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**Neurological Conditions:  
An Exploration of Positive Consequences**

**By**

**Marianne Jayne Durran**

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

**Warwick University, Department of Psychology  
Coventry University, Faculty of Health and Life Sciences**

**May 2011**

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## Chapter 1: Literature Review

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## List of Abbreviations

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BFS	Benefit Finding Scale <sup>1</sup>
BFiMSS	The Benefit Finding in Multiple Sclerosis Scale <sup>2</sup>
HBM	Health Belief Model <sup>3</sup>
MS	Multiple Sclerosis
NHS	National Health Service
PES	The Positive Experiences Scale <sup>4</sup>
PG	Positive Growth
MS PG	Positive Growth in Multiple Sclerosis
QoL	Quality of Life
SPSS	Statistical Package for the Social Sciences
UK	The United Kingdom
WHO	The World Health Organisation

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<sup>1</sup> Mohr, Dick, Russo, Pinn, Boudewyn, Likosky & Goodkin (1999).

<sup>2</sup> Pakenham & Cox (2009).

<sup>3</sup> Rosenstock (1966).

<sup>4</sup> Philips & Stuifbergen (2008).

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## Acknowledgements

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Special thanks go to Dr Eve Knight, my Academic supervisor, for taking me under her 'academic wing' when I was one year into the project. Her relentlessly positive supervision style and never once saying "is this all you've done?" were greatly appreciated. Thanks also to Dr Claire Pavlou, my clinical supervisor, for her assistance with study design, recruitment, and proof reading. Claire, thanks for also being so down to earth, helping me to keep things in perspective and having confidence in me. The support of Dr Ruth Telfer, her secretary Jas, and Dr Gavin Farrell was also invaluable for recruitment. Thanks also to Maria McDermott for being superbly brilliant for the last three years.

I would like to express my gratitude to the participants who freely gave their time from their already busy schedules. This study would quite literally, not have been possible without you.

Peer support from the 2008 cohort, and from my friends on other courses has been important. Particular comfort was found in their existing knowledge of the unique pressures of thesis writing. Best of luck with the job hunt and I'll look forward to seeing you in the Psychology world at large where we'll no doubt look back on this whole process with nostalgia!

Special thanks to my parents, without their support and encouragement I would not have been able to get this far. Lastly, thanks to my lovely boyfriend Damien for being so deliciously good natured, always having smiles, occasionally having bunches of roses, often reminding me that 'we finish work at 4:45,' (but not minding that I didn't), and of course, for possessing a seemingly unending supply of midget gems!

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## Declaration

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This thesis has not been submitted for an award at any university other than the Doctorate in Clinical Psychology at The University of Warwick and Coventry University.

This thesis was prepared with the assistance of Dr Eve Knight and Dr Claire Pavlou who provided support with study design, and made comments on drafts of chapters prior to submission.

**Chapter 1:** The Literature Review; *‘Living with Multiple Sclerosis: A Critical Review of the Evidence for Positive Growth’*, was prepared in accordance with the submission guidelines for The Journal of Positive Psychology (Appendix 1).

**Chapter 2:** The Empirical Paper; *‘A Grounded Theory Study of Factors Affecting Health Behaviours in Female Partners of Stroke Survivors’*, was prepared in accordance with the submission guidelines for Psychology, Health and Medicine (Appendix 1).

Ethical approval for the research conducted within chapter 2 was granted by Coventry University Ethics department, Birmingham, East, North & Solihull NHS ethics and two Warwickshire / West Midlands Research and Development departments. (For approval documentation see Appendix 2).

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## Summary

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It appears that over time, individuals appraise challenging health situations differently; they take a variety of meanings from them and report differing outcomes for similar events (Scherer, Shorr, & Johnstone, 2001). This variability has been attributed to differences in coping processes employed by individuals.

**Chapter 1** is a critical review of the evidence for Positive Growth in Multiple Sclerosis (MS PG). Whilst MS PG is not reported by all individuals with the condition, evidence suggests that it is particularly evident in areas of psychosocial functioning and health benefits. Implications for future research and clinical practice are also discussed.

The wide reaching implications which invariably arise as a result of neurological conditions affect people's families as well as individuals, this can lead to re-appraisal of circumstances in family member's themselves.

**Chapter 2** examines the implications a partner's stroke has on a spouse's own health and their desire to remain healthy. 8 females were interviewed using semi-structured interviews. Within this chapter a grounded theory model is proposed which describes barriers and facilitators to an individual's health following their partner's stroke. Within the results section the 3 main categories and 11 sub-categories are illustrated by participant quotes. Clinical implications, methodological limitations and directions for future research are outlined.

The final chapter, a reflective account, introduces and reflects upon the research process using therapeutic letters. This chapter also explores the dual purpose of therapeutic letters and includes two letters; one to the research participants and one to the principal researcher. The usefulness of each letter is assessed in terms of the functions identified for therapeutic letters. Finally the author reflects and decides upon whether to send the letter to participants.

