?' (voice sounded concerned) "What's the matter" and he didn't answer... and something said...to me then 'He's had a stroke.' So I sat him on a chair..and I rang..999 (quietly spoken). And they they, they said don't give him anything to drink and they'll be out. Erm... then I I rang my neighbour [] ...and erm she wasn't' in anyway, she must of been out and she she did ring me when she got back... and erm... then the paramedics came... and erm... did all the tests...and then erm we erm off we went to the hospital. Erm...when they sort of looked at him he couldn't swallow ...and he couldn't drink ...and I thought he was getting worse so I went and told someone." (Lynn)

The 'power' of the stroke event in the quote above is emphasised by the contrast between the mundane everyday narrative and the significant changes that occurred. The accounts appeared to transport the individual back to the time it occurred, and the vivid nature of these descriptions highlighted the freshness of these events in the participants' minds. It was clear that for some carers it remained difficult for them to think back to the initial time of the stroke. This was also the case for those who had been caring for over several years. One participant answered the initial question stating 'Erm, very quickly. (pause). My husband had a severe stroke. Erm, very tragic circumstances' (Daphne). The brevity and staccato nature of Daphne's reply perhaps hints at

unspoken distress associated with the event and this highlights the persistent emotions and memories attached to the event for caregivers.

b. Severity of stroke – instantaneous total devastation

The words “severe” and “tragic” were frequently used by carers to describe the stroke, indicating the level of suffering that individuals experienced. One caregiver, Harold, highlighted the violence and power of the stroke, describing it as “instantaneous total devastation. Absolute.” Brian described the speed of the stroke and his struggle to comprehend these events even now.

“And then, I happened to, one morning, one Monday, it was a Monday morning, [date], it was impressed on my memory last year, in the last year. And I just, she was sitting there watching television and then I went into the kitchen, just to check on her (pause) on the er midday meal and when I came back she couldn't speak. (pause) Not a word. Couldn't lift her arms up, her right arm. (pause) And er, fortunately we've got some very good neighbours around here, and I had to call them from next door and she came in and she confirmed my worst fears. (Long pause 4 sec) It's it's very difficult to take it all in” (Brian).

Again Brian's descriptive account demonstrates the unexpected and frightening power of stroke in contrast to the description of everyday events. Caregivers also described stroke in terms of life and death, and talked of a story of survival by their partners. Two of the participants, Harold and Brian, suggested that stroke was worse than other chronic conditions due to the uncertainty and lack of time for mental adjustment. Uncertainty concerning the prognosis of stroke also appeared to add to these difficulties. For example, Harold didn't know whether his wife would “have a miraculous recovery and the following day be back to normal? Or would she never ever get any better from what she was when she went in to hospital 2 minutes after having had the stroke?” emphasising the uncertainty that he felt at this time. Amanda gave an example of her anger and frustration at her own powerlessness against stroke, describing her battle to understand it:

“And then I used to sort of rage and think ‘Stroke?’, why a silly word like stroke, that’s what you do to a kitten, [] a nice gentle action and this isn’t gentle its very (pause) horrible and severe, [] (sigh) it’s just, (pause) you want to lash out at something”(Amanda).

Amanda’s frustration seems to relate to the failure of the word ‘stroke’ to convey the sheer enormity and severity of the event and its consequences. The power of the stroke and Amanda’s wish to ‘lash out’ is contrasted with stroke’s alternative meaning as a ‘nice gentle action’. The power and force of the language used to describe the stroke also contrasted with caregivers’ feelings of impotence. In a number of accounts the physical paralysis of the individual appeared to be mirrored in feelings of paralysis and powerlessness in the caregiver.

c. Gradient of adjustment – being on a journey

The third sub-theme described the gradient of adjustment that caregivers appeared to move through from the days immediately following stroke, to later into the caring role. Daphne described this as “ a journey, it’s [a] life changing journey” (Daphne). Although the stages of the journey varied for each participant, there appeared to be a shared process of adjustment, mediated by participants’ level of acceptance, length of time caring, and previous experiences. Caregivers appeared to move iteratively through this journey of adjustment. Kate described ongoing difficulties in adjusting to the changes brought about by the stroke.

“At the, well I wouldn't say just at the start, you think (pause) that as time goes on your getting further forward and things are getting in place and then something else 'll happen and your right back to the start again and it's just an ongoing situation.” (Kate).

She describes how despite the progress she had made in terms of acceptance there are continuing struggles in coming to terms with the consequences of stroke. Acceptance appeared to be an iterative process with participants’ levels of acceptance varying within the same account. One caregiver, Amanda, spoke of her battle to come to terms with the stroke:

“He’ll never be as he was before, they told me that at (sigh), I think that was a bit cruel in a way. They told me that almost straight away ‘Oh he’ll never be back as he was’ you know. I had to really rail against this inside me head, [] But obviously they knew exactly what they were talking about and I’ve come to realise he won’t be back as he was. But he’ll be a lot better than he is now and a lot better than he was a year ago.” (Amanda).

Amanda described the effort she had to exert to continue to adapt and manage the impact of the stroke. As highlighted above, caregivers’ adjustment did not appear to be solely related to time, but was an ongoing individual process. Daphne, caring for 4 years, said

“I remember her [O.T] saying to me ‘It will get better, It will get better Daphne, It will get better’. And I can say to you now (pause) it doesn't get any better. (pause) You learn to live with it. It becomes a way of live.” (Daphne).

The above quote appears to describe an ongoing battle between acceptance and getting on with things, countering the otherwise overwhelming reality.

d. Previous experience - tempering the shock

Three of the participants described how their previous roles and experiences had helped to prepare them for the caregiving experience. Lynn described how she had “dealt with a stroke before” previously caring for her father who had a stroke when she was 17 years old. Brian described how, due to Gill’s previous health problems, he felt he “was in training” for caregiving. He also suggested that he was “sure it's helped [him to cope with the stroke] because other than that it's a very frightening experience.” In addition Kate described her job as enabling her to know what to do “I suppose it helped in the job that I do, coz I knew straight away what had happened and it all sort of er kicked in from there” (Kate). These short extracts suggest that previous experience may have a key role in terms of increasing caregivers’ confidence (self-efficacy) in their ability to respond to the stroke and caring situation.

Theme 2: Loss and changed relationships

Throughout the interviews loss was a pervasive theme. Caregivers frequently described their lives prior to stroke and the ‘lost’ or ‘past’ care-recipient. It felt important for participants to explain this context in order for them to convey the impact of stroke on their lives.

a. Lost Life/Lost future – “ Things I miss of our life before ”

There was a sense of disappointment at the inevitable changes that the stroke had meant for caregivers’ lives. These included previously enjoyed activities coming to an end, and future plans (such as shared holidays and retirement plans) being put ‘on hold.’

“We thought that we would travel in Europe quite a bit and we we had plans to buy a motor home erm and spend the winters in Europe. And erm when we'd both finished work if we hadn't had this situation [] we'd probably would have acted on that right then and there, we would have started travelling earlier than anticipated but now we can't do that.” (Sarah).

Most participants described extensive restrictions to holiday plans brought about by stroke.

These appeared to be linked to expectations around what a ‘normal’ retirement would entail. The descriptions appeared to describe a loss of freedom to take holidays, and captured images of being ‘grounded’ by stroke, unable to make spontaneous plans.

b. Loss of partner – “You're talking about a total stranger in effect”.

All participants discussed experiencing changed relationships, describing their partner changing from the person ‘they knew’. This was emphasised by frequent comparisons with how individuals had been before. It appeared important for caregivers to preserve a sense of their partners as they used to be before the stroke. Perhaps keeping this ‘past’ individual in mind helped caregivers to maintain other aspects of the relationship. The language used by caregivers

suggested that stroke had taken away elements of the individual, in some cases leaving a complete stranger in their place. Brian said “It totally changes the person’s personality. Absolutely. You’re not talking about the original person any longer. You’re talking about, until they come out of it, a totally, total stranger in effect.” This appears to emphasize the inability Brian felt to connect with his wife until she began to ‘come out of it.’

Similar to Brian’s account, a number of spouses discussed feeling distanced from their partner. This appeared to be linked to feelings of isolation and being unable to share everyday roles, for example, Daphne explained, “You go from being a couple to being completely on your own. Having to deal with everything” (Daphne). Amanda compared this to being like a widow, emphasising the isolation and shift in the marital relationship.

“Obviously it falls to me now doesn’t it, mowing the lawn and, you know, that’s the sort of thing you miss when your husband isn’t there. [] You You’re not a widow but you’re, it’s almost almost like, (pause) you know, because (pause) you’re still at home to do everything and cope but.” (Amanda).

This distance was also described physically in some cases. A number of caregivers talked about sex no longer being a part of the marriage. Daphne explained “We’re not a husband and wife anymore because I’m I’m I’m I’m I’m just his carer.” Changes in relationships were intensified in cases where the care-recipient’s communication had been affected.

c. Acceptance of what life has become

Caregivers discussed the importance of accepting the current circumstances. The male caregivers suggested that there was no sense in making plans:

“You have to change your lifestyle. You have to change what you do enjoy from one thing to another. I mean as I said we miss dancing. We miss the fact that we can’t go dancing. But since we can’t go (Long pause 7 sec) there’s absolutely no point in er thinking about it, is there.” (Brian).

These strategies appeared to help carers to adapt to the changes brought about by stroke, and reflected a more flexible style of thinking.

Theme 3: Motivations to care

Motivation to care relates to the themes that carers discussed regarding providing care to their spouses and relatives.

a. Obligation – “either you do it you or you don’t do it and er I better do it”

Participants appeared to indicate an expectation that they should provide care. This expectation appeared to be based upon their relationship to their care-recipient, (e.g. spouse or daughter) alluding to societal expectations of the commitments of marriage, or familial expectations of care. One caregiver described this, saying “Well (long pause) it’s another part of your marriage isn’t it, it’s something that’s happened and you either do it or you don’t do it and er I better do it? - (inaudible)” (Lynn). Lynn’s concept of marriage appears to guide her feelings of responsibility to care.

Caregivers also described their ‘duty’ to care based upon their relationship to their care-recipient. John and Brian described a reciprocal conception of the marital relationship saying,

“It means looking after the lady that I married and love. It’s as simple as that. She would do it for me. I’m sure she would.” (Brian).

“Well, we got married for better or for worse (pause). And if the worst is what is it now (pause) then I’ve got to do what she would do for me. You know. I can’t run away coz she’s poorly. And she, she wouldn’t run away if I was poorly.” (John).

These extracts appear to allude to the moral obligation within the sanctions and expectations of marital roles. This appeared similar to the motivations described by the female participants but suggests a more altruistic rationalisation.

In three cases female spouses made comparisons between looking after their children and their experiences as caregivers. This appeared to be linked to the idea of motherly duty and obligation for example, “You can’t just go off and leave them, as anybody that’s a mother knows” (Amanda). Interestingly the one caregiver who was not in a spousal relationship also touched upon the themes of reciprocity and altruism “I feel as though this is my time to erm to pay them both back really but especially mum. So I do feel that I have to do it in a strange way” (Sarah) suggesting that relational ties were fundamentally important for carers motivations to care.

b. Commitment – part of your duty and love for someone

These relational ties were also described in caregivers’ commitment to care recipients. Kate gave an example of this saying “Just that he’s. It’s your husband and you know (Long pause) you feel as if it’s your job. No not job. You want to do it. You want to do it 24 hours a day. (pause)” (Kate). One carer, Amanda, alluded to the avoidance of the caregiving ‘duty’ as irresponsible and reckless: “Your marriage is a partnership, isn’t it, you don’t just abandon them and skip off over the hills just because, you know they’ve er, had the stroke, you know.” (Amanda). This illustrates Amanda’s level of commitment to her spouse. Similarly to marital obligations, this appeared to be based upon the relationship caregivers had with their care-recipient. Sarah describing her close relationship with her mother, summed up this connection: “Yes I feel I have a responsibility to them. Erm but I also feel that I have a duty, erm I do feel it’s

my duty to help them. Especially mum” (Sarah), She described caregiving as a ‘commitment’ to help those that you care for.

c. Personal characteristics – part of who you are

In a way similar to how caregivers described their previous roles and experiences as preparing them to deal with stroke, personal characteristics also appeared to play a role in acceptance of caring roles. Participants described themselves as ‘caring’ and ‘loyal.’ Lynn said, “I think I’m a caring person actually and so I just do it.” Amanda discussed this in terms of her previous caring roles with caregiving a continuation of this.

“I mean I’ve always (laughs) sort of looked after him haven’t I really. I’ve looked after the family, having three children, (pause) You’re you’re you’re into a caring way aren’t you and you when your children are little” (Amanda).

This is in keeping with other research which found prior experience to minimise caregiver distress (Greenwood et al., 2010)

Theme 4: Continuing Fragility

Caregiver appeared to describe a number of barriers to living life for themselves. Fragility of their partners or relatives seemed to be an over-arching theme which ran throughout the main story for carers. This fragility was divided into fragility of partners’ well-being; of participants’ own ‘lifeline’ (autonomy); and balancing the demands of caring and coping.

a. Fragility and Vulnerability of partners well-being

Caregivers described ongoing worries about their partners’ health and well-being. This appeared to be linked to the severity and unexpected nature of stroke with the majority of carers

expressing concern that stroke may reoccur “That's one of the biggest things. You’re constantly worried about is he okay. Is it going to happen again.” (Kate). One participant said:

“Well hopefully he will carry on living (intake), I know once you’ve had a stroke your quite, very likely to have another one. I do understand that and I know that and think about that quite often, most days. And I know very well, unless something untoward happens he will die before me” (Amanda).

Caregivers described feeling weighed down with continued concern for their partners’ well-being and ongoing health difficulties added to this. Participants’ also discussed their anxieties about care-recipients’ risks-to-themselves, for example, leaving the cooker on. John described his ongoing concerns for his wife’s safety,

“You know she tries to do things for herself. Frightens me to death if I'm boiling some water, for like the pasta and she'll go in there messing about, and I'm frightened to death that she'll just pull it on top of herself” (John).

This anxiety led to some caregivers rarely leaving their partner alone or out of sight. Some even described asking care-recipients to stay where they were until they returned when running errands.

Seeing them as child

The perceived vulnerability of the care-recipient appeared to have a significant impact upon close personal relationships making it difficult for caregivers to move between the role of caregiver and spouse. Harold described seeing Jean as his patient and described how he was “afraid she'd break if [he] made love with her.” This demonstrates Harold’s concern about Jean’s continued fragility and his fears about causing her any unnecessary stress. This extended to other areas for carers, for example, choosing not to involve care-recipients in decision making due to concerns about worrying them.

On several occasions, caregivers described having ultimate responsibility for care-recipients well-being. Re-reading the transcripts reinforced the idea of care-recipients' dependence on the caregiver, removing their independent adult status. Lynn described this saying "I feel sometimes as though I'm dealing with a child... it really is [] I don't know it's just (long pause) you just worry about them, like a child coz you have to watch them, all the time." As discussed, this anxiety about care-recipients' ability to function independently appeared to raise caregivers' anxieties about leaving individuals alone. In addition, caregivers gave cases where care-recipients demanded to have their needs met, or disliked being left alone. Amanda described that "a stroke, a really bad stroke like my husband had, puts you back to the status of when you are, when you're an infant really. You're completely and utterly helpless, couldn't feed himself or (pause) errr..." This idea was reinforced by participants' descriptions of things that care-recipients were no longer able to achieve. While this was slightly different for Sarah, who was caring for her mother, there was still a suggestion that they had switched roles: "it was completely reversed and she asks me now about my opinion on things. [] I've become the senior member of the family." This highlights the transition towards a parental role.

b. Fragility of carer's lifeline

The ongoing responsibility clearly impacted on caregivers' ability to make time for themselves. The fragility of this 'life line' was primarily dependent on the recovery and progress of the care-recipient and entrusting care to other family members. Caregivers also emphasised the importance of care-recipient's recovery for reclaiming their lived life together. As Harold says "As she improves, our life is getting more as we would like it, as we had planned and as it was before the stroke. There's a long way to go. But it's improving all the time." (Harold). This

suggests that getting ‘back to normal’ was important for the couple, with their future plans dependent on Jean’s recovery.

Importance of having a lifeline

All caregivers described breaks as important for their health and well-being, valuing the opportunity to “just completely switch off from your day to day worries.” (Amanda). For some carers having one or two hours away from the home was beneficial and carers looked forward to these ‘breaks.’ Brian described this saying:

“Well it gives me a a a (struggling) break from (pause) caring if you like and cooking and cleaning. And it's it's something I look forward to. That's why I look forward to it.” (Brian).

It appeared important for participants to have time out of the situation, providing stimulation, from seeing different people and doing different things. Amanda went on to describe the importance of doing other things for her own self-concept saying:

“It started when the children were little. That was so nice to have a break, you know, from being the children’s mother or or Nick’s wife, you know. You go somewhere else and then you’re you aren’t you? ” (Amanda).

Having time outside the role enabled Amanda to be ‘herself’ without solely being seen as a carer.

It is likely that the care-recipient and being ‘off duty’ from the caring role also relieved participants of the responsibility they felt for caring for another. Harold echoed these reasons saying, “Whatever problems you have for a couple of hours, not to have them, just to be able to forget about them.”

A number of caregivers referred to difficulties arising from being ‘stuck within four walls’. Amanda clarified this saying:

“When I felt that I had just got to get out, and un, you know, this is awful, you know, and I’d walk up the lane holding back the tears, you know what I mean, but it was a reason to go out. I should imagine that your sort of in four walls, that’s when depression and dark moods come. Don’t they, it you can’t get out.” (Amanda).

This engenders an image of caregivers and care-recipients feeling imprisoned by the stroke suggesting that leaving the house helped to improve their psychological well-being.

