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Carers' and survivors' experiences following a stroke

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This thesis is submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

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List of Abbreviations

BPS   British Psychological Society

CASP   Critical Appraisal Skills Programme

GDPR   General Data Protection Regulation

IPA   Interpretative Phenomenological Analysis

PRISMA   Preferred Reported Items for Systematic Review and Meta-analysis

TIA   Transient ischemic attack

List of Appendices

Acknowledgements

Firstly, I would like to thank all of the male carers who took part in this research. I am grateful for them making the time to talk with me and their willingness and openness in sharing their experiences. I also appreciate the support from the stroke support groups who welcomed me to their groups and enabled recruitment for this research.

Thank you to my supervisors, Tony and Kate, for all your guidance, advice and encouragement along the way. I really appreciate all you have both done to support me throughout the whole process.

Thank you to my family for being my secure base I can always rely on. Thank you for your endless support and endless supply of tea!

I thank my friends for their patience, understanding and ongoing words of encouragement along the way. With an extra thank you to the wonderful group of friends I have in my cohort. You have all made this journey easier with your compassion, care and humour.

Declaration

I declare that this thesis has not been submitted for any other degree or at another university. The thesis is the candidate's own work. It was conducted under the academic and clinical supervision of Dr Anthony Columbo and Dr Kate Martin who were involved in the research design and provided feedback on drafts throughout the process.

The literature review and the empirical paper have been prepared for submission to the journal Qualitative Health Research.

Summary

This thesis explores experiences related to stroke survival, firstly, from the perspective of stroke survivors themselves and secondly in the context of husbands caring for their wives post-stroke.

The first chapter presents a meta-ethnography investigating stroke survivors' experiences of their 'identity'. Eighteen qualitative studies were identified for inclusion. Two major themes were identified: Loss of Self and Renewed Self. It was recognised that although survivors lost aspects of their identity, they were able to maintain a core sense of self and engage in a process of transformation, leading to a renewed self-identity. The findings highlight a need for greater sensitivity to the relationship between the nature of physical impairments and their interaction with psychological loss. Further recommendations are made relating to interventions to support survivors in the process of both continuity and transformation of the self.

The second chapter reports a qualitative study exploring the experiences of husbands who provide care for their wives who have survived a stroke. Six husbands participated in semi-structured interviews. Interpretative Phenomenological Analysis was used to gain an in-depth understanding of their experiences. Three superordinate themes were identified: Role-identity, Self-identity and Dyadic-identity. Husbands experienced changes to their roles and identity, an impact on their psychological wellbeing and changes in the connection with their wives. Three clinical implications are discussed, firstly, the carers should be supported to maintain their identity alongside the caring role, secondly, there is a need for a more supportive framework designed with the needs of male carers in mind, and thirdly, services need to recognise and address the issue of loneliness amongst informal carers.

The third chapter is a reflective paper exploring the author's experiences of the research process. This paper discusses their learning and development as a reflective scientist-practitioner and highlights action points to inform their future clinical and research practice.

Overall word count: 19,200 at submission, 20,401 following amendments (excluding abstracts, tables, figures, references and appendices)

Chapter 1: Systematic Literature Review

Experiences of 'identity' amongst stroke survivors: a meta-ethnographic review

Written in preparation for submission to Qualitative Health Research

(see Appendix A for author guidelines)

Final chapter word count (excluding abstract, tables, figures and references): 7,779

Abstract

This review aimed to investigate how 'identity' is experienced by stroke survivors. A systematic review of qualitative literature was conducted using key search terms and Boolean search strategy. Eighteen studies were identified for inclusion. The analysis was conducted in line with Noblit and Hare's (1988) meta-ethnography approach. Two major themes were identified relating to the experience of identity: Loss of Self and Renewed Self. The Loss of Self is understood in terms of disruption to self-identity due to a loss of roles and an emerging state of self-incongruence. The Renewed Self comprises of two aspects, firstly, continuity of the self is experienced through recognition of the core-self and adaptation to retain identity, and secondly, some survivors experience a process of transformation in their identity. The findings are discussed in terms of a proposed theoretical concept of 'biographical renewal'. The implications for future research and clinical practice are explored.

1.1. Introduction

1.1.1. Background

The aim of this systematic literature review is to investigate how survivors experience their sense of 'identity' following a stroke. Stroke is defined as a medical emergency where brain cell death occurs due to obstructed blood flow in the brain (Green & King, 2009). Survivors can be left with ongoing physical and cognitive impairments, communication difficulties and emotional changes of varying severity (Alaszewski, Alaszewski, Potter, Penhale, & Billings, 2003). This can cause sudden and dramatic life changes leading to survivors having to rebuild and restructure their individual world (Burton 2000; Ellis-hill, Payne, & Ward, 2008), which often has a profound impact on their perceived identity (Lapadatu & Morris, 2019).

The terms 'self' and 'identity' are used interchangeably (Oyserman, Elmore, & Smith, 2012) and refer to elements of one's psychological characteristics, physical attributes, role participation and social group memberships which, collectively, inform how an individual sees themselves (Zahavi, 2005). An individual's perception of their unique identity is understood to be dynamic and can be modified by salient life experiences (Batory, 2015).

The impairments as a result of stroke have the potential to disrupt all of these aspects of identity. Developing an understanding of how stroke survivors experience their identity can make a significant contribution towards the development of more meaningful support services including rehabilitation and psychological input post-stroke.

1.1.2. Evaluation of previous reviews

Satink et al. (2013) conducted a thematic review which aimed to synthesize patients' views on the impact of stroke on their roles and self. The authors reviewed 33 qualitative studies published prior to 2010. They identified three main themes, 1) managing discontinuity is a struggle, 2) regaining roles: to continue or adapt?, and 3) context influences the management of roles and self. They concluded that regaining or developing a new self and new roles post-stroke was challenging, and rehabilitation interventions should recognise this difficulty and aim to facilitate adjustment and continuity.

Hole, Stubbs, Roskell, and Soundy (2014) conducted a meta-ethnography to investigate how patients' experiences of stroke rehabilitation influence and evolve their identity, and to consider the different psychosocial concepts and interactions that may influence this. They reviewed 13 qualitative articles published between 2000-2012. The authors developed a model to conceptualise how the recovery of a stroke survivors' sense of identity evolves during rehabilitation. This review established that a recognition of identity change was an important consideration during the course of rehabilitation.

Other reviews of qualitative research have tended to focus on experiences following a stroke within the context of specific population groups. Often, an outcome from these studies related to the notion of 'identity'. For example, Lawrence (2010) reviewed the experiences of young adult stroke-survivors finding a theme of "disrupted sense of self". Williams and Murray (2013) reviewed studies which explored the experiences of engaging in occupation post-stroke, reporting a theme of

"impact on identity" in the context of inability to perform occupations and roles relevant to one's identity.

Lou, Carstensen, Jørgensen, and Nielsen (2017) conducted a systematic review of qualitative systematic reviews which had explored survivors' and carers' experiences of rehabilitation and life after discharge. They included seven reviews, containing 108 primary studies, published between 2005 and 2015. Five of these reviewed stroke survivors' experiences and two reviewed informal carers' experiences. Following thematic analysis, this review concluded that stroke causes a profound disruption which requires a process of adapting, reinventing and rebuilding life and identity for both the survivor and the carer. The authors identified five key experiences in this dynamic process: autonomy, uncertainty, engagement, hope and social relations.

1.1.3. Rationale and Aim

There are three main limitations to the previous work on understanding 'identity' amongst stroke survivors. Firstly, reviews have been conducted in the context of rehabilitation or adaptation post-stroke which could limit the scope of the exploration of experiences of identity post-stroke. For example, Hole et al. (2014) specifically reviewed literature regarding how stroke rehabilitation influenced and evolved identity, and Satink et al. (2014) searched for literature related to concepts of role- or self- management and adaptation post-stroke.

Secondly, issues around identity often appear as a single theme in the research findings and reviews, rather than as an aim of the investigation. As a result, the nature of identity and how it is experienced post-stroke is not always explored in-depth and the findings are fragmented throughout the literature. This limitation is

further exacerbated by a lack of clear definitions of 'identity', with variation in the focus across disciplines.

Thirdly, Lou et al. (2017) highlights that most studies are grounded in the theoretical concept of biographical disruption (Bury, 1982), and recommend further exploration of processes of continuity. This reinforces the findings related to the experience of 'biographical flow' following a stroke (Faircloth, Boylstein, Rittmann, Young, & Gubrium, 2004).

Finally, in recent years there have been more publications of qualitative literature exploring stroke survivors' experiences of their identity. Therefore, this subject could benefit from a more wide-ranging and updated review of the literature.

This literature review will seek to address the limitations identified and bring the existing literature together to create a more cohesive understanding of survivors' experience of identity post-stroke. The review will take a broad focus on survivors' experiences of identity rather than limit the context, for example to the rehabilitation setting. Further, the review uses a definition of identity which recognises the influence of physical, psychological, occupation and social networks in the development of one's sense of self; therefore, bringing together findings from across the literature and disciplines. This review is not being conducted from a pre-defined theoretical perspective, such as biographical disruption, and therefore will allow for an understanding beyond this concept grounded in the experiences of the stroke survivor.

Most of the previous research on this subject has adopted a qualitative methodology which requires a meta-synthesis of the literature. More specifically, a meta-

ethnography approach was selected in order to draw together and interpret the findings.

The aim of this review is to answer the question: How is 'identity' experienced by those who have survived a stroke?

1.2. Methods

1.2.1. Systematic literature search

1.2.1.1. Search Process

This review was approved by Coventry University Ethics committee (Appendix B). A systematic search of qualitative literature investigating experiences of identity in the context of surviving a stroke was carried out. Research relevant to this review has been published within different disciplines such as psychology and occupational therapy, therefore databases covering literature within a range of fields were used. These were Psychinfo, CINAHL, Medline and Scopus. The reference lists of the extracted articles were examined for additional relevant articles. A search for additional grey literature was completed using the British Library e-theses online service, EThoS and Google Scholar. The searches were carried out in March 2019.

1.2.1.2. Search terms

Table 1.1. Key search terms and synonyms

	Main Concept	Synonyms	Location
Population	Stroke survivors	Stroke sufferers With stroke After stroke	Title, Abstract, Key words
Outcome	Identity	Sense of self Social identity Self-concept Self	Title, Abstract, Key words
Context	Experience	Impact Consequence Effect Influence	Title, Abstract, Key words
Methodology	Qualitative	Phenomenology Phenomenological	Title, Abstract, Key words

Table 1.1 presents the key search terms used to identify relevant literature. The terms were organised using the POC framework in terms of the population, outcome and context (Butler, Hall, & Copnell, 2016). The population referred to 'stroke survivors', the outcome was 'identity' and the context was 'experience', relevant synonyms were included to broaden the search. The search also included terms related to qualitative methodology. All terms were searched for within the Abstract, Title and Key words.

1.2.1.3. Search strategy

Boolean search strategy was employed to combine the search terms. The operator 'AND' was used to retrieve literature which included the main concepts of "stroke", "identity", "experience" and "qualitative". The search was broadened to include the synonyms using the operator "OR". The symbol * was used to truncate words in order to search for variations of words, e.g. surviv* would search for 'survivor',

'survived', 'surviving'. Double inverted commas were used to search for several words as a phrase. To improve the specificity of the search the limiters of 'English Language' and date range from 2000 to present were used.

The Boolean search statement was:

(Stroke AND (Surviv* OR "with stroke" OR "after stroke" OR suffer*)) AND (identity OR "sense of self" OR self-concept OR self OR "social identity") AND (experience* OR effect* OR impact* OR influence* OR consequence*) AND (Qualitative OR phenomenolog*)

1.2.1.4. Inclusion and Exclusion criteria

Articles were exported into the online programme Refworks and were screened for duplicates. Once duplicates were removed the remaining articles were initially screened for relevance by title and abstract and to confirm they met the following inclusion criteria: a) peer reviewed, b) written in English, c) published since 2000, d) utilised a qualitative methodology and e) the full text was accessible.

Following this screening, the full text of remaining articles were obtained and assessed for eligibility in accordance with the inclusion and exclusion criteria set out below.

Table 1.2. Inclusion and Exclusion Criteria

Criteria	Include	Exclude
Participants	Clinical Stroke survivor Patient/ Survivor Adult (18+) at the time of stroke	Other forms of acquired brain injury Carer or professional
Study design/ Methodology	Empirical qualitative research Mixed methods research where qualitative aspects could be drawn out.	Commentaries, books, case studies
Variables/ Concepts	Investigates or identifies concepts relating to identity post-stroke. Describes identity in relation to having a stroke Exploration of identity as an aim of research AND/OR Experiences of identity, or related concepts as per definition, identified as a major theme in the results of the paper	Discusses consequence of stroke e.g. physical, psychological however does not connect these to the impact on self. Describes identity related to an intervention post-stroke Minimal reference to identity, which is limited in exploration or description of the nature and experience of this.

Studies were retained if the participants were stroke survivors. Studies which also included participants with other medical conditions were considered but only retained if the stroke-specific outcomes could be distinguished. Studies were exluded if they only assess carers' or professionals' perspectives rather than the stroke survivor. Where studies included both the perspective of the stroke survivor and

carers they were retained if the survivors' perspective could be drawn out seperately. This review focused on adults only, where the stroke had occurred over the age of 18, however there were no further limitations set for the age of the participants. It was decided not to differentiate on the basis of gender. Articles were drawn from westernised societies.

This review only included qualitative research. Studies which utilised mixed methods were retained if the qualitative results could be analysed separately from the quantitative. Commentaries, books and case studies were excluded.

Studies were included if they either directly stated the exploration of identity as an aim of research, or if an aspect of identity experience was described as a major theme within the findings. For clarification, in line with the definition of identity used in this paper, studies were included if they discussed an individual's sense of self in relation to their psychological characteristics, physical attributes, activity and role participation and social group membership following a stroke. Studies were excluded if they discussed these areas in terms of the stroke however did not connect them to the impact on the self. Studies were also excluded if they discussed identity change in relation to an intervention, rather than in relation to the stroke. Further, studies were excluded if they made minimal reference to identity but did not explore or describe the nature of how this was experienced in depth.

1.2.2. Classification of studies

The guidelines of the Preferred Reporting of Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement were followed. These standardised reporting guidelines demonstrate the systematic method taken in the process of identification,

screening and selection of articles for review (Moher, Liberati, Tetzlaff, & Altman, 2009). Figure 1 depicts this process.

Records identified through database searching (n =602)

Additional records identified through other sources (n = 2)

Records after duplicates removed (n = 301)

Records screened (n =301)

Records excluded (n = 249)

Full-text articles assessed for eligibility (n = 52)

Full-text articles excluded, with reasons (n = 34)

Unable to distinguish stroke-survivor from other participants: 7

Unable to distinguish stroke from another condition: 1

No/ limited exploration of identity experience: 24

Adolescent at time of stroke: 1

Unable to draw out qualitative data: 1

Studies included in qualitative synthesis (n = 18)

Identification

Screening

Eligibility

Included

Figure 1: PRISMA Flowchart

The flowchart above outlines the systematic stages taken to select the articles for review. The database searches resulted in 602 records. Two additional relevant records were found for inclusion during a review of reference lists of the papers identified for inclusion. One was a thesis which had been initially identified during search of the grey literature, however the published version was obtained and

therefore this was retained instead. The second was published in 1999, however, it was decided this would be retained due to its relevance to the review.

These articles were then reviewed for duplicates using Refworks, and the remaining 301 articles were screened by title and abstract for relevance and compliance with the inclusion criteria as detailed above. At this screening stage, 249 papers were excluded. Therefore, 52 full texts were retrieved and reviewed for eligibility against the inclusion and exclusion criteria. At this stage, 34 texts were excluded. The majority, 24, were excluded because they had limited or no exploration of the experience of identity in relation to the stroke, seven were excluded because it was not possible to distinguish the stroke survivors' experiences from other participants, one reported on participants whose stroke occurred during adolescence, one was mixed methods and the qualitative findings could not be drawn out and one combined findings from stroke survivors with participants with other conditions. One paper reviewed was conducted in Iran, however it was decided to retain this due to its relevance and similarities with the other papers identified. This resulted in the identification of 18 relevant studies which were retained for quality assessment.

1.2.3. Quality assessment checks

The quality of the identified studies was assessed in terms of rigour and credibility using the Critical Appraisal Skills Programme (CASP, 2018) framework. This tool is frequently used in health-related research and was considered suitable for this review. The CASP is comprised of ten questions. The first two questions are screening questions which must be passed to warrant proceeding with the quality assessment. The first question asks, "Was there a clear statement of aims of the research?" and the second, "Is a qualitative methodology appropriate?". All papers

passed these initial two questions. The remaining eight questions relate to the research design, data collection, analysis, reflexivity, ethical considerations and the study's implications.

These eight questions were rated using a three-point system (scored 1-3) developed by Duggleby et al. (2010), where 1 is a 'weak' score given when there is little or no justification or explanation of an issue, 2 is 'moderate' indicating that an issue was addressed but not fully elaborated, and a 'strong' score of 3 was awarded where issues were extensively explained and justified. Each paper obtained a score between 8 and 24. The scores assigned to the papers identified for the review were between 16 and 23, as seen in Table 1.3. The lowest score of 16 was given to one paper, and two scored a total of 17. The lower scores were mainly related to a lack of information about reflexivity and ethical considerations. This can be a common limitation in the reporting of qualitative research as authors often leave out full exploration of issues such as reflexivity due to restricted journal word counts (Mays and Pope, 2000; Ring, Ritchie, Mandava, & Jepson, 2010). Due to this understanding, it was decided that all papers would be retained.