### **Reference**

Scherer, K. R., Shorr, A., & Johnstone, T. (Ed.). (2001). *Appraisal Processes in Emotion: Theory, Methods, Research*. *Canary, NC: Oxford University Press*.

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## **Chapter 1: Literature Review**

### **Living with Multiple Sclerosis: A Critical Review of the Evidence for Positive Growth**

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**This paper has been prepared for submission to  
The Journal of Positive Psychology  
(Appendix 1 - Notes for Authors)**

**Word Count - 6015**

(Excluding Abstract, Tables, Figures, References & Appendices)

Keywords: Multiple Sclerosis, Positive Growth, Benefit

## **Abstract**

Multiple Sclerosis (MS) is a disabling neurological condition. It can have a variety of biopsychosocial implications for individuals which can include; physical disability, cognitive impairments and disruptions in work, family and social routines. Despite this, some people report that their experience of having MS has actually benefitted them in some way. This phenomenon is known as Positive Growth. The evidence suggests that this growth seems to be particularly evident in areas of psychosocial functioning and health benefits. This paper provides a critique of the literature on Positive Growth in Multiple Sclerosis and discusses implications for future research and clinical practice.



## **1.0 Introduction**

### **1.1 Multiple Sclerosis**

#### **1.1.1 Definitions**

Multiple Sclerosis (MS) is a disabling neurological condition. It is the result of damage to myelin, a protective sheath which surrounds the nerve fibres of the central nervous system. When myelin is damaged, it interferes with messages between the brain and other parts of the body. The impact of MS can vary between individuals, from so slight that its presence is not known, to so severe that a person is severely disabled. Currently, there are thought to be four types of MS; Benign, Primary Progressive, Secondary Progressive and Relapsing and Remitting (The MS Society, 2010). The different types can account for the diversity in symptoms experienced and in the disease progression rate. All types may cause an individual to suffer any number of physical or psychological symptoms which can impact on functioning. Symptoms reported have included for example; loss of function or feeling in limbs, loss of bowel or bladder control, sexual dysfunction, debilitating fatigue and weakness, blindness due to optic neuritis, loss of balance, pain, cognitive dysfunction, and mood disorders (Mohr & Cox, 2001a).

#### **1.1.2 Prevalence Factors**

MS is one of the most common neurological conditions (World Health Organisation, WHO, 2008), and currently affects around 100,000 people in the UK (The MS Society 2010), and 1.3 million globally (WHO, 2008). The prevalence of MS is greatest in countries regarded as 'high income countries'

(WHO, 2008). There is some evidence to suggest that sufferers tend to be well-educated individuals (Rumrill, Roessler, & Denny, 1997) whose chosen career fields involve skilled occupations (Rumrill, 1996).

### **1.1.3 Prognosis**

MS symptoms are usually wide reaching and can negatively impact upon a person's quality of life (QoL). Most find their symptoms are such that they restrict physical activity and disrupt routine (The MS Society, 2010). At twenty years post diagnosis, approximately two thirds of people are still able to mobilise using a walking stick or crutches and do not need to use a wheelchair (WHO, 2008). However, the progression rate of MS varies from person to person and is largely unpredictable (The MS Society, 2010). Prior to diagnosis the majority of people are employed, although within a decade approximately half will have left their jobs (Rumrill, Roessler, McMahon, Hennessey, & Neath, 2007). MS is not a fatal condition; most people have normal or near-normal life spans and usually die from the same conditions that affect the general population (Weinshenker, 1995).

### **1.1.4 Psychological Factors Associated with Multiple Sclerosis**

A Cochrane Review (Thomas, Thomas, Hillier, Galvin, & Baker, 2009) detailed numerous psychological factors reported to be associated with a diagnosis of MS. These included; difficulties due to disruptions in education, employment, sex life, family functioning and friendships. It illustrated problems with; dealing with medication side effects, anxiety, depression and suicidal ideation. It also

described the struggle to adjust to what an individual's life had been like then and now, and how it may be in future. MS is depicted as a psychological and financial burden, demanding that a person remains constantly alert for the next relapse. It requires a learning curve of adjustment to the unpredictability of this condition which typically strikes within the most active and productive years of people's lives (Huseyin, 2010). Active people, who had previously established their identity as a person without a disability, must reappraise their beliefs about themselves and their future when they face a diagnosis such as MS (Kramer, 2004).