Contemplating making a life for oneself

Despite all participants recognising the importance of respite for their own mental health, participants had difficulty identifying goals for themselves. Caregivers found it difficult to think about their own life goals. Indeed, in contemplating making a life for oneself caregivers appeared to describe having to face what this would mean for them. Choosing to either move forward alone or wait for the physical improvement or recovery of the partner. Some caregivers alluded to the finality of moving forward describing the guilt attached to this. Amanda emphasised this saying:

“Well I suppose I take my erm, example from loads and loads of ladies I know who’s, haven’t got a husband through divorce or, or they’ve died, you know. And they sort of, they go to now end of different clubs (laughs) and the life of Reilly, you know. Whereas I wouldn’t like that at the moment but I, I think I would cope, I think I would cope.”(Amanda).

likening her situation to that of a widow. Other caregivers also discussed guilt at contemplating activities without the partner, particularly those that they had previously shared. For example, Daphne describing how she would like to get back into rambling said,

“And I mean I have been, like I said with my sister and that on occasions. But I feel sad for leaving him behind. You know when he, we’ve always enjoyed doing it together. So I don’t really emphasise [going out] too much with him. Erm (Long pause 6 sec)”.
(Daphne).

This highlights the feelings of betrayal and separation involved in being able to lead their own life, as it once was together.

c. Fragility of balancing demands of caring and coping

Caregivers appeared to deal with this struggle by balancing the demands of caring and coping in different ways. All eight participants described caregiving as a full time commitment with Lynn reporting she has had just one and a half days out in two and a half years. Other caregivers also described similar feelings. For example, Daphne talked of “feel[ing] restricted, [] always watching the clock, [and] always [being] aware of your limitations.” (Daphne). This also impacted on caregivers at work. Kate recognised this saying, “If I know he's asleep before I go. I'm fine. If he's still awake and a bit restless or something, I can't relax at work either.” This highlights the total responsibility caregivers described throughout the interviews and demonstrates the struggle that participants faced, putting themselves first when they were ‘holding’ complete responsibility for the other.

Caregivers described feeling many competing pressures related to the caregiving role and these often took priority over ‘leisure’ time. Sarah described a list of “things at the back of [her] mind”:

“Worried about mum and dad erm worried if dad's coping or not. Erm If anything happens to dad, what would happen, mum would automatically have to go into nursing home. We, I couldn't look after her on my own. Erm worrying if, if she has another stroke. Erm, worrying if, coz they usually have a list of things to do for them, and strike [them off my list]. I put everything in writing. But trying to go through the list at night and sometimes I wake up and remember that I haven't done anything. Perhaps haven't ordered their medication or picked, picked up the prescription or somebody I should have telephoned or written to and I haven't. Erm (pause) there always seems to be nagging things at the back of your mind.” (Sarah)

This extensive ‘list’ highlights the competing demands and the unrelenting responsibility that caregivers experienced in the role. Many of the participants appeared to have put their own needs aside to care for their spouses. Daphne said:

“I mean you [] spoke about goals at the beginning and I thought I don't know what, I don't really know what our goals are any more. I knew what they before Alistair had his stroke. But all I, all my goal is, is to keep erm Alistair well and cared for to the best of my ability.

This appeared to be one of the ways that caregivers managed the competing pressure and demands, As discussed above, all caregivers described difficulties balancing the demands of caregiving and identifying time for themselves. This highlights how providing care to the best of their ability became one of the main goals for many participants.

Caregivers life on hold

Caregivers also described a struggle to prioritise their own needs. For these reasons some carers had stopped considering a life for themselves or put their own lives ‘on hold’. Sarah, who was providing care for her mother, described waiting for the time when her and her partner would be able to re-start their lives. She explained:

“I can't reconcile my personal goals at the moment with the caregiving. And I think that my goals and needs have been put on hold and I realise that and I accept it. Erm I'm not sure it should happen and I'm not sure it's right (sigh) but that's the only way that I can operate at the moment. I can't operate any other way because I would just be pulling myself in too many directions. So (intake) they're not reconciled because at the moment I I don't have any. Erm but in the future when mum and dad aren't here then I would be freed up for my personal goals and I'll be able to pursue them.” (Sarah)

This clearly describes Sarah’s recognition that in order to manage the demands of caregiving she has to temporarily put her own her plans on hold to focus on her caring duties emphasising this as a management strategy.

Living life through stroke

Another theme common to participants experiences was the ways that caregivers reported balancing the demands of caregiving. This involved taking enjoyment in the new activities in their lives with many caregivers becoming involved in stroke groups and additional volunteering.

Lynn said, about her involvement in stroke groups:

“Because all, all you have, when you have a stroke people, like with us, people don't tend to bother with you anymore. (Pause) Probably because you're different. And the social life now is all round Stroke club and young Stroke club, [] and that's what I have to do now is sort of, keep enjoying all these things, that I take him to”(Lynn)

This suggests an acceptance of the new things in Lynn's life and indicates the effort to take enjoyment from the opportunities available to her. This was something that all the participants shared and some caregivers listed numerous activities they had “immersed [their] life[ves] into.”

Daphne went on to say:

“So the week starts, Monday is a free day. Tuesday I take him to him stroke group, from about half ten till half two which enables me to have a couple hours shopping or in town. [] Wednesday he goes to a computer class [] Thursday is a free day. And Friday I take him down to [X] for eleven o'clock, half past 11 till 1 o'clock [] On a Saturday I take him to erm another stroke group [] And it's very well attended that is and I I stay there.”
(Daphne)

Caregivers described activities becoming functional and partnered, living for the other and alludes to activities becoming partnered and shared in different ways. Interestingly, the three younger caregivers discussed the importance of having something in their lives that was not related to stroke, expressing concerns about their own mental stimulation.

Theme 5: Adapting as a team

a. Importance of previous relationship context

It should be noted that the above theme ‘adapting as a team’ does not suggest that all participants were able to do this. It instead emphasises the importance of the previous relational context in how couples were able to adapt and adjust. A number of participants identified previous affinity as pivotal for how they coped with the caregiving. Amanda explained this saying:

“Like I say we we always have been close (pause) and I could imagine it’s hell on earth if you, if you’re not very close or if you don’t like your husband very much.”(Amanda)

This emphasises the vital role that positive relationships contribute to the caregiving relationship.

Sarah went on to say:

“Erm I think if you've got the right framework in place and you've got the right attitude and relationship with the person you're caring for it can be a wonderful experience. But everything has to be, has to be right. and you don't know until you're in the middle of it unfortunately.”(Sarah)

This highlights the emotional uncertainty that caregivers adapt to in relation to the physical and relational changes brought about by stroke. Therefore, caregivers may require external support due to the intensity of the caregiving relationship.

b. Importance of feeling supported

Caregivers described the importance of knowing someone was there. Sarah suggested that it was the level of support that allowed caregivers to glean benefits from the role: “Erm (intake) its its really diff[icult], if you get the right level of support and people around you it can be a very rewarding experience.” Interestingly, this seemed to go further than physical and tangible

support, and knowing that there was someone there to turn to in an emergency appeared to be more important for caregivers than having them provide support. This appeared to be related to support outside of the dyad. Brian gave an example of this saying, “If I was in trouble I'd only have to pick the phone up and one of [his family] would be here.” Caregivers appeared to be most comfortable in asking family members for support and they seemed to be the primary source of respite. Being able to trust those providing care appeared to be facilitate caregivers being able to take time for themselves. Amanda described this, saying:

“You mean er, to go to my er (pause) (sigh) (pause) Well, well knowing that Nick, Nick, my husband was being looked after, my son and his and his wife where there, fine. I didn't have to worry or concern myself I could just go out., meet (pause) ladies that I'm friendly with, have a good old gossip,” (Amanda)

Knowing that Nick was with family members helped her to take time for herself. Caregivers also sought formal support from services. However, some caregivers found it difficult to hand over responsibility and preferred to provide care themselves. Kate talked about “knowing how to accept that support”, going on to say that “to say that, no I can't cope is like being a failure. (pause) Even though you know up here it isn't actually accepting it is is quite difficult” (Kate). Stroke groups appeared to provide a legitimate space for caregivers to talk openly about their feelings. Lynn captured the emotional support available from the groups

“Yes well I think really going to the stroke club erm you're meeting other people, carers, that have also dealing with stroke and often when we go in we put our arms round each other and we wouldn't do that going to,... somewhere else but we all put our arms round each other and give us a hug, you know and that's nice. And we all, I feel we all look the same (laughs) you know” (Lynn)

Lynn's description of feeling that caregivers looked the same indicates a sense of belonging and there was a sense of emotional support discussed around the stroke groups. All participants described knowing that others understood their situation without needing to have it spoken.

Participants described gaining emotional support from their shared experiences feeling closer to others in similar situations.

c. Importance of feeling valued

Feeling that their efforts were appreciated, particularly by the person they were caring for, also appeared to enable caregivers to feel supported. Daphne, talking about the boost from positive feedback said:

“Erm, one thing I do draw from and one thing I do er get a lot of er feedback from are people that you know, and friends and that, they do say, to me (Long pause) you know, you're doing a fantastic job and all that business, you know. And it is, that is a boost and er.” (Daphne)

Daphne seemed to benefit from being recognised for doing the job well, boosting her mood and reinforcing her efforts. Other caregivers also described this. Sarah, who was of working age, highlighted that for her although there was a sense of achievement from the role, it was different from a professional sense of achievement. This perhaps reflects that unpaid work is seen as less ‘worthwhile’ by society.

d. Seeing it as a job – keeping things separate

Approaching caregiving as a job enabled some carers to maintain the sense of themselves and improve their function both within and independently of the role. It also appeared to maintain motivation by taking on a new job and doing it to the best of their abilities. Daphne described this saying:

“I did thoroughly enjoy working I loved being out and about and working. And I will say that I've taken what happened, like Bill, my husband, as, on as a project, in a way. You know erm (Long pause 4 sec) This is what I've immersed my life into now you know.” (Daphne)

Daphne appeared to describe finding enjoyment at immersing her efforts into caregiving, doing another job to the best of her abilities. This was possibly another way in which caregivers could gain satisfaction and positives from the altered situation. Sarah, echoed this saying:

“I try to keep the, our two life’s quite separate. I try not to bring mum and dad’s life back home here. I almost see it as a job actually. Where I, I try to leave the problems at work, when I worked full time and tried not to bring them home” (Sarah)

Whilst Sarah went on to say that this was not as always easy it appeared to be a helpful way of maintain her life with her husband. Participants also described trying to keep the two lives separate by protecting friends when they met socially. They described by not going into too much detail with them about their problems preferring to use Stroke Groups as a release in this way.

d. Features of the role:

Participants appeared to fulfil many roles within the caregiving relationship. These roles described caregivers’ input into individuals’ progress and recovery, and were linked to the ongoing responsibility for others, such as being a motivator, (*my job at the moment is to help motivate*) facilitator (*If I didn’t do that then no-one else would*) and advocate (*If you don’t ask you don’t get*).

All participants had managed to build comparatively active lives despite the restrictions brought about by stroke. This appeared to be motivated by caregivers wanting to do a good job and do their best by their partner, including improving their quality of life. Harold put it this way: “Yes. That’s my job at the moment, is to help and motivate Jean.”

Interestingly all caregivers discussed their role as rehabilitators encouraging their partners to push that little bit further, by focusing on the positives and the ‘small steps.’ These descriptions also gave rise to a feeling of satisfaction that caregivers felt when they did make progress. As Brian

described, “But slowly but surely, with hard work, I improved her,” (Brian). Caregivers also described facilitating and organising activities, for example, the list of activities or groups carers organised. A number of carers discussed the importance of this for the mental health of the care-recipient. Sarah emphasised this describing the role that caregivers play in adding to quality of care-recipient’s life. Another role that caregivers commonly took on was the role of advocate. This appeared to relate to making sure that caregivers were doing their best for the care-recipient by ensuring they had the support they needed and were entitled to. Lynn described enlisting help and finding support for Kevin:

“And I got the referral within the fortnight so that's where you've got a bit of power and you've got a power with stroke club as well with [] because [you] can move things so its finding out who'll help you, without, [] being stuck at the doctors all the time there, there are ways round it” (Lynn)

There was a sense of empowerment and improved self-efficacy as caregivers understood how to get things when they were required.

e. Learning to cope

Self-Realisation

Caregivers’ ability to cope and adapt was not solely linked to adjustment but also a process of self realisation and self development. Participants discussed learning about themselves through the process of caregiving, referring to inner strength. Kate described this,

“(cough) Well I think that everybody, in their life, when shove, when shove comes to push they always find it from somewhere. You know er, (Long pause 6 sec) there's always something inside you tells you you can't give up. No. (Long pause) although there are some days, and you think oh is it worth it. (Long pause) erm (pause) but in the end your common sense and your (Long pause) personal, inner strength will help you come out. It's erm (pause) it's a funny thing. You've got to be in the situation, first.” (Kate)

Kate described having to be in a difficult situation in order to realise how strong they could be. This was linked to mastery of the role and recognition when they were doing things well or gaining confidence in new skills, for one caregiver organising a suitable vehicle for her husband was something she took great pride in. One caregiver felt effective as a caregiver when she had ‘a bit of power’ from requesting services and appointments, all linked to self-efficacy and motivation.

Remaining positive – “Thinking positive, at all times”.

Personal characteristics also played a role in learning to cope. All participants emphasised the importance of thinking positively and focusing on progress, Amanda talked about noting the milestone, no matter how small:

“How would anybody else cope? (Long pause) I suppose, (pause) look to the little milestones, as they go along, and put that as a little mental tick, yes that’s another little, little achievement. [] And, And I think you’ve got to think of these positives some of the time, not think of the negatives, the negatives are there, you don’t, need to have half a brain to, think of the negatives [] Otherwise you, you’d just go into a pit [] won’t you.”(Amanda).

Focussing on the positives also appeared to facilitate acceptance of the situation and be linked to caregivers’ awareness of the benefits of this to their own mental health.

Living life in the past

The majority of caregivers also described thinking of the past and focusing on the good memories as a way of coping with the restrictions they were now facing. When asked how she coped with the caregiving role, Lynn said:

“(Long pause) Oh (sigh) (Pause) I don't know. I mean I don't think about that I always think about the past and how much I, it keeps me going what I did. I think about that because really the future it's just looking after Kevin.” (Lynn)

Lynn described her use of memories to help to keep her going. Thinking about her good life and good marriage has helped her to accept the current changes related to stroke. Daphne contextualised this saying “You know, you do er, you do think back to what you have done with your life. (Intake) And erm there's a very, there a tremendous acceptance to what life has dealt you.” These extracts appear to suggest that positive memories of life before the stroke can facilitate carers' acceptance of ‘the hand’ they have been dealt. This alludes to a position of fatalism. It also perhaps suggests that those caregivers who do not perceive these positive memories may not be able to look to these as a coping mechanism.

Keeping life full – life's for living

Caregivers discussed the importance of having mental stimulation for own psychological well-being. Activities such as being with the family, being outside, interacting with grandchildren, and having breaks and holidays were all described as an important and positive focus. Both Amanda and Harold highlight the importance of activities for caregivers' mental health:

“Yes, Yes, What I did last year I just went for a good walk (pause). And I think the actual physical exercise, the adrenalin, is a sort of bit of a pick me up anyway isn’t it, and the and the sunshine and seeing different. You know, walking around a long, go down to the canal, you know, where the ducks are and things like that, that’s the sort of person I am I like, I like walking about” (Amanda)

“Jean didn't (die) so she's still here I am eternally grateful for that. Let's not waste it. She's here for a reason.” (Harold)

Harold suggests that he perceives that ‘life is for the living’ and caregivers described stroke as re-focusing what is important. A number of participants discussed the importance of stimulation for themselves and the care-recipient. This appeared to be linked to immersing themselves in lived life rather than becoming ‘stuck’ behind four walls and existing, describing the importance of meeting different people and doing different things as a way of keeping stimulated. In this way participants talked about the importance of family and groups to facilitate their participation. Caregivers highlighted the importance of getting out, in spite of the previously discussed barriers to this, to “remind me I’m alive”.

Discussion

The aim of this study was to investigate how caregivers reconcile their individual life goals with their ongoing care giving commitments. This was with the further aim of understanding how these goals relate to caregiver psychological wellbeing. However, in exploring caregiver coping, the fragility of caregivers' own life-lines became apparent and emerged as a central theme. The caregivers in this study found it difficult to think about their own life-goals and the study found that focussing on personal goals appeared to be an inappropriate question. Instead, participants told a story of continual re-adjustment to the changes brought about by stroke; through shock and loss, to describing their motivations to care, and adapting as a team. Carers' own life goals tended not to be a part of this story, and were not brought to mind easily, or without reference to their partners or relatives, their partners' vulnerability, and carers' own feelings of obligation and guilt. The study found that in place of focusing on their own needs, carers typically made efforts to embrace the care giving role, opting to suspend or put 'on hold' their own life goals, taking enjoyment from the activities that were available to them as carers, such as organising opportunities for those that they were caring for e.g. finding computer courses, or becoming involved in support groups.

The main story described by caregivers in this study, shares similarities with previous qualitative research, for example, the initial shock, taking on new demands, dependence on others for support, and the necessary reassessment of goals (Anderson, et al., 1995; Coombs, 2007). A recent review by Greenwood and Mackenzie (2010) emphasised the significant change, loss, and uncertainty that caregivers experience in response to stroke. Their review also highlighted the process of acceptance and adjustment that caregivers go through in order to move forward. In keeping with this study, other research has also highlighted lost independence and restricted

activity amongst caregivers (Greenwood, Mackenzie, Cloud and Wilson, 2009; Pearlin et al, 1990; Nieboer et al., 1998; Wade et al., 1986). Caregiver attempts to get ‘back to normal’ were also dependent on care-recipients’ recovery and physical capabilities. Greenwood et al. (2009) described a variety of coping strategies caregivers used to manage their experiences and increase their control on their environment, for example prioritising some activities over others. This was seen in the current study with caregivers refocusing their efforts into the caregiving role; gaining satisfaction from becoming motivators, facilitators and advocates. This is similar to other research which describes caregivers re-focussing their activity on their partner and involving themselves in the caring role (Cao et al., 2010; Ekwall & Halberg, 2007). Shulz and Heckhausen (1996) also talked of selection, optimisation and compensation strategies in the SOC model. They discussed delimited opportunities in relation to age and reducing opportunities to participate in desired activities and can be paralleled to the restrictions enforced upon couples by stroke. Shulz and Heckhausen (1996) also distinguished between ‘elective decisions’ to reduce activities (e.g. stopping an activity due to lack of interest) and ‘loss-based’ decisions (e.g. stopping an activity due to decreased mobility). This perhaps indicates another psychological factor in caregiver well-being and reduced activity.