In order to assess the reliability of the reviewer's quality assessment ratings, another assessor independently rated all 18 articles using the same tool and rating system. The reliability between the two sets of scores for each paper was tested using Cohen's kappa statistic. The kappa score ranges from -1 to +1, where +1 represents perfect agreement between raters. It takes account of the level of agreement which could be expected by chance, represented by a score of 0 (McHugh, 2012). The kappa values obtained ranged between 0.60 and 1.00, these values indicate moderate/ substantial to complete agreement (McHugh, 2012). The kappa value for each study can be found in Table 1.3. Overall, the agreement was considered acceptable given

that the CASP only contains 8 questions, thereby limiting the room for variability within the scores.

1.2.4. Characteristics of the Studies

A summary of the studies identified for this review can be found in Table 1.3. The studies were conducted in a range of countries: five in the UK, three in Norway, two in Sweden, two in the USA, two in Australia, one in New Zealand, one in Canada, one in Iran, and one in Denmark.

The research aims varied across studies with only five specifically stating identity or sense of self as the area for investigation. Other aims included exploration of general experiences of stroke and issues surrounding quality of life and occupational participation post-stroke. Generally, the papers were conducted by different authors, although Tham was a named author on three of the papers included. All papers used interviews as their method of data collection.

The participants ages ranged from 23-93 years old. Three papers specifically aimed to investigate the experiences of younger stroke survivors, with participants aged up to 55 years old. One paper specified a minimum age criteria of 65 years old. One paper specifically recruited participants at retirement age, defined as 55-75 years old. The remaining papers had participants of a broad age range.

The majority of papers included mixed-gender samples. One specifically aimed to investigate men's experience. Two papers had only female participants, however only one of these intentionally set out to investigate female's experiences.

The length of time post-stroke varied across the papers, with an overall range of two months to 31 years. Two papers investigated experiences within the first six months of stroke, four papers specifically looked at the first year post-discharge and two

recruited participants whose stroke occurred within 2.5 years. Seven papers recruited

participants at least one year post-stroke, with a range between 1-25 years. Three

papers had a broad range which covered from six months to 31 years.

Table 1.3. Characteristics of Studies

Author, Date, Country	Study Aim	Sample	Design and Method of data collection	Key findings	Quality rating & reliability co-efficient (κ)

Arntzen, Borg, & Hamran
 	
2015
 	
Norway
	To explore what stroke survivors' long term (1-13 years) negotiations involve when they experience progress, wellbeing and faith in future.	**Participants:**
		9 stroke survivors 13 relatives
		Gender:
		6 male, 3 female
		Age: 39-72
		Time since stroke:
		1-13years
			Qualitative
			Longitudinal design
			
			Phenomenological hermeneutical approach
			
			Repeated interviews
				• Long term stroke recovery involves a process of overcoming tensions between three phenomena:
				  - A modified habitual body
				  - Re-engagement with everyday life contexts
				  - A transformed sense of self
					Quality rating: 21/24
					
					(κ=0.75)

Clarke & Black
 	
2005
 	
Canada
	To gain an insight into the underlying process by which quality of life is maintained or lost following a stroke.	**Participants:**
		8 stroke survivors
		Gender:
		3 male, 5 female
		Age: 60-81
		Time since stroke:
		7months – 9years
			Qualitative
			
			(Paper reports the qualitative findings of a mixed)
			
			Focused Interviews – interview guide was developed based on findings in the quantitative analysis
				• Stroke has a significant impact on quality of life
				• Survivors who were able to adapt to their functional disabilities reported a higher quality of life
				• This adaptation was focused around maintaining continuity and retaining salient aspects of an individual's identity.
				• This process was aided by:
				  - Re-ordering priorities to focus on identity-salient activities
				  - Drawing on existing resources such as health services and social support
					Quality rating: 16/24
					
					(κ=0.64)

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Author, Date, Country	Study Aim	Sample	Design and Method of data collection	Key findings	Quality rating & reliability co-efficient (κ)
Ellis-Hill, Payne, & Ward 2000 UK	To explore perceived life and identity changes described by individuals following a single stroke using life narrative approach.	**Participants:** 8 stroke survivors **Gender:** 5 male, 3 female **Age:** 56-82 **Time since stroke:** Repeated interviews at time of stroke, 6months and 1year post-discharge	Qualitative Narrative interviews in hospital, 6 months and 12months post-discharge	• Respondents described a fundamental change in their lives and identity • Identified a split between themselves and their body • By one year respondents still described their body as unreliable and their physical ability was influenced by the social setting	Quality rating: 18/24 (κ=0.81)
Erikson, Karlsson, & Tham 2016 Sweden	To describe and understand the experienced impact of stroke in everyday life 11-13 years after stroke.	**Participants:** 11 stroke survivors **Gender:** 6 males, 5 female **Age:** 50-67 **Time since stroke:** 11-13 years	Longitudinal qualitative follow-up study Empirical Phenomenological Psychological method Interviews	Three main themes identified: • Going through the loss of previous life • Struggling to reclaim the former existence • Finding meaning in a "new" and different world.	Quality rating: 20/24 (κ=1)
Eriksson & Tham 2010 Sweden	To identify how occupational gaps were characterised in the lived experiences of performing everyday occupations in the first year after stroke.	**Participants:** 4 stroke survivors **Gender:** 3 male, 1 female **Aged:** 50-61 **Time since stroke:** 1 year - interviewed at 1, 3, 6 and 12months post-stroke	Longitudinal qualitative Empirical Phenomenological Psychological method – using an occupational perspective. Four interviews – 1, 3, 6 and 12 months post-stroke	Five main themes identified: • Encountering occupational gaps in formerly taken-for-granted activities • Striving to narrow gaps in desired activities • Recognising oneself in doing • Searching for a new sense of self in doing • Creating strategies to enable doing	Quality rating: 22/24 (κ=0.60)

Author, Date, Country	Study Aim	Sample	Design and Method of data collection	Key findings	Quality rating & reliability co-efficient (κ)
Fallahpour, Jonsson, Joghataei, Nasrabadi, & Tham, 2013 Iran	To describe and understand the lived experience and identify what characterises the phenomenon of participation in everyday occupations after stroke, in Tehran.	**Participants:** 8 stroke survivors **Gender:** 4 male, 4 female **Age:** 45-68 **Time since stroke:** 5-22months	Qualitative Empirical Phenomenological Psychological method Interview	Three main themes relating to the phenomenon of participation in everyday occupations: • I cannot do activities as before • I am not the same person – discovery of a different self • I am not living my life	Quality rating: 21/24 (κ=0.71)
Hutton & Ownsworth 2019 Australia	To explore the experience of sense of self and continuity in younger adults after a stroke	**Participants:** 10 stroke survivors with stroke onset between 18 and 55 years old **Gender:** 3 male, 7 female **Age:** 26-70 **Time since stroke:** 6months - 31years	Qualitative Phenomenological Semi-structured interview	Two main themes identified: • Centrality of stroke • Impacts of stroke on the self Participants who perceived their stroke as having lower centrality experienced a sense of continuity of self. Participants who viewed their stroke with higher centrality experienced interruption of self. Interruption of self often co-existed with growth of self. Perceptions of stroke centrality and the impact on sense of self shifted over time and context.	Quality rating: 23/24 (κ=1)
Kitzmüller, Häggström, & Asplund 2013 Norway	To illuminate the significance of the long-term influence of bodily changes on the perception of self after stroke	**Participants:** 23 stroke survivors **Gender:** 14 males, 9 females **Age:** 32-68 **Time since stroke:** 3-25 years	Qualitative Phenomenological hermeneutic approach Narrative interviews	One main theme was identified: • Living with an altered perception of self Three themes related to this altered perception were: - Living in a fragile body - Living in increased attention to bodily functions - Living in a body that is not me	Quality rating: 19/24 (κ=0.78)

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Author, Date, Country	Study Aim	Sample	Design and Method of data collection	Key findings	Quality rating & reliability co-efficient (κ)

Kuluski, Dow, Locock, Lyons, & Lasserson
 	
2014
 	
UK
	To understand the experience of stroke as a disabling life situation among young people and the strategies they use to recover and cope.	**Participants:** 17 stroke survivors
		Gender: 6 male, 11 female
		Age: 23-55
		Time since stroke: 1-12 years
			Qualitative
			
			Directed content analysis using concepts of "Biographical disruption" and "Biographical repair" as a guide
			
			Interviews – drawn from a database of stroke survivor interviews
				Two main theme, and six subthemes were identified:
				• Altered sense of self
				  - Loss of identity
				  - Family disruption and role change
				  - Loss of valued activities
				• Adapted sense of self
				  - Seeking external support
				  - Restoring normality
				  - Positive reflection
					Quality rating: 17/24
					
					(κ=0.74)

Kvigne, Kirkevold, & Gjengedal 2004 Norway	To explore how female stroke survivors experienced life following stroke and how they manage their altered situation	**Participants:** 25 stroke survivors (20 completed both interviews) **Gender:** 25 female **Age:** 37-78 **Time since stroke:** Repeated interviews – within 6 weeks post-stroke, then 6 months and 12 months post-discharge	Longitudinal phenomenological study Repeated interviews – within 6 weeks post-stroke then 6 and 12 months post-discharge	Stroke survivors experienced a struggle to preserve the self after stroke. This was particularly in relation to deep-rooted female identities and the female caring role. Five themes were identified in relation to this: • Fighting off disabling feelings and maintaining the will to live • Striving to regain the power to accomplish necessary and valued activities • Striking a balance between attending to the needs of others and addressing increased personal needs • Attempting to maintain control of valued female roles and accept help • Negotiating relationships on equal terms	Quality rating: 19/24 (κ=0.78)

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Author, Date, Country	Study Aim	Sample	Design and Method of data collection	Key findings	Quality rating & reliability co-efficient (κ)

Lawrence & Kinn
 	
2012
 	
UK
	To gain understanding of young adults' experience of stroke and associated rehabilitation needs, priorities and desired outcomes	**Participants:**
		10 stroke survivors
		Gender:
		5 male, 5 female
		Age: 37-54
		Time since stroke:
		3 – 22months
			Longitudinal qualitative
			Existential phenomenology
			
			Interviews –
			4 interviews conducted at 6month intervals over a period of two years
				One main theme and three subthemes were identified:
				• Embodied disorientation
				  - Mortal body
				  - Situated body
				  - Embodied perception of difference
					Quality rating: 22/24
					
					(κ=0.60)

Lobeck, Thompson, & Shankland
 	
2005
 	
UK
	Explore how men manage when two significant life events, stroke and retirement, occur in close proximity.	**Participants:**
		7 stroke survivors
		Gender:
		7 male
		Age: 64-70
		Time since stroke:
		6-12months
			Qualitative
			
			Interpretative Phenomenological Analysis
			
			Semi-structured interview
				Three interrelated processes were identified:
				• Ambivalence about retirement
				  - Pleasures and fears
				• The impact of stroke
				  - Biographical rupture
				  - Support
				  - Coping
				  - Taking control: "I can do it"
				• Healing and adjustment
				  - Feeling different, only half a person
				  - Altered outlook
				  - Uncertain future
					Quality rating: 20/24
					
					(κ=0.74)

Murray & Harrison 2004 UK	To investigate the meaning and experience of being a stroke survivor.	**Participants:** 10 stroke survivors **Gender:** 4 male, 6 female **Age:** 38-81 **Time since stroke:** 4-20years	Qualitative Interpretative Phenomenological Analysis Interviews: 5 face to face, 5 via email	Four main themes were identified: • Disrupted embodiment and loss of self • Invisibility of the emotional difficulties • Gender, romance and sexuality • Social interaction	Quality rating: 20/24 (κ=1)

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Author, Date, Country	Study Aim	Sample	Design and Method of data collection	Key findings	Quality rating & reliability co-efficient (κ)
Pallesen 2014 Denmark	To identify, from a long-term perspective, stroke survivors' self-identity, their views of any associated disabilities and how they manage their lives after stroke.	**Participants**: 15 stroke survivors 6 family members supported interviews, however any contributions analysed separately **Gender:** 10 male, 5 female **Age:** 42-84 **Time since stroke:** 5years	Qualitative Phenomenological Interviews Some were supplemented with telephone conversations, email correspondence and material sent by post.	• Participants described a continuous process of change related to dealing with their disabilities, changes in self-identity and life patterns. • Coping appeared related to either resignation or personal growth Two main processes were described: • Body experiences and Coping - Body experiences - Coping - An altered life • Identity - View of themselves in relation to the stroke - Relation to others and self-perception - How others look at them	Quality rating: 22/24 (κ=0.71)
Rittman, Boylstein, Hinojosa, Hinojosa, and Haun 2007 USA	To explore the psychosocial domains of the transition experience following discharge home post-stroke	**Participants:** 125 veteran stroke survivors **Gender:** 123 male, 2 female **Age:** 40-93 **Time since stroke**: Less than 6months Interviews conducted 1month post-discharge	Mixed methods (Only qualitative data used for review) Semi-structured interviews	Three main domains of the transition experience were identified: • Changes in sense of self and bodily experiences • Changes in connectedness • Changes in community integration	Quality rating: 17/24 (κ=0.78)

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Author, Date, Country	Study Aim	Sample	Design and Method of data collection	Key findings	Quality rating & reliability co-efficient (κ)
Secrest & Thomas 1999 USA	To investigate quality of life as experienced by stroke survivors following rehabilitation.	**Participants:** 14 stroke survivors **Gender:** 7 male, 7 female **Age:** 40-93 **Time since stroke:** 9months to 23years	Qualitative Existential-phenomenological Interviews	The stroke survivors experience was understood to be grounded in a life of loss and effort. This emerged from three interrelated themes: • Independence/ dependence • In control/ out of control • Connection/ disconnection with others The experience of the self was understood in terms of co-existing continuity and discontinuity.	Quality rating: 22/24 (κ=0.60)

Timothy, Graham, & Levack 2016 New Zealand	To gain an in-depth understanding of embodiment for people after stroke while transitioning from the hospital to the home.	**Participants:** 7 stroke survivors **Gender:** 5 male, 2 female **Age:** 66-89 **Time since stroke:** 2-4months	Qualitative Grounded theory Semi-structured interviews	Two main themes, and six subthemes, relating to the embodied experience of stroke were identified:
				• A divergent body-self
				  - Bodily strangeness
				  - An unpredictable body
				  - An effortful body
				• A cohesive body-self
				  - Regaining control
				  - Freedom
				  - Sense of self
					Quality rating: 23/24 (κ=1)

Wolfenden & Grace 2012 Australia	To explore the experiences of young, higher functioning, stroke survivors in re-establishing identity and returning to work.	**Participants:** 5 stroke survivors **Gender:** 5 female **Age**: 34-44 **Time since stroke:** 1-9years	Qualitative Critical interpretivist approach Semi-structured interviews	• Participants pursued identity continuity in the face of biographical disruption • Identity re-establishment involved the resumption of life roles and responsibilities • Challenges to resumption of roles were experienced	Quality rating: 19/24 (κ=1)

1.2.5. Analytic review strategy

Synthesis can develop a broad understanding of an issue by bringing together findings from multiple qualitative studies investigating the same experience (Ring, Ritchie, Mandava, & Jepson, 2010). Meta-ethnography aims to go beyond the findings of the individual studies, thereby "making a whole into something more than the parts alone imply" (Noblit & Hare, 1988).

This review followed the seven stages of meta-ethnography, as developed by Noblit and Hare (1988). The first two stages relate to identifying the area of interest and the scope of the synthesis. An initial scoping search was conducted to explore the research area and define the question to be reviewed. Once the literature for inclusion had been identified, the five phases of the analysis process were followed.

Reading the studies: the first stage of analysis involved repeatedly reading each of the identified papers and drawing out the main concepts and themes. Some papers only had one theme which related to identity experiences, however the full paper was read at this initial phase to develop an understanding of the context. Mind maps were developed for each paper to create a visual representation of the main concepts.

Determining how the studies are related: The next phase was to compare and contrast the concepts from across the studies. This involved looking for common or recurring concepts across the papers to draw out meaning within the themes and the overarching explanations of experiences of identity as described. A mind map was developed where concepts were preliminarily grouped into common themes.

Translating the studies into one another: Each study was re-read and details added to develop the mind map (Appendix C). Quotes and key words from the studies were written down to retain the meaning and stay close to the individual participant

accounts (first-order constructs) and the authors' interpretations (second-order constructs). This process identified shared meaning and concepts across the studies, described as a reciprocal translation.

Synthesising translations: The 3rd order interpretation was developed by taking the concepts drawn out of the studies and synthesising the findings to explore new understanding or interpretations. This involved exploring how the concepts from the mind maps related and how they could be understood together to create a greater meaning. The key concepts and initial ideas of themes were discussed with the research team. Discussion with the research team allowed for exploration of the reviewer's position in relation to the research findings and consideration of alternative understandings or interpretations. This was an important aspect of the analytic process as meta-ethnography acknowledges the multi-level interpretations involved which requires the reviewer to reduce their personal influence on the process. Through this process the translated concepts from the phase above were compared further with one another to develop the over-arching interpretation.

Expressing the synthesis: The expression of this synthesis is presented as the findings of this paper. This process involved consolidating the connections between the themes and 3rd order constructs to present a coherent narrative. This was discussed with the research team, during which the reviewer linked the findings back to key papers to ensure the context was maintained.

1.3. Findings

This review found two main themes, each with two subthemes. The first theme describes how stroke survivors experience a Loss of Self with regards to a disrupted self-identity and the experience of a state of self-incongruence. The second theme

explores how survivors can also experience a Renewed Self post-stroke as survivors describe elements of both continuity and transformation in their sense of self.