### **1.1.5 Cognitive Factors Intrinsic to the Disease**

The most commonly reported cognitive deficits in MS include changes in; complex attention, efficiency of information processing, executive functioning, processing speed, and long-term memory (Chiaravalloti & DeLuca, 2008). However, the cognitive abilities for tasks such as repeating digits, word naming and comprehension tend to remain relatively intact (Rao, Leo, Bernardin, & Unverzagt, 1991). General intelligence is also thought to remain largely intact (Macniven, Davis, Ho, Bradshaw, Szabadi & Constantinescu 2008), although there is some evidence to suggest a slight, but significant decrease in levels over time (Rao *et al.*,1991). The overarching conclusion regarding cognitive deficits in people with MS is that they seem to vary substantially between individuals (Fischer, 2001).

### **1.1.6 Consequential / Secondary Factors Associated with MS**

The wide reaching impact of MS can detrimentally affect many aspects of daily life, such as; the ability to run a household, to participate fully in society, and to maintain employment. Consequently, this could be considered to be an ongoing stressor whereby choices associated with childcare, transport, the family home and home roles all need to be reviewed. There is some evidence to suggest lifetime prevalence rates for depression in people with MS are as high as 47-54% (Aikens, Fischer, Namey, & Rudick, 1997). Literature also suggests increased anxiety and anger related to the uncertainty in MS prognosis (Maurelli *et al.*, 1992). Naturally the accumulation of all of these factors can impact negatively on an individual and families' Quality of life (QoL). However, in spite of this evidence, not all factors associated with MS are negative. There is increasing evidence that some people report positive aspects in their life as a result of their experiences.

### **1.1.7 Positive Growth**

It appears that over time, individuals appraise challenging health situations differently, take a variety of meanings from them and report differing outcomes for similar events (Scherer, Shorr, & Johnstone, 2001). This variability has been attributed to differences in coping processes employed by individuals. There is evidence that some people report 'detrimental experiences' as having actually benefitted them in some way. This phenomenon is often referred to as Positive Growth (PG).

PG is a particularly important, and unique coping process in that it that helps to convert stressors into more positive events (Pakenham, 2005). Literature suggests that finding meaning in the face of adversity actually helps protect both mental and physical health (Taylor, Kemeny, Reed, Bower & Grunewald, 2000).

The phenomenon of PG, has been referred to using a number of different terms including; Adversarial Growth (McBride, Dunwoody, Lowe-strong, & Kennedy 2008), Positive Impact (Beach, 1997), Benefit Finding (Pakenham, 2005), Post-Traumatic Growth (Tedeschi, Park, & Calhoun, 1998), Positive Consequences (Gillen, 2005), and Positive Reframing (Tuncay, Musabak, Gok, & Kutlu, 2008). PG does not seem to be limited to MS and has been cited with reference to health conditions such as; arthritis (e.g. Evers, Kraaimaat, Van Lankveld, Jongen, Jacobs, & Bijlsma, 2001), breast cancer (e.g. Cordova, Cunningham, Carlson & Andrykowski, 2001), and stroke (Gillen, 2005).

#### **1.1.8 Aims of the Review**

There has not been a literature review collating the published literature in MS PG where MS is the only clinical group sampled. Therefore, the aim of the review is to critically appraise literature which suggests PG is a psychological framework that can be applied to people with MS. Using the outcome of this review, clinical and service delivery implications will be highlighted. For clarity and cohesion, reports of benefits, positives and growth as a result of an MS diagnosis will be referred to as MS PG within the remainder of this review.

## **1.2 Method**

### **1.2.1 Search Strategy**

Searches were carried out in August and September 2009, and from June 2010 to December 2010. In order to locate studies which fulfilled the aims of the review, two search strategies were implemented;

- 1) Traditional Literature Search: The databases searched were; PsycARTICLES, PsycINFO, Medline, ASSIA, SCOPUS, and The Pilots Database. Search terms included; 'Positive Growth Multiple Sclerosis,' 'Benefit Finding Multiple Sclerosis,' and 'Positive Impact Multiple Sclerosis.'
- 2) A reference list review of studies located with method 1 identified additional articles and book chapters.

In order to identify papers for review, the titles, abstracts and, where necessary, the full text article, were screened by the first author against the inclusion criteria. Full text versions of all material which met these criteria were then obtained and reviewed.

### **1.2.2 Inclusion and Exclusion Criteria**

Inclusion and Exclusion criteria were set as per Table 1.2.2. There is a small body of literature looking at PG in the wider family system of those with MS (Pakenham, 2005; Pakenham & Bursnall, 2006; Turpin, Leech & Hackenberg, 2008) and the original searches were carried out for both types of PG.

However, due to the insufficient literature and over reliance on one author, the current review focused solely upon PG as reported by the individual with MS and excludes papers which focus on PG within the wider family.