This study also highlights other barriers and concerns that caregivers face in reconciling caregiving with their own life goals, for example guilt and anxiety (as described above). Previous research conducted with caregivers of those with stroke identified similar barriers to making time for themselves. Cao et al. (2010) reported that caregivers described feelings of guilt when taking time for their own activities. Their research also pointed to caregivers’ activities becoming increasingly partnered, with caregivers re-focusing upon their partners’ needs. However, this description does not encompass the relational aspects of caregiving highlighted in this study.

Adapting as a team was a theme which appeared to underpin readjustment to the changes brought about by stroke, with caregivers stating the importance of the previous relationship with the individual, thereby emphasising the relational aspect of caregiving. Indeed, it is increasingly being recognised that attention must be paid to the holistic needs of the care dyad. Hellstrom, Nolan, and Lundh (2005) stressed the importance of ‘couplehood’ in coping with dementia in terms of maintaining a sense of self and agency for the individual with dementia. However, it is likely that working together can create a sense of agency and control, improving self-efficacy in both the caregiver and care-recipient. Interestingly, Hellstrom et al. (2005) suggested that in the case of couples, it may not simply be that caregivers put care-recipients’ needs before their own but that the couple becomes the primary focus. This appears to be supported by this study, as caregivers seem to manage the situation by taking agency and living their life through stroke. Bute, Donovan-Kicken and Martins (2007) exploring the relational perspective in those with communication difficulties also emphasised the role of commitment to the other, suggesting that the ability to take part in shared activity was fundamental to the relationship.

Although the findings of this study did not suggest that caregivers’ own life-goals were fundamental to caregiver coping and mental health, they did suggest that improved mental health might be facilitated through establishing opportunities for caregivers and their partners to take part in valued activities outside of the home, such as integrating with others. A number of participants emphasised the importance of ‘stimulation’ (being mentally stimulated) for both their and their care-recipient’s mental health. This is in keeping with other research identifying the benefits of activity on caregiver mental health (Nieboer et al., 1998; Reich & Zautra, 1981; Rochette, et al., 2007; Wade, et al., 1986). It was also notable that having a focus unrelated to stroke was also important for some carers, for example spending time with family or friends.

Participants recognised the importance of getting outside of the ‘four walls.’ The study indicated that having opportunities away from the responsibility of the caregiving role appeared to be related to participants’ quality of life, having a positive effect upon caregivers’ sense of agency and self-identity. However, as discussed above this did not necessarily have to be time away from the care-recipient. Caregivers themselves identified the importance of ‘feeling appreciated’ and discussed and discussed gaining satisfaction from feeling they had done their role well.

An interesting link can be made to the ‘Capabilities Approach’, used by the UN to measure human development. Originally introduced by Sen (1985) in relation to welfare economics and social poverty, the capabilities approach is concerned with ‘evaluating an individual’s life in terms of his or her active ability to achieve various valuable functionings as a part of living’ (Sen, 1993 cited in Naussbaum & Sen, (1993) p.30). Sen (1985) believed that recognising the barriers that individuals face to realising their potential may facilitate the process of development. This holistic model of quality of life and well-being has been applied to health, disability and mental health. Having opportunities to become involved in activities where individuals themselves feel valued may enable caregivers to feel held in esteem by society (Ekwall & Halberg, 2007; Knoop, 1994). It is likely that social recognition of the importance of the caregiving role is important to this.

Hopper (2007) has discussed the capabilities approach in relation to people with a diagnosis of schizophrenia, highlighting the importance of societal re-integration in terms of allowing people to regain their competencies. He also discussed the importance of ‘re-calibrating’ goals and lowering aspirations to be more in keeping with the new possibilities. This was also discussed by caregivers in this study, who recognised that re-directing and putting their own goals on hold was necessary to facilitate their adjustment to their new circumstances and improve

their well-being. Caregivers did not appear to spontaneously speak about the positives change brought about by stroke, but instead described the effort required to remain positive.

Hopper (2007) listed five areas in which services can increase patient capabilities; renewing a sense of possibility, regaining competencies, reconnecting and finding a place in society, and reconciliation work (re-building a sense of a functional individual). Again these areas have potential implications for improving the number of opportunities caregivers can have to become involved in valued activities where they themselves feel valued, with the aim of improved self-efficacy and mental health. This seems to overlap with some concepts of caregiver self-efficacy, in terms of increasing confidence in their abilities. It also touches upon building self-identity outside that of a patient or caregiver and upon the themes of self realisation and mastery identified in this study.

Hopper (2007) discussed that patients did best when the choice of activities was not restricted saying “What one chooses is less important than the range of valued options actually entertained, developmentally available and socially sanctioned” (Hopper, 2007, p.874). It is therefore important that caregivers find activities that they themselves find reinforcing. Offering choice could also facilitate caregivers well-being by enabling them to not to feel restricted and to ‘keep their lives full’. Empowering people to have ‘agency,’ and control with the potential to make choices, may be another way of renewing a sense of possibility and finding a valued place in society (Knoop, 1994b; Nieboer, 1998). Shulz and Heckhausen (1996) emphasised that having control over the choices we make, and ‘reconstructing’ goals (p.616) successfully is an important part of psychological well-being in the ageing process.

Unfortunately current opportunities for caregivers, either singularly or with their partner, are limited and caregiver intervention typically tails off in the months following discharge

(Cameron & Gignac, 2008). In addition the take-up of respite remains poor (Shaw et al., 2009). This study builds on existing knowledge we have about the psychological challenges that caregivers face, and highlights feelings of guilt, anxiety and commitment as additional barriers to considering respite options. An improved awareness of these additional factors may help services to plan more effective caregiver provision and interventions. It appears that having time away from the caring role rather than having time away from the care-recipient is important to caregivers. This may be linked to caregivers' readiness to move forward to make a life on their own but also the fundamental enjoyment in the sharing of recreational activities. The study recognises that the burden of care giving does not weaken bonds of personal feeling, commitment and affection for a loved one, rather that 'time off' from the responsibility for another may benefit caregivers. This has also been found elsewhere; van den Heuvel et al. (2001) found that caregiver strain was not related to time spent caring but to the opportunity caregivers had to spend time away from the role. These findings recognise the importance of taking a break from the role but suggest that rather than enforcing respite, taking a break from the caring role (but not the care recipient) may be one method of enhancing caregiver support and well being. This seems particularly pertinent as the numbers of informal caregivers continues to increase.

The research findings above suggest that it is important for services to recognise that successful adaption to the caregiving role requires ongoing support. In addition, recovery is not solely linked to the care-recipients physical limitations but also to the social restrictions brought about by stroke. Therefore, interventions addressing these factors may be best placed to improve caregiver outcomes. There are many potential avenues for community-led interventions but these would require strategic provision to create meaningful opportunities for caregivers, and their partners. Building up relationships with a key-worker whilst caregivers are visiting hospital may

be a way of caregivers being able to access support when they are ready, for example, signposting caregivers to stroke support and other community activity groups. Wallcroft (2010) speaking on the applications of the capabilities approach with mental health suggested that services and interventions should be measured in terms of how well they enable people to develop their chosen capabilities. The success of this could also be measured using psychological outcomes and caregiver well-being.

Several limitations to this study should be mentioned. The study only included a small sample. However, the use of IPA methodology provided detailed and in-depth insights into the experiences of eight individual's caregivers. Five of the eight participants were female, and all participants were white British, limiting the potential diversity of the sample. This is typical of other caregiving samples and representative of the caregiving population (Office of National Statistics, 2001). Due to the nature of the recruitment process, all participants attended an organised Stroke support Group. In addition, a number of participants also volunteered for and attended other groups. This may have been indicative of caregivers' motivation levels and self-efficacy in accessing meaningful and valued opportunities improving their psychological outcome, which may contrast with those caregivers not part of such groups. Whilst the similar backgrounds of the participants may have influenced the homogeneity of the results, the analogous experiences and concerns described by the participants' increases confidence in the shared aspects of caregiver experiences in relation to their life-goals. The level of interpretation required by IPA may have also affected the conclusions drawn from the interviews. To improve their credibility, the themes were discussed with my supervisor and colleagues familiar with IPA. A personal reflection on the research has also been included (please see appendix 5).

To better understand how decreased opportunity for valued goals may affect caregiver coping, future research may benefit from exploring these ideas with those not accessing support groups or who are geographically isolated. It is likely that the recruitment of these participants would present challenges. Perhaps building relationships with caregivers whilst patients are in hospital or involving service users in research planning may improve recruitment. One of the recommendations from the National Institute for Health Research: Health Technology Assessment review of respite care in the frail elderly (Shaw et al., 2009, p.4) suggested that ‘more qualitative research is needed to explore the meaning of a ‘mental break’ and how interventions may be developed to help carers achieve this.’ This paper shows that taking a ‘mental break’ does not have to be time away from the care recipient but instead a break from the responsibility of care. It is therefore hoped that the findings from this study can be built upon to better understand how to support caregivers in fulfilling their capabilities, by expanding their opportunities to be involved in meaningful activities with the aim of improving their long-term mental health.

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PUBLIC DOMAIN BRIEFING PAPER

THE LIVED EXPERIENCE OF INFORMAL CAREGIVERS OF STROKE.

Lorna M. Gill

This document provides an overview of the research conducted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology programme at the University of Birmingham. This document summarises the literature review and a research paper both written in preparation for submission to peer-reviewed journals.

1. Literature review: A Narrative Synthesis of the qualitative literature on the lived experience of family caregivers for those with stroke.

Background

Research has consistently demonstrated that caregivers have an increased likelihood to develop depression and anxiety compared to the general population and consequently, caregiver well-being has received a wealth of research attention. This attention has predominantly focused upon caregiver burden and the negative impact of stroke on caregiver outcomes e.g. caregiver strain. More recently research has begun to consider a more holistic view of the caregiving process and qualitative research has begun to add to previous research, highlighting issues such as the coping strategies that carers use to manage the caregiving situation, and the positive aspects of caring. However, due to the nature of qualitative methods (that is, the requirement to focus on the experiences of the individual), there has been little synthesis of qualitative findings.. Therefore a narrative review was conducted to ‘pull together’ the findings from qualitative studies which examined caregivers’ experiences of caring for those with stroke.

Conclusions

The review found that the caregivers in the included studies appeared to describe a process which they moved through in adjusting to their caregiving role. This story appeared to fit under 5 over-arching themes, these were: ‘on becoming a carer’, ‘being a carer’, ‘acknowledging what was lost’, ‘managing the caregiving role’, and ‘an added element’. For a further break-down of the themes please refer to figure 1 below.

On becoming a carer	Being a carer	Acknowledging what was lost	Managing the caregiving role	An added element
<ul style="list-style-type: none"> • Shock • Uncertainty • Feeling Outside the system • Unpreparedness • Why Care? 	<ul style="list-style-type: none"> • Unrelenting responsibility • Constant demands • Burden 	<ul style="list-style-type: none"> • Loss of individual • Loss of self • Loss of valued activities • Loss of normality 	<ul style="list-style-type: none"> • Restructuring and adjusting • Support • Information 	<ul style="list-style-type: none"> • Meaning making • Perspective Taking • Personal Growth • Closer Relationships

Figure 1: Table of Emergent themes

The themes identified in the review also shared some similarities with themes identified in caregivers for those with other chronic conditions, for example caregivers for those with dementia, and multiple sclerosis. The research suggested that whilst no individual is the same there may be common experiences associated with the caregiving role.

2. Research paper: An explorative study of what caregivers understand the relationship to be between their own life goals and their caregiving commitments.

Background

Past research has shown that self-efficacy (an individual’s confidence in their ability to achieve a certain outcome) can influence life satisfaction and psychological well-being. Knoop (1994) explored the role of self-efficacy in relation to job satisfaction and found that workers

experienced reduced stress if they valued their role and saw it to be purposeful. Therefore, if caregivers find satisfaction in caregiving it seems reasonable to suggest that they are less likely to experience depressive symptoms. Whilst there have been a number of studies investigating self-efficacy in caregivers abilities to manage the caregiving tasks, to date, the relationship between self-efficacy for obtaining life goals and psychological well-being has remained a largely unexplored area. This study hoped to explore how caregivers reconcile their own life goals and their caregiving commitments, using one-to-one interviews with caregivers, with the secondary aim of understanding the effect of self-efficacy on caregiver psychological well-being.

Design

A qualitative (interpretative phenomenological analysis (IPA): Smith, 2003) approach was taken to explore what caregivers understand the relationship to be between caregiving commitments and their own life goals. IPA was chosen as it engages with the meaning of the account to better understand individual experience.

Participants

Caregivers were contacted through local stroke support groups. The lead co-ordinators from each group were asked if they were happy to pass on information about the study to their group members. A recruitment poster was also put up at the group's meeting place. Those who were interested in taking part in the study were given a participant information sheet to read before agreeing to take part. Those wishing to take part then contacted the researcher or gave permission to be contacted to arrange a convenient time and place for the interview. A total of 8 carers, (5 females and 3 males) caregiving for those with stroke took part in the research. This is in keeping with the sample size for such projects due to the detailed analysis with the transcribed texts.

Method

The interviews with participants were tape recorded and participants gave written consent for this. The questions followed a semi-structured schedule. Questions were open and non-leading and asked caregivers about the daily activities and whether caregiving prevented them from doing things that were important to them. Questions were piloted to assess for validity, and reviewed following the first interview.

Analysis

The recorded interviews were then anonymised and transcribed verbatim. The transcripts were then re-read several times, making notes of any things of interest in the accounts or emerging themes. This was done independently for each participant to allow the author to engage with the concerns of the individual. A list of themes was produced for each participant. These were then added to and thought about throughout the whole process of analysis, this included the writing up of the data with new interpretations emerging whilst re-ordering the data.

Findings

There were 5 main over-arching themes which emerged from the participants' data.

1. Shock: Caregivers described the enduring trauma associated with the events of stroke.
2. Loss and changed relationships: Stroke necessitated significant change for both the caregiver and care-recipient, including changes in their relationship, roles and activities.
3. Motivations to care: Participants described feelings of marital obligation and commitment as reasons to provide care.

4. Continuing fragility: Caregivers struggled to bring to mind their own goals instead focusing upon the well-being of the care-recipient. Recovery of caregivers' lives also appeared to be related to care-recipient recovery. However, all participants spoke of the importance of 'having a break' for their own mental health.

5. Adapting as a team: A number of caregivers spoke about the importance of previous relationships on establishing a successful caring partnership post-stroke.

Conclusions

The study highlighted caregivers' difficulties in prioritising their own life goals. Caregivers described a number of barriers to taking time for themselves, such as partners or relatives, ongoing vulnerability and carers' own feelings of obligation and guilt. In addition the study highlighted another barrier to moving forward; caregiver recognition that moving forward would mean doing so alone. Caregivers emphasised finding enjoyment in shared activities. The study found that in place of focusing on their own needs, carers typically made efforts to embrace the care giving role, opting to suspend or put 'on hold' their own life goals, taking enjoyment from the activities that were available to them as carers, such as, organising opportunities for those that they were caring for. This relational aspect to participation in activities has also been found in other research and suggests that establishing more opportunities for shared activities may be an effective way of improving caregiver well-being, and offer an alternative to respite care.

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APPENDICES

APPENDIX 1

INSTRUCTIONS TO AUTHORS TO SUBMIT TO 'DISABILITY & REHABILITATION.'