Table 1.4: Themes emerging from the review

Theme	Subthemes
1. Loss of self	1.1 Self-identity: disrupted occupations and roles 1.2 Self-incongruence: reconciling perceived-self and actual-self
2. Renewed self	2.1 Continued self: core-self and adaptation 2.2 Transformed self: reformulation, rediscovery and re-evaluation

A broader breakdown of how each study contributed to each theme can be found in Table 5, below.

Table 1.5: Study contribution across the themes

Studies	Theme 1: Loss of self		Theme 2: Renewed self	
	Self-identity	Self-incongruence	Continued-self	Transformed-self
Arntzen, Borg, & Hamran, 2015	✓	✓	✓	✓
Clarke & Black, 2005	✓		✓	
Ellis-Hill, Payne, & Ward, 2000	✓	✓		
Erikson, Karlsson, & Tham, 2016	✓	✓	✓	✓
Eriksson & Tham, 2010	✓		✓	✓
Fallahpour, Jonsson, Joghataei, Nasrabadi, & Tham, 2013	✓	✓		
Hutton & Ownsworth, 2019	✓	✓	✓	✓
Kitzmüller, Häggström, & Asplund, 2013	✓	✓	✓	
Kuluski, Dow, Locock, Lyons, & Lasserson 2014	✓	✓	✓	✓
Kvigne, Kirkevold, & Gjengedal, 2004	✓	✓	✓	
Lawrence & Kinn, 2012	✓	✓	✓	
Lobeck, Thompson, & Shankland, 2005	✓	✓	✓	✓
Murray & Harrison, 2004	✓	✓		
Pallesen, 2014	✓		✓	✓
Rittman, Boylstein, Hinjosa, Hinjosa, & Huan, 2007	✓	✓	✓	
Secrest & Thomas, 1999	✓	✓	✓	
Timothy, Graham, & Levack, 2016	✓	✓	✓	
Wolfenden & Grace, 2012	✓	✓	✓	

1.3.1: Loss of self

The findings from all 18 studies included in this review highlighted aspects associated with the theme: Loss of Self. More specifically, these studies suggest that the debilitating consequences (physical, emotional and cognitive impairments) which often result following a stroke, cause this loss of self to be experienced in two significant ways. Firstly, stroke survivors experience disruption to their sense of self-identity, brought about by an inability to perform their occupational and social roles and responsibilities. Secondly, there is an emergence of an emotive state of self-incongruence, as stroke survivors struggled to reconcile the difference between their perceived sense of self (who they thought they were), with their actual self (who they had become as a consequence of surviving a stroke).

1.3.1.1: Self-identity: disrupted occupations and roles

All the studies reported that, following a stroke, participants felt they had lost their sense of identity, which had traditionally been defined by a range of social roles and responsibilities. Typically, participants talked about the impact that the stroke had on their personal routine activities, occupational and leisure status, and social networks.

Throughout the literature, participants frequently remarked on how the loss of personal routine activities such as "eating", "bathing", "dressing" and "walking", left them feeling as though their sense of who they once were had been discredited (Kuluksi, Dow, Locock, Lyons, & Lasserson, 2014; Kitzmüller, Häggström, & Asplund, 2013; Kvigne, Kirkevold, & Gjengedal, 2004). Participants reported how they often felt "exhausted" and "fatigued" both physically and cognitively, and they reported that these everyday tasks now required thought and concentration

(Lawrence & Kinn, 2012). The inability to perform basic tasks, for example combing their hair, left survivors viewing themselves as "only half a person" (Ellis-Hill, Payne, & Ward, 2000; Lobeck, Thompson, & Shankland, 2005).

According to the evidence, this loss of self-identity was most notable in terms of the impact the stroke had on participants' occupational and leisure status. Fallahpour, Jonsson, Joghataei, Nasrabadi, & Tham (2013) explain how, for their participants, the greater the gap in "doing", the greater they experienced difference between the present and former self. Lost occupations led to reduced opportunity to connect with and express elements of the self, for example as a "creative craftsman", "a swimming champion" or a "fitness instructor" (Eriksson & Tham, 2010; Fallahpour, et al., 2013; Kuluski et al., 2014). Further, survivors reported change in their whole sense of being, such as one participant who previously described herself as an "active person" now states she is a "vegetable" and she feels "more like something that's planted than a person" (Timothy, Graham, & Levack, 2016).

Self-identity is closely linked to, and informed by, social connections with others such as family, friends and colleagues. Changes in occupational status can lead to a loss of social networks and one's sense of belonging (Kitzmüller, et al., 2013; Pallesen, 2014). Participants shared that they often declined social engagements due to challenges in communication, feeling fatigued and reduced ability to be spontaneous (Pallesen, 2014; Kuluski et.al, 2014; Hutton & Ownsworth, 2019). A participant in Hutton and Ownsworth's (2019) study states how this creates a "feeling of exclusion, not by people but by circumstance". Reduced social interactions led survivors to feel less valuable, for example, when explaining that their friends no longer asked for their advice one survivor stated, "it feels like I don't exist as a person, not at all" (Fallahpour, et al., 2013).

The studies suggest that identity was also threatened when impairments reduced survivors' ability to fulfil social roles in the way they had before the stroke, such as being a parent or a partner. A mother with paralysis described how her son "just wanted my arms around him, and I couldn't do it, it just didn't move" (Hutton & Ownsworth, 2019). Others could no longer read to their children, and one participant explained that his inability to physically play with his children meant he could no longer be the "dad that perhaps I once was" (Kuluski et al., 2014). Survivors' roles within their romantic relationships were also disrupted as they described a loss of reciprocity and needing to rely on their partner for help (Pallesen, 2014). There was a challenge to their sense of self as a partner and in the context of days out together one participant commented, "I've got to rely on my wife to push me in the chair which I don't think sounds very romantic … having to be taken rather than me taking my wife" (Kuluski et al., 2014).

1.3.1.2: Self-incongruence

One consequence resulting from changes in the stroke survivors' sense of self, as described above, was the emergence of difficult emotional states brought about by experiencing a state of incongruence. Fifteen of the studies reported findings related to self-incongruence in the context of a loss of the taken-for-granted, a self-body divide, and disrupted personal constructs.

This first state of incongruence was reflected when participants spoke about a sense of having previously taken life for granted, finding their current self was at odds with this former self. Participants acknowledged everyday tasks, and higher-level achievements, that they had accomplished in the past taking their body for granted. One participant stated, "there's so much one can take for granted" as she described

the loss of her ability to "walk like a normal person" and the loss of her "fantastic memory" (Kuluski, et al.2014). Other participants reflected on the amount of concentration and energy that everyday tasks now require, such as eating and walking (Ellis-Hill et al., 2000; Lobeck, et al., 2005; Kitzmüller et al., 2013; Hutton & Ownsworth, 2019). The studies described a loss of autonomy, often framed in the terms of a loss between the former and the new self, "the new [Debora] can't be active or get out and do things, she can't drive, so she just can't get up and go and do something" (Hutton & Ownsworth, 2019). Some participants spoke about the shock of having a stroke, reflecting "we think we are immortal. It doesn't happen to you, it happens to other people" (Lobeck, et al., 2005).

The evidence describes a further area of conflict as a self-body divide, where survivors express a disconnection between their physical body and their sense of identity. Participants report alienation from their bodies which now feel "out of control", "unpredictable" and "in conflict" with the sense of self (Erikson, Karlsson, & Tham, 2016; Ellis-Hill et al., 2000 & Timothy et al., 2016). Traditionally, the body and self are seen as inseparable, however for the survivors these have become separated and their unfamiliar bodies feel "strange" and like a "senseless object", as if "my own arm was somebody else's" (Ellis-Hill et al., 2000; Kitzmüller et al., 2013; Fallahpour et al., 2013). The participants struggle to reconcile the reality of their new bodily status with their image of themselves. For example, when talking about playing football with his sons one participant reports: "the fact is I just can't do it any more at all, but you really don't think that way, your brain still says to you, I can do that!" (Lawrence & Kinn, 2012). Arntzen, Borg, and Hamran (2015) summarise that the body, and its newfound limitations, hinder the survivors from living how they used to and being who they want to be.

Ultimately, across the papers, survivors described a disruption to their personal construction of who they are. They identified a loss of defining constructs such as being an "intellect" or "macho", as well as threats to gendered identities and roles (Clarke & Black, 2005; Ritmann, Boylstein, Hinjosa, Hinjosa, & Huan, 2007; Murray & Harrison, 2004; Kvigne et al., 2004). The loss of previously held constructs shook the survivors' whole sense of being. This left some to wonder "maybe I'm not quite the same person as before", while others stated their "whole personality has changed", further still, one participant reports looking in the mirror thinking, "it looks like me, but it's not" (Kitzmüller et al., 2013; Hutton & Ownsworth, 2019; Murray & Harrison, 2004). This disconnection meant that the survivors felt they had to "get to know yourself all over again" (Arntzen et al., 2015; Fallahpour et al., 2013). For some this represented a loss and having to let go of who they were before, "apparently I have to find a new [Debora] which I'm not very happy about. I'd prefer to just have the old [Debora], I was quite comfortable with the old [Debora]" (Hutton & Ownsworth, 2019).

1.3.2. Renewed self

Although loss was evident across the studies, 15 papers also explored how survivors experienced a renewed sense of self. This renewed self, appeared to be related to a process of recovery and adjustment and was based around two fundamental aspects, namely, the continued self and the transformed self.

1.3.2.1. Continued self

Evidence from these fifteen studies suggests that participants' sense of self continued in two main ways. Firstly there was a notion that a core component of the self

transcends the stroke, and secondly, survivors engaged in a process of adaptation in order to maintain the important aspects of their identity.

Participants described that their sense of self transcended the stroke-identity and their physical capabilities, thereby the stroke did not define who they were. These participants were able to integrate the stroke into part of their life narrative, expressing that "you can be someone who has had a stroke and still be who you were before that" (Hutton & Ownsworth, 2019; Wolfenden & Grace, 2012). Evidence showed that participants acknowledged enduring personal characteristics, often by drawing on aspects of their identity which were less reliant on their physical abilities. For example, survivors spoke about continuing to be someone who is "helpful", "diligent" or "the strong one" (Clarke & Black, 2005; Arntzen et al., 2015).

Across the studies, survivors were seen to engage in a process of adaptation in order to find ways to maintain their pre-stroke identity. They sought to adapt and modify how they engaged with salient activities and occupations in order to re-establish their role, feel "useful" and find meaning again (Clarke & Black, 2005; Lobeck et al., 2005; Wolfenden & Grace, 2012; Kuluski et al., 2014). Participants also described engagement in rehabilitation to regain lost skills and develop strategies to help them manage impairments. For example, relying on the recognition of voice and clothing to manage facial recognition difficulties, or re-learning skills such as reading and how to write with a different hand (Clarke & Black, 2005; Kitzmüller et al., 2005; Eriksson & Tham, 2010). This supported them to maintain connection to social networks and re-engage with occupations, expressing this made them feel "on the road to recovery again" (Eriksson & Tham, 2010). Where activity couldn't be maintained or re-established participants found new ways to fulfil aspects of their pre-stroke identity by redefining the scope of identity defining concepts. For

example, broadening the scope of "work" in order to maintain their view of themselves as a "workaholic", likewise, re-defining their previous occupation as a "project manager" and acknowledging how they continue to fulfil this role outside of employment (Hutton & Ownsworth, 2019). However, the desire for continuity of self, led some participants to over-exert themselves and put a lot of pressure on themselves (Arntzen et al., 2015; Erikson et al., 2016), and this was described as a struggle and a fight to regain or retain their ability and roles (Kuluski et al., 2014; Kvigne et al., 2004).

1.3.2.2. Transformed self

Seven of the studies evidenced that continued-self was not the end point, but that stroke survivors were often engaged in a process of self-transformation. This was evident across three areas, reformulating one's identity, rediscovering the self and re-evaluating life.

The studies suggest that survivors re-formulate their identity through engaging with new occupations and roles (Erikson et al., 2016). Some participants incorporated 'stroke survivor' into their identity and took on new roles in relation to this, such as volunteering for user-organisations and engaging in research (Artntzen et al., 2015; Clarke & Black, 2005). Others took on new roles around the home such as childcare and housework, with some male participants expressing that these were roles they had not previously seen as "manly", thereby altering their conceptualisation of their gendered identity (Kuluski et al., 2014; Lobeck et al., 2005). New identities were also created by adapting previous roles, for example one survivor talks about how DIY was "part of me" and although he can no longer physically do the tasks he now teaches his wife how to do them, therefore reformulating himself as the "organiser"

rather than the "doer" and describing himself as "a good boss" (Eriksson & Tham, 2010).

Evidence also showed that some survivors go through a process of rediscovery, where they identified new personal qualities and aspects of themselves as a result of having the stroke. One participant describes moving from being "plain Jane" to "superwoman", while another reflects that he is now referred to as "cheeky" stating that this new approach is "part of me since I had the stroke", a third survivor simply states "I have become kind" (Hutton & Ownsworth, 2019; Arntzen et al., 2015). Arntzen et al., (2015) reflect that the survivor's identity isn't necessarily a modified version of the former self, rather it can be a "wholly new and highly valued self". This was supported by a participant in another study who described that his life has "added value" as he has developed himself into what he feels is more "reflective, less prestigious and more empathic person" (Erikson et al., 2010).

Finally, survivors voiced that the stroke had led them to re-evaluate their outlook on life, which opened up a new way of approaching life and valued roles. The stroke led participants to reflect on how their life had been and reappraise what was important to them, reporting it had been a "massive lot of life lessons to learn" (Lawrence & Kinn, 2012; Hutton & Ownsworth, 2019; Eriksson & Tham, 2010). One participant reflects that before the stroke she was "having a good time but didn't think past that", however now she's "got goals, and I need to see where my life is going" (Hutton & Ownsworth, 2019). Others spoke about reprioritising and changing the pace of life, with one participant sharing that "the big change is that before I worked like a fool, it's a big change and it was what was great about this" (Erikson et al., 2016). While others recognised a changed attitude towards looking after their

physical health, seeking to gain control over their lives and regain a positive sense of self (Pallesen, 2014). Survivors reflected that the stroke had created an opportunity for them to enjoy life in a new way, expressed by one participant as, "I'm glad I had a stroke so I can smell the roses" (Erikson et al., 2016; Hutton & Ownsworth, 2019).

1.4. Discussion

1.4.1. Overview of findings

The aim of this review was to draw together and understand the current evidence-base relating to how people experience their sense of identity after having survived a stroke. Overall, two themes were identified, 'Loss of self' and 'Renewed self'. In terms of the first theme, it appears that stroke survivors initially suffer a great sense of loss. This was evident in terms of both their self-identity, as they were no longer able to engage in previous roles and occupations, and a sense of self-incongruence which emerged as they attempted to reconcile their previous identity, as defined by their world prior to their stroke, with their current identity, experienced as a stroke survivor. Despite experiencing loss, stroke survivors also seemed to experience a sense of renewal, the Renewed-self. This involved a sense of continued-self, both through adaptation in order to continue former roles, and through recognition of aspects of a core self which continued beyond their physical impairments. Further to this, some survivors appeared to experience a process of transformation as they reformulated their identity through engaging in new activities, rediscovered aspects of the self and re-evaluated their priorities and outlook on life. Continuity and loss appeared to be dynamic and were not mutually exclusive processes (Timothy et al., 2016; Secrest & Thomas, 1999).

1.4.1.1. Loss of Self

The first sub-theme indicated that the experience of identity post-stroke was highly associated with the loss of occupational roles due to physical and cognitive impairments, a finding strongly supported in previous reviews (Satink et al., 2013; Williams & Murray 2013). In agreement with the current review, these described that the loss of roles undermined survivors' previous sense of self and therefore created discontinuity in their identity. Further, in line with the findings of this review, Satink et al. (2013) reported that survivors experience a disconnection between the physical body and the sense of self. They go on to suggest that survivors are in a state of flux between their current and former identities. This supports the findings of the current review which has further explored the psychological component of loss of self-identity through the notion of self-incongruence. Beyond describing the disconnection between the physical body and the self, this review also identified how this creates disruption in survivors' personal construction of their identity and their previously taken-for-granted life. Previous research has often focused on the physical consequences of stroke and the associated loss of roles, without fully exploring the significant psychological impact of what is lost in terms of a person's own sense of identity. This review highlights the importance of recognising the interaction between the nature of physical loss and its impact on psychological loss in terms of identity construction.

1.4.1.2. Renewed-Self

The theme of continued-self highlights that survivors engage in a process of adaptation in order to maintain their sense of self, this is supported by the findings of previous reviews (Satink et al.,2013; Hole et al., 2014). These all identify that

survivors have a desire to regain or retain their identity through adaptation and modification of activities, roles and social positions. The current review adds to the understanding of continuity with the finding that survivors have a core sense of self which transcends beyond the stroke and their physical capabilities. This is an important finding as it suggests that there is stability in one's identity which does not need adapting. This could serve as an important protective factor for survivors who are unable to regain aspects of their identity through adaptation. It was recognised in the results that this may be easier for survivors whose sense of self is less dependent on their physical ability.

The second subtheme relating to the renewed-self was the transformed-self. This theme identified that some survivors not only found continuation in their pre-stroke self, but their identity developed and moved beyond this. None of the previous reviews significantly considered the experience of transformation of the self in depth. Lawrence (2010) identified that stroke led survivors to re-appraise their lives and develop a new sense of appreciation, however the findings of the current review explore this further. The transformed-self suggests that survivors draw out a new positive future through engaging with new roles (reformulation), identifying new personal constructs and qualities (rediscovery) and finding new purpose and meaning (re-evaluation).

1.4.1.3. Theoretical interpretations

Lou et al. (2017) highlighted that the qualitative research into stroke survivors' experiences is often grounded in the theory of biographical disruption (Bury, 1982). This theory positions chronic illness as a crisis leading to 'discontinuance' in the physical body and coherence of the self. Interestingly, only four of the reviewed

studies explicitly referenced this theory. However, discontinuance of the physical body and coherence of self were both predominant issues contributing to identity loss throughout the studies.