**Table 1.2.2 Inclusion and Exclusion Criteria**

<b>Criteria</b>	<b>Inclusion</b>	<b>Exclusion</b>
1	MS client opinion of personal Positive Growth	1 Articles with only minimal reference to search terms, for example one phrase or one sentence without further investigation of this theme within
2	Published 1990 - 2010	2 Articles where full text articles were not available through the British Library
3		3 Articles published in languages other than English
4		4 Dissertation abstracts
5		5 Autobiographical Accounts (i.e. not research studies)

### **1.2.3 Details of Papers Left for Review**

Articles sourced through either of the two search methods which met the inclusion / exclusion criteria were retained and form the basis of the current review. This resulted in a total of 7 studies. An asterisk (\*) in the references section denotes a reviewed study.<sup>5</sup>

### **1.2.4 Rationale for Review Structure**

The review will appraise the literature surrounding PG for the person with an MS diagnosis, before discussing the inherent methodological limitations and making suggestions for future research. The review then utilises the findings in relation to the MS PG to consider potential service delivery and clinical implications.

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<sup>5</sup> Further details of the reviewed studies are available in Table 1.2.3.1, Appendix 3.



## 1.3 Critical Review

### 1.3.1 Critique of the Evidence Relating to PG Associated with MS

The first published study to investigate PG effects in people with MS (Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, & Goodkin, 1999) resulted in the production of a Benefit Finding Scale (BFS) and suggested that MS PG, in the form of 'psychosocial benefits,' were more frequently reported than the negative effects of MS. This American study adopted a mixed methods design, utilised telephone interviews, and was based on a sample size of 50 for initial data collection, and a further 94 who rated statements made by the 50 participants using likert scales. No data was provided on the ethnicity of the sample.

The results of the Mohr *et al.*, (1999) study showed that the percentage of participants reporting PG was 59.2%, almost double that of the second most popular category, 'Demoralisation,' which produced responses from 33.3% of participants. The final category, 'Deterioration in Relationships' produced only one third as many responses as PG with only 20.4% of participants describing this as a factor associated with their MS. PG appeared to be reported more frequently by participants with elevated levels of tension-anxiety and anger-hostility<sup>6</sup> and those who were unemployed. This suggests that MS PG may have developed as a coping strategy borne out of particularly difficult and stressful experiences.

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<sup>6</sup> As measured by The Profile of Mood States, (POMS), McNair, Loir & Droppleman (1981).

In the second part of Mohr *et al's.*, (1999) study, 7 of the 19 MS PG statements were rated unfavourably by between 51% and 68 % of the 94 participants. However, the results were presented to suggest that between 49% and 32% of participants evidenced MS PG. These results did not highlight the percentage of participants who rated PG neutrally, or negatively and therefore suggests MS PG is not a universal experience.

Importantly, the original purpose of the study had not been initially targeted towards describing MS PG, in fact, the aim had been to describe the subjective experience of those with MS. Nonetheless, even with this in mind, this study was pioneering as the first published study sampling participants on MS PG. The 3:1 ratio of positive to negative results implied that research aiming only to investigate 'illness deficits' could 'overlook an important part of the illness experience' (Mohr *et al.*, 1999 p380). Another strong point of the study was that it utilised a number of screening measures validated for telephone administration<sup>7</sup> to ascertain the neuropsychological functioning of the participants. This would have allowed assessment of the cognitive impairments which are intrinsic to an MS population. The authors also handled the topic sensitively and with care to acknowledge that their attempts to highlight MS PG were in no way meant to minimise the impact MS can have on people.

Whilst the BFS seemed to highlight key areas of PG, an Australian researcher thought the measure did not cover enough breadth. As such, to test the adequacy of BFS, his qualitative study sampled 404 MS community-living

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<sup>7</sup> For further information please see table 2.

Australians with self report questionnaires (Pakenham, 2007)<sup>8</sup>. Content analysis showed 35% of participants reported PG not already covered within the BFS categories. Surprisingly, 16% of participants reported their health had actually improved since their diagnosis; Pakenham cited this as a health benefits category of MS PG. Other benefits identified within the study included; appreciation of life, spirituality and evaluation of life priorities. Whilst five out of six of the BFS domains addressed interpersonal benefits, the current study found just a quarter of the reported benefits were accounted for within this domain. Just under a quarter of participants identified PG in the form of greater appreciation for life, whereas this was accounted for within only one BFS question. Similarly, one BFS item investigated spirituality whereas 9% of Pakenham's participants reported PG in the form of increased spirituality. Pakenham suggested his study was able to fully demonstrate the breadth of improvements in relationships, for example with health professionals and others with MS, that the BFS was unable to account for<sup>9</sup>.

Pakenham's (2007) study sampled a considerably larger group of participants than Mohr *et al.*, (1999) were able to, although given that the studies were in different countries this could have implications on the comparison of the two. Whilst the BFS was groundbreaking and served as an exploration of MS PG and psychosocial benefits, Pakenham's (2007) findings seemed to indicate a more inclusive, up to date picture of MS PG.

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<sup>8</sup> This study reports the qualitative information from a larger short-term mixed methods study investigating coping processes in adaptation to MS, (Pakenham, 2005).