APPENDIX 2

Extract from Study Theme Table - Table 4: Preliminary Synthesis

Study	Themes found	Quotes	Authors Notes	Notes Expansion
Buschenfeld et al. 2009 (UK)	<p>Adjustment –changed lives</p> <p>Home life – partnership</p> <ul style="list-style-type: none"> - protectiveness, anxiety, apprehension - Relationship, loss of familiarity, intimacy, - Wider family <p>Employment – issues giving up or taking up employment, crucial to coping,</p> <p>More central role</p> <p>Social Life –</p> <p>Enduring effects on self – Trauma</p> <p>Centrality of caregiver role-</p> <p>Devaluation of the self was evident –</p> <p>Physical and emotional isolation</p>	<p>(My wife) can't do anything , I do the cooking the ironing, the housework. I never did a great deal in the house, I find it very difficult</p> <p>I was terrified really, because I was worried I didn't want him falling over, hurting himself so I was maybe mothering I suppose but I just wanted to make sure he was safe</p> <p>I've lost my man/ There was no intimacy, there was nothing..you there, me there, that was it. So we were complete and utter strangers</p> <p>Our son helps lift her on the bed and will change her and all sorts. I guess it was a big adjustment for him..I feel like he hasn't had a life as such</p> <p>I wasn't able to be there as much as I really, really wanted to be, because obviously I was seeing to () needs..we would have had a much more hands-on relationship with the four grandchildren</p> <p>I'm really please I kept my job. I need that break. Before Christmas our jobs were on the line and I was thinking 'oh please don't let me go, I couldn't cope with being at home all day.</p> <p>Money isn't everything. Hard at times but you know we'll survive. I've got no wish to go back to work.</p> <p>Because the income stream that she had was going. I then had to appraise exactly where we were going to go as a family from here.</p> <p>Now I virtually don't have any time to myself</p> <p>I just wait for that phone to ring..But I cannot turn the phone off ..and he rings. And if he doesn't ring I'm just thinking that something's happened. So I'm not really enjoying myself.</p> <p>Oh for somebody to phone up and say oh what are you doing, fancy coming down town? Oh yes I'd love to say yes for once instead of saying oh no I can't but nobody don't phone me up, because they know my situation</p> <p>"I don't talk about those first few day so much anymore. They still have the same intensity, because it's still when I think back to that time, it's shock of still seeing him as he was."</p> <p>"At the time when you're up against it, sorting out the shopping, sorting out the kids, sorting out school, sorting out this and the other..you feel like walking away"</p> <p>"My main and only role basically now, is a carer..I feel I haven't got a life as much anymore. Not an individual life. My life revolves around my wife/I have no real individuality anymore"</p> <p>"You become less important, I was the least important person there was. //It's a downward spiral..and you start not caring for yourself"</p> <p>Terrible, so so awful..because who was there to help you?</p> <p>I felt sort of different to people, I though well I know not many people his age have had strokes</p>	<p>Established patterns disrupted</p> <p>protectiveness, anxiety, apprehension</p> <p>Quality of relationship, loss of familiarity, intimacy, wider family</p> <p>Wider family-keep caring within the family</p> <p>Difficulties other family roles, rel.</p> <p>issues giving up or taking up employment dep on how valued crucial to coping, contrast wanted more central role</p> <p>financial concerns</p> <p>restricted activities, time to self, distress at being left alone,</p> <p>isolation</p> <p>New friends, stoke support or other families at hospital</p> <p>Emotional impact, same intensity,</p> <p>Strain and exhaustion, responsibility</p> <p>Loss of individuality</p>	<p>Role reversal</p> <p>Established patterns disrupted</p> <p>protectiveness, anxiety, apprehension</p> <p>Quality of relationship, loss of familiarity, intimacy</p> <p>Difficulties other family roles, rel.</p> <p>issues giving up or taking up employment dep on how valued crucial to coping, contrast wanted more central role</p> <p>financial concerns</p> <p>restricted activities, time to self, distress at being left alone,</p> <p>responsibility</p> <p>Loss of individuality</p> <p>regained a sense of harmony</p> <p>Different path</p> <p>grown in strength</p> <p>Belief in further growth</p>

	Growth-	<p>You couldn't return to where you were..people think that getting better is getting back to as you were. She got better but in a different way. We evolved our life in a different way</p> <p>Whilst he relies on me, I rely on him, works both ways, I think the bond has got stronger, it definitely has got stronger</p> <p>Things are good, getting better all the time, it's not stopped. We're not in the situation where it's going to be like this for the rest of our lives. We've still got our lives to live and we will</p>	<p>regained a sense of harmony Different path</p> <p>grown in strength</p> <p>Belief in further growth</p>	
	<p>Coping- managing emotions Problem focused copin Suppression Humour</p> <p>Past experiences-</p> <p>Comparisons -</p> <p>Social support important</p>	<p>I think at the time the emotions don't really come into it really, you just do what you have to do. I think for a long time I just ignored what I was going through and feeling</p> <p>I think the sense of humour keeps you going through it really, without that you haven't got much hope in this life</p> <p>If I could go through that (divorce) and not feel suicidal and think 'right I need to get on with the rest of my life' I knew I could do the same again</p> <p>I know our friends, his wife had to give her job up to look after him full time./ So I kept thinking well I'm lucky in that respect if you like</p> <p>He wants somewhere to go where it's got his group, his age, but there ain't very many around here that have had a stroke his age</p> <p>There is nothing in (country) for X or younger people unless you're completely disabled or a child..And that made it very very hard. We've got an elderly person's home down the road that takes respite but they are so old there would be no communication at all.</p>	<p>Early stages avoid emotional expression to manage practical task suppression Humour important in defusing emotions</p> <p>Exp of other caregivers/survivors</p> <p>Instrumental support family, friends and services Lack for young carers/stroke</p>	<p>Early stages avoid emotional expression to manage practical task suppression Humour important in defusing emotions</p> <p>Exp of other caregivers/survivors</p> <p>Instrumental support family, friends and services Lack for young carers/stroke</p> <p>Past experiences-</p> <p>Comparisons -</p> <p>Social support important</p>

APPENDIX 3

Complete Supporting Studies Table: Table 5:Table of supporting studies

Literature Review Study Themes: Table 5:Table of Supporting Studies

Super-ordinate theme	Studies showing
<u>On becoming a carer</u> Shock/suddenness Unpreparedness (not having any warning) Anxiety Vulnerability Future stroke About the future Uncertainty	White Limited time to acquire skills Buschenfield Johansson Wallengren Hunt & Smith Backstrom Green & King Buschenfield White Johansson Wallengren King & Semik, Petterson Green & King Smith Johansson Greenwood at al. 2009 Wallengren Green & King Greenwood Hunt & Smith Coombs White Buschenfield King & Semik,
<u>Being a carer</u> New role/ New responsibilities responsibilities Role reversal Multiple roles Demands on time Physical demands Sacrifice others first positions considerations of patient Unrelenting dependency Restricted activities	Cao Green & King Coombs White White Silva-Smith King & Semik Pierce Cao Coombs King & Semik, Hunt & Smith, Silva- Smith Pierce Hunt & Smith Cao Green & King Buschenfield Coombs Pierce Backstrom Cao Coombs Silva- Smith Pierce King & Semik Coombs Cao Johansson Hunt & Smith Bocchi Hunt & Smith Greenwood

<p>Become purposeful</p> <p>Social isolation</p> <p>Time for self</p> <p>Sleep</p>	<p>White Cao</p> <p>White Buschenfield Brittain Bocchi Coombs</p> <p>Backstrom Greenwood Pierce Silva- Smith Petterson</p> <p>Silva- Smith Cao Backstrom Green & King Johansson Coombs Pierce</p>
<p><u>Overwhelming</u> <u>responsibility</u> Responsibility for well- being Responsibility health</p> <p>Extends to devices</p> <p>Protector</p> <p>Anxiety leaving Hypervigilance</p> <p>Obligation</p> <p>Making the decision to avoiding institutionalised care Not wanting outside</p> <p>Being outside the system</p> <p>Information Fighting the system</p>	<p>Buschenfield Johansson Coombs White</p> <p>White Backstrom Johansson Green & King</p> <p>Petterson</p> <p>Wallengren Johansson (supervised)</p> <p>Buschenfield Wallengren</p> <p>Silva- Smith Bocchi Wallengren</p> <p>Cao Coombs Hunt & Smith Backstrom Bocchi</p> <p>Coombs Strudwick & Morris</p> <p>Bocchi</p> <p>Backstrom White Wallengren Greenwood</p>

Appropriateness of service	Backstrom White et al Strudwick & Morris Strudwick & Morris Buschenfield
<u>Acknowledging what was lost/changed life</u> Loss of life as was Loss of home as was Loss of relationship – mutuality Loss of individual Physical/social Loss of autonomy Loss of identity Guilt Distress Uncertainty of future	Cao Wallengren Silva- Smith Buschenfield Petterson Brittain Green & King Wallengren Brittain Petterson White Pierce Johansson Hunt & Smith Green & King Backstrom Buschenfield Coombs Wallengren (physical change) Brittain Johansson Petterson Unpleasant sounds-lose appetite Saliva upset family members. Feeling discomfort- reflux, Acceptability Unboundness Accidents in public Odour Adult status Incorporated security enabling requirement Greenwood Green & King Buschenfield Johansson Wallengren Coombs Hunt & Smith Cao Backstrom Hunt & Smith Buschenfield Greenwood Greenwood Green & King Coombs Silva- Smith Petterson Backstrom
<u>Adjustment/Coping</u> Benefiting from Tangible support Benefiting from Formal support	Bocchi Cao Studwick & Morris Greenwood Backstrom Greenwood Buschenfield Johansson Smith Coombs White Pierce King & Semik, Pierce Studwick & Morris Bocchi (spirituality) Smith (older vs younger) Wallengren Greenwood

<p>Needing support for respite</p> <p>Dependence on others</p> <p>Dependence on formal</p> <p>Unreliability of sppt</p> <p>Diff. others family</p> <p>Normalcy</p> <p>Altered ways</p> <p>Adjusting redefining</p> <p>Meaning making</p> <p>Previous experience</p>	<p>Backstrom Silva- Smith Cao Greenwood Coombs Hunt & Smith, Pierce – feeling inadequate</p> <p>Bocchi Greenwood (rotas) Coombs Wallengren, White Hunt & Smith</p> <p>Greenwood Greenwood</p> <p>Johansson</p> <p>Coombs Pierce White Backstrom Wallengren Johansson Wallengren</p> <p>Backstrom Silva- Smith Green & King Buschenfield Petterson Coombs Wallengren</p> <p>Wallengren Hunt & Smith</p> <p>Greenwood Smith</p>
<p>Planning – helping to make things certain,</p> <p>Selecting, compensation</p> <p>Optimism</p> <p>Positivity</p> <p>Progress</p> <p>Comparisons</p> <p>Humour</p> <p>Avoiding the future</p>	<p>Backstrom Greenwood Johansson Brittain King & Semik, Greenwood Petterson</p> <p>Greenwood</p> <p>Greenwood Greenwood Cao Backstrom Coombs Johansson</p> <p>Greenwood Greenwood Coombs Smith (older) Pierce</p> <p>Wallengren Silva- Smith Smith Backstrom Greenwood Buschenfield Wallengren Bocchi Coombs Green & King</p> <p>Greenwood Buschenfield</p>

One day	Greenwood (couched in vague terms) Buschenfield Wallengren Wallengren Greenwood
<u>Needing a job</u> Working to cope Worrying about finances	Buschenfield Bocchi Buschenfield Backstrom White
<u>Identity</u> New self Mastery Get rid of role realise not possible Growth	Wallengren (no quotes?!) Wallengren White Bocchi - get rid of role and resume life plan when realise not possible positions considerations of patient. Buschenfield
<u>Anxiety on part of recipient</u> Distress for relation	Buschenfield Greenwood Hunt & Smith
<u>Practical versus emotional</u>	Greenwood Buschenfield – early stages avoid emotional to manage practical tasksF
<u>Information</u>	Johansson Smith older versus younger Johansson
<u>Faith</u>	Studwick & Morris Pierce Coombs Appreciation of being alive - Grounding

APPENDIX 4

Brief Introduction to Participant

Appendix 4: Participant

Caregiver Alias	Caregiver Age (yrs)	Care - Recipient Alias	Care-recipient Age (yrs)	Relationship to care-recipient	Length of time caring (yrs)	Occupation	Ethnicity
Amanda	68	Nick	65	wife	2	Retired post-stroke	White British
Lynn	67	Kevin	70	wife	3	Retired pre-stroke	White British
Sarah	57	Elizabeth	89	daughter	3 ½	Retired post-stroke	White British
Daphne	59	Alistair	65	wife	4	Retired post-stroke	White British
Harold*	66	Jean	61	husband	1 ½	Retired post-stroke	White British
Kate	49	Simon	61	wife	1	Full time work	White British
Brian*	81	Gill	80	husband	1 ¼	Retired post-stroke	White British
John	64	Isabelle	60	husband	2	Retired post-stroke	White British

Table 1: Participants' Demographic Information (Carers who chose to have their partners present are indicated with *)

1. Amanda and Nick

Amanda asked to be interviewed somewhere other than her home; a room was found in the Stroke Association offices. Amanda is three years older than her husband Nick, for whom she provides full time care. Nick suffered a stroke 2 years previously and she described the circumstances behind the stroke as tragic and severe and described Nick's loss of speech as the most difficult thing to manage as she felt that she was alone and "almost a widow." It was difficult to gauge what prevented the couple from doing shared activities. Nick was mobile and capable of the majority of his own self-care but there appeared to be some embarrassment about his condition. She described getting support from her daughter by telephone and the couple also had a son. In addition Amanda made a number of references to her poodle being the saving of her state of mind. At the end of the interview Amanda stated that she wished I could meet Nick, saying she thought I would like him.

2. Lynn and Kevin

Lynn and Kevin lived in a rural setting and Lynn described feeling isolated. Kevin suffered a stroke 3 years previously, post-retirement. Lynn also discussed Kevin's difficulties with his speech and described his reliance on her. Although Lynn asked Kevin to come and introduce himself before the interview he declined due to anxieties around his communication. Lynn discussed her previous caring experiences caring for her father from the age of 17 years after he suffered a stroke. She explained that she had just 'gotten on with it'. Throughout the interview Lynn appeared to be surprised at the questions and to really consider her answers, this was particularly related to questions regarding what she did for herself and the future, stating that she 'hadn't really thought about that before'. Lynn did manage to go to choir practice once a week but this was the only thing that she 'allowed' herself time to do. She also described that her daughter lived far away so could not provide support.

3. Sarah and partner Michael, caring for mum with dad

Sarah was interviewed in her own home. She lived separately from her mother whom she cared for daily from 9am to around 2pm, except Sundays. Sarah was a professional career woman who had left her job to support her father to care for her mother. She described being used to a large amount of responsibility and stress in her professional capacity and discussed a perceived drop in status being in a caring role. Sarah suggested that she viewed her caring role as a job and enjoyed getting to know her mother and father better, and in a 'different way'. She was very articulate in the interview, describing the impact of her caring responsibilities on both herself and her husband Michael. She discussed the limits to her own social life, and was concerned with a lack of mental stimulation for herself. She described that their life as a couple was on hold and felt that Michael was more considerate than other husbands might be.

4. Daphne and Alistair

Daphne was the caregiver to her husband Alistair. She had given up work to look after him full time after he had suffered a stroke 4 years earlier. The interview was arranged at a time when Daphne had dropped Alistair off at one of his many classes. Daphne was very chatty, and spoke quickly. She talked about Alistair's vulnerability and pain, and her own feelings of not being prepared for the role. She told me she still felt very young and described that, at 6 years Alistair's junior she was sometimes mistaken for his daughter. She also described how physically large he was and the difficulty she had in manoeuvring him. There appeared to be a lot of sadness around changes in the physical relationship and that the focus of her attention was now on comfort and caring. She described wishing that she got back just a little of what she put in. Daphne also talked about her caring nature and being a people person, describing caring for others in her family. It felt that Daphne had a number of things she wanted to say and I found it difficult to leave. Wrapping up the interview took a further 20 minutes after the final question. Daphne was also the only participant to ring up a few days after the interview to add some other things that she felt she had not said.

5. Harold and Jean

Harold and Jean came as a pair. They met me at the door together and appeared to find it difficult to separate for the interview; with Jean sitting next door and expanding on points from the other room. Harold also often called through asking whether there was anything that Jean would like to add. The couple had met and worked together within the same company. They had both stopped working as a result of the stroke. They described moving each year with their job and they had one son who lived in America. Harold described his son as similar to himself, someone who enjoyed 'giving something back' to the community. They appeared to be content as a couple and most goals for the future were related to improving Jean's recovery. In addition Harold appeared to take pride in Jean's recovery and discussed his previous role motivating personnel in the armed forces.

6. Kate and Simon

Kate was the youngest carer interviewed as part of the research. She had also been in the caring role the shortest length of time, caring for Simon for just 12 months. When I

arrived her sister was present and remained in the room throughout the interview. In comparison to the other interviewees Kate was the only participant still in full time work. She described the difficulties of juggling the demands of caring and work and financial pressures of being a young carer. Of all the interviews I felt the most concerned for Kate due to her acknowledged difficulty turning to others for help. As a result I felt the most pulled to offer advice and support. However I was unable to offer this within my research role. Positively the relationship between Simon and Kate seemed positive and strong. At the end of the interview Kate said how helpful it had been to have her sister present and to know that she had heard how she feels about the caregiving role.

7. Brian and Gill

Brian and Gill were another couple who were interviewed together and in the same room. Again they were very close and began the interview describing their 58 years together. Brian mainly discussed Gill's long-term health problems and suggested that in fact he had been a carer in training right up until the stroke which occurred after his own retirement. The questions raised in the interview seemed less relevant for Brian since he appeared content with his role as a carer. Brian appeared somewhat frustrated by the questioning and he expressed relatively few goals outside of this relationship. The majority of the interview was taken up discussing his pride in their family and his granddaughter. He also alluded to his past profession on a number of occasions suggesting that this had helped to prepare him for the caring role.

8. John and Isabelle

John was the first carer to agree to take part in the research after meeting him and his wife at their first stroke carers support group. They came across as a young couple recently affected by stroke but were actually two years down the line. Isabelle was 60 years old and was comparatively young and active. However, her speech and confidence had been significantly affected. John had retired post-stroke to become a full time carer for Isabelle. He was quite anxious but happy to be involved in the interview with the initial part flowing quite well, however, about 20 minutes into the interview asked whether we were finished. John was aware that Isabelle may be listening and was partially aware of this throughout the interview. At the end of the discussion he said that he thought it had been helpful to talk about his experiences.

APPENDIX 5

Authors Reflections on the process

Authors' Reflections on the process

Interpretative phenomenological analysis (IPA) acknowledges the role of both the participant and researcher in the re-construction of the data and recognises that the researcher contributes to the process in equal measure to participants. Smith (2003) refers to this as the double hermeneutic, describing the multiple levels of interpretation and analysis. The following section provides a brief account of my own experience of the research process.

One of the most striking aspects of the process was how remarkably honest and forthcoming participants were when talking about their experiences. I was aware of the unique and privileged relationship the research interview engenders, in such a brief but deep exchange. Participants were motivated to recount positive and challenging episodes, and to provide a detailed and nuanced account of the personal impact of these. I felt that caregivers had a story they wanted to be heard and that this was one of the few opportunities for it to be told. Some participants openly said how that they stopped themselves from talking about the difficulties due to feeling that people wouldn't want to know. One care-recipient interrupted an interview to ask if I would be discussing the limited focus on caregivers, stating;

“and still no one talked to him and if ever they did it's "How's Jean ?" Not how's Harold. And I think even now at this time, if it was offered, any counselling, he would take it. Because no-one has ever said how are you coping with all this? Jean (care-recipient).