In contrast, other researchers have suggested that some stroke survivors do not experience biographical disruption, and instead propose a concept of 'biographical flow' (Faircloth, et al., 2004). The authors argued that survivors who make sense of their stroke as part of the normal aging process, or in the context of other health conditions, are able to incorporate the stroke into their life narrative without disruption.

This review found that some survivors described incorporating the stroke into their life narrative. However, the stroke also had implications for their identity beyond this and they developed and grew as a result of the stroke. Here the findings could be understood in the context of 'biographical renewal'. The reviewer posits that although survivors will recognise that some elements of the self are lost due to the stroke, they also identify stability of the core self which remains and seek to engage with who they are now. That is, they bring together core elements of the pre-existing self with a transformed state and reshape their identity in line with this. This suggests that there is something more than trying to adapt to regain the 'old' self, instead recognising that survivors can hold onto the core components of the self and also embrace who they have become following the stroke.

It is acknowledged that there is a growing body of literature exploring the concept of post-traumatic-growth (PTG) in the context of physical illness (Grace, Kinsella, Muldoon, & Fortune, 2015; Hefferon, Grealy, and Mutrie, 2009; Beckwith, 2013). PTG suggests that, following a traumatic incident, people can find positive

psychological change as a result of their struggle with the challenging experience, and find benefit and meaning in the event (Tedeschi & Calhoun, 2004). PTG could potentially be a process within the concept of 'biographical renewal', and further research could address the relationship between these two theoretical concepts.

This proposed theory provides a more holistic understanding of the core psychological-self and the process of transformation and developing the renewed self. It acknowledges that survivors experience loss of their self-identity, leading to self-incongruence, however it is possible to then move beyond this with positive re-emergence and renewal of a new coherent self.

1.4.2. Clinical implications

This review has several implications for clinical practice. Firstly, the review highlights a need for a greater emphasis on the transactional relationship between physical impairment and the resultant physical, social and psychological losses. There is a need for greater sensitivity to the link between the nature of the physical impairments and how they impact on an individual psychologically. For example, recognising that the physical occupational role loss may have a more significant impact on someone whose identity hinges on their physicality, such a builder who may experience more global self-incongruence as opposed to an accountant who can continue a desk-based job. This understanding needs to be shared across the multi-disciplinary rehabilitation team in order to tailor services to these individual nuances.

Secondly, the review suggests that a 'core-self' continues. While this review confirms the importance of supporting survivors to regain their sense of self through adaptation, it is possible that this could serve to neglect the psychological continuation of the self. It is therefore recommended that clinicians, such as clinical

psychologists, support survivors to become grounded in who they are and create the stability in their continued-self. Approaches such as narrative therapy have been shown to support stroke survivors to move away from problem-saturated narratives and reconnect to their lives within the constraints of their physical illness (Chow, 2015).

Finally, the concept of 'biographical renewal' suggests a need to work in the long-term with survivors to see life beyond the initial loss caused by the stroke. Building on the two implications above, there is a need to focus on developing the renewal of the self. Therapeutic input should be grounded in values and meaning in order to connect with the core-self and move into a valued renewed identity. For example, Acceptance and Commitment Therapy is a transdiagnostic approach which recognises pain, grief and illness as inevitable parts of life, however, supports the individual to adapt to these and live a valued life (Dindo, van Liew, & Arch, 2017). Here, psychologists could work closely with the occupational therapists to support engagement and development of a renewed self.

1.4.3. Limitations

There were three main limitations to this review which need to be considered.

Firstly, the literature included covers a broad range of socio-demographic factors which could benefit from more in-depth focus. For example, participant samples included a broad range of ages, varying lengths of time since the stroke and were of mixed gender, as such it was not possible to explore if or how these factors influenced the experience of identity. Specifically, no clear patterns could be identified between the different aspects of identity loss and renewal in terms of these factors. Further, the results suggest it could be valuable to explore differences

between individuals with different physical roles/ occupations. The review covered literature from different cultural and geographical backgrounds and although consistency was found across the studies it would still be valuable to explore cultural differences further.

Secondly, there are several challenges to collating qualitative data for the purpose of conducting a systematic literature review. As found in this review, there may be relevant data within qualitative studies that have a different research focus to the planned synthesis. Further, databases are not always accurate when searching for qualitative literature (Ring et al., 2010). These challenges resulted in the reviewer having to draw together fragmented literature and make decisions about the inclusion and exclusion of data, for example only including material where identity represented a dominant theme. Due to identity being an intangible concept, the reviewer recognised the need to consult with the research team regarding the agreed definition and inclusion/ exclusion process. While every effort was made to capture the relevant data, these limitations remain and need to be acknowledged.

Thirdly, as this review was dealing with the abstract concept of identity, it is important to recognise the hermeneutic process due to the multi-level interpretation involved in meta-ethnography. That is, the reviewer recognised the potential for their own experiences and views to influence their interpretation of the findings. However, in order to address this the reviewer liaised with the research team about the themes and the meanings attached, as well ensuring the data was interpreted close to the literature itself, for example, through the use of direct quotes.

1.4.4. Future research directions

Future research should focus on understanding the experience of 'biographical renewal' post-stroke. This should include further exploration of how, and in what circumstances, the core-self continues, and the survivor experiences a process of transformation. As this research would be aiming to develop a greater understanding of experience it would be best approached through an Interpretative Phenomenological Analysis which could draw out meanings associated with such experiences.

1.5 References

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Chapter 2: Empirical Paper

Husbands' lived experiences of providing care to their wife who has survived a stroke

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Abstract

This research aimed to investigate the experiences of husbands who care for their wives following a stroke, using interpretative phenomenological analysis (IPA). The participants were recruited through peer stroke support groups which were attended either by just the wives or, in two cases, as a couple. Semi-structured interviews were conducted with six men who had been caring for their wives for at least one year. Three superordinate themes emerged from the analysis: 1) Role-identity: husbands expressed confusion/uncertainty about their new role alongside a process of adjustment and taking control; 2) Self-identity: husbands lost their sense of self, driven by limited autonomy and the impact of the caring role on their emotional wellbeing; 3) Dyadic-identity: husbands acknowledged a loss of who their wives were before the stroke and described a change in their connection as a couple. Overall, the caring role impacted on the husbands' identity, wellbeing and relationships. The role became all-consuming and there was an overarching sense of loneliness amongst the carers. The implications for clinical practice and further research are discussed.

2.1. Introduction

2.1.1. Background

The aim of this study is to explore men's lived experiences of providing 'informal care' to their spouse who is a stroke survivor. Stroke is the interruption of blood flow to an area of the brain caused either by a blood clot or ruptured blood vessel, resulting in cellular damage (Camack, 2015). It can result in sudden and potentially permanent loss of physical, cognitive, emotional and social functioning (Kuenemund, Zwick, Rief, & Exner, 2016). In the UK there are an estimated 1.2million stroke survivors (Stroke Association, 2017). Of these, one-third are dependent on others for support with daily living, and for one-in-five this support is provided by 'informal carers' (Pindus, et al. 2016).

An 'informal carer' is defined as someone who provides unpaid care, without formal training, to a relative or friend who needs support to live independently due to age, disability or illness (CarersUK, 2014). The degree and nature of the care required following a stroke can vary significantly because stroke can impact the survivor in multiple ways.

Caring roles are typically viewed as being occupied by women, particularly in the informal context of caring for family members (Kluczyńska, 2015; Milligan & Morbey, 2016). Comas-d'Argemir & Soronellas (2019) argue that men are not socialised into the caring role like females are from a young age. Dominant models of masculinity, such as hegemonic masculinity, tend not to include care-giving roles as part of men's life expectations (Comas-d'Argemir & Soronellas, 2019; Kluczyńska, 2015). Given this context, taking on the caring role may be experienced

as a deviation from a man's expected life course and therefore impact how they construct their care-giving role and their masculinity (Milligan & Morbey, 2016).

There has been a lack of research attention to understanding if men experience the caring role differently to females in the context of stroke (Greenwood & Mackenzie, 2010). It has been suggested that clinical support may need to be adjusted to be more sensitive to the needs of male carers, who reportedly access less support and can feel ambivalent or guilty about seeking support (Greenwood & Smith, 2015). Despite the fact that in the UK, 42% of informal carers are male, they report a lack of recognition by professionals, services and wider society (Slack & Fraser, 2014).

2.1.2. Previous Literature

There is limited research exclusively investigating the experiences of men who care for stroke survivors (male stroke carers). Two studies have explored male stroke carers' experiences through the analysis of conversations on a web-based support group (Pierce & Steiner, 2004; Pierce, Steiner, Hicks, & Dawson-Weiss, 2007). They found that the carers experienced unwanted changes in their daily routines, however they also reported closer family ties and feeling more connected to their wives (Pierce & Steiner, 2004). It was identified that men gained a sense of stability and control over their situation by seeking concrete information about the stroke and caregiver tasks in order to take responsibility for their wife's care (Pierce & Steiner, 2004; Pierce, et al., 2007).

Studies with mixed-gender samples of stroke carers have explored the impact of the caring role on men in comparison to women. Some findings suggest that men are less negatively impacted by the role. For example, men have reported a greater sense

of coherence and a higher quality of life, with less depressive symptoms and a lower sense of burden (Jessup, Bakas, McLennon, & Weaver, 2015; Larson et al., 2008; Tiegs et al., 2006). However, other studies have found contradictory results, for example, Pucciarelli, et al. (2018) found male gender to be a predictor of higher caregiver burden. The authors suggest that higher burden could be explained by male carers having to adopt unfamiliar daily activities and provide more physical care, exacerbated by the context of having fewer coping strategies and limited social support.

Simon, Kumar and Kendrick (2009) found that men's levels of psychological distress increased between discharge and 6 weeks post-discharge. They suggested that male carers had not anticipated the implications of the caring role until it had become a reality. In addition, they highlight that men may have initially under-reported their distress due to unfamiliarity with the interviewer. Further, Alexander and Wilz (2010) found that male carers with a spouse who had substantial cognitive and emotional impairments experienced higher levels of depression and anxiety than females. The authors suggested that female carers' childhood socialisation meant they were better able to adjust to their partners' impairments, whereas males had not been encouraged to be as attuned to others' emotional experiences from a young age.

It is reported that spousal caregivers experience higher levels of depression than non-spousal caregivers (Jessup et al.,2015). Findings also suggest reduced quality in spousal relationships by six months post-stroke (Simon, Kumar, & Kendrick, 2009). Anderson and Keating (2017) conducted a review of how marriage is experienced after stroke. Overall, they found that the need for care undermined the emotional quality of the relationship. However, these findings were drawn from research on

both survivor and carer experiences, and they did not explore the difference between how male and females experience this.

2.1.3. Rationale and Aims

There are several limitations in the previous literature on the experiences of stroke carers that need to be addressed. Firstly, few studies have investigated the experiences of male stroke carers exclusively, and the majority of mixed-gender samples are predominantly female. For example, Zhang & Lee (2017) report that only 18% of participants in their review were male, and Quinn, Murray, & Malone (2013) reviewed 12 studies, of which only one had predominantly male participants. Yet, as evidenced above, research suggests that men's experiences could be different to females.

Secondly, much of the previous research on male stroke carers has used quantitative methods to measure impact in terms of depression, stress and caregiver burden. Although this provides an overall impression, qualitative methods would allow for a more in-depth understanding of the experience of the caring role.

Thirdly, while some consideration has been given to how the caring role impacts on male carers, there is limited exploration of how these men experience their relationship status when caring for their wife post-stroke.

To address these limitations, the current study employs the qualitative methodology of Interpretative Phenomenological Analysis (IPA) in order to explore husbands' experiences of caring for their wife following a stroke. Thus, the main research question is: What are husband's lived experiences of providing care to their wife who has survived a stroke?

2.2. Methodology

2.2.1. Research Design

This study conforms with an interpretivist epistemological position. Interpretivism proposes that there are multiple subjective realities, thereby refuting positivist claims of an objective and measurable reality. Within this methodology, this research adopts an IPA approach which studies individual's qualitative experiences in order to gain an understanding of their social reality (Gray, 2014; Smith, Flowers, & Larkin, 2009). As an idiographic approach, IPA requires deep engagement with the complexity of an individual's experience of a specific phenomenon, allowing for the participants' voice to be interpreted in terms of the nature and meanings they attribute to their lived world.

The theory of hermeneutics underpins IPA, this recognises the active role of the researcher throughout the process of making sense of how a phenomenon appears (Shaw, 2010). The researcher is required to recognise, and set aside, their own assumptions and pre-conceptions about the topic and acknowledge the potential for these to influence the research process (Smith et al., 2009).

2.2.2. Sampling Design

2.2.2.1 Nature of Sample

Purposive, non-probability sampling was used to recruit male spouses of stroke survivors in line with the inclusion and exclusion criteria described in Table 2.1. This sampling method enabled the recruitment of a homogenous sample which is important in IPA for the meaningful investigation of a particular phenomenon, in this case the experiences of husbands of stroke survivors (Smith et al., 2009).

Smaller sample sizes are deemed suitable within an idiographic approach to allow

for the in-depth exploration of participants' experiences. This study recruited six

participants, which is considered a suitable sample size for an IPA methodology and

for a clinical psychology doctoral thesis (Thompson, Larkin, & Smith, 2011).

2.2.2.2. Inclusion and Exclusion Criteria

Table 2.1. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Male	
Aged 18 or over	
Carer for stroke survivor	Carer for someone due to a different health condition
Stroke survivor had their stroke at least one year ago	
Stroke survivor diagnosed with a clinical stroke	Stroke survivor not diagnosed with stroke (including, diagnosis of functional stroke symptoms or TIA)
No prior informal caregiving responsibilities, i.e. new to role of caring	Acting as informal carer for stroke survivor prior to stroke, due to other illness/ disability or informal carer for another individual
Husband/ intimate partner of the stroke survivor	
Self-identifies as carer/ has significant caring responsibilities for their relative	Does not identify self as carer or identifies self as occasional carer
Informal carer i.e. does not receive payment (not including government benefits)	
Provide care 10 or more hours a week	
Stroke survivor lives in the community with the carer	Stroke survivor resides in residential care

In line with the aim of the study, participants were recruited if they were adult males providing care for their wife[1], or intimate partner, following a stroke. This is in contrast to a transient ischemic attack (TIA), where the side effects are more acute and temporary, or a functional stroke where the presentation, prognosis and needs may differ from a clinical stroke. The confirmation of a stroke diagnosis relied on participant self-report; this was deemed acceptable given the nature of the research being on the participant's own perceptions and experiences as carers.

Participants were recruited at least one year following the stroke onset. This time frame was set to ensure that the husbands had occupied their caring role for a substantial amount of time. In addition, it is more likely that the stroke survivors' functional ability will have stabilised and their rehabilitation input will have ended (Smith, Lawrence, Kerr, Langhorne, & Lees, 2004).

Evidence suggests that carers with prior caring experience were able to identify coping strategies sooner than new carers (Greenwood, Mackenzie, Wilson, & Cloud, 2009). Therefore, the participants in this study were required to have only become carers due to the stroke, rather than having existing caring responsibilities.

The participants recruited lived with the stroke survivor, had significant caring responsibilities and were not paid for the role. Husbands of survivors who resided in

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[1] Early in the recruitment process the opportunity arose to interview a fifty-year-old man who cared for his mother following a stroke. Although this deviates from the homogeneity of the rest of the sample the decision was made to retain his interview for analysis because it was considered unethical to ignore his voice. His experience contributed by adding emphasis to the experiences described by the husbands. He was given the pseudonym "Paul".

residential care were not included as most of the survivor's needs would be met by the formal care system.

2.2.2.3. Sample Access

The study was promoted at voluntary stroke and carer support groups in the West Midlands. The researcher contacted the groups via email with information about the study and an advert (Appendix D). Following email contact, the researcher was invited to visit and talk at some of the support groups. Further copies of adverts were provided with the researchers contact details. The study was also publicised through an advert on the Stroke Association website and forum 'My Guide'.

Eligibility was established with carers who expressed an interest in taking part. They were then provided with a participant information sheet and consent documents. The interviews were arranged at a mutually convenient time and location.

2.2.3. Participants

Six participants, meeting the inclusion criteria, were recruited through three different support groups. Two of the participants (Jeremy and Brian) regularly attended the support group with their wives, the rest would take their wives to the group but not attend the session themselves. From the information collected, all husbands were aged over 65, and had retired from full time employment prior to their wife's stroke. The husbands had been caring for their wives for between 1 and 6 years. All participants were given a pseudonym to maintain their anonymity which have been used alongside quotes presented in the findings.

Table 2.2. Participant characteristics

Participant	Age	Year of stroke (time as carer)
Jeremy	Not provided	2015 (3 years)
Karl	69	2015 (3 years)
George	70s (exact age not provided)	2014 (4 years)
Stuart	76	2014 (4 years)
Brian	73	2017 (1 year)
Graham	79	2012 (6 years)

2.2.4. Interview Guide

This study collected data through informal interviews, facilitated by a semi-structured interview guide (Appendix E). IPA studies commonly use semi-structured interviews because they allow for open and non-directive questioning which helps create to opportunity for the participant to share their personal experience (Willig, 2009).

The interview guide comprised of open-ended questions developed on the basis of key themes in the existing informal carer literature and including issues related to roles and responsibilities, relationships, personal impact, adaptation, coping and help-seeking.

The aim of the guide was not to create a structured schedule of interview questions, but to present some issues raised in previous literature and to allow the participants to express their own experiences and attributed meanings, using their own voice. Therefore, the interview guide was used flexibly to allow the researcher to be open and responsive to the participants' experiences as they were presented. It was developed in line with IPA principles (Smith et al., 2009).