<sup>9</sup> This study also provided the data for the construction of the Benefit Finding in Multiple Sclerosis Scale (BFiMSS, Pakenham & Cox, 2009).

A year later, an American study by Phillips & Stuifbergen (2008) presented results of the seventh year of their longitudinal study. A previous participant informed researchers that she found the annual completion of self-report questionnaire measures aimed at reporting on QoL of MS community dwelling individuals, to be 'less than uplifting' (p44). She suggested sampling participants with 35 of her positive experiences, to comprise The Positive Experiences Scale (PES), which she hoped may help fellow participants to 'make their day better' (p44).

Phillips & Stuifbergen (2008) conducted a correlational study investigating the relationship between self initiated positive experiences and depressive symptoms in people with MS and the impact on QoL. They highlighted the benefits for blood pressure, cholesterol and increased sleep quality, that taking part in positive activities can have. They wondered whether there might also be a place for these positive experiences to contribute to a decrease in the likelihood of MS exacerbations. At time 7, 443 participants, aged 27 – 87, of whom 84% were female and 92% white were sampled. Results reported an endorsement rate for positive social experiences in up to 91% of participants. Interestingly and similarly to Pakenham's findings, up to 74% of participants also reported positive experiences relating to their physical and mental health. Positive outcomes had been attributed by 55% of people who had learned something new, 45% who had pampered themselves, 21% who had signed up to do volunteering, 18% who enjoyed helping someone with MS, and 7% who attended an MS support group.

Whilst Phillips & Stuifbergen's (2008) findings do not necessarily indicate the presence of MS PG, they do show many positive experiences following an MS diagnosis and that in some of these cases they may be experiences that individuals had not previously considered. Whilst a sea change could have occurred within this particular sample, it is perhaps more likely that the novelty of being asked questions encouraging the appraisal of positive aspects of life still achievable with MS may have been regarded favourably by participants. The inclusion of PG aspects allowed the authors to conclude that regardless of illness severity, participants who reported a higher frequency of positive experiences also demonstrated a lower level of depressive symptoms. They suggested that engaging in positive experiences may contribute to longer periods of wellness which could have implications for both research and clinical practice in future.

Phillips & Stuifbergen (2008) acknowledged that a limitation of their study was that people reporting higher QoL may be more readily able to take part in positive experiences or have had more opportunities to do so. However, the study was helpful for the emergent MS PG debate as it was the first to link positive aspects of life with MS to a decrease in depressive symptoms. The study also had some further limitations, for example, there were 90 more participants at time 1 than at year 7 and so it is worth considering that the levels of positive experiences and depression could have differed in the people who declined to take part at time 7. 621 people were originally invited to take part at time 1 but only 533 did so. Perhaps people taking part at time 1 may

already have been invested in ascertaining MS QoL which would not have been captured within the results. Whilst the PES suggestions were relatively cheap and accessible to all, encouraging participants to generate their own examples of MS PG / positive experiences may have led to an increase in the 91% of participants endorsing them.

Finlayson, Van Denend and Dalmonte, (2005) also reported examples of MS PG split into distinct themes. These were identified within a mixed methodology American study of older adults, where 27 MS support group members, mostly women, aged between 55 and 82 were interviewed. 1:1, semi-structured interviews elicited positive and negative beliefs about living with MS. Results indicated that 16 of the 27 participants reported MS PG within the areas of; social benefits (such as group membership), becoming a better helper, realising potential, strengthening family and discovering resources. Whilst this study seemed to demonstrate the presence of MS PG within older individuals, it may be noteworthy that when asked to rate their own health, those who reported MS PG did not report it as 'poor'. Therefore, one could infer that the state of the participant's health may have affected their PG report. The responses available to participants with which to rate their own health and the participant's actual responses did not appear to be included within the write up and therefore it is not possible to make further inferences about the relationship between self appraised health and PG report. The quantitative analysis consisted of SPSS t-test analysis of the mean scores within the positive and negatively reported categories. Unfortunately, the small sample size meant little consensus in the

types of PG and negative aspects of life associated with MS, thus the quantitative analysis was limited. The exploratory analysis indicated that individuals who scored higher on the Mental Health Inventory<sup>10</sup> were also statistically more likely to report PG in the form of social benefits than those who scored lower on this measure.

A single methodological approach in Finlayson *et al's.*, (2005) study might have allowed time for a more detailed qualitative analysis such as Grounded Theory or Interpretative Phenomenological Analysis (IPA). Similarly, a larger sample size may also have allowed for more in-depth statistical analysis and greater cohesion of the results. In fact, Finlayson *et al.*, themselves acknowledged a limitation of their own study; that positive and negative data arose as a result of content analysis and that more in depth purposeful investigation of PG might have produced different results.