The emotional content of the conversations was evident, and discussing the impact of stroke from the caregivers' perspective led me to consider how stroke would change my own life and relationships. In each of the interviews there were moments of sadness. Some participants became tearful discussing how their situations had altered as a result of stroke. In these moments I felt helpless to change things for the individual. Although I felt empathy I

was very much aware of my position as a listener and someone unable to share in their experiences and disconnected from their accounts.

Considering life goals was difficult for caregivers to think about and felt like the ‘wrong’ question to ask. As a result it felt punitive for some carers, as though I was not listening to their story when I directed the conversation back to the questions of the study. I felt sensitive about progressing with the prepared topics when carers were possibly actively avoiding considering the future. The conflict between being a researcher and a trainee clinical psychologist seemed difficult to reconcile. I wanted to be able to support participants but was also aware of my role in the research, to hear their experience fully and facilitate them to describe it in their own words. Positively, a number of the carers appeared to appreciate the opportunity to talk and some participants described the interview as time to process the situation for themselves and some said they felt better for talking.

In relation to the process of analysis it is inevitable that my clinical work with adults and caregivers has influenced the sense I have made of the transcripts. In addition whilst conducting this study I was also writing a piece of work examining the experiences of caregivers. It is likely that this made me more aware of the literature around areas of concern however, it is hoped that this would have added to the comprehensive thinking behind caregivers experiences.

APPENDIX 7

Participant Invitation Letter

APPENDIX 8

Participant Information Sheet

APPENDIX 8: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

What is the purpose of the study?

We are interested in the experiences of those who care for someone who has had a stroke. In particular we are interested in how you are coping and the changes this may have had on your life since you became a carer. We would ask you questions about how you feel about your role, and whether, and how, it affects your ability to do other things that may be important to you. It is hoped that the study will identify factors which are important in predicting a good quality of life, and for successful coping with the experience of caring. This information can then be used to develop better ways of supporting those who find it difficult to adjust to being a carer.

Why have I been chosen?

You are invited to take part as you are the main carer of someone who has suffered a stroke. It is hoped that up to nine other carers will also take part in the study. All participants will receive the same information.

Do I have to take part?

No, you do not have to take part; it is up to you to decide whether or not you wish to take part and your participation is completely voluntary. If you do decide to take part, you are free to withdraw at any time up to and during the interview with no repercussions. You will also have the opportunity to withdraw some or all of your data after the interview, within a 2 week period, before data analysis.

What will happen to me if I take part?

When you agree to take part, an appointment will be arranged at a time of your convenience. The appointment can be carried out wherever is most suitable for you, either at your home or the carer support group venue.

During the appointment you will take part in semi-structured interview asking you about your experiences and about things that you hope to achieve in your life. This will last for approximately 60 minutes. You will also be asked to complete 4 short questionnaires. The questionnaires will ask about your well-being over the last two weeks and a number of

questions about how caring impacts on you, for example, what support you feel you have and about how well you feel you are managing. The questionnaires should not take more than 15 minutes to complete and your total involvement in the research should take no more than one and a half hours.

When we meet you will also be asked to sign a written consent sheet stating that you have read and understood the information and agree to participate in the research. Signed consent will also be sought for the audio-taping of the interview and for quotations to be used. All information will be anonymised.

What will happen to the information?

After the interview I will make a detailed written copy of what was said (a transcript) which will then be used in the data analysis. On completion, the results of this study may be sent for publication in a scientific journal. In the report I will use extracts of the things you and others have said, however, you will not be personally identifiable in this report. Each participant will be given the option to be informed about the results of the study. If you are interested in the outcome of the research a copy of the findings can be sent to you or accessed through the University of Birmingham.

Will my taking part in this study be kept confidential?

Your participation in the study will be kept confidential. Your name will remain anonymous - being changed to a personalised code. Computer based data will be kept on file at the University of Birmingham and will be password protected. All of your paper data will be kept in a locked cabinet. Paper records from this study will be kept for five years and destroyed once the study is complete. Nothing that you contribute will be seen by anyone other than the research team. Please be aware that, although your information will be confidential, if you disclose any illegal activities or harm to yourself or others this will have to be reported to the appropriate authorities.

What are the possible benefits/risks of taking part?

There are no direct benefits for taking part in the study. However, it is hoped that the information provided by participants will increase the knowledge of health professionals and have direct implications to better support and advise those caring for victims of stroke. There are no risks involved. However, if the answers that you give to the questionnaires cause us concern about your own well-being, we will contact you and may suggest that you contact your GP for further advice. In addition if you disclose any illegal activities or harm to yourself or others this will be reported to the appropriate authorities. If you do become distressed by the questions asked in the first instance we will discuss any difficulties with you. If you require professional help, we will discuss this with you first and may suggest that you contact your GP. There are no special compensation arrangements and if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact the University.

If you do become distressed as a result of your participation, please let us know, either at the time or using the contact details below or alternatively contact one of the suggested independent support groups detailed underneath.

- Carers Direct on **0808 802 0202** or email CarersDirect@nhschoices.nhs.uk.
Lines are open 8am to 9pm Monday to Friday, 11am to 4pm at weekends.
Calls are free from UK landline
- Stroke Association Helpline on **0845 3033 100** or www.stroke.org.uk

Contact For Further Information:

If you have any further questions or matters which concern you can contact any of the Researchers in charge of this project on the following number:

Lorna Gill, School of Psychology:



or



Dr Arie Nouwen, School of Psychology: 0121 414 7203.

Dr Michael Larkin, School of Psychology: 0121 414 6036

Should you require any independent information you could also contact:

Research Support Office, 65 Davies Street, London, W1K 5DA,

Telephone: **020 7514 6262** who can provide independent advice.

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION.

If you decide to take part, you will be given another of these information sheets to read and keep, together with a copy of the signed consent form.

APPENDIX 9**Participant Consent Sheet**

APPENDIX 9: Participant Consent Sheet

(Form to be on headed paper)

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Stoke Caregiver Experience and Depressive Symptoms

Name of Researcher: Lorna Gill

Please initial box

- | | |
|--|--------------------------|
| 1. I confirm that I have read and understand the information sheet. | <input type="checkbox"/> |
| 2. I have had the opportunity to ask questions and had them answered. | <input type="checkbox"/> |
| 3. I understand that my participation is voluntary. | <input type="checkbox"/> |
| 4. I understand I am free to withdraw at any time without giving a reason. | <input type="checkbox"/> |
| 5. I give consent for the interview to be audio-taped. | <input type="checkbox"/> |
| 6. I understand/and give consent for anonymised quotations to be used. | <input type="checkbox"/> |
| 7. I agree to take part in the above study | <input type="checkbox"/> |

Name of Patient Date Signature:

Name of Person Date Signature taking consent:

APPENDIX 10

Interview Schedule

Appendix 10: Qualitative Interview Schedule

What do caregivers understand the relationship between care-giving and their goals, to be?

- A.** 1. Could you tell me a little bit about how you came to be a carer for X?
2. What are things like for you at the moment?
- B.** 1. Tell me about your care giving commitments?
2. What do kinds of things shape your day, your week ..?
3. Who do you spend your time with?
- [prompt: who else other than X?]
- C.** 1. Are there any other things that fill your time?
2. Are there any things that you'd like to do with your time?
3. ... that you used to do with your time?
- D.** 1. What would you have like to see yourself doing in the future?
2. Why are these important?
3. What would you have like to see yourself doing in the future if you didn't have these commitments
4. What kinds of things do you think you could do to make them happen?
- [pick the most important two]
5. Would there be anything that would make it difficult for you to achieve that?
- [prompt: Reflect back on rel. to caregiving commitments?]
6. Are there any resources could you draw on to overcome these?
- E.** 1. In light of the above how do you reconcile these demands with your own personal goals?
2. What does caring mean to you? How does it fit with your own personal goals

APPENDIX 11

Sample of Analysis: Transcript One Initial Noting

Appendix 11: Sample of Interview One Transcript with initial noting

Notes of interest	Transcript: Amanda and Nick	Emerging themes
	<u>Transcript One: Participant 001: Friday 5th February 2010</u>	
	<u>'Mandy and Nick'</u>	
Factual description	Researcher: Could you tell me a bit more about how you came to be a carer for Nick?	
I'm his wife?	P1: Well basically my husband had a stroke in July 2008 and er (sigh) I'm his wife. He was	Marital obligation?
What does that mean?	in hospital for six months, all told. During which time I was, I was able to continue with	
	my job erm at Stafford Hospital. When he came out of hospital just before Christmas	
Get used to	2008, I had time of work to to care for him and carry on, and get used to looking after	
- sense of adjustment	him. (pause) Then I took my annual leave (pause) and when that was all used up I erm,	
	(pause) in March I realised that I couldn't carry on with (02.32) my part time job. And	
Used up – finished	so very reluctantly, because I loved that little job, I had to finish (pause). And er then,	Enjoyment from previous
Realised couldn't –	(pause) well I was a full time carer before, but I did sort of, (pause) because my husband	work
wanted to?	went to the day centre at X hospital I (02.59) was able to work longer at work on those	
	particular days (intake)and do shorter days (pause) to, so I wouldn't leave him too long.	
Able to – stroke stopped	(pause)	Anxieties about leaving him
It	Researcher: What was it that made you realise you would have to er, you couldn't go	too long
Too long?	back to work?	

<p>Encourage Important?</p> <p>Mustn't – why not</p> <p>Finally had to because unsafe</p> <p>Tried- effort, struggle</p> <p>Embarrassment? Heard From neighbours</p> <p>Fell – dangerous</p> <p>Needs me</p> <p>Reckless/not to try and be selfish by continuing job</p> <p>Gave up – sacrifice</p> <p>Exisiting – not really there</p> <p>Reactive depression – didn't have it?</p> <p>Proud/wants to be seen to cope?</p>	<p>P1: Yeah er, er er er everybody encouraged me to carry on with my part time job, his consultant did, he said you mustn't give up the job (laugh) and the G.P. But what finally did it was, my husband whose, had lost his speech (Long pause) tried to walk down to the end of the lane, ver (pause).erm.. awkwardly, and tried to get on the bus to go into town. (Long pause)</p> <p>The bus conductor told him he couldn't travel that he, the pass was out of date. (more asserted)I've heard this from neighbours that saw, who witnessed it. Also he went to get the wheelie bin in, er one morning and fell and bruised his knee 04:12 (laughs/sigh)</p> <p>so obviously it it brought it home very (pause) very quickly to me that he needed somebody to look after him, all the time. (pause).And er not to be erm, you know, to try to continue with my job at the same time. So that was how come, I became a full time carer for my husband. (pause) Erm.</p> <p>04:40 Researcher: So how long have you. been a full time carer now?</p> <p>Well, since March last year when I gave my job up. But before then I was sort of existing on, weeks off you know, and then er, the doctor er gave me a fortnight off. (pause) He said yes er,. now what did he say erm reactive depression he said, he sort of if you like, put something down to give me a fortnight, you know (pause) I mean I wasn't, you know, he was very, very kind really.</p>	<p>Anxieties about leaving him too long</p> <p>Dependent on Amanda To be needed? Importance?</p> <p>Obligation</p> <p>Rel- husband/wife</p>
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<p>Could be at home</p> <p>Hadn't got any option Circumstances forced to leave Sad to have left Should feel lucky worked past 65yrs</p> <p>Deal with things as the come – no choice</p> <p>Pootles –</p> <p>Little dog Saving of mental health</p> <p>Real sense of</p>	<p>Researcher: What that helpful do you think?</p> <p>P1: To have the the, well, yes, it was because I could be at home with Nick, you know.</p> <p>(pause)</p> <p>Researcher: And how do you feel now about that change?</p> <p>P1: (pause) You mean from working? (pause) Well I knew I hadn't got any option, erm. I regretted it, but then I had carried on working after 65, which obviously now you can do.</p> <p>I wasn't intending to work much longer, but perhaps I wasn't (pause) intending to give up my job at that particular time. (pause) Erm, I mean that's life isn't it you just deal with things as they come, you know. I , Not particularly. I don't regret giving up because I had to, I hadn't got any choice.</p> <p>06:12 Researcher: So (what) how would describe things at the moment?</p> <p>P1: At the moment, erm. (pause).(sigh) life poottles along - we go a walk. We had a little dog last last year (telephone rings) which has made a made a er.... big big difference to my state of mind, because she is a sweet little dog (waiting for answer phone).</p> <p>Participant laughs 06:49 Researcher: Its always the way isn't it: Participant: Yeah.</p> <p>Researcher: No-one likes leaving messages.</p> <p>06:55 As I was saying last, last erm, was it, last march, or about, yes October, February, March, A, no erm last April we had a little puppy and she's been delightful. And she has</p>	<p>Needs looking after</p> <p>Circumstances forced to leave</p> <p>Circumstances forced to leave</p> <p>Sense of existence – no real meat to it</p>
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<p>engagement.</p> <p>In contrasts to depression low mood – sitting</p> <p>Helped Nick too</p> <p>If not got a pet get one – that important to Amanda’s coping</p> <p>In contrast to Worst part Loss of communication</p> <p>Beginning to say phrases tempering the reality with progress staying positive</p> <p>Automatic phrases Not fluent speech Less of person used to be</p> <p>Double impact – used to be so fluent</p>	<p>lifted my spirits, and and my husband’s very much. She’s a lovely little dog. She</p> <p>(interrupted by researcher)</p> <p>07:19 Researcher: How has she er.....What difference has she made?</p> <p>07:20 Argh (Exclamation) goodness. Well for a start off it’s er another little life isn’t it, running about, playing, and. I can take her a walk. And I mean that was a god send last year when I felt that I had just got to get out, and un, you know, this is awful, you know, and I’d walk up the lane holding back the tears, you know what I mean, but it was a reason to go out. I should imagine that your sort of in four wall, that’s when depression and dark moods come. Dont they, it you cant get out. (mood shift)And then again, it’s Nice for Nick. He’ll take the little dog a walk around the lanes, you know. Coz we we we live in a village just outside Stafford. So I would say to anybody if they haven’t got a pet then do get one because it’s another focus, you know. (08:13). (Long pause) Erm (pause) (sigh) er the worst part about my husband’s stroke is the language, communication. Erm he is is having speech and language therapy now.they began in er January. He did have it at the Day centre but that all came to an end at the of October, so we had a couple of months where he didn’t have any sort of treatment at all erm (pause) and he is beginning to say phrases, (pause) can’t have a conversation yet but erm (pause) obviously I can ask, you know, if he wants a cup of tea and er “yes please” and. (pause).</p>	<p>Little - dog- life Playing, living</p> <p>another distraction/focus</p> <p>Worst part Loss of communication</p> <p>Keeping positive</p> <p>Lost Nick as was Is a very clever man</p>
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<p>If I dwell on it – choice to block in out keep going #</p> <p>Lost your husband Not same person Lost as personality can't be expressed Connect with words</p> <p>Shifting again backj to positive – coming along well</p> <p>- in keeping with shifting focus – not letting herself dwell in loss</p>	<p>Just your automatic responses that he's beginning to, come back with. (pause) Er, He's a very clever man, he used to, you know, he's got a degree and he used to be a lecturer at the college at, at Stoke, in computing and er (pause) he's taught at schools so (long pause) for something to happen to somebody like him whose, well I know its awful for anybody, but it just seems doubly (pause) (sigh) horrible, you know..It's just the, the very thing that thing that he earned his living with, (pause) speaking, er has been taken away from him. (pause) Er</p> <p>09:48 Researcher: So how is that for you living in the situation?</p> <p>P1: (Long pause 4sec) It it it makes me feel very sad if I dwell on it. Because, and that's the thing that can bring me to tears if anything can, I, I think. (pause) You know I just, you feel that you've lost (pause) lost your husband almost, you know, because er (pause) our personality's expressed in, in the things we say, isn't it, you know and the way we make jokes and remarks and everything, you know. So If somebody just, can't communicate with you it (pause) you know. So (sigh). As I say I actually saw his consultant yesterday. He went yesterday to see Dr O (pause) (intake) who was very pleased with his progress. And said it takes a lot of time for the brain to make new pathways and communications most basic thing that we all have. (pause) And I would imagine, although Nick was sort of paralysed all down his (pause) his lefts hand, his right</p>	<p>Lost Nick as was Is a very clever man</p> <p>Shift focus – don't dwell on loss</p> <p>Lost Nick as was Communication worst thing</p>
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APPENDIX 12

Sample of Analysis: Transcript One Emergent Themes

Appendix 12: Description of Experience for Amanda and Nick

- 1.4 Para 1 – Had to give up job because I'm his wife
- 1.19 Para 2 – Explaining why couldn't continue to work – bruised knee, on bus, vulnerability
- 2.34 Para 3 – coping with the caring – existing, 2.44 Para 5 – regret in giving up, something of self missing but deal with it, no choice but to accept it
- 3.53 – life pootles along, 3.59 – little puppy – lovely little dog (new), 3.65 – reason to go out – little life, helped to stave off depression, another focus
- 3.76 – worst part of husband's stroke is communication, progressing, how he was how he is.
- 4.93 – Loss - makes me feel sad if dwell on it, communication how communicate self
- 5.112 – Now – what he can do, can walk quite well, very good with left hand, adapted, connection through discourse, personalities, humour,
- 5.133 – past Ken, drama, tap, language
- 6.139 – past Anne, past life together, current life together focused on his need
- 7.164 – practical duties, life as it is now, anxiety about leaving him, quiet life, pensioners now
- 8.192 couldn't leave him at night. Can be self when out, – can go out if he's being looked after
- 9.213 – antidepressants – realised full extent then pull me down too
- 9.228 – better coping with someone who is cheerful, never mind, anxious about Nick coming off antidepressants impact on her – effort to keep positive
- 10.252 – depression his mental health linked to hers, protective for her, focusing on life of dog, roles, loss, widow – alone, when husband isn't there
- 11.267 – practical things, meals, got to be there to do the meals
- 11.275- life for self but can't still diff dressing, shave? Children can't just go off and leave them (irresponsible?)
- 12 – thinking about starting more of a life for herself but can't duty partnership, Understanding of stroke, Future depending on recovery, telepathic
- 14.352 close marriage, had a good marriage - that's all in the past without communication writing, verbal, connection? Plans for the future 'depends a lot on Nick's recovery'. Anxiety about going out, when sure can leave him
- 15.374 going out is important to anyone – no one wants to stay in the house. Sense of past – we both loved walking, past Nick, so easily could have been killed, near to death events at hospital.
- 16 diff to see him so close to the edge, healthy? Plans. Job
- 17 stimulation – cup of tea, how coped – optimist, progress
- 18 communication, puppy, coping, past
- 19 brain repair, communication, family support and coping, what does caring mean to you?
- 20 into a caring way aren't you – children. Contact emotion – we always have been close hell on earth if not.
- 21 married 1966, described self, envious, just fleeting
- 22 rage at first, then tears, future
- 23 loads of other ladies living the life of Reilly, future, ashes, advice – pet
- 24 communication, remaining positive, anti-depressants
- 25 children, love, role satisfaction
- 26 end - loving family