The interview guide was reviewed by multi-disciplinary team members of a local Stroke Outreach Team, as well as the carer of a stroke survivor who was accessing their service.

2.2.5. Reflexivity and Bracketing

As highlighted above, the emphasis of the interviews was to allow for the exploration of the husbands' experiences in their own words. The IPA approach aims to avoid imposing pre-conceived ideas and assumptions on to the participant's experience, however it is recognised that the researcher plays an active role in interpreting the participant's account of their experience (Smith et al., 2009). Due to this, reflexivity is an important part of the IPA approach. The lead researcher engaged in a bracketing interview conducted by their research team prior to the participant interviews. The bracketing interview involved exploration of the researcher's motivation to research this area and their previous knowledge of stroke and male caregivers. This sought to identify and explore the researcher's preconceptions about the interviews, creating a greater awareness of their personal and professional position within the context of the research. The researcher also kept a reflective journal throughout the interviewing and analysis process.

2.2.6. Methods of Data Collection

Data was collected through one-to-one informal interviews. Interviews were held either in the participant's home or in a private room at the community venue where the stroke support group was held. Interviews conducted in the participant's home were held in private, away from the stroke survivor. The interviews lasted between

50 minutes and 110 minutes, with an average length of 76 minutes. The interviews were audio recorded and transcribed verbatim. The researcher made reflective notes following each interview and during the transcription process. This included information from the interview which could not be heard on the recording, as well as reflections relevant to the analysis process (Smith et al., 2009).

2.2.7. Ethical Considerations

This study was approved by Coventry University ethics committee (Appendix F). Permission was granted to promote the study with the Stroke Association. The research was conducted in line with British Psychological Society Code of Human Research Ethics (2014).

Participants were provided with an information sheet (Appendix G) outlining the study, to ensure they were giving fully informed consent to participate. All participants signed a consent form (Appendix H) prior to their interview to confirm they were willing to take part and they understood how their data would be used. They were informed of their right to withdraw from the research, and provided with information about how to do so after the interview, if they wished.

Participants were offered the opportunity to receive a summary of the results, and invited to provide feedback on these (Appendix I). Consent to contact participants in these circumstances was provided by four of the seven participants.

Participants were informed that their data would be stored in accordance with the General Data Protection Regulation (GDPR). To ensure participant data was kept securely, after each interview the digital recording and interview transcription was transferred to Coventry University's secure OneDrive server, and the original

recording was deleted. In order to maintain anonymity, participant names were replaced with pseudonyms during transcription, and identifying information was removed from all quotes used.

It was acknowledged that the interview process could have an emotional impact on the participant, and a protocol was planned for this scenario, however it was not required during the course of the interviews. At the end of the interview time was given for a debrief, allowing participants to ask questions about the research or interview process. Participants were also provided with a debrief form including information about support services they could access if they required (Appendix J)

2.2.8. Method of Data Analysis

The analysis was conducted in line with the six stages of IPA outlined by Smith et al., (2009). In line with the principles of idiography, each interview was addressed individually in turn, in order to appreciate the individuality of each participant's account (Biggerstaff & Thomson, 2008). It is recognised that these stages can be used flexibly and often overlap and merge, for clarity the general processes followed at each stage are presented.

Reading and re-reading: The lead researcher transcribed all of the interviews as part of the initial stage of familiarisation with the data. Transcripts were re-read several times and notes were made regarding any initial reflections or relevant recollections from the interview process, for example noting the participant's mood or approach to the interview.

Initial noting: An exploratory analysis of the content was then conducted. This included notes made in free-association when reading the texts, and as well as closer coding using descriptive, linguistic and conceptual codes (Appendix K).

Developing emergent themes: During the coding process notes were made of emergent themes based on patterns and connections identified in the exploratory analysis. This involved developing concise statements and phrases which captured the overall essence of the codes assigned to the transcript.

Searching for connections across emergent themes: Emergent themes were extracted from each transcript and collated onto a mind map. This allowed for visual exploration of how the emerging themes fit together (Appendix L).

Moving to the next case: Once these stages had been followed with one transcript the process was started again with the next. Once all transcripts had been coded and emergent themes developed the researcher moved on to the final stage of analysis.

Looking for patterns across cases: The key themes and patterns derived in the mind-mapping process were then written on to separate pieces of paper and organised to explore the interrelationships across the data set (Appendix M). This led to the development of broad higher-order themes. These were initially discussed with one member of the research team (KM), following which the superordinate and subordinate themes were derived. These were then discussed together as a whole research team for further refinement.

To add to the validity of the findings a summary of the themes was sent to participants for their comment. The summary was presented in accessible language and was only sent to participants who opted in to receive this (Appendix N). Participants were invited to provide feedback regarding the findings and how they fitted with their personal experience. The feedback received reported that the findings were reflective of their experience.

2.3. Findings

Three superordinate themes emerged from the data, each had two subordinate themes as outlined in Table 2.

Table 2.3. Superordinate and Subordinate themes

Superordinate themes	Subordinate themes
Theme 1: Role Identity	1.1 Confusion/ Uncertainty
	1.2 Adjustment: Passive and active
Theme 2: Self Identity	2.1 Limited autonomy
	2.2 Impact on Wellbeing
Theme 3: Dyadic Identity	3.1 "She's not the person she was before"
	3.2 "The funny thing is, you're lonely"

2.3.1. Theme 1: Role Identity

One of the key issues experienced by the participants was the changing nature of their role in relation to their wife. There were two prominent aspects of this changing identity: 1) confusion/uncertainty regarding roles, responsibilities and how the stroke survivor should be cared for, and 2) the process of role adjustment in order to cope and adapt to these new circumstances.

2.3.1.1. Confusion/Uncertainty

The first state of confusion and uncertainty related to the health services. This began during hospital admission following the stroke. Participants tried to make sense of

their role whilst their wife was in hospital, with participants expressing both a desire and a need to be involved in the hospital care, including supporting with meals and making suggestions for how to improve their wife's care.

"I went there a lot. Mostly twice a day, particularly to help at meal times because, well, for two reasons … nurses don't have time or the inclination to be patient and find out what it is that [wife] is trying to say … also to help with erm, to make sure things were ok and…to know how things were and to be involved" (Jeremy; 14-21)

However, they did not feel this was always welcomed, adding to a sense of confusion about what their role should be.

"it continues to amaze me that they weren't welcoming somebody who wanted to provide support." (Jeremy; 123)

Following this, at the time of discharge there was an assumption that the responsibility for care would fall to the husband. However, participants did not recall this being discussed or explained prior to discharge. There was a sense that the participants felt thrown in at the deep end, feeling uncertainty about what their role would entail.

"they give you a bag of tablets and your wife and you've got to go home you see. Now that is, that is most petrifying because you don't know what to expect. Nobody's told you anything." (Graham; 73-76)

This appeared to be compounded by a lack of clarity over what to expect in terms of the stroke survivors' ongoing functional needs, with a lack of formal information in this regard.

"She must have had a discharge note from the hospital I suppose, and that probably did give [medical information], but it meant nothing to me, it didn't give me any advice." (Stuart; 406-408)

"she was walking, talking and I thought – this is going to ... this is only going to improve … but I didn't realise that you can't catch up on 74 years' worth of brain cells" (George; 944-948)

Further, participants expressed confusion when navigating the support available post-discharge. They often expressed that they felt they were not provided with enough information about what was available, and were often let down by services they did try to engage with.

"Nobody tells you anything you see, this is the problem. Now, I blame our doctors for one thing … he should have a sheet there telling me this, that and the other" (Graham; 605-608)

"I continue to be unhappy really that NHS input in that sense, rehab input, ceased after six months, given that the hospital doctors never lost an opportunity to explain to me and to [wife] that recovery and rehab after stroke is a long long slow process." (Jeremy; 49-53)

It was apparent that participants' role confusion didn't end with the statutory services, continuing into the division of roles in their new status as carer and survivor. Participants discussed taking on roles which had previously been their wife's responsibility such as cooking and cleaning. For many this involved learning new skills, and some participants described that this brought with it criticism from the survivor about how they completed the tasks.

"It's a big shock because of all the little things that she used to do, I've got to do them now because she can't do anything, she just doesn't do anything." (Graham; 1293)

"the whole running of the house has changed, she used to do those things" (Stuart; 561)

"every time I do a meal you've got something wrong with it, well if you could do it better do it yourself." (George; 656)

Participants also struggled with making sense of how much the survivor was able to do, and trying to strike the balance between encouraging independence and not creating dependence.

"There's times when she can't or won't think for herself, or she wants me to think for her, and I resist … so in that sense I'm perhaps a little cruel, but cruel to be kind, I'm trying to instil a little bit of, you know, self-reliance" (Karl; 373-378)

"You start coming in and go, I'll cook all the meals … they've got nothing to do anymore then they go down hill really quickly, so have I let them down by trying to let them keep their independence?" (Paul; 897-902)

Participants also spoke about conflicts arising within their wider family networks, which appeared to grow out of confusion around expectations of each other's responsibilities.

"don't get me wrong, my daughter has been a lovely woman … but she comes over here and she will look at something and say – this needs doing, you haven't done that, oh, I wouldn't have done that. Oh it's silly things but

… she never gives me any praise or any credit for what I do." (Brian; 651-656)

"family relationships have changed. They made me bitter towards them you see, for their actions. Not playing the bloody game you see, and they knew the position I was in, none of them offered any help and they couldn't even be bothered to pick the phone up" (Graham; 1141-1145)

2.3.1.2. Adjustment: Passive and Active

Participants appeared to engage in both passive and active strategies in an effort to adjust to their changing circumstances.

With regards to passive approaches to adjustment, participants seemed to rationalise their new role in terms of an unquestioned sense of duty. This acknowledged an idea of fulfilling their marital vows and perceived husband role, however there was also a sense of resignation into the caring role for some of the husbands.

"I think it's just, what is it they say, for better for worse, you know … I feel the problem is ours, I don't think it's something that I can share with somebody else" (Karl; 235-238)

"I'm married to her so that's the cards I've been given so I'm going to have to put up with it you know, you have to play the cards the best you can" (Stuart; 152-154)

"how could you just leave somebody in their old age and just get on with your life?" (Paul; 337-346)

Participants adopted a 'soldiering on' attitude, expressing a need to take each day as it comes and just get on with it. On the whole this appeared to be a passive approach to the challenges they faced, however, for some, it also captured a sense of slowly adjusting over time.

"Just cope with it don't you. You just grin and bear it, there's nothing else" (Brian; 449-450)

"You just have to get on with it, ... well we didn't tend to think about it, we just adjusted. I mean you don't adjust overnight, you live with it, you find out ways of doing things differently, more efficiently." (Karl; 468-471)

At times, this coping style served to minimise the significance of the caring role and there was some evidence of deflection where it appeared participants were finding it difficult to acknowledge or express difficult experiences.

"*Interviewer:* How did you find taking on that role [dressing his wife]

George: [pause] ok, you know, we've lived with each other for forty years, there wasn't a part of her body probably that I hadn't seen [laughs]" (George; 392-396)

"*Jeremy:* I suppose the hardest thing is the communication challenge [3 second silence]

Interviewer: Yeah [4 second silence]

Jeremy: but you know, we haven't been sitting here moping about it" (Jeremy, 304-306)

Alongside the passive coping, participants also demonstrated some more active adjustment to their new role.

Some participants appeared to make sense of the new role by connecting it to previous skills and other parts of their identity or character, for example, skills from their professional life.

> "I'm not skilled in anything like this, this is way out of my league, when I was a first aider at work we had a couple of crises and they used to say – even the paramedics – they'd say, oh you did that well, well done" (Brian; 836-839)

> "one of my functions when I was working … you're planning things that are practical and real you know" (Karl; 483-485)

Participant accounts also suggested a need to take control, especially as they often felt dissatisfied with support services.

> "Interviewer: [Regarding declining paid carer support] … you decided you'd take that on yourself?
>
> Graham: yeah, well if someone came in for five minutes and never spoke a word and went out again, I don't need strangers coming in to my place for that – I can see to that" (Graham; 165-169"

> "Well, where's our local stroke support group? And it became clear that there wasn't one, so we concluded that we had better start one" (Jeremy; 256-258)

Participants also took an active role in self-care and recognised a need for 'time out' of the caring role. All participants identified a hobby or social support which appeared to serve as a temporary escape and allow for some maintenance of their previous self, although time to engage with these activities was often limited.

"without my golf, I'd have a problem, that has kept me sane basically,"
(Stuart; 201)

"one of our granddaughters ... she comes in two days a week … which allows me to escape now and then, yeah, and do my own thing" (Karl; 186-190)

2.3.2. Theme 2: Self-identity

Participants' accounts of their experiences reflected a strong sense of a loss of self-identity. They reported that time was no longer their own and that their previous level of autonomy and independence had now changed, they also noted that this had a significant impact on their wellbeing.

2.3.2.1. Limited Autonomy

Participants' sense of self-identity was lost principally due to the fact that their lives were organised around the needs of the stroke survivor, they also reported that the stroke survivor was always on their mind.

"I'm never far away and when I'm far away I worry" (Brian; 1399)

"things have changed a lot, and basically I have to adapt to her needs, you know" (Karl; 197-198)

"it's in the background of my mind all the time that she's there, and suffering, and I need to just keep her in my mind" (Paul; 241-243)

As a result, time was no longer their own. Participants spoke about self-sacrifice with either loss, or restricted access, to previous interests and hobbies. Their time was now dedicated to caring for their wives, including taking on tasks and roles that she had done before the stroke.

> "Well, it's restricted freedom, you can't do all the things without making arrangements to keep her occupied, to keep her safe" (Stuart; 470-471)

> "It was a bit of a stretch and I'd found that I then couldn't do things that needed doing as I was so tied up with you know, things that she needed, wanted, doing." (Karl; 75-77)

> "I don't have the freedom to choose what I want to do" (Paul; 381)

Participants spoke about a loss of connection with others such as friends and wider social networks. When they did socialise as a couple the carers felt a responsibility to keep conversations going and maintain social connections for their wives where possible.

> "I think some proportion of our friend network has sort of dropped off, you know. But anyway, we are surviving" (Jeremy; 390-392)

> "that is one thing I hate … people don't come. I mean visitors don't hardly come now. At first they did but now it's very rare, people just don't, just don't come anymore." (Brian; 629-632)

> "It's like you can imagine being, visiting, somebody in hospital bed and … eventually you run out of things to talk about don't you, and it's a bit like that" (Stuart; 292-294)

2.3.2.2. Impact on wellbeing

Participants described a significant emotional impact in taking on this role, including depression and frustration. Interestingly, participants didn't explicitly discuss the impact on their physical health apart from in the context of staying well for the caring role.

"mentally it's had a big impact on me you see, because I never ever thought I would curse and swear at my wife. That's the thing that bothers me more than anything, because I feel ashamed of doing it, I feel so sad that I've done it and I feel so sorry for her that I'm doing it." (Graham; 1153-1157)

"physically I wouldn't say it's had any effect, it's the mental, the mental side of it is because … like I'm on a short fuse and things like that now." (Graham; 1229-1231)

"I had an incident a couple of weeks ago where I was just, I just sat all day and did absolutely nothing, and the phrase I used was being fed up of being fed up" (Karl; 286-289)

"depression can visit sometimes … you can't feel sorry for yourself, I mean, but I did, you do get – you sort of sit and think – God is this ... sometimes I just sit and say – is that it? Is this what life's left for me? ... you do get very low sometimes" (Brian; 1170-1179)

Participants expressed anxiety about their own health and mortality, however this was in relation to the impact it would have on the stroke survivors' care. This emphasises how much the role as a carer had engulfed their sense of self.

"I did feel it at the time [depressed] but then you think why would I commit suicide, or feel suicidal, because who looks after [wife] when I'm gone? That's the last thing I want isn't it? So I want to be here for her." (Brian; 1190-1193)

"I've got to try and remain strong, because I know if anything happens to me, God knows what would happen to her" (Graham; 732 -733)

2.3.3. Theme 3: Dyadic identity

Participants' narratives suggested that adopting the caring role had a significant impact on the nature of their relationship with the stroke survivor. This impact occurred in two ways: how the participant perceived the survivor as a person, and their sense of connection with one another.

2.3.3.1. "She's not the person she was before"

Participants acknowledged loss of some aspects of the stroke survivor and expressed that they are a different person to who they used to be.

"She's not a shadow of what she was you see … she was so forthright and upfront and you know, boisterous and efficient … it hits you like a bolt in the blue. I mean, one minute everything's fine, and it's instant [clicks fingers] like that … it's just turned upside down in a matter of minutes" (Graham; 1341-1346)

"Well, there's no question about it, it was a very hard very hard to cope with, [wife] is not the person she was before she had the stroke" (Jeremy; 300-302)

"She was always immaculate, impeccable" (913), "She doesn't always wear the most appropriate clothing" (George; 1100)

The stroke survivors were now described as vulnerable and there was a sense that the carers therefore felt they needed to take on a protective role. The relationship appeared to have moved from a shared equal partnership to one of taking care.

"as a man and wife, you know, she does the things that she can do and I do the things that I can do … but things like that are out of the question now" (Karl; 100-103)

"I worry about her every time she goes out" (George; 437)

Whilst there was a sense of sadness at the loss of aspects of the stroke survivor, many participants appeared to have developed a new found appreciation for the stroke survivor's role prior to their stroke.

"They take a lot on, they'll do things that you as a man would accept that you'd have to do but they will do it, think nothing of it and not mention it, and they do it. And then, when they don't do it you realise what they've been doing … until something happens like this you don't realise how much their contribution was" (Graham; 1277-1282)

2.3.3.2. "The funny thing is that you're lonely"

There were clear descriptions of disruption to their relationships throughout all of the interviews. Participants describe a loss of connection and affection with the stroke survivor, this was particularly salient where there were communication difficulties as a result of the stroke.