The Finlayson *et al.*, (2005) study features one of the highest frequencies of MS PG reported in this review. Therefore, age may aid adjustment and the ability to report MS PG. Consideration should however be given to the factor of expected life course trajectory, for example, a person in their late 70's might expect they will experience some physical restrictions, whilst someone younger but experiencing the same restrictions may have more difficulties in coming to terms with and make meaning of their situation. It is important to highlight that

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<sup>10</sup> Scores on the Mental Health Inventory (Veit and Ware, 1983), range from 0 – 100 with higher scores indicating better mental health.

one third of participants were unable to identify any aspect of PG within their experience of MS, whilst all were able to report negative aspects, and in fact did so at a ratio of almost 2:1. Given that this study reported more negative aspects of MS than PG it would be wrong to interpret the results of this study as universally positive. However, given the global nature of the difficulties encountered with MS, one might have expected this ratio to be even higher in favour of negatively reported experiences. This suggests MS PG is an important area for focus. Regardless of limitations, the study highlighted socially derived MS PG, and a major strength was that it provided a voice to older adults with MS and therefore enables the knowledge base in MS PG to cover a more complete age spectrum.

In contrast, at the opposite end of the age spectrum, a qualitative study including children (Mazur 2006), investigated the positive and negatively perceived aspects of being parented by someone with a disability. Four distinct groups were sampled by telephone interview; disabled parents<sup>11</sup>, spouses of disabled parents, adolescent children with disabled parents and professionals<sup>12</sup>. Participants were recruited through the MS Society, a 'parents with disabilities' project and via email. Whilst the depth and quality of MS PG seemed less than reported earlier within this review, 47% of parents said that being able to openly discuss disability was a positive experience whilst 27% regarded the extra 'enjoyable free time,' they were able to spend with their children as a

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<sup>11</sup> 14 of the 15 sampled parents had an MS diagnosis and therefore this study has been included for review.

<sup>12</sup> Details of positive and negative aspects of parenting with a disability as reported by Mazur's other 3 participant groups have not been described within the current review.



consequence of MS, was PG. 73% also regarded their child assisting with household chores such as 'cooking and cleaning' as being a positive factor associated with their condition.

Mazur conceded that families under acute stress may be less likely to respond to recruitment campaigns to take part in a study and therefore this could have affected the results. The study sought to interview 4 distinct groups and whilst it can be helpful to receive differing viewpoints, at times, this became difficult to comprehend. For clarity, given that it only had a total of 50 participants, the study may have been easier to understand and interpret had the sample been a more homogenous group.

More recently, there appears to have been some consideration for how people's MS experience changes over the years. A qualitative study in New Zealand (Barker-Collo, Cartwright & Read, 2006), sampled 16 individuals; 5 male and 11 female, using semi-structured interviews. It aimed to compare experiences of people diagnosed with MS within the last 5 years to that of those diagnosed 15 years ago. Thematic analysis demonstrated some evidence of PG in participants within the theme of 'Living with MS.' Many participants described 're-evaluating priorities and living life to the fullest,' and one participant described that if she 'missed out on anything' then she would feel that the 'MS had won.' Three participants spoke of positive lifestyle and health changes which included

'becoming more health conscious, taking the right supplements and increasing knowledge on homeopathic remedies.'

A drawback to the Barker-Collo *et al.*, (2006) study was in the reliability of sampling people with MS to retrospectively recall information regarding their experiences. A screening measure to determine the level of any cognitive impairment, specifically long term memory, which is intrinsic to MS (Chiaravalloti & DeLuca, 2008), may have been helpful in order to ascertain the reliability of retrospective testimonies. Whilst this study provides only a small amount of literature to the MS PG debate it serves to add further support to its existence, especially around health benefits.

The final study within the current review, and the only UK based research, emotively described MS PG in one participant's words as:

*"Sticking jewels in your life in order to negotiate an acceptable quality of life"*

*(Reynolds & Prior, 2003, p1244).*

In this study, 27 white females were recruited through a local MS therapy centre and 5 additional participants were recruited via snowballing<sup>13</sup>. The authors did not set out to investigate PG within MS, instead aiming to ascertain women's strategies for achieving an acceptable QoL alongside MS. However, amongst other results, the semi-structured interviews, once transcribed and

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<sup>13</sup> Snowballing is a recruitment method whereby someone who has already taken part in the study recommends the research to people they know who may also be eligible to take part.

analysed, seemed to identify aspects of PG. One participant spoke of her recognition that her condition was not terminal as a brain tumour might have been, which made her thankful she was able to see her children grow up and still meant that she was able to experience and reflect upon new positive experiences and not take them for granted.