Theme Table for Interview One

<u>Object of concern/theme</u>	<u>(Page/line) Description</u>	<u>Notes</u> <u>What does it mean for them?</u>
Obligation Had to take on caring role – I'm his wife	Throughout text 'obviously' 'you know' 1.4 Well basically my husband had a stroke in July 2008 and er (sigh) I'm his wife. 2.29 it brought it home very (pause) quickly to me that he needed somebody to look after him, all the time (pause). And er not to be erm, you know, to try to continue with my job at the same time. So that was how come, I became a full time carer for my husband.*	It's certain, without question Expectations around what it means to be a wife Needed – couldn't do it alone Not to be selfish to put own wants first?
Partnership, Duty,	12. 299 I mean, you know. Your marriage is a partnership, isn't it, you don't just abandon them and skip off over the hills just because, you know they've had a stroke, you know. It's part of your duty and you love for someone	Institution of marriage has expectations Commitment contractual Duty, <u>way of demonstrating love</u>
Responsibility Life of Reilly vs. responsibility	10.265 you're still at home to do everything and cope but. Making sure you're there to cook meals, and you just can't waltz off for the day, can you've got to be there to do the meals you know and (pause) and make sure that well (laugh/tut).	Commitments are always there Waltz off sense of irresponsibility Make sure that well – they're getting done – pressure that it doesn't happen without you
Responsibility as Mothering role?	19.503 It's er, thinking of somebody else's well-being before your own. Seeing they're warm, comfortable, clean. They have their medication and that have their food. Basically	Caring – putting others first Meeting basic needs
Obligation as a mother Mother, role is to care protect To protect – safety selfless (selfishness to do own things) Guilt Switch of role	1.27 Also he went to get the wheelie bin in, er one morning and fell and bruised his knee (laughs/sighs) so obviously it brought it home very (pause) very quickly to me that he needed somebody to look after him, all the time. And not to be erm, you know, to try to continue with my job at the same time 7.167 I well (sigh) (pause) obviously erm I have give him his medicine, first of all, he has to have quite a few, few medicines in morning, and tablets. Er obviously I get [] get all his clothes ready. Erm (pause) prepare his meals. 8.206 knowing that Nick, Nick, my husband was being looked after, my son and his wife where there, fine. 11.282 (pause) When it says carer you, it, you really are like when you're looking after your children. You're looking after their well-being and you you can't just go off and leave them, as anybody that's a mother knows. You've got to be there to see they're clean, they've got clean clothes and every things washed and they're (laughs) they're eating a reasonable diet. I mean if I wasn't there to do it he he couldn't, he couldn't, he	I was scared by that – worried for him/about him, not to be selfish, my job to look after him. Doing everything for him, think about getting him up and ready first My duties were being seen to – respite Any mother – expectation of role Go back to same role as when have children, can't leave – total responsibility
Basic needs		Look after them physically. Fulfil needs

<p>Sacrifice/selfless Prioritising their needs before own</p> <p>Prioritising their needs before own</p> <p>Just as with your children [] their well being is paramount</p> <p>Vulnerability, not safe, need watching, protection</p>	<p>couldn't really cook for himself or (pause) or make sure he'd got clean clothes. You know, caring it what is says, you are caring for him, for somebody just just the same as when they were a child and your own interests come second.</p> <p>17.444 Because a stroke, a really bad stroke like my husband had, puts you back to the status of when you are, when you're an infant really. You're completely and utterly helpless</p> <p>19.503 It's er, thinking of somebody else's well-being before your own. Seeing they're warm, comfortable, clean. They have their medication and that have their food. Basically. [] I mean I've always (laughs) sort of looked after him haven't I really. I've looked after the family having three children, (pause) Your your into a caring way aren't you and when your children are little. I don't know personally have got any children but (pause) (sigh) it, as I say it puts you back when you have something like this a very severe stroke. It puts you back to being very dependent again/someone else's well being really.</p> <p>25.644 Well it fits in because just as with your children, you love then and you, and their well being is paramount, exactly the same as for my husband. When he cannot er do everything er things for himself, although there are lots of things he can do now but he couldn't. Then I help him just the same as you do your little child, you know.</p>	<p>unable to fill himself, priority is caring.</p> <p>This has been a massive change of him He's not the man I married – he's an infant</p> <p>I'm used to having the responsibility for my husband and my children</p> <p>Caring is demonstrating your love for someone Unrelenting dependence, totally reliant Like a child</p>
<p>Reluctant sacrifices Sacrifice vs. Selfish Had to leave something enjoyed – employment – sacrifice</p> <p>Contradiction regretted/don't regret</p>	<p>1.6 He was in hospital x months, all told. During which time I was able to continue with my job at X.</p> <p>1.10 Then I took my annual leave (pause) and when that was all used up I erm, (pause) I realised that I couldn't carry on with my part time job. And so very reluctantly because I loved that little job, I had to finish.</p> <p>2.45 Well I knew I hadn't got any option erm. I regretted it, but then I had carried on working after 65 which obviously you can do now. I wasn't intending to work too much longer, but perhaps I wasn't (pause) intending to give up my job at that particular time. (pause) Erm, I mean that's life isn't it you just deal with things as they come, you know, I. Not particularly. I don't regret giving up because I had to, I hadn't got any choice.</p>	<p>Able to continue own life</p> <p>Had to leave something enjoyed Stopped life as was</p> <p>Obligation sense of had to – expectation Where from Not too much of a change</p>
<p>Life for self (selfish) Contemplating making more of a life for self</p> <p>Risk to being selfish so realised not to be selfish - Guilt</p> <p>dependence selfless</p>	<p>2.28 Also he went to get the wheelie bin in, er one morning and fell and bruised his knee 04:12 (laughs/sigh) so obviously it it brought it home very (pause) very quickly to me that he needed somebody to look after him, all the time. (pause).And er not to be erm, you know, to try to continue with my job at the same time. So that was how come, I became a full time carer for my husband.</p> <p>11.276 (Long Pause) Yes, I mean obviously before, I had a part time job so a lot of my days were taken up like that. (Pause) In the future I would I would like to start going out more. And I think I will do actually, I think I will start. making more of a life for myself. It's been quite difficult this past year, because Nick, still has difficulty dressing, he can do it, and sometimes he wants me to shave him as well if he's feeling a bit</p>	<p>Responsibility – what it looks like, neighbours told her, couldn't look after himself, not to be selfish. There was another reason not just the stroke itself.</p> <p>Life used to be quite full Like to do more but restrictions on living</p>

	<p>sort of tired or not feeling too well. (Pause) er (sigh) er. (Pause) when it says carer you, it, you really are like when you're looking after your children. You're looking after their well-being you know, you you can't just go off and leave them, as anybody that's a mother knows, you know. (pause) You've got to be there to see their, they've got clean clothes to put on and, and every things washed and their (laughs) and they're eating a reasonable diet. I mean if I wasn't there to do it he he couldn't, he couldn't he couldn't really cook for himself or (Pause) or make sure he'd got clean clothes. You know, caring is what it says, you you are caring for him, for somebody just just the same as when they were a child, and your own interests (Pause) comes second.</p> <p>12.292 So I'm thinking maybe I might try to make more of a life for myself. But then I don't like the idea of Nick sitting at home by himself. I mean you know. Your marriage is a partnership, isn't it, you don't just abandon them and skip off over the hills jut because, you know, they've er,had a stroke. You know. It's part of your duty and your love for somebody isn't it really? That's what it is.</p>	<p>life His feeling on vulnerability, tired, He is vulnerable</p> <p>Like to do more but guilt of moving on – life single life alone. Given vows to be together till death do us part?</p>
<p>Stages of adaptation Adjusting accepting the situation</p> <p>Comparing it to life as was/used to be</p> <p>Comparing it to life had/was going to be</p>	<p>1.8. When he came out of hospital, just before Christmas 2008, I had time off work to care for him and carry on, and get used to looking after him.</p> <p>7.180 We We usually go a walk or walk or I might go shopping, I mean, obviously we're both pensioners now. Nick's er he's 3 years younger than me, he's 65 now and I'm 68, erm (pause) so I (laughing) suppose we would be er, pretty sort of, it would be like thousands of others, we would be in the house (pause) quite a bit. We just don't go out at night, like we used to, you know. I mean we've got 3 children and they come to see us and well we, you know</p> <p>21.560 There's a little element of why me, why us but then, then you think it happens to just (tut) thousands of people. I mean before Nick had his stroke I must admit I didn't know anything at all about it. I really didn't. And then I used to sort of rage and think Stroke, why a silly work like stroke, that's what you do to a kitten, you know, a nice gentle action and this isn't gentle its very (pause) horrible and severe, you know (sigh) it's just, (pause) you want to lash out at something, you know, almost, at first you know and then.</p>	<p>Adapting to new role</p> <p>We manage to do small things, not a big change from where we might have been, like 1000s of others, well we – that's it. Life stages</p> <p>Emotional stages Trying to rationalise the situation, unfairness, was unexpected – anger at unfairness</p>
<p>Personal impact Shock of it all/trauma Tempered with positivity</p>	<p>Anecdotal (Story first – you need to know this before you can understand the rest)</p> <p>4.104 communication's most basic thing we have. And I would imagine, although Nick was sort of paralysed all down his (pause) his left hand, his right hand side when it first happened. I mean I was ecstatic when he first moved his (laughs) his big toe on his right side (sigh) and that was (intake) about a month, 6 weeks after he was, he had the stroke. So you can tell how severe it was (pause) And (pause) he couldn't walk or do anything. You can tell how severe it was (pause)</p> <p>16.407 It's very hard to see your husband in such a state, that cannot speak to you and cannot eat er and can't move one side of his body. From being reasonably healthy and I, I know he had a heart bypass, but I mean he he got through that and was reasonably healthy, you know, he held down a job, a full time job. (Intake)</p>	<p>It was this bad</p> <p>This has been a slow and difficult journey, the smallest things have taken so long</p> <p>It's been really difficult – I've been helpless, such a change, loss, sudden and unexpected.</p>

	<p>18.479 (Long pause) I suppose I do think of the life as it was (pause) and wish to goodness that I could just obliterate that horrible day (pause) but of course I can't.</p> <p>21.591 I mean before Nick had his stroke I must admit I didn't know anything at all about it. I really didn't. And then I used to sort of rage and think stroke/, why a silly word like stroke, that's what you do to a kitten, a nice gentle action and this isn't gentle it's very (pause) horrible and severe, you know (sigh) it's just, (pause) you want to lash out at something, you know, almost, at first you know and then.</p> <p>22.569 A lot of tears, a lot of tears, you know, I'd come to the hospital and (pause) see how he was and then I'd go home by myself and er, obviously you know, you've got to haven't you, that's the release. You can't be hard hearted and you know, you've got too. I know you (pause) and then you cry and then you feel a bit better.</p> <p>22.580 it's pretty horrible seeing your husband reduced to such a state, but then again, I'm not going to dwell on that because he's, he's coming out of it now and he's a lot better, you know.</p> <p>25.657 Erm He'll never be as he was before, they told me that at (sigh) I think that was a bit cruel in a way. They told me that almost straight away "(voice) Oh he'll never be back as he was" you know. I had to really rail against this inside me head, how d'you know he won't be back as he was, you know. He He'll be alright once he gets..get over this, he'll be he'll be back to how he it was, you know. But obviously they knew exactly what they were talking about and I've come to realise he won't be back as he was. But he'll be a lot better than he is now and a lot better than he was .a year ago. Its progress all the time and that's (pause) and I (sigh) I suppose that what keeps you going really, keeps your your spirits up, coz you can actually see very steadily a progress. (pause)</p>	<p>Want to go back to how things were</p> <p>Seeing how he was was hard – being helpless? Crying helped – having a release</p> <p>Unhelpful to think about it for too long</p> <p>Sense of loss (loss of husband/life/rel) Taken a while to accept What helps is to focus on the progress – getting some of his abilities back</p>
Loss Ken as was	<p>4.86 Er, He's a very clever man, he used to, you know, he's got a degree and he used to be a lecturer at the college at, at Stoke, in computing and er (pause) he's taught at schools so (long pause) for something to happen to somebody like him whose, well I know its awful for anybody, but it just seems doubly (pause) (sigh) horrible, you know..It's just the, the very thing that thing that he earned his living with, (pause) speaking, er has been taken away from him. (pause) Er . <i>Researcher: So how is that for you living in the situation?</i> (Long pause 4sec) It it it makes me feel very sad if I dwell on it. Because, and that's the thing that can bring me to tears if anything can, I, I think. (pause) You know I just, you feel that you've lost (pause) lost your husband almost, you know, because er (pause) our personality's expressed in, in the things we say, isn't it, you know and the way we make jokes and remarks and everything, you know.</p> <p>6.152 A lot of things I missed of our life before. We very often used to go to the theatre, you know (laughs) you know either Stoke or, or er Wolverhampton, (pause) and er, or go for days out . All that comes to a big sudden stop (pause). Coz it just does. Whether we'll manage to have a holiday this year I don't know.</p> <p>7.182 suppose we would be er, pretty sort of, it would be like thousands of others, we would be in the house (pause) quite a bit. We just don't go out at night, like we used to, you know.</p>	<p>Lost your husband, sense of Nick – Nick's identity - who he was</p> <p>Lost sense of connection through communication action emphasised by loss of lived life together</p>

	<p>14. 353 I think it's because we're,, we've always been very close, we've had a good marriage and (pause) er like I said, you know. I don't know if it happens for other people, you can only speak from you own experience can't you but erm. (long pause) You know, we've always been (long pause) (tears) very close. (pause) (sigh) (long pause 5 sec) it's alright (to researcher) I was going through some draws the other day and I found some birthday cards, anniversary cards that he'd written(pause) and er, it really makes you want, and then again I was looking through some photographs, you know, different times and it really makes you, er feel very sad that (pause) you know, that's all in the past (pause- sniff) but there you go. (pause) We've had a good marriage when we were (pause) er when he was healthy.</p> <p>15.379 we both loved walking (pause) and obviously when I go a walk now it's me with the dog. We do go a little walk together but it's not very far</p>	<p>Good marriage in the past – sense of lived life together has come to an end All in the past (we've had)</p> <p>Loss of connection –</p> <p>Things enjoyed together now do alone – not enjoyable</p>
Nick past and present sense of loss	<p>4.86 He's a very clever man, he used to, you know, he's got a degree and he used to be a lecturer at the college at, at Stoke, in computing and er (pause) he's taught at schools so (long pause) for something to happen to somebody like him whose, well I know it's awful for anybody, but it just seems doubly (pause) (sigh) horrible, you know..It's just the, the very thing that thing that he earned his living with, (pause) speaking, er has been taken away from him. (pause) Er</p> <p>5.126 I think we're probably very similar in our personalities actually, I always used to think we were, you know. I mean that's what attracted me in the first place. We'd both got the same sorts of humour, and, more or less felt the same way things. <i>Researcher: What kinds of things?</i> (Sigh) I don't know you know when you, you talk to somebody and they've got a very strong opinion about something and you might think I don't really agree with that, you know but. I mean Nick was always very involved with things, he was erm he was in the local amateur dramatics. And he was in several plays at the local theatre, that was great. Erm just before his stroke he , he was going to tap dancing classes (laughs) (wow) yeah I know, I know, and he was also learning Spanish. So you can tell he was a a vibrant man, you know</p> <p>14.353 I think it's because we're,, we've always been very close, we've had a good marriage and (pause) er like I said, you know. I don't know if it happens for other people, you can only speak from you own experience can't you but erm. (long pause) You know, we've always been (long pause) (tears) very close. (pause) (sigh) (long pause 5 sec) it's alright (to researcher) I was going through some draws the other day and I found some birthday cards, anniversary cards that he'd written(pause) and er, it really makes you want, and then again I was looking through some photographs, you know, different times and it really makes you, er feel very sad that (pause) you know, that's all in the past (pause- sniff) but there you go. (pause) We've had a good marriage when we were (pause) er when he was healthy.</p> <p>15.286 There's not many men in their 60's go tap dancing is there (laughs). He's he's got his tap dancing shoes at home you know, I wonder whether to get the taps taken off. Er (sigh laugh) and as I say his</p>	<p>is/was - sense of loss</p> <p>Sense of altered closeness, Was attracted to all the things he did Something attracted to gone – taken away – vibrancy taken away Now monotonous</p> <p>Now he can't – not same man vibrancy taken away</p>