"There's nothing, she doesn't talk very much, so there's not a great deal of company at home … there's no emotion either, there's no emotion with her at all, so that side of life has gone" (Stuart; 98-104)

"changes in relationship, erm, well, it destroys it to put it bluntly, because there's no relationship." (Graham; 728-729)

Connection was also lost through changing routines and reduced opportunity to do activities together.

"she was very active, she had an allotment and we did lots of things together that, much that we can't do now. But I suppose the hardest thing is the communication challenge" (Jeremy; 302-304)

"the problem that I have more than anything else is (wife) goes to bed at half past 5, 6, every night, she won't stop up any later than that … It's a sort of, the funny thing is that you are lonely" (Brian; 621-626)

For some participants the role of carer appeared to now dominate their relationship and connection with the stroke survivor.

"I do feel I'm more of the carer, not so much of the husband" (Stuart; 447-449)

Despite these challenges, participants spoke with great warmth and care for their wives. There was evidence of continuing strong bonds between the carers and survivors,

"Well, I'm her partner aren't I? I'm not just her husband, I'm her, she's a partner, she's probably my best friend" (Brian; 900-904)

"You see a good wife is the backbone of any relationship … and of course when that's taken away from you it's like having your right arm cut off" (Graham; 715-719).

2.4. Discussion

2.4.1. Overview of findings

This research sought to explore men's experiences of caring for their wife who had survived a stroke. The findings highlight that taking on the caring role impacts on their identity and sense of self in three main ways. Firstly, the carers' role-identity is initially thrown into a state of confusion as they attempt to make sense of their new context and what that means for their role and responsibilities. This led them to engage in a process of both passive and active adjustment and attempts to regain control. Secondly, carers described significant changes to their self-identity as the constraints of the caring role impacted on how they spent their time, and in turn, negatively impacted their wellbeing. Finally, the carer-survivor dyad was affected as carers reflected a change in how they perceived their wives and a loss in connection in their relationship with them. These themes are discussed in relation to previous literature, before considering over-arching issues from across the findings.

A key finding arising from the theme of role-identity was that the husbands did not feel adequately informed or equipped when they initially took on the caring role. This resulted in ongoing confusion about their role which often led to frustration and anger, particularly towards services. Pierce and Steiner (2004) highlighted that male carers seek concrete information in order to gain a sense of control. In the current

study, the men often took control by taking on the responsibility for their wives' care themselves. This was in-line with findings in the case study reported in Pierce et al., (2007). For the husbands in this study, taking responsibility appeared to relate to the men's sense of marital duty to care for their wives. It is suggested that this sense of duty could be a narrative they employed to manage the confusion felt in the new role they had found themselves in. Greenwood and Smith (2015) report that male carers' sense of duty and reluctance to relinquish responsibility can become a barrier to accessing support.

The husbands in this study expressed the significant impact the caring role had on their routine, activities and autonomy, a finding also common in other research (Jessup et al., 2015; Simon et al., 2009; Pierce, 2004). They also described becoming socially isolated as a result of the caring role, which is supported by the finding that male carers have less emotional support networks (Larson et al. 2008). Previous research has found that male stroke carers report depression, burden and stress (Simon, et al., 2009; Alexander & Wilz, 2010; Pucciarelli et al., 2018). This study provides further insight into the psychological impact of caring for a spouse. It was evident that the husbands had become pre-occupied by the needs of the survivor, at the expense of their own needs. This resulted in a disconnection from their self-identity, and it was found that the husbands' lives had become consumed by the caring role both in terms of what they can do, but also in that it is always on their mind.

This study indicated that husbands experience the stroke and caring role as having a significant impact on their relationship in terms of their loss of their wife as she once was and a loss of connection. This is supported by the findings of studies which have

explored male and female stroke carers experiences. López-Espuela, et al. (2018) describe stroke as a "relationship disrupter", also reporting that their participants experienced the survivor as a changed person. Further, carers reported reduction in the quality of their relationship (Simon, et al., 2009). In contrast, Pierce and Steiner (2004) reported that male stroke carers described more connection in their relationships post-stroke. The review by Anderson and Keating (2017) concludes that the emotional quality and connection is undermined in the carer-survivor dyad, however many couples are able to regain connection. The husbands in this research spoke with great warmth and love for their wives, however, it was apparent that they had lost aspects of their partner and their relationship due to the stroke. Jessup et al. (2015) reported that spousal caregivers had higher levels of depression than non-spousal caregivers. The current research could provide insight into this increased depression, suggesting it could potentially be related to the loss of connection and sense of responsibility experienced by the husbands.

2.4.1.1. Over-arching issues

Three overarching issues arose from the findings. Firstly, the husbands appeared to have lost their sense of identity outside of the all-consuming caring role. Secondly, the impact of the responsibilities were not fully appreciated as they 'soldiered on' in their new role. Thirdly, there was evidence of hidden loneliness in the caring process.

Sense of identity and the caring role

Further to the theme above describing loss of self-identity, it was evident that the husbands had to organise their lives around the demands of the caring role, and this

had become their pervasive identity. This was apparent during the interviews as the husbands would often answers questions in the context of the survivor and their experience, rather than from their own position. They appeared to have lost their own identity beyond being a carer. This is in line with recent findings of a study of both male and female spousal stroke caregivers, who reported the caregivers' life to be "caregiving and that's all" (López-Espuela, et al., 2018). This has implications for their psychological wellbeing currently, as well as in the future when they may lose their identity as a carer; for example, if their wife moves into residential care or passes away, or if their own health deteriorates meaning they can no longer continue in the role. Further, it is important to consider that prior research also suggests that men do not always identify themselves as carers (Milligan & Morbey, 2016). This could create a dynamic where they do not seek support as a 'carer', however lose their self-identity beyond the functions of the caring role.

Playing down the role

Although it appeared evident that the husbands' identity had been consumed by the caring role it was also noted that at times participants played down the impact that the role had on their lives. Whilst it is evident that the participants in this study were able to share challenges and difficult experiences related to the caring role, it was also apparent during the interviews that the husbands would minimise or deflect the impact that this had on them personally. This was noted in the interviews where some participants would either deflect the conversation away from an emotionally sensitive topic or would follow an emotional statement with something to either minimise or dismiss what they had said. This could be understood in terms of traditional views of masculine identity which uphold ideals of stoicism and coping,

thereby creating resistance in fully expressing distress or burden (Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014). Further, the men may not want to describe themselves as 'burdened' by their wives who they love and care for (Greenwood & Mackenzie, 2010). The narrative of duty and responsibility to take on the caring role may have served to reinforce this as a positive valued role in society. Framing the role in these terms could make it difficult to express negative experiences related to it. Another consideration is that the husbands could be so consumed by the role that they do not recognise the negative impact it has on them. The potential to minimise and dismiss the impact of the role could offer some explanation for the conflicting findings across some of the quantitative research discussed in the introduction of this paper with regards to male carers' level of burden and depression. A propensity to play down distress, alongside their 'soldiering on' approach, leads to the risk that the significant emotional impact will be overlooked and neglected by the men themselves and support services.

Hidden loneliness

The caring role created a situation where the men were always busy and spent nearly all of their time with their wives. Despite this, there was a strong sense of loneliness amongst the carers evidenced both implicitly and explicitly in the findings. This is supported by the findings of López-Espuela, et al. (2018) who identify that male and female spousal caregivers feel their experiences of loneliness and loss are misunderstood by others, including the stroke survivor. As highlighted, the husbands' social networks were reduced due to the responsibilities of their caring roles. Further, they described isolation and a loss of connection with their wives, particularly for those with communication difficulties. Alexander and Wilz (2010)

identified that men caring for someone with substantial cognitive and emotional impairments reported higher levels of depression and anxiety. Social isolation and loneliness have also been identified as risk factors for poor physical and mental health (Courtin & Knapp, 2017). It is recognised that older adults are vulnerable to social isolation and loneliness due issues such as to decreasing economic and social resources, changes in family structures and functional limitations (Courtin & Knapp, 2017). These issues could therefore exacerbate the loneliness experienced by the husbands in this study, with implications for their physical and mental health.

The most significant consequences arising from these three issues together is the severe impact on the husbands' psychological wellbeing. In turn, this may impact on the quality of care they are able to provide and the survivors' recovery (Woodford, Farrand, Watkins, & Lewllyn, 2017).

2.4.2. Theoretical interpretations

The findings of this study can be explored in the context of Self-determination theory (Deci & Ryan, 2000; Gagné & Deci, 2005). This theory of motivation describes a continuum between autonomous motivation, that is acting with volition and experiencing choice, and controlled motivation, where one acts in response to a sense of obligation. In the context of the carer experience, it is suggested that carers are more likely to have positive experiences when they perceive their own behaviour as something they freely chose and value (Kietzman, Benjamin & Matthias, 2013). Further, a perceived lack of choice in taking on a caring role has been found to be associated with higher levels of emotional stress, physical strain and negative impact on health (Schulz et al., 2012). Within this study, the husbands' experiences can be understood as a form of controlled motivation as they appeared to have little choice

in taking on the caring role. There was an apparent presumption from health services that the husbands would be providing care following their wife's discharge from hospital and the husbands themselves described a sense of duty and obligation to take on the role. Further, the husband's sense of autonomy was restricted as their lives became dictated by the caring responsibilities.

Self-determination theory provides an explanation for the emotional distress and the apparent lack of positive experiences of caring identified in this study. That is, because the caring behaviours appeared to be motivated by a sense of obligation, rather than autonomous choice, they are more likely to lead to impaired physical and psychological wellbeing (Deci & Ryan, 2000).

2.4.3. Clinical implications

The above overarching issues lead to three implications for clinical practice. Firstly, to address the apparent loss of self-identity, interventions could be designed to help carers recapture their identity. This could include highlighting the importance of engaging with valued activities and supporting carers to identify ways in which these can be maintained given the constraints of the caring role. This could be achieved through a values-based therapy such as Acceptance and Commitment Therapy, which promotes engagement with valued and meaningful activities (Hayes, Stosahl, & Wilson, 2012). This could also lead to movement towards more autonomous motivation as it could allow the carer to evaluate their motivations for taking on the caring role and develop connection to the valued elements of the role (Gagné & Deci, 2005).

Secondly, it is suggested that a propensity to minimise or dismiss the impact of the role could lead to men neither seeking nor being offered support which they might

require. A more supportive framework for carers at the point of discharge could begin to address this. For example, information could be provided from the outset which highlights the implications of taking on the role and acknowledges the potential challenges it may bring. It has been found that education and support programmes for carers of people with chronic conditions can improve the carer's quality of life and levels of competence and reduce depression and burden (Corry, While, Neenan & Smith, 2014). This would also have the potential to reduce the presumption of care by healthcare providers as it invites a more open discussion about becoming a carer. Further, barriers to engagement with support should be addressed. For example, with consideration of men's narrative of 'soldiering on' and their sense of duty, support such as respite could be framed in terms of a way for them to 'refuel' in order to carry on caring efficiently for their wives.

Finally, in line with the over-arching issue of hidden loneliness, it is important to address this potential loneliness experienced by male carers. This could be approached in two ways. Firstly, a peer befriending service would allow for men to rebuild their support networks and create an opportunity to share their experiences with someone in the same situation. This could also be organised around activities which would support men to reconnect to their identity. Secondly, psychological therapy should be offered to the carer-survivor couple together. This would provide support for the couple to retain or regain their connection. Further, it would be an additional opportunity for information sharing and exploration of the survivors' impairments and the responsibilities of the caring role, which could help address any issues of role-confusion. It has been found that co-creation and agreement of a carer-survivor dyad's relationship-identity and roles was associated with better relational outcomes (Anderson, Keating & Wilson, 2017).

2.4.4. Limitations

There were three main limitations of this research which need to be considered. Firstly, the majority of the carers were recruited through the stroke support group. Although they were not all regular attendees themselves, their wives all attended regularly. Therefore, the sample consisted of men who were actively engaged with support services at least for their wives if not for themselves. It is difficult to determine the implications of this with regards to the husbands' caring role. It could suggest a higher level of need and/or less adjustment for the wives attending these groups and therefore a more demanding caring role. Alternatively, the group could provide appropriate support for the wife and respite for the husband, therefore making the caring role more manageable. Although some participants did highlight the benefits of the stroke support groups for themselves and their wives, this could have been investigated further. In addition, this research does not capture the experiences of husbands who do not have any association with these groups.

Secondly, the husbands were part of a cohort of older, married men. Consideration needs to be given to the fact that some of the findings could be understood as being very specific to their generation, where traditional male and female roles within the home remain more prevalent. Therefore, these findings may not be relevant to a younger generation of husbands caring for their wives post-stroke.

Finally, although an attempt was made to validate the findings of this study with the participants, if more time had been available it would have been preferable, and in line with the principles of IPA, to explore this more thoroughly. For example, by inviting the participants to attend a focus group to discuss the findings in more depth.

2.4.5. Future research

The hidden loneliness of the caring role has far-reaching implications for the psychological wellbeing of the carer and, consequently, the stroke survivor. Future research should aim to understand this experience of loneliness within the carer-survivor relationship further. Dyadic IPA would be a suitable approach to investigate the experiences of this shared phenomenon from the perspective of both the carer and the stroke survivor.

2.5. References

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Chapter 3: Reflective Paper

Learning and development as a 'reflective scientist-practitioner'

Final chapter word count (excluding references): 3,808

3.1. Introduction

This chapter is a reflective account of my experiences of the research process, presented in the context of my development as a 'reflective scientist-practitioner'. It mainly draws on my experience of developing and conducting the research for my empirical paper which explored the experiences of husbands who care for their wives following a stroke.

The term reflective scientist-practitioner acknowledges the different elements of clinical psychologists' roles, as clinical practitioners as well as critical consumers of and contributors to research. This term also encompasses critical reflection and self-awareness skills, which promote the development and transfer of knowledge and skill across different settings, from researcher into clinical practice (BPS, 2019). In this account I will reflect on these aspects of my identity as a trainee clinical psychologist, considering where they relate, how they differ and how I have developed within them.

Throughout my training I have used different models to guide my reflective process. Schön (1987) describes the processes of reflection-in-action and reflection-on-action. This recognises that it is often necessary to reflect in the moment, 'in action', bringing in a rapid analysis of the situation and making decisions about how to act next. However, it is also valuable to reflect after the event, 'on action', making use of supervision or reflective journaling. Lavender (2003) developed Schön's work by suggesting two further processes of reflective practice, reflection about our impact on others and reflection about the self. Lavender highlights that we need to recognise our own contexts, such as our personal background and meanings, and how these might shape how we relate to others and the impact we have on them. Further, we

need to acknowledge our own vulnerabilities, considering how these can influence our practice, and pay attention to our own development.

When reflecting 'on action' I have often found it useful to employ Gibbs' reflective cycle (1988) to provide structure to the reflective process. This cycle guides reflection by bringing focus to a clear description of the event including reflection on thoughts and feelings, before moving on to evaluate and analyse the situation. Importantly, Gibbs' cycle promotes the user to draw conclusions and develop action plans from their reflections.

Reflexivity is required throughout the research process from the formulation and development of the research question and protocol, to data collection, and during the analysis and write up phase (Bradbury-Jones, 2007). This account draws on my pertinent reflections throughout the research process, and in line with Gibbs' cycle I conclude by outlining key learning and actions points to take forward.

3.2. Why stroke? – Clinician turned researcher

My interest in this topic area began as a clinical interest based on my experiences during my first placement on the clinical psychology doctorate. I was assigned to a physical health psychology service with half of my time dedicated to the stroke service. I did not have any personal experience of stroke, however, within my extended family I had experienced and witnessed the psychological impact other long-term debilitating conditions can have on an individual and their family.

Working with this client group, I was struck by the sudden and abrupt nature of stroke, which was often described as 'out of the blue' and resulted in a multitude of life changing impairments and disabilities. It was evident from the clients I worked with that the stroke had far-reaching implications for the individual and those around

them, such as family members who often took on a caring role. The clients I worked with, both survivors and their partners, were often going through a process involving making sense of the implications of the impairments and adapting to their new found situation.

When I came to develop a research idea, I was keen to deepen my understanding of the world of both the stroke survivor and their family around them. This coincided with various media campaigns increasing the awareness of men's mental health as a priority issue, for example through the charity Campaign Against Living Miserably (CALM). As I started to explore the research, I was surprised by how little had been conducted into men's experiences of providing care in the context of stroke and felt it was important for their voice to be heard. Interpretative phenomenological analysis (IPA) was chosen as a suitable method to explore experiences and put the participants' voices at the forefront (Smith, Flowers, & Larkin, 2009).

It felt important to reflect on the potential challenges involved in moving from the position of being a clinician to being a researcher, with the same population but a different purpose and aim. In particular I needed to recognise that the clients I had worked with were a specific group who had engaged with a psychology service, and their experiences could be different to others who had not.

Reflexivity is recognised as a crucial part of IPA. It acknowledges that the researcher is involved in a double hermeneutic process, that is, the researcher is trying to make sense of the participant's understanding of their experience (Smith, Flowers, & Larkin, 2009). It is therefore necessary for the researcher to reflect on their own context and preconceptions in an attempt to 'bracket' these, so they do not encroach on the participant's account.

I engaged in a bracketing interview with my research team and kept a reflective journal throughout the process. This gave me opportunity to explore my previous understanding and preconceptions and to create the necessary space and openness to be able to hear about the experiences of the participants. Throughout the rest of this account I discuss some of the issues explored during the bracketing interview, and others which arose through my reflective journal and supervision throughout.