Another participant in the study spoke of the importance of ordering her life so that she was not fatigued by the mundane aspects of life and had energy left for the living of it. As such, she viewed paying someone to do her ironing and cleaning as PG which helped her to live her life fully. Another participant felt that her son's experience of growing up alongside a mother with MS had led him to be particularly caring towards other children who were having a hard time. This feeling gave her the sense that this was PG that would not have occurred had MS not 'intruded upon their lives.' One of the main identified PG coping strategies seemed to be the use of humour and laughter. This extended to the new social networks available to the women through the MS centre which would not have been available to them without an MS diagnosis. Another participant felt MS had been 'a catalyst for her life' (p1236), which led her to open her life in different directions.

One of the strengths of Reynolds & Prior's (2003) study lay in one of the ethical considerations which allowed each participant an advanced copy of the interview schedule so that they were able to offer their full informed consent to

take part. A further advantage was this allowed participants further time to reflect on the questions. A limitation was that the sample size of this study was relatively small compared to others within this review and the authors conceded that this may have made the results less descriptive of the MS population as a whole. The authors also acknowledged that the effect of a healthy researcher interviewing people with MS was unknown but could have led to an overly positive upbeat response from participants. The researcher's own perceptions or desires for the data could have also affected the results during the IPA analysis. However, limitations considered, the study demonstrated further support for MS PG particularly around social benefits.

### **1.3.2 Summary of Findings**

Consideration of PG within individuals who have a diagnosis of MS is a relatively under-researched area. Only 7 articles were identified that explored PG within this population. Most of these studies adopted a qualitative approach, or used mixed methods, as would be expected within a new area of study.

Initial findings were mixed, but there appeared to be some evidence that PG is evident in this population. Social and health benefits seemed to be more freely reported than any other type of PG. There was also evidence that MS PG may be supportive of mental and physical health in the long term. Therefore, in future, social PG may be a good area for professionals to begin when supporting the facilitation of discussions regarding MS PG. Whilst evidence suggests PG exists

and this is an important set of findings for future research and clinical work, findings need to be considered alongside limitations of existing evidence.

#### **1.4 Methodological Limitations and Suggestions for Future Research**

All participants within the sampled studies were recruited from community populations. It would be estimated that at any given time a proportion of people with MS would be residing within hospitals, health care establishments and care facilities. Therefore this review may not take into account individuals whose MS has developed to such a stage that they are not able to live independently. A study of individuals no longer living independently may add to the completeness of the data.

Similarly, the majority of participants seemed to have been recruited via their MS Society membership or similar local organisation. Whilst data suggests that many people in westernised society are registered with their local MS organisation, this does not allow for inclusion of those who choose not to be registered or are unaware of them. A further difficulty with recruiting from this type of organisation is that social aspects of MS PG seemed to feature highly within this review and that MS Society groups are intrinsically social by nature. It is of course possible that individual's desires to join such a society may have been socially motivated in order to seek out social support and information from others. As such there could have been a reporting bias in the samples used which may have placed more importance on social PG than may have been found via different sampling methods. Whilst it is likely that there will always

be some element of bias regarding participants in research, in an attempt to redress the bias it could be advantageous to conduct research through MS clinics for example.

The samples used within the research were predominantly female; naturally this may have impacted on the results and could mean that it is not possible to generalise them to the wider MS population as a whole. The current review has not discerned between the types of MS experienced by individuals in each study; as such this could have implications for the relevance to the wider MS population. It would seem reasonable that PG may be different in a more rapidly progressive disease. Therefore, further research comparing gender, different types of MS and levels of reported PG could be advantageous. Most of the research participants were white which has implications on the validity of the data for describing the MS population as a whole. There was also only one study conducted in the United Kingdom and given the unique nature of the National Health Service provision, it may be beneficial to conduct further UK based studies and those which include participants with ethnically diverse backgrounds.

Only one study within this review had adopted a longitudinal methodology. For the remainder of the studies the information gathered was more of a snapshot in time. Given that MS is degenerative in nature, in order to highlight change over time; it may be beneficial for more research to adopt longitudinal

methodologies. Similarly, the majority of studies adopted a qualitative design; this critique has demonstrated that there now appears to be sufficient direction to enable a range of quantitative studies.

None of the reviewed studies adopted measures to test memory of historical facts and perceptions and given the cognitive nature of the disease this may have been helpful. Therefore, further thought could be given to data collection methods and the use of cognitive measures in future research.

Whilst this review seems to have highlighted instances of MS PG, this has sometimes been reported upon with reference to downward comparisons (Taylor, 1983). For example, Reynolds and Prior's (2003) study described a participant who felt thankful that her condition was not immediately terminal and as such she would then get to see her children grow up. Whilst it would not seem right to risk minimising this participant's statement, it seems evident that there may be different types of MS PG. There seems to be examples of people finding new things about life which are to be enjoyed as a genuine consequence of having MS, on the other hand there also seem to be individuals who feel thankful that they do not have a more disabling condition or are just reporting positive aspects of their lives with MS rather than actual growth.