	Spanish he, he was learning that as well, he could speak French.	Now monotonous – put the dancing shoes away
Loss of self Anne past and present	6.140 Well I, I used to go to painting classes. I was erm in the local townsman's guild, I was the treasurer. (pause) erm on the committee and er (sigh) I've joined another one now and I'm, I'm not going to volunteer, I'm not an anything now I just (intake) pootle along. On (laugh) Tuesday, second Tuesday in the month	Sense of lost self-identity Now just a carer I was active now I'm not
Not carer/mother	8.193 (Intake) Well, I couldn't really leave at night because, for a start off he needs his medicines before he goes to bed. So I erm (laughs). I would worry myself to death. I erm, as I say, I go out one, one night in the month to my lady's club, erm maybe er, er in a in a month or so I could perhaps take up another evening class because I, I'm doing a good, different classes, you know. I've been to, well we both have done that in our married life. Er It started when the children were little. That was so nice to have a break, you know, from being the children's mother or or Nick's wife, you know. You go somewhere else and then your you aren't you? Do you know what I mean (Yes). Yeah sorry.	Become a full time carer – always responsible can't live life for self come second.
	20.534 Like I say we we always have been close (pause) and I could imagine it's hell on earth if you if you're not very close or if you don't like your husband very much. As I said earlier in the conversation I've known lots of women that, you know there not very happily married its habit more than anything but. We always had sort of gone out together and had our own separate interests, you know, but I'm not saying it's been ideal but there you go.	Importance of relationship with individual relationship helps you to manage difficult situation – not ideal but coping
	21.548 How I describe myself? (clears throat) (long pause) I would say I was very level headed (pause) I try to sort of think things out properly er I don't very often go down into a depressed state, well hardly ever. Just now and again, when things seem very hard and I think why, why us, you know. And (short laugh) I know this sounds silly but if you see neighbours walking past and they're, couple are walking past and they're chattering away together you can't help but feel envious, you know. And I think that how we used to be you know. But I think that's understandable, that's human nature isn't it.	Matter of fact, try to rationalise things Do get down and depressed Unfairness of the situation try to rationalise
Communication Loss of connection Affinity/personality	3.76 the worst part of my husband's stroke is the language, communication 4.86 He's a very clever man, he used to, you know, he's got a degree and he used to be a lecturer at the college at, at Stoke, in computing and er (pause) he's taught at schools so (long pause) for something to happen to somebody like him whose, well I know its awful for anybody, but it just seems doubly (pause) (sigh) horrible, you know..It's just the, the very thing that thing that he earned his living with, (pause) speaking, er has been taken away from him. (pause) Er [] (Long pause 4sec) It it it makes me feel very sad if I dwell on it. Because, and that's the thing that can bring me to tears if anything can, I, I think. (pause) You know I just, you feel that you've lost (pause) lost your husband almost, you know, because er (pause) our personality's expressed in, in the things we say, isn't it, you know and the way we make jokes and remarks and everything, you know. So If somebody just, can't communicate with you it (pause) you know. 4.101 As I say I actually saw his consultant yesterday. He went yesterday to see Dr O (pause) (intake)	Communication affects closeness Affinity, coherence, intimacy, relations

	<p>who was very pleased with his progress. And said it takes a lot of time for the brain to make new pathways and communications most basic thing that we all have.</p> <p>258 Erm and (pause) I am very lucky that I've got good health. And mobile, so I can do jobs and things, perhaps jobs that maybe Nick would have done. before. You know if there was a bit of painting wanted doing or you know just handyman (laugh) you know, just different things. Obviously it falls to me now doesn't it, mowing the lawn and, you know, that's the sort of thing you miss when your husband isn't there. You You're not a widow but you're, it's almost almost like, (pause) you know, because (pause) you're still at home to do everything and cope but.</p> <p>13.325 Or maybe, and I think we can do this, go to the theatre again Now and I think that'll be alright, because although he can't talk that well he can understand perfectly. And if he was sitting here now he'd know everything that was going on, you know. It's just actually the path from the brain to the mouth just get the correct word and he's lost. Very difficult to understand.</p> <p>13.325 Or maybe, and I think we can do this, go to the theatre again now and I think that'll be alright, because although he can't talk that well he can understand perfectly. Speech and language lady told me that the clot must have landed right in the middle of his language centre and just blotted out, his erm, his memory of words. I mean put, if I think (pause) what his speech was like when he came out of hospital. Which was virtually (laugh) one sentence which was "say no more." I know it sounds a bit silly but that, you know, they, I have heard that and I heard. One nurse told me that an old lady that she knew that .had also has stroke similar, she, all she would say was "bugger it" (laughs). And she was a lady, her daughter, the daughter had told her that she had never ever swore but whatever you'd said to her she'd say that. (pause). But I've been told that's also a mark of frustration to swear, you know, in fact Nick used to swear sometimes and he's not a man that swore (pause) so erm....</p> <p>14.353 I think it's because we're,, we've always been very close, we've had a good marriage and (pause) er like I said, you know. I don't know if it happens for other people, you can only speak from you own experience can' t you but erm. (long pause) You know, we've always been (long pause) (tears) very close. (pause) (sigh) (long pause 5 sec) it's alright (to researcher) I was going through some draws the other day and I found some birthday cards, anniversary cards that he'd written(pause) and er, it really makes you want, and then again I was looking through some photographs, you know, different times and it really makes you, er feel very sad that (pause) you know, that's all in the past (pause- sniff) but there you go. (pause) We've had a good marriage when we were (pause) er when he was healthy.</p> <p>14.457 And er if you met him he'd say"Hello how are you?" and he'd put out his hand communication as I'm talking to you no is one of the most basic things we've got [] I mean I don't know anything about you but I can sort of sum you up, you know (laugh) by what you've said to me and what I'm saying to you</p>	
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	<p>19.489 communication as I'm talking to you now, is one of the most basic things we've got, isn't it. I mean well it is! I mean I don't know anything about you but I can sort of sum you up, you know (laugh/sigh) by what you've said to me and what I'm saying to you, you sort of. You communicate with words, don't you, what type of person, well all sorts of messages,. (pause) you know (laughs).</p> <p>20.519 Mainly, and the emotional er er. I deliberately go and give him a hug, put my arms round him erm and give him a, a kiss so he feels, he knows I still love him and everything and you know, I tell him I love him. Obviously anything erm physical erm sort of thing is not, is, as you can gather that's not part of life anymore but (change of tone) never mind, it doesn't matter he's there, you know, erm. (pause) I should imagine that if you were a younger person that side, would be very very hard to endure, you know if you're say a young women of 30 or 40 and, you know, obviously when you get older it does happen now and again but perhaps, you know I mean, you know what I mean like it's not the be all and end all of things. Whereas perhaps when you were younger. (pause) But I think it's very important to show affection and, and just put your arms round somebody, not, just you know a nice hug and he'll put arms round me, you know. And Very often, when we go, or I perhaps when I'm in the kitchen he'll come and he'll put his arm round me, you know. Like I say we we always have been close (pause) and I could imagine it's hell on earth if you if you're not very close or if you don't like your husband very much.</p> <p>22.569 A lot of tears, a lot of tears, you know, I'd come to the hospital and (pause) see how he was and then I'd go home by myself and er (Long Pause). obviously, you know, you've got to haven't you, that's the release. You can't be hard hearted and, you know, you've got to. I know you (fade) (pause) and then you cry and then you feel a bit better.</p> <p>23.615 Because a pet couldn't care less when. When Nick's talking to her, the fact he's not saying proper words doesn't matter to her at all the fact he's not saying proper words doesn't matter to her at all. The fact, his his tone of voice and everything, you know and she'll wag her little tail and jump on his knee and, you can imagine can't you.</p> <p>24.622 My husband for instance, we went to the local shop and he said "paper please" and he gave the young girl the paper and some money and she gave him. And that sounds very trivial I know, but (pause) it's a milestone</p>		
Resigned to fact Perspective taking	<p>1.08 I had time of work to to care for him and carry on, and get used to looking after him. (pause) Then I took my annual leave (pause) and when that was all used up I erm, (pause) in March I realised that I couldn't carry on with my part time job.</p> <p>2.45 (pause) You mean from working? (pause) Well I knew I hadn't got any option, erm. I regretted it, but then I had carried on working after 65, which obviously now you can do. I wasn't intending to work much longer, but perhaps I wasn't (pause) intending to give up my job at that particular time. (pause) Erm, I mean that's life isn't it you just deal with things as they come, you know. I, Not particularly. I don't regret giving up because I had to, I hadn't got any choice.</p>	Trying to rationalise Contradiction Regretted/don't regret	

	<p>12.303 I mean I should imagine if you if you didn't love somebody or you didn't get on well with them, you know, er there's a lot of couples like that I've I've known over the years, their, they lead almost separate lives And when, if that happens to one partner and the other ones to, there must be a lot of resentment. I don't resent Nick at all. I just feel for him, I think well he's, he doesn't deserve this. He was always a good father, he didn't smoke. He (sigh) ,he didn't drink, in excess, you know just like a social drink, you know like. But then life's not some. There isn't somebody up there saying. You know, erm, making life fair for people, it isn't like that is it? Yeah I mean (laugh) do you know what I mean, he's had a heart bypass, er in 2005, that was very very worrying,. (Pause) so (sigh) you just cope.</p> <p>25.658 They told me that almost straight away (voice) "Oh he'll never be back as he was" you know. I had to really rail against this inside me head, how d'you know he won't be back as he was, you know. He He'll be alright once he gets..get over this, he'll be he'll be back to how he it was, you know. But obviously they knew exactly what they were talking about and I've come to realise he won't be back as he was. But he'll be a lot better than he is now and a lot better than he was .a year ago.</p>	Trying to understand the stroke, make sense of what's happened	
Living vs. Existing	<p>3.54 At the moment, erm. (pause).(sigh) life pootles along - we go a walk.</p> <p>6.140 Well I, I used to go to painting classes. I was erm in the local townsman's guild, I was the treasurer. (pause) erm on the committee and er (sigh) I've joined another one now and I'm, I'm not going to volunteer, I'm not an anything now I just (intake) pootle along. On (laugh) Tuesday, second Tuesday in the month,</p> <p>3.65 <i>Researcher: How has she er.....What difference has she made?</i> Argh (Exclamation) goodness. Well for a start off it's er another little life isn't it, running about, playing, and. I can take her a walk. And I mean that was a god send last year when I felt I just had to get out, and un, you know this is awful you know, and I'd walk up the lane holding back the tears, you know what I mean, but it was a reason to go out. I should imagine that your sort of in four wall, that's when depression and dark moods come. Dont they, it you cant get out.</p> <p>15.372 <i>Researcher: Why would you say that going out is important to you?</i> Well there important to anybody aren't they, sort of seeing. No-one wants to stay in the house all the time do they, whatever age you are, you know. Just because you get old you don't erm...you know you don't change.</p> <p>15.381 What is it about staying in the house? Well I don't think that needs spelling out really, none of us would like to stay in the house all the time would we? And you do, you want stimulation don't you, to see different people and do different things, erm perhaps we've got more interests than other people our age, I don't know.</p>	Getting out of the 4 walls	
Depression Optimism - effort Avoidance	<p>3.55 We had a little dog last last year (telephone rings) which has made a made a er.... big big difference to my state of mind, because she is a sweet little dog (waiting for answer phone). [] As I was saying last, last erm, was it, last march, or about, yes October, February, March, A, no erm last April we had a little puppy and she's been delightful. And she has lifted my spirits, and and my husbands very much. She's a</p>		

	<p>lovely little dog.</p> <p>3.65 <i>Researcher: How has she er.....What difference has she made?</i> Argh (Exclamation) goodness. Well for a start off it's er another little life isn't it, running about, playing, and. I can take her a walk. And I mean that was a god send last year when I felt I just had to get out, and un, you know this is awful you know, and I'd walk up the lane holding back the tears, you know what I mean, but it was a reason to go out. I should imagine that your sort of in four wall, that's when depression and dark moods come. Dont they, it you cant get out.</p> <p>9.214 the consultant put him on an anti-depressant. Which I think's been er (pause) the saving of our (sigh) (pause) our state of mind really. Of my state of mind because my husband's sort of fairly cheerful about things. (pause) Where his normal er sort of demeanour, er, like we all are, sometimes you'll feel pretty (pause) you know, lifes up and down, isn't it. For all of. Although he's probably a more emotional personal than, I'm bit more level headed, you know. Er so er, with..... him being on this erm, 'Fluroxetine' it's called, it's er like a Prozac. I think that's a really good thing to, because I think if he really realised just what his (pause) disabilities are in all seriousness that would make him feel quite er, down, you know. Well he does realise but if if he's trying to tell me something and I really can't tell then he'd say Never mind then, No.</p> <p>9.229 (pause) Well obviously it's it's er it's a lot better coping with somebody that er (pause) you know (pause) in a sort of (pause) reasonable state of mind than somebody that was really depressed and miserable and grumble. Well I mean, you know, or shouted or something like that, that would be awful to life with wouldn't it.</p> <p>10.247 Well (sigh) I mean it's (pause) pretty obvious that it would be (laugh/sigh) unbearable, wouldn't it, to be somebody that would, with somebody who was really down who was down in the depths of despair and you know you. <i>Researcher: What would it mean for you though to kind of be in that environment?</i> (pause) (Sigh) Well, you you, you would start going down yourself wouldn't you, because(pause) you know, we all need sort of, I said er er I've said to you before though in this interview the importance of having that little puppy. (pause) She's a lovely little poodle, Gemma and she's such a lovely little dog. She really is and that has been the er (pause) my saving I think. It really has.</p> <p>18.464 I keep going back to this little puppy don't I. That's been the saving of me really. Because of the sort of person I am (pause) I'm not going to look on the black side, it's very easy to look on the black side if you wanted to and think, poor old me, you know.</p> <p>22.569 A lot of tears, a lot of tears, you know, I'd come to the hospital and (pause) see how he was and then I'd go home by myself and er, obviously you know, you've got to haven't you, that's the release. You can't be hard hearted and you know, you've got too. I know you (pause) and then you cry and then you feel a bit better.</p>	<p>Effort to remain focused on positives</p>	
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	<p>23.608 Yeah, as you've seen, tears come very close sometimes, if you just dwell on a particular aspect of it, but er, I try not to, I try not to because, that doesn't serve any purpose does it, at all.</p> <p>24.626 And I think you've got to think of these positives some of the time, not think of the negatives, the negatives are there, you don't need to have half a brain to think of the negatives, you've got to think of the positives all the time. Don't you think so? You have haven't you. Otherwise you'd just go into a pit and you won't./Coz I make myself not go down that little path.</p>		
Progress	<p>4.82 and he is beginning to say phrases, (pause) can't have a conversation yet but erm (pause) obviously I can ask, you know, if he wants a cup of tea and er "yes please" and. (pause). Just your automatic responses that he's beginning to, come back with. (pause)</p> <p>4.106 As I say I actually saw his consultant yesterday. He went yesterday to see Dr. (pause) who was very pleased with his progress. And said it takes a lot of time for the brain to make new pathways and communication's most basic thing that we all have. (pause) And I would imagine, although Nick was sort of paralysed all down his (pause) his left hand, his right hand side when it first happened. I mean I was ecstatic when he first moved his (laughs) his big toe on his right side (sigh) and that was (intake) about a month, 6 weeks after he was, he had the stroke. So you can tell how severe it was (pause) And (pause) he couldn't walk or do anything.</p> <p>5. 115 he should do exercises but I'm afraid he's not very good at doing them he'd prefer to just do everything with his left hand, which he's very good with. And he can sign his name with his left hand (laughs) anything he needs to do, getting dressed all with his left hand. And because he was a right handed man (pause) but he's sort of, you know adapted, it's amazing how you do adapt isn't it.</p> <p>9.234 he would probably have to start reducing this er Prozac as time went on (pause). Which I didn't like the idea of, but hopefully, to coincide with that will be my husband's, his speech will improve and his mobility you know, so hopefully. He'll, you know, who's to...as he's less, has a lesser dose of Prozac, coz they won't take it off his just like that but reduce it and hopefully Nick will be more mobile and er (pause) hopefully(sigh/laugh)</p> <p>13.329 It's just actually the path from the brain to the mouth just get the correct word and he's lost. Very difficult to understand. Speech and language lady told me that the clot must have landed right in the middle of his language centre and just blotted out, his erm, his memory of words. I mean put, if I think (pause) what his speech was like when he came out of hospital. Which was virtually (laugh) one sentence which was "say no more."</p> <p>15.392 Erm (pause) I don't know that, who can tell the future I, I tried to er (pause) make the best of what's happened and try to be upbeat, you know because he so easily could have been killed. He was, I think as near to death as he could have been, (pause) because erm. (pause) he, he, the hospital he was initially taNick to in France. Erm which I think it was X, and that he has to be transferred from X. Which</p>	<p>Weight attached to Dr.s d info</p> <p>Adapating Different but hopeful?</p> <p>Hope "hopefully" – defended against idea if things remaining the same – effort to keep positive</p>	

	<p>specialised more (pause) in Stroke patients. And er they were treating him and we'd go every day, twice a day. And very often he was in a sort of, almost vegetative state,</p> <p>17.455 But Nick unfortunately, wasn't mild for Nick, it was very very severe and er, as I've told you he's, it's knocked him for six. But he's fighting back. And er if you met him he'd say "Hello, How are you?" and he'd put out his hand to, as far as he could you know, are you alright, the basic phrases that we all say automatically, he's got. (pause)</p> <p>24.620 How How would anybody else cope? (Long pause) I suppose, (pause) look to the little milestones, as they go along, and put that as a little mental tick, yes that's another little, little achievement. My husband for instance, we went into the local shop and he said "Paper, please" and he gave the young girl the paper and some money and she gave him. And that sounds very trivial I know, but (pause) it's a milestone, (pause) you know. And, And I think you've got to think of these positives some of the time, not think of the negatives, the negatives are there, you don't, need to have half a brain to, think of the negatives you've got to think of the positives all the time. Don't you think so? You have haven't you. Otherwise you, you'd just go into a pit and you won't.</p> <p>24.663 I've come to realise he won't be back as he was. But he'll be a lot better than he is now and a lot better than he was .a year ago. Its progress all the time and that's (pause) and I (sigh) I suppose that what keeps you going really, keeps your your spirits up, coz you can actually see very steadily a progress. (pause) I almost wish that you could meet him actually (laugh) after all all this. You'd like him, he is a nice man, you know.</p>		
Comparison	<p>17.440 (How) Have I coped? (throat clear) (long pause). Well, I think basically I'm an optimist rather than a pessimist. I'm always thinking yes he will get better, yes you know, just remember what he was like a year ago.</p> <p>17.448 I mean most, a lot of people are killed by strokes (pause). I think as many strokes there are it affects people different ways. I means there's a lady I know, she had a stroke just before Christmas. I think she was about a few days in hospital/But unfortunately, wasn't mild for Nick</p> <p>18.480 (Long pause 4 sec) I suppose I do think of the life as it was (pause) and wish to goodness that I could just obliterate that horrible day, (pause) but of course I can't. So what do I focus on. (pause) I focus on er my children and my grand children. And erm the the good things in my life and the good thing that Nick didn't die from it. And the good thing that he is getting better, very very slowly.</p> <p>20.533 Like I say we we always have been close (pause) and I could imagine it's hell on earth if you, if you're not very close or if you don't like your husband very much.</p> <p>21.558 Well it's just a fleeting thought isn't it, you know, like we all have, you know (pause) (laugh) but er like anybody does. Im sure er. There's a little element of why me, why us, but then you think it happens to just (tut) thousands of people.</p>		