3.3. 'Outsider position'

One key area explored in my bracketing interview was to consider how different aspects of my identity positioned me in relation to the population I was researching. It is recognised that researchers need to acknowledge the different parts of their personal and professional identity which may influence the research process (Fontes, 1998). This highlights the importance of Lavender's (2003) processes of reflection about the self and reflection about the impact on others. Although I had some previous knowledge of the impact of stroke from my clinical work, in many respects I was an 'outsider' to the population I was researching in terms of my gender, age, marital status and caring responsibilities.

There are debates around the benefits and challenges of being in an outsider position. Some argue that it is not possible for a researcher to comprehend an experience they have not themselves encountered (Fontes, 1988). Others, such as Berger (2013), acknowledge that an outsider position has potential to pose questions from a new perspective. That said, Berger (2013) also highlights several ways in which being separate from the research population can impact on the research, which require consideration. Firstly, it can affect the recruitment of participants, secondly, it may influence the information participants choose to share, and finally the researcher's

worldview and experience can affect the questions they ask and their interpretation of the answers they receive. I explore each one of these in turn.

Prior to recruitment I considered if differences such as my age and gender would be barriers or facilitators to participants opting to engage. This is one of the reasons it was decided to initially broaden the inclusion criteria to men of any relation to the stroke survivor. Although I could clearly not change my demographics, I attempted to address this by promoting the research in person. This created the opportunity for the potential participants to meet me in advance of agreeing to take part which could serve to begin building rapport prior to the interviews taking place. I cannot know if these factors did influence the number of participants I recruited, although I was able to recruit the required amount for the research. Further, it is notable that one participant commented that he wouldn't be talking to me if it wasn't for the fact that I was a stranger to him. It appeared that, for him at least, this was the key factor that enabled him to participate and speak openly.

As noted, it is important to consider if my outsider position could have influenced the information participants shared about their experience. Here, it is worth considering that a finding of my research was that the participants appeared to minimise and downplay the impact the role had on them. I had recognised this throughout the interviews and raised it in discussion with my supervision team. We explored several explanations including whether this was about their response to me during the interviews or whether it could be understood more broadly in their approach to coping with the caring role. We identified that this was not dissimilar to experiences described elsewhere in the literature where traditional views of masculinity and a need for stoicism led to men being reluctant to disclose feelings of distress (Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014). It was attempted to

limit any further influence on this minimisation by working to build rapport with the interview participants and respond to their accounts with openness and a non-judgmental approach.

As Berger suggests, the researcher's world view can impact on how they approach the interview and analysis process. The use of language, and being sensitive to a population's language, is a key element of this. This was brought to light for me when I spoke to a stroke co-ordinator about recruiting 'carers' for my research. He raised that some people might not associate themselves with the term 'carer' as they just saw themselves as supporting someone they loved. This reminded me of a research paper which suggested older male carers did not always identify as such because they made sense of the role as part of being a husband (Milligan & Morbey, 2016). I reflected on my continued use of the term carer despite my initial reading. I recognised that I had needed to use the term in my research for clarity and to operationalise the concepts I was using. However, I did not need to rigidly use this term in my other interactions with the stroke support groups and participants. Going forward, I sought to be more mindful of the terminology I was using and the impact this could have had on the participants. It is possible that focusing the research in terms of 'carers' could have influenced who chose to participate and how they responded during the interview. However, the findings reflected the men's experience of the caring role as part of their marital duty and role as a husband, similar to Milligan and Morbey's (2016) findings. This suggests that using the term 'carer' did not limit their expression of this understanding of their role.

Throughout the process it was important to bring awareness to aspects of my position which could have influence on the research. As well as considering my own position, it was also helpful to reflect on the composition of my research team and

what they brought. For example, one supervisor was male and therefore held a partial 'insider' position in this respect. He was able to offer insights and reflections from a different perspective and help question and explore my own assumptions and biases as a female researching men's experiences.

3.4 Ethics in recruitment

As mentioned above, I initially set recruitment criteria as men of any relation to the stroke survivor. Due to the sparsity of research into male stroke carers' experiences it was initially decided that male relatives would be an acceptable homogenous sample for this study. In line with this, early in the recruitment process I interviewed a man who cared for his mother who had survived a stroke. However, by the end of the recruitment process the rest of the participants were retired husbands aged over 65 caring for their wives. Therefore, with the exception of the son, I had a recruited a much more homogenous sample than had initially been anticipated.

Increased homogeneity is preferable within an IPA study and therefore I took this to my supervision team to discuss how best to address the sample. This discussion was from the perspectives of both ensuring research validity and ethical practice. Ethically, I felt it was important to ensure that the voice of the son was still represented in some way within my study as he had given his time to contribute. Further, when analysing his transcript, it was evident that there were many common themes between his experiences and those identified across the other interviews. Therefore, it was decided that his interview would be retained and would contribute by adding emphasis and weight to the themes identified. However, there were also some differences identified in his experience, for example describing feeling he was entering a new stage in his life as a carer for parents, and more complex family

dynamics with siblings who did not play such an active role in caring. These differences highlighted to me that it would also be valuable to explore sons' experiences in more depth in future research.

This experience allowed me reflect on how much I valued the input of each of my participants and initially I felt that I was doing a disservice to the son. However, I recognised that I needed to take a pragmatic approach to the research and that I was able to make a compromise which still reflected his experience but also ensured I was able to produce a more discreet piece of research describing the experiences of husbands of stroke survivors.

3.5. Clinician in an interviewer's chair

In this section I reflect on my experiences of the interview process, specifically in terms of noticing divergence and convergence from my experience and skills as a clinician.

Initially, I described feeling like a 'clinician in a researcher's chair'. I entered the interviews feeling clear that I was there to hear the participants' stories and understand their experience. However, I often noticed conflict within myself as I felt pulled into my clinician role and wanted to offer advice or information. Although I didn't act on these pulls, I considered afterwards how they indicated that I was entering the interview in an 'expert' position. The desire to intervene suggests I was making an evaluation or judgment of the participants' experiences. Instead, I needed to suspend this evaluation and listen openly to the entirety of their accounts.

At times it felt unnatural to hold back my 'clinician knowledge', however it was important to acknowledge that participants had not consented to be in therapy but to share their experience for the purpose of research. Further, I reflected on the aim of

the research project as whole, and that creating a space for participants to share their experience would lead to developing a deeper understanding of the overall picture, with broader implications and recommendations for supporting these men going forward.

Although I recognised that the research interview was different to therapy, I was able to draw on my clinical skills, such as active listening, to build rapport and promote the carers to speak openly. As noted in the section above, at times I had a sense that participants were minimising the impact of the caring role and they deflected the conversation away from talking about emotionally sensitive topics. At times I only noticed this during the transcription and analysis phase, however other times I was able to reflect 'in-action' (Schön, 1987) and note it at the time which enabled me to gently approach the topic in a different way to encourage further explanation from the participant where possible.

Reflection in-action not only required me to pay attention to the participants' behaviours, but also to monitor my own responses and reactions to the content being discussed, another skill developed and utilised in my clinical work. This was particularly useful when I noticed myself becoming anxious during an interview which could have influenced the outcome if I hadn't monitored and regulated it. This occurred when I was trying to strike the balance between allowing a client to talk openly, whilst also feeling pressure to move the interview on due to the participant only having a limited amount of time. I noticed my anxiety led me to be distracted whilst the participant was talking, for example scanning the interview guide to review what we had covered. If I had not noticed these behaviours and re-engaged with the participant, it is likely that this would have shut down the conversation and reduced the depth of information shared.

Rossetto (2014) discusses how participants can find therapeutic benefit from the process of sharing stories in qualitative interviews as it can serve a meaning-making function and act as an emotional release. However, she also highlights the importance of maintaining boundaries as a researcher. I considered this to be particularly important because, as a trainee clinical psychologist, I operate in both roles at different times. The reflective process helped me maintain this distinction. It was also important that participants were aware of this distinction (Rosetto, 2014). This was achieved through explanation of the aim and nature of the research relationship and also by providing a debrief after the interview which included information about support services which could be accessed if the participant required.

3.6. Learning and development as a 'scientist-practitioner'

Reflecting on the process of conducting my doctoral research has allowed me to consider key areas of learning and development, both personally and professionally. During the process of writing my thesis, I noticed myself feeling a combination of surprise and pride. I questioned myself as to where this had come from and realised that I had always seen research as something that other people do. Despite being involved in research projects previously, and completing service evaluations, I had not conceptualised myself as a 'researcher'. However, I have developed confidence and competence as a researcher, which has also fed into further developing in my clinical practice.

Firstly, I have gained a deeper understanding of the research process which means I am better able to interpret research from a more critical perspective. This allows me to engage in a more rigorous interpretation of literature which informs my clinical

practice and will benefit me in any future research I conduct. I feel more able to take this critical and analytic approach because I have more conviction in my research knowledge and skills. Further, having belief in myself as a researcher encourages me to disseminate my findings and the implications arising from these.

Secondly, the analysis process of both research papers has made me more aware of the symbolic nature of language, and the challenges that this brings in interpreting meaning from others' words. Personal construct theory emphasises the bipolar nature of constructs, and the importance of understanding the contrast pole in defining any given construct (Fransella, 2016). That is, in order to fully understand the meaning someone assigns to a word, you have to know what they perceive to be the opposite word. When analysing transcripts and published literature I was required to interpret the language based on the contextual information I had available. Therefore, I had to make assumptions about an individual's personal meaning, which inevitably will have been influenced by my own personal language construction. I therefore recognised that it was important that I discussed my interpretations in research supervision, and also asked participants for their feedback on the findings through participant validation.

Finally, in parallel to completion of my thesis has been a process of self-reflection and personal development. Balancing the commitments of placement, teaching and research has at times felt challenging. However, I have developed strategies to improve my time management, such as recognising the need for self-care to promote both productivity and wellbeing when meeting this demanding schedule. I have also become more aware of my inner-critic and recognise that it can lead to either avoidance or attempts to over-prepare, neither of which help me to move forward in my work. Paying attention to this process has reduced the power of the critical voice

therefore enabling me to respond pro-actively to feedback, for example when writing the thesis, and develop my autonomy in my research and clinical practice. Further, throughout this time, I have felt humbled when listening to the accounts of the carers who took part in my study and immersing myself in research about stroke survivors' experiences for my literature review. This experience has encouraged me to reflect on my own life and the need to value things I can often take for granted.

3.7. Action points and future directions

In line with Gibbs' (1988) reflective cycle, I have drawn together three action points derived from my reflections, which I will take forward to inform my future practice.

Firstly, reflecting on the impact of being an outsider to the research population has heightened my awareness of how these issues can also be relevant in other settings. It will be important for me to pay attention to how these dynamics can play out across a range of professional interactions, with clients, staff teams and in training. This increased awareness will help me address any potential barriers to engagement which could arise.

Secondly, increased recognition of the importance of personal meaning in language will encourage me to be more mindful of this in practice. In particular, I will endeavour to understand and appreciate the nuances of language relevant to the population I am working with or researching. I will also continue to reflect on my own assumptions and pre-conceptions of meaning and seek clarification and understanding from others.

Thirdly, researching the experiences of carers has consolidated my belief in the importance of considering the wider system when working with an individual. My findings highlight that stroke does not only impact the carer and survivor

individually, but also in the context of their relationship. I recognise it is not always appropriate or possible to include family and social networks in an individual's therapy, however it is important to acknowledge their social and relational context. Further, it is also important to recognise the wider societal, cultural and political context. For example, understanding the implications of limited availability of social care resources and societal expectations surrounding the caring role. I will seek to bring this understanding and approach into my future clinical practice.

As described in this reflective paper, completing this thesis has not only developed my research skills but has also provided the context for further professional and personal growth. This project, alongside my clinical placements, has helped me to clarify and establish my clinical interests, as such, my post-qualification role includes working in an acute setting with older adults with physical health complexities. I now feel more able to recognise myself as a 'reflective scientist-practitioner' and believe that the learning and development derived from this process with serve me well in any further research I undertake and my clinical work going forward.

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4. Appendices

Appendix A: Target Journal: Qualitative Health Research - Author Guidelines

4. Preparing your manuscript
4.1 Article Format (*see previously published articles in QHR for style*):
Title page: Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.

Blinding: Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.

Abstract: Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.

Length: QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.

Methods: QHR readership is sophisticated; excessive details not required.

Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.

Results: Rich and descriptive; theoretical; linked to practice if possible.

Discussion: Link your findings with research and theory in literature, including other geographical areas and quantitative research.

References: APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:
Please do not refer to your manuscript as a "paper;" you are submitting an "article." The word "data" is plural.

4.2 Word processing formats
Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

Full details available at: https://uk.sagepub.com/en-gb/eur/journal/qualitative-health-research#submission-guidelines

Appendix B: Certificate of Ethical Approval from Coventry University: Literature Review

Certificate of Ethical Approval

Applicant:

Abbie Littlewood

Project Title:

Experiences of identity post-stroke: a metaethnography

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

04 April 2019

Project Reference Number:

P89834

Appendix C: Mind-map – Example of analysis process

Appendix D: Research Advert
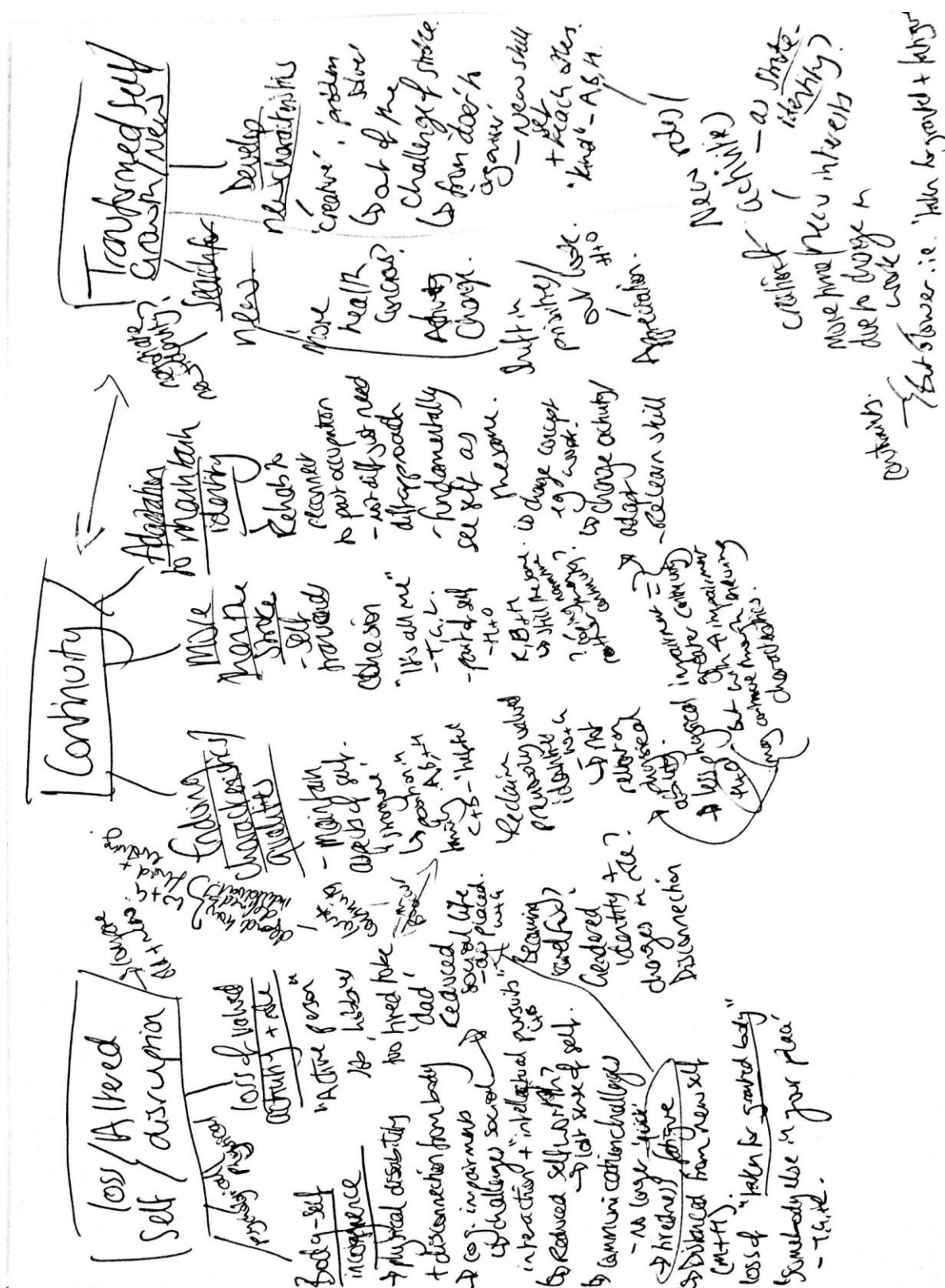
Men's experiences of caring for a relative after a stroke

Are you a male informal carer of a stroke survivor?

We need your help!

- I am looking to interview men, aged over 18, who provide unpaid care for a relative who had a stroke over one year ago to hear about your experiences.

- It is hoped that the findings from this study will help new and existing services become more aware of the specific needs of men who care for relatives after a stroke.

- This study is part of a Clinical Psychology Doctorate course and has been approved by the Coventry University Ethics Committee.

- For further information or if you'd like to take part please email me: littlewa@uni.coventry.ac.uk

Appendix E: Interview Guide

Interview Schedule

I'm interested in finding out about your experiences of caring for your relative, I have a few questions I will ask to guide our conversation, but I am more interested in hearing about what you feel are the important things to discuss in terms of the experiences you have had.