They – linking Nick with those who've had s stroke	13.347 Living with somebody with the stroke you do get a bit telepathic. To understand what <i>they</i> actually want, even if <i>they're</i> not actually saying the words, you know. So he might say something and I'll say do you mean so and so (imitate Nick's voice enthusiastic) "Yes" you know.		
Social Embarrassment	<p>1.19 Yeah er, er, er everybody encouraged me to carry on with part time job, his consultant did, he said you mustn't give up the job [] But what finally did it was my husband whose, had lost his speech (long pause) tried to walk down to the end of the lane, very awkwardly and tried to get the bus to go into town.</p> <p>13.324 Hopefully we can we can start going out again, maybe I can erm, we could of gone on holiday again. Or maybe, and I think we can do this, go to the theatre again Now and I think that'll be alright, because although he can't talk that well he can understand perfectly.</p> <p>18.457 And er if you met him he'd say "Hello, How are you?" and he'd put out his hand to, as far as he could you know, are you alright, the basic phrases that we all say automatically, he's got. (pause)</p> <p>24.620 How How would anybody else cope? (Long pause) I suppose, (pause) look to the little milestones, as they go along, and put that as a little mental tick, yes that's another little, little achievement. My husband for instance, we went into the local shop and he said "Paper, please" and he gave the young girl the paper and some money and she gave him. And that sounds very trivial I know, but (pause) it's a milestone, (pause) you know.</p>	Awkwardly, tried? – social embarrassment?	
Lost life and Future	<p>6.153 A lot of things I missed. of our life before. We very often used to go to the theatre, you know (laughs) you know either Stoke or, or er Wolverhampton, (pause) and er, or go for days out . All that comes to a big sudden stop (pause). Coz it just does. Whether we'll manage to have a holiday this year I don't know. We had one, one day away last year and that's our son and his wife (laugh) we. He said where do you want to go mum, so I said Llandudno. Because I don't know if you've been to Llandudno but it's very very flat. And Nick could walk along there. And I bought him a a erm, a stick.</p> <p>8.193 (Intake) Well, I couldn't really leave at night because, for a start off he needs his medicines before he goes to bed. So I erm (laughs). I would worry myself to death. I erm, as I say, I go out one, one night in the month to my lady's club, erm maybe er, er in a in a month or so I could perhaps take up another evening class because I, I'm doing a good, different classes, you know. I've been to, well we both have done that in our married life. Er It started when the children were little. That was so nice to have a break, you know, from being the children's mother or or Nick's wife, you know. You go somewhere else and then your you aren't you? Do you know what I mean (Yes). Yeah sorry.</p> <p>10.265 Making sure you're there to cook meals, and you can't just, waltz off for the day, can you, you've got to be there to do the meals you know and. (pause) And make sure that well (laugh/tut). I don't really know what else to say.</p> <p>11.276 (Long Pause) Yes, I mean obviously before, I had a part time job so a lot of my days where taNick up like that. (Pause) In the future I would I would like to start going out more. And I think I will do actually, I think I will start. making more of a life for myself. It's been quite difficult this past year, because Nick, still</p>		

	<p>has difficulty dressing, he can do it, and sometimes he wants me to shave him as well if he's feeling a bit sort of tired or not feeling too well. (Pause) er (sigh) er. (Pause) when it says carer you, it, you really are like when you're looking after your children.</p> <p>11.293 Erm (long pause) I er I might try to go to more day time classes er, there's. In Stafford there is, I think its.. country wide actually, some, something called the Phoenix Club. And this scrabble that I go to its part of that but there are other.. erm little clubs er I think there's a gardening one,.. I wouldn't mind going to that. That's on a Thursday morning I think. So I'm thinking maybe I might try and make more of a life for myself. But then I don't like the idea of Nick sitting at home by himself. I mean, you know. Your marriage is a partnership, isn't it, you don't just abandon them and skip off over the hills just because, you know they've er, had the Stroke, you know. It's part of your duty and, and your love for somebody isn't it really? That's what it is.</p> <p>12.318 Oh yeah, I'm obviously not answering your question properly answer Researcher: I would have said that there is no right or wrong answer. I'm just opening it Plans for my future.Well it obviously depends a lot on Nick's recovery (pause). That's how we can go on. I mean, (pause) hopefully. I mean obviously I'm getting older all the time(pause). Hopefully we can we can start going out again, maybe I can erm, we could of gone on holiday again. Or maybe, and I think we can do this, go to the theatre again Now and I think that'll be alright, because although he can't talk that well he can understand perfectly.</p> <p>14.365 33:15 Researcher: Obviously I mentioned about plans for the future? Oh yes you keep coming (laughs) back to his don't you. Well obviously it depends a lot on Nick's recovery . Obviously er er as he recovers I would like us to start going. You know going out to the theatre, perhaps going out for the day. Erm, I would also like, when I am sure that I can sort of leave him and that everything will be fine then I will start going out more myself. I mean erm</p> <p>22.586 Well hopefully he will carry on living (intake), I know once you've had a stroke your quite, very likely to have another one. I do understand that and I know that and think about that quite often, most days. And I know very well, unless something untoward happens he will die before me.</p> <p>23.590 How do I see myself? Well I suppose I take my erm, example form loads and loads of ladies I know who's, haven;t got a husband through divorce or, or they've died, you know. And they sort or, they go to no end of different clubs (laughs) and the life of Reilly, you know. Whereas I wouldn't like that at the moment but I think I would cope, I think I would cope. Probably have to sell the house and get something smaller coz that's er, it was the house, there were 3 children and me and Nick there, but er, so (sigh). In the future hopefully he's going to carry on improving and we can perhaps go out a bit more this year.</p>		
Future tog. vs. future alone	<p>11.277 (Pause) In the future I would I would like to start going out more. And I think I will do actually, I think I will start. making more of a life for myself. It's been quite difficult this past year, because Nick, still has difficulty dressing, he can do it, and sometimes he wants me to shave him as well if he's feeling a bit sort of tired or not feeling too well. (Pause) er (sigh) er. (Pause) when it says carer you, it, you really are like when you're looking after your children. You're looking after their well-being you know, you you can't</p>		

	<p>just go off and leave them, as anybody that's a mother knows, you know. (pause) You've got to be there to see their, they've got clean clothes to put on and, and every things washed and their (laughs) and they're eating a reasonable diet.</p> <p>14.365 Researcher: Obviously I mentioned about plans for the future? Oh yes you keep coming (laughs) back to his don't you. Well obviously it depends a lot on Nick's recovery. Obviously er er as he recovers I would like us to start going. You know going out to the theatre, perhaps going out for the day. Erm, I would also like, when I am sure that I can sort of leave him and that everything will be fine then I will start going out more myself. I mean erm</p> <p>16.416 Well it held a really nice holiday for a start (laughs). Which, it was a beautiful place where we were. Erm I suppose more of the same really, continuing our life. I'd got a part time job. Nick was working. He was actually working for the police when he had the stroke. He er taken early retirement from his er teaching jon and erm (long pause) so I mean that would ne it, you know, as we were, you know.</p>		
Life together focused on Recovery/rehabilitation	<p>6.156 Whether we'll manage to have a holiday this year I don't know. We had one, one day away last year and that's our son and his wife (laugh) we. He said where do you want to go mum, so I said Llandudno. Because I don't know if you've been to Llandudno but it's very very flat. And Nick could walk along there. And I bought him a a erm, a stick.</p>		
Preparing for leaving before go out	<p>7.169 Erm (pause) prepare his meals. Can't really do that, although he does sometimes make himself some toast. I've left him some soup nad a sandwich today, so he can just warm it up. But I erm (long pause) yeah I wouldn't, sort of want to leave him for any length of time.erm He likes watching videos and DVDs of course, as you might gather.</p> <p>8.205 You mean er. To go to my er (pause) (sigh) (pause. Well, well knowing that Nick, Nick, my husband was being looked after, my son and his wife where there, fine. I didn't have to worry or concern myself I could just go out, meet (pause) ladies that I'm friendly with, have a good old gossip. And erm, you know there's usually a speaker at the ladies club I go to. And er, it's just completely switch off from your day to day worries.</p> <p>14.368 Obviously er er as he recovers I would like us to start going. You know going out to the theatre, perhaps going out for the day. Erm I would also like, when I am sure that I can sort of leave him and that everything will be fine then I will start going out more myself.</p> <p>17.432 Televisions alright, thank goodness for television, thank goodness for videos and DVDs. Which I put one on for him before I've come away because he does like watching, you know, (pause) Bruce Willis and Mel Gibson and what not , ones which I stand personally but er I like having a read that's what I, I loos e myself in a book, but thank goodness I do like reading, you know, erm</p>		
Distraction	<p>8.206 knowing that Nick, Nick, my husband was being looked after, my son and his and his wife where there, fine. I didn't have to worry or concern myself I could just go out., meet (pause) ladies that I'm friendly with, have a good old gossip, And erm, you know there's usually a speaker at the ladies club I go to. And er, it's just completely switch off from your day to day worries.</p>		

	<p>11.273 <i>Researcher: So are there any other things that you would like to be doing with your time? Erm possibly things that you used to do or things that you possibly could see yourself doing in the future.</i> (Long Pause) Yes, I mean obviously before, I had a part time job so a lot of my days were taken up like that.</p> <p>15.380 Yes ,we both loved walking (pause) and obviously when I go a walk now it's me with the dog. We do go a little walk together but it's not very far. What is it about staying in the house? Well I can't think that er, needs spelling out really, none of us would like to stay in the house all the time would we? And you do, you want stimulation don't you to see different people and do different things, erm (pause) perhaps we've got more interests than other people are age, I don't know. There's not many, men in their sixties go tap dancing is there (laughs).</p> <p>17.428 well interest, that er different things happening, you know. You imagine being in the house all day there's (sigh) you can't get much stimulation from er making a cup of tea, can you or huh or (laughs). Television's alright, thanks goodness for television, thanks goodness for videos and DVDs.</p> <p>17.434 I like having a read that's what I, I lose myself in a book, but thank goodness I do like reading, you know erm</p> <p>18.471 Yes yes, what I did last year I just went for a goof walk (pause). And i think the actual physical exercise, the adrenalin, is a sort of bit of a pick me up anyway isn't it and the sunshine and seeing different. You know walking around a long, go down to the canal, you know where the ducks are and things like that, that's the sort of person I am, I like, I like walking about</p> <p>19.482 So what do I focus on? (pause) I focus on my children and my grandchildren. And erm the good things in life and the good thing that Nick didn't die from it. And the good thing that he is getting better, very very slowly.</p> <p>19.494 my coping mechanism is I like to have a good old read, I like to go walking er, I take the dog a walk and. My daughter is very very good. She phones up most nights, and so I'm able to off load. She's very understanding and I know a of people wouldn't have, haven't got anyone like that in their lives. It is the family who really help me cope I would say.</p> <p>22.574 I think actually going to work was a lot better for me. (Pause) In fact it must be horrible if you've been at home by yourself. (Pause) But next day, of course I get up and get ready and go off to work and people'd talk to you "How's Nick" and then you'd hear about their lives and then you wouldn't think about what was happening to you particularly, would you, you know. (pause) It's diversion really</p> <p>23.613 If they haven't got a pet then please get one (pause) true, honestly, it's another focus away from the trauma and the, and everything that that's happened to your your own life, you know.</p>		
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Job	<p>1.19 Yeah er, er, er everybody encouraged me to carry on with part time job, his consultant did, he said you mustn't give up the job</p> <p>16.423 Well, my job, er I loved at the hospital. It was mainly the group of people who I worked with. Yes and it was a lovely little job. It was erm sending out appointments, and I'd meet patients as well.</p>		
Role widow Widow	<p>10.258 Erm and (pause) I am very lucky that I've got good health. And mobile, so I can do jobs and things, perhaps jobs that maybe Nick would have done. before. You know if there was a bit of painting wanted doing or you know just handyman (laugh) you know, just different things. Obviously it falls to me now doesn't it, mowing the lawn and, you know, that's the sort of thing you miss when your husband isn't there. You You're not a widow but you're, it's almost almost like, (pause) you know, because (pause) you're still at home to do everything and cope but.</p> <p>13.321 Well it obviously depends a lot on Nick's recovery (pause). That's how we can go on. I mean, (pause) hopefully. I mean obviously I'm getting older all the time (pause). Hopefully we can we can start going out again, maybe I can erm, we could of gone on holiday again. Or maybe, and I think we can do this, go to the theatre again I mean, (pause) hopefully.</p> <p>22.586 Well hopefully he will carry on living (intake), I know once you've had a stroke your quite, very likely to have another one. I do understand that and I know that and think about that quite often, most days. And I know very well, unless something untoward happens he will die before me.</p> <p>23.590 How do I see myself? Well I suppose I take my erm, example form loads and loads of ladies I know who's, haven;t got a husband through divorce or, or they've died, you know. And they sort or, they go to no end of different clubs (laughs) and the life of Reilly, you know. Whereas I wouldn't like that at the moment but I think I would cope, I think I would cope.</p> <p>23.601 He always says he wants his ashes spread over there</p>	Aware die before her – waiting to live own life/on pause	
Services/family enabling future due to anxiety about leaving alone	<p>1.13 because my husband went to the day centre at hospital I was able to work longer on those particular days (intake) and do shorter days (pause) to, so I wouldn't leave him too long.</p> <p>2.28 Also he went to get the wheelie bin in, er one morning and fell and bruised his knee 04:12 (laughs/sigh) so obviously it it brought it home very (pause) very quickly to me that he needed somebody to look after him, all the time. (pause).And er not to be erm, you know, to try to continue with my job at the same time. So that was how come, I became a full time carer for my husband.</p> <p>6.146 Well obviously I couldn't carry on going at night, to the night classes, evening classes, could I, to the painting because. I can't go out at night, oh my son and his wife will come and look after my husband when I go to the ladies club and er (pause) I erm (laughs) I go to the scrabble club on a Tuesday morning which I really love, coz I love scrabble.</p> <p>7.170 Erm (pause) prepare his meals. Can't really do that, although he does sometimes make himself</p>	Dependence on others for respite	

	<p>some toast. I've left him some soup and a sandwich today, so he can just warm it up. But I Erm (long pause 4 sec) He sort of (pause) yeah I wouldn't, sort of want to leave him for any length of time. (pause).erm. He likes watching videos and dvds of course, as you might gather erm.</p> <p>8.193 (Intake) Well, I couldn't really leave at night because, for a start off he needs his medicines before he goes to bed. So I erm (laughs). I would worry myself to death. I erm, as I say, I go out one, one night in the month to my lady's club, erm maybe er, er in a in a month or so I could perhaps take up another evening class because I, I'm doing a good, different classes, you know. I wouldn't leave him by himself at night now</p> <p>8.203 <i>Researcher: What was it about, you said it was nice to kind of have that break, what was it that was so nice about that, can you kind of.</i> You mean er, to go to my er (pause) (sigh) (pause) Well, well knowing that Nick, Nick, my husband was being looked after, my son and his and his wife where there, fine. I didn't have to worry or concern myself I could just go out., meet (pause) ladies that I'm friendly with, have a good old gossip, And erm, you know there's usually a speaker at the ladies club I go to. And er, it's just completely switch off from your day to day worries.</p> <p>14.368 when I am sure that I can leave him and that everything will be fine then I will start going out more myself</p>		
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APPENDIX 13

Sample of Analysis: Over-arching Emergent Themes All transcripts

Event

Shock and severe

Shock of it all - stages to adjustment

Why care?

Obligation (personal, relational and social 'shoulds')

Commitment

(Preparedness) (Sacrifice)

Better do it

Partnership

Part of marriage/part of duty

Lived experience Dual demands

Anxiety about leaving

Complete responsibility (care and safety)

No respite - isolation

Having a life-line – breaks

“Nice to be out” “not think about it for a while”- break from the norm.

Contemplation – making more of a life for myself – what that means

Adapt by making life through stroke

Overwhelming -ve emotional content

Sense of interview as partner

Importance of relational context

Aspects of changed relationship

Loss of partner – isolation/inequality role reversal/widow

Frustration

Loss of future

suspended future

Dependence on recovery – striving for normality

Aspects of changed self/life

Life on hold –slow normal life on hold

Coming second

waiting – existing versus living

Adapting as a team

Well-being / Fragility

Vulnerability of partner

Seeing them as a patient/child

Sex 'might break'

Features of the role - motivator

facilitator

advocate fight – power/mastery

organiser

day to day duties

Inner strength

Seeing it as a job (keeping things separate) Caregiver not husband/wife

Motivations of role

remaining positive - comparison

being values/appreciated/satisfaction fulfilling in seeing progress in project

Keeping life full /good to be alive/lucky (work and care)

The importance of support

Previous experience – job/roles/prev. Exp in preparation

Personal characteristics