Age	
Ethnicity	
Education level	
Employment status	
Household composition	
Stroke survivor's living arrangement	
Relationship to stroke survivor	
Average amount of time caring per day/ week	
Other support stroke survivor receives (formal or informal)	
Support received by carer (formal or informal)	
Length of time since stroke	
Type of care provided	

1) Becoming a carer – *Can we start by talking about how you became a carer?*

Prompts: unexpected or planned / circumstances of stroke / initial thoughts & feelings about what is involved/ initial thoughts & feelings about managing-coping.

2) Caring responsibilities – *What things do you have to do as a carer?*

Prompts: initial knowledge about caring responsibilities / what responsibilities currently have / wider family/job responsibilities / help-seeking behaviour.

3) Relationship dynamics – *Has your caring role changed relationships in family?*

Prompts: With stroke survivor? With partner, children, friends / how change in terms of social roles / changes in personal relationships / negative aspects of change / positive aspects of change in nature of relationships.

4) Personal impact – *Has your caring role changed you?*

Prompts: mental health / quality of life / interpersonal (boredom, social isolation) / impact on personal goals and aspirations/ Compassion / growth/

5) Coping and help-seeking – *Can we talk about how you cope your caring responsibilities?* Prompts: Strategies employed and effectiveness / social and psychological difficulties / sources of help and their value.

END by asking whether there is anything else participant wishes to talk about and reflect positively on their caring role. Thank for involvement.

Appendix F: Certificate of Ethical Approval from Coventry University: Empirical research

Coventry University

Certificate of Ethical Approval

Applicant:

Abbie Littlewood

Project Title:

What are men's lived experiences of providing care to a relative who has survived a stroke?

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

08 May 2018

Project Reference Number:

P66771

Appendix G: Participant information sheet

<u>What are men's experiences of providing care to a relative who has survived a stroke?</u>

Participant Information Sheet

You are being invited to take part in a research project about men's experiences of providing informal care to a relative following a stroke. This research is being led by Abbie Littlewood, Trainee Clinical Psychologist at Coventry University.

Before you decide to take part it is important that you understand why the research is being conducted and what it will involve. Please take time to read the following information and ask the researcher any questions you have.

What is the purpose of the study?
We wish to interview men who provide unpaid care for a relative who had a stroke at least one year ago. It is hoped that understanding more about your experiences will help increase our understanding of your particular circumstances, which in turn might help improve the level and quality of services that are provided to help support male carers of stroke survivors.

We will be gathering this information through 1-1 informal interviews/ conversations between you and a researcher. These will be audio recorded and then written out to provide a record of the conversation.

Why have I been chosen?
You have been asked to take part because you are an unpaid, male carer of a relative who has survived a stroke, and because you have been a carer for at least 1 year.

What are the benefits of taking part?
Taking part in this research will be an opportunity for you to discuss and reflect on the experience of becoming a carer. It is hoped that this research will provide insights into men's experiences as carers, which could influence further research and potentially service provision in the future.

What are the risks associated with this project?
This study has been reviewed and approved through Coventry University's formal research ethics procedure. It is not anticipated that taking part in this research should lead to any harm, however it is recognised that the topics discussed could be sensitive in nature which could lead to upset or distress. Following the interview the researcher will allow time to debrief, and will provide information about support services if required.

Do I have to take part?
No. Participation is entirely voluntary. If you decide to take part please keep this information sheet and complete the informed consent form to show you understand your rights in relation to the research. Please note down your participant number as this will be required if you wish to withdraw from the study at a later date.

If you change your mind about taking part you can withdraw at any point during the interview, and up to 7 days after the interview, at which time your personal data will be anonymised. You can withdraw by contacting the lead researcher on the contact details below. Please also contact the Faculty Research Support Office (email: researchproservices.fbl@coventry.ac.uk; telephone +44(0)247 765 8461) so that your request can be dealt with promptly in the case of researcher absence. If you decide to withdraw, all your data will be destroyed. You do not have to give a reason for withdrawing or choosing not to participate, and this will not affect you in anyway.

What will happen if I decide to take part?
The researcher will contact you to arrange a mutually convenient time and location to meet for the interview. It is important that the interview is conducted without the stroke survivor present. This is so that you are able to talk freely about your experiences. The researcher will have some questions to ask and will invite you to share your experiences. We would like to audio record the interview and will require your consent for this. It is anticipated that the interviews will last between 60-90 minutes, however this will vary with each individual.

Data protection & confidentiality
Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. The interviews will be audio recorded. Following the interview the conversation will be written up (transcribed) and the audio file will be deleted. The transcribed file will be saved as a password protected file and stored in Coventry University's secure OneDrive server.

Only the research team will have access to the raw data (your interview transcript). All consent forms will be stored in a separate location in a locked cabinet at Coventry University in order to minimise risk of a data breach. The data and consent forms will be retained by Coventry University for 5 years after the research has been completed and then destroyed.

Quotes from the transcripts will be used in the write up of this project. Any quotes used will have any identifying information removed to ensure anonymity of the participants.

Data protection rights
Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer – enquiry.ipu@coventry.ac.uk.

What will happen with the results of the study?
The results will be written up and submitted to the University of Coventry as part of a Doctorate in Clinical Psychology. The findings will also be used to inform academics and practitioners through conference presentations and publications. A summary report will be sent to the Stroke Association. Participants will be sent a summary report if they opt to do so.

Making a complaint
If you have any concerns or complaints about this project, please first contact the lead researcher. If you still have concerns and wish to make a formal complaint please contact Olivier Sparagano (Associate Pro-Vice-Chancellor of Coventry University)

Telephone: 024 7765 9732
Email: Olivier.sparagano@coventry.ac.uk
Address: Coventry University, Coventry, CV1 5FB

Please provide information about the research project and the name of the researcher.

Further information/Key contact details of researcher and supervisor:
If you require more information or have any queries about the research process please contact the lead researcher on the first instance, or their supervisor at the details below:

Lead Researcher:	**Academic Supervisor:**
Abbie Littlewood	Anthony Colombo
Coventry University	Coventry University
littlewa@uni.coventry.ac.uk	hsx412@coventry.ac.uk

Appendix H: Consent form

What are men's experiences of providing care to a relative who has survived a stroke?

Informed Consent Form

You are invited to take part in this research study for the purpose of collecting data about men's experiences of providing care for a relative who has survived a stroke.

Before you decide to take part, please read the accompanying Participant Information Sheet.

Please do not hesitate to ask any questions you have about any aspect of this research. It is important you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by circling "Yes" against each of the below statements and then by signing and dating the form.

1. I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions. Yes   No

2. I understand that my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher of Faculty Research Support Office at any time until the date specified in the Participant Information Sheet. Yes   No

3. I have noted down my participant number (top right corner of this form) which will be required by the lead researcher if I wish to withdraw from the study. Yes   No

4. I understand that all the information I provide will be held securely and treated in confidence, within the limitations of confidentiality (see point 5. below). Yes   No

5. I understand that if I say anything which indicates there is a risk to either myself or someone else then the researcher has a duty to inform relevant others such as social services or the police. Yes   No

6. I agree to the interview being audio recorded and understand that this will be transcribed and the audio file deleted. Yes   No

7. I agree the information I provide can be used (anonymously) in academic papers and other formal research outputs. Yes   No

8. I agree to take part in the research project Yes   No

Participant name: Researcher name:

Participant signature: Researcher signature:

Date: Date:

Appendix I: Consent to send results summary

<u>What are men's lived experiences of providing care to a relative who has survived a stroke? – Consent to receive results</u>

I consent to receiving a summary of the results of this study at the email address/ postal address [Delete as appropriate] provided below. I understand that I will have the opportunity to provide feedback on these results should I choose to do so.

Email address:

Postal address:

Participant name: Researcher name:

Participant signature: Researcher signature:

Date: Date:

Appendix J: Debrief sheet

<u>**What are men's lived experiences of providing care to a relative who has survived a stroke? - Participant Debrief**</u>

Thank you for taking part in this research project. We really appreciate your time and the valuable information you've shared about your experiences. We hope this information will help improve quality of services that are provided to help support male carers of stroke survivors.

We understand that talking about these experiences can be sensitive and it is possible that this will have brought up some difficult feelings. This information sheet provides details of support services you can contact if you feel distressed and wish to talk to someone.

Stroke Association Helpline: 0303 3033 100
For practical advice and a listening service for anyone affected by stroke

<u>Opening hours:</u>
Monday: 9am – 5pm
Tuesday: 8am – 6pm
Wednesday: 8am – 6pm
Thursday: 9am – 5pm
Friday: 9am – 5pm
Saturday: 10am – 1pm

Carers UK Adviceline: 0808 808 7777
For information and advice, and a listening service.

<u>Opening hours:</u>
Monday: 10am – 4pm
Tuesday: 10am – 4pm

Samaritans: 116 123
Available 24hours a day, 7 days a week

Your participation in this study is now complete. If you opt to do so, you will be provided with a summary of the results when all interviews have been completed. You will be invited to provide feedback on these to compare them with your own experiences.

If you would like to receive a copy of the results please complete the attached consent form and return to the researcher.

Appendix K: Excerpt of coded transcript

Participant 6

627 you're so busy otherwise, and then suddenly, especially with the
628 dark nights coming, I can't do.. can't go in the garden, can't do
629 anything, it's cold and cold, so that is, that is one thing I hate, but
630 erm, people don't come. I mean, visitors don't hardly any come
631 now. At first they did but now it's very rare, people just don't, just
632 don't come anymore. In fact I don't think...

633 I: and why do you think that's changed?

634 P: well they know she's gone to bed, they learnt that. And people
635 don't ring me now as they know she's gone to bed so they think
636 they'll disturb her. But she's fine, I just have to put up with it don't I?
637 I mean, I can't say, I can't say I enjoy it obviously, but I don't mind
638 being busy, I think it might be what keeps me going, keeps me going,
639 the exercise, the gardening, the vacumming, I've bought a carpet,
640 you see the mats down there, I had the shock of my life when I see
641 how filthy the carpets got without the runner, so I've got a carpet
642 cleaner, there's a stain over there, a stain over there, I tried to get a
643 stain out here oh well all I finished up doing was taking some of the
644 colour out of the carpet. I kept on at it and suddenly realised oh
645 that's an amazing white spot. But, there's a few by the door. I, erm,
646 I'm going to have another go, Friday maybe because the weather is
647 bad Friday, so I can't go out anywhere so that's when I'm going to..
648 we're going to, I'm going to take her over to her daughter's on
649 Thursday that's in (⬛⬛⬛⬛⬛⬛⬛), near (city), because she's
650 asked her to go over, she's invited her because she said she wanted
651 to go. I'm fine with her, my daughter, don't get me wrong, my
652 daughter has been a lovely woman and she's (inaudible), but she
653 comes over here and she will look at something and say – this needs
654 doing, you haven't done that, oh, I wouldn't have done that. Oh it's
655 silly things but I never get a good praise off her. She never gives me
656 any praise or any credit for what I do. I do care, but I know that she
657 still blames me, and people say you're being neurotic, but I know
658 she blames me to be fair, she thinks it's my blumming fault. Of
659 course, when people think that, the first thing you do is think right,
660 well, what have I done? And technically I can't see how I could have
661 done anymore. I couldn't have stopped her from having a stroke.

662 I: no, no

663 P: as the doctor said when he came here to see her the first time, he
664 came here, he said, she said, you haven't been, you haven't had any
665 prescriptions, anything off us for thirty years. You should be on
666 statins at your age, you should have had this and should have had
667 that

668 I: yeah, but she just wasn't willing to go to the doctors

669 P: you've got no high blood pressure tablets at all, would have been
670 a great, and I said, there you go, if she'd took all the tablets that she

121

Appendix L: Mind-map of emerging themes
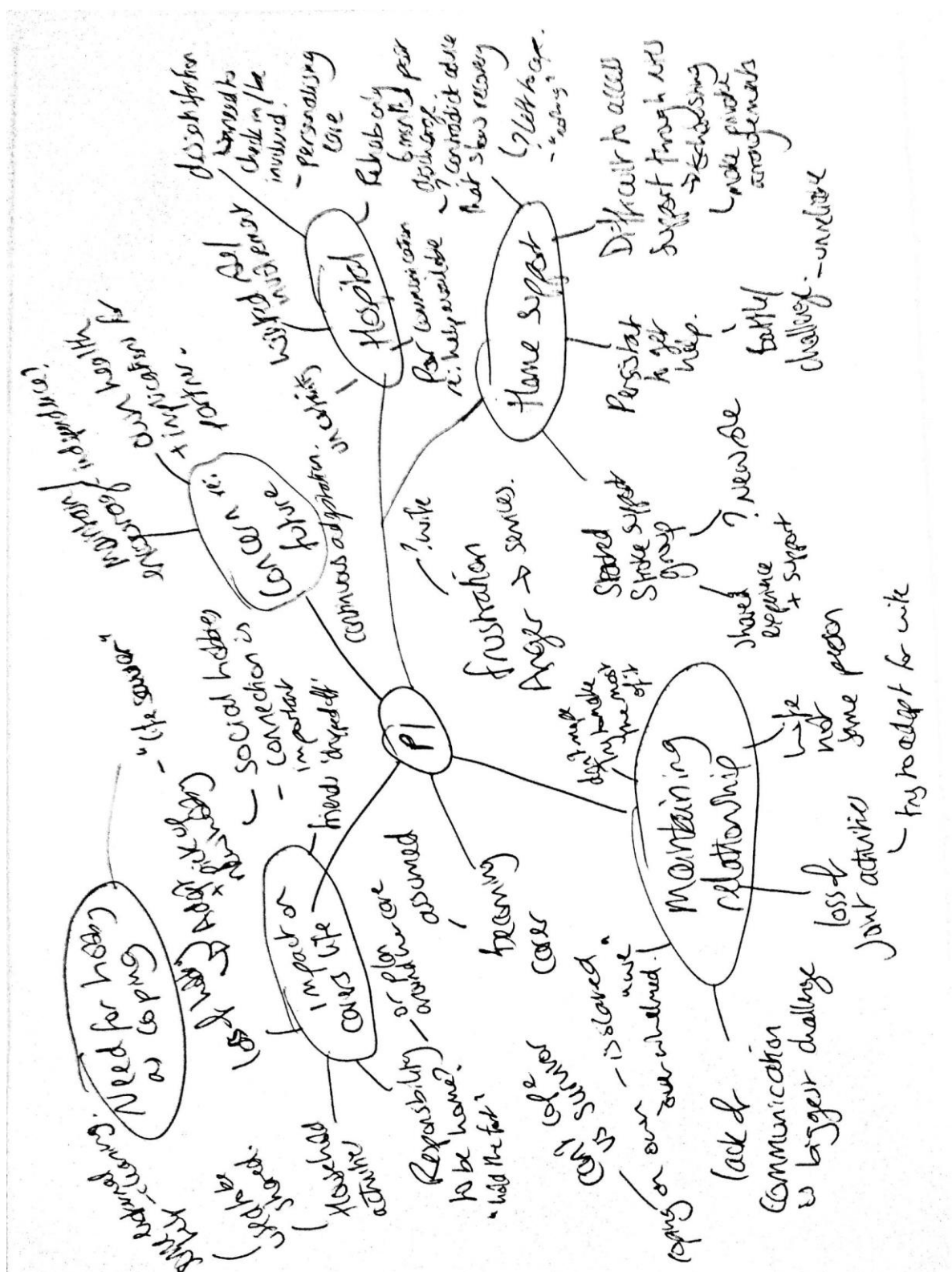
Appendix N: Summary of result for participants

**Men's lived experiences of providing care to a relative
who has survived a stroke**

Hello,

We met a few months ago to discuss your experience of caring for someone who has survived a stroke. This was part of a research project I am leading at Coventry University. A number of participants were interviewed. I have studied these interviews in depth and whilst each participant had their own unique experiences I have identified some similarities amongst them. Please see below a list of similarities identified. These will be described as themes:

Theme 1: Role Identity
One of the key issues first experienced by participants related to their new role as a carer. There were two important aspects of this changing identity and they related to: 1): **Confusion/Uncertainty** over how the stroke survivor should be cared for. Here, carers said that they wished to be involved in caring for their loved one but were given little information and advice about what they needed to do and what kinds of support they could expect from hospital and social services, and 2) the need to make **Adjustments and Take Control** in their new role as a carer. This involved carers taking charge of their loved one's needs, especially when support services were poor. Carers also talked about adjustment and trying to look after their own wellbeing by taking 'time out' when they could.

Theme 2: Self-Identity
In this theme participants felt that the caring role took up so much of their time, that they had in some ways lost their own sense of who they were as an individual person. There were two important aspects to this theme: 1) Carers felt that they had **Limited Independence** to follow hobbies and meet friends because time was no longer their own, and 2) carers reported that because their lives were organised around the needs of the stroke survivor, their own **Health/Wellbeing** was suffering, both physically and emotionally, especially in terms of feeling exhausted and sometimes depressed as a result of the continuous demands placed on participants in their caring role.

Theme 3: Shared Identity
This theme describes participant's experiences of how the caring role had changed the nature of their relationship with their loved one, particularly if that person was their wife. There were two important aspects to this theme: 1) Carers said about their partner that – **"she's not the person she was before"** – and that they no longer had a shared, equal partnership with one another. In particular, carers talked about their wives as more vulnerable after the stroke, and in need of a greater degree of protection. 2) Carers also felt that despite spending a lot of time with their wives, they often felt isolated – **"The funny thing is that you're lonely"** – this was especially so where the stroke had caused speech problems making it difficult to talk/communicate with one another, or where mobility problems, as a result of the stroke, meant that the range of opportunities to get involved in shared activities was reduced.

Your thoughts about whether these findings fit with your experience are most welcome. I would like to thank you again for your time and honesty in sharing your experiences with me. Again please be assured that whilst the themes and supporting quotes will be shared, your individual contributions will remain anonymous.

With best wishes,

Abbie