In some cases, participants reported problems and deteriorations since MS diagnosis more frequently than those who reported positive changes as a result

of MS PG. Therefore it would be wrong to report that MS PG is found by all, or even that all individuals have the ability to perceive it. It also seems that there is a tendency for researchers to highlight the positives reported by people or to frame research positively. Nonetheless, MS PG has been reported in a variety of circumstances and therefore exists for some. This critique seems to have demonstrated that in the majority of cases, MS PG was found almost as a by-product of the original study aims. Therefore, the results of further research aiming to purposefully explore the existence and characteristics of MS PG would be pertinent.



## 1.5 Clinical Implications

The evidence suggests that the physical and mental health of people facing adversity can be increased through the discovery of meaning making and PG (Taylor *et al.*, 2000). Therefore, this seems to place additional importance upon health professions to explore MS PG. However, it is also worth considering that lifetime depression rates for people with MS (Aikens *et al.*, 1997), may make it difficult for people to recognise MS PG. Given that MS PG has been highlighted as an important way to assimilate meaning making and coping with MS, it is imperative that depression in people with MS be recognised and treated appropriately.

The importance of allowing people time to reflect upon and invite thoughts about MS PG was demonstrated well by Phillips & Stuifbergen (2008). Studies such as this invite enquiry into whether clinical appointments encourage or allow such reflection or discussion, and what may be reported if this time was allowed. The realisation guided by the current review, appears to be that this time is not offered. This seems to demonstrate the illness-led nature of the health professions and studies like these, serve to remind us of the value of engaging in 'wellness-led' discussions with people, even if we consider them to have a degenerative condition such as MS. Mohr *et al.*'s (1999) study also reminds us that continuing to focus on deficits associated with disease 'may overlook an important part of the illness experience' (p380).

Lastly, it seems important to note that not all participants included within this review were able to report MS PG. As such, clinicians must be aware of the fiduciary relationship, and desire to please which often exists between client and health professional, and be sure not to try to elicit MS PG where there is none. Whilst MS PG has been regarded as ‘sticking jewels in your life’ (Reynolds and Prior, p1244), it seems important that the ‘jewels’ be the client’s own rather than those borrowed from their clinician.

## **1.6 Conclusion**

There is evidence to suggest that the widely reported negative aspects of MS do not paint the full picture of life with this neurological condition. In fact, for some, MS has a positive impact or leads to a form of positive growth in some areas of that person’s life (MS PG). A critical review found 7 studies which investigated MS PG in the life of a person with an MS diagnosis. The evidence suggested that MS PG was most frequently reported in areas of psychosocial functioning and through the appreciation or improvement of other areas of that person’s own health. Whilst MS PG was not reported by all participants within all of the studies, this review demonstrated its existence and showed that further investigation of this under-researched area could be helpful. This review highlighted that MS PG is rarely asked about but when found can be beneficial for the long term protection of an individual’s mental and physical health. This highlights important considerations when working clinically with people with MS diagnoses.

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## **Chapter 2: Empirical Paper**

### **A Grounded Theory Study of Factors Affecting Health Behaviours in Female Partners of Stroke Survivors**

**This paper has been prepared for submission to  
Psychology, Health and Medicine**

**(Appendix 1 - Notes for Authors)**

**Word Count – 6464**

(Excluding Abstract, Quotes, Tables, Figures, References & Appendices)

Keywords: Stroke, Carer, Modifiable Risk Factors, Desire to Remain Healthy

## **Abstract**

This qualitative study used semi-structured interviews with eight females, aged 49 – 85 years (mean 64.63), married to survivors of stroke aged between 56 – 89 years (mean 69.63). It investigated knowledge of stroke, modifiable risk factors and the impact the experience had on the women's own health. Grounded Theory was used to analyse the data and 3 core categories emerged from the data; 1) Knowing, 2) Perceiving Barriers to Health Behaviours and 3) Facilitators to Health. Each core category had additional sub-categories, with a total of 11 sub-categories being generated. Results indicated some women had knowledge of stroke prior to their partner's stroke, all women had knowledge of the effects stroke had on their husband and all women knew of the six key modifiable risk factors for stroke. A number of evident factors affected the women's abilities and desires to implement health change behaviours guided by their knowledge. Clinical implications, methodological limitations and directions for future research are outlined.

## **2.0 Introduction**

### **2.1 Stroke**

The World Health Organisation (WHO), has, for many decades, recommended the global standard for stroke definition as, 'a syndrome of rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin,' (Hatano, 1976, p 541). In the UK during 2008 it was reported that as many as 150,000 people experienced a stroke, this roughly equated to one person every five minutes (The Stroke Association, 2008a). Within a year of onset more than 50% of people who have strokes are still dependant or pass away (Hankey & Warlow, 1999).

#### **2.1.1 Risk Factors for Stroke**

The WHO (2005), produced a paper on healthy ageing which challenged the belief that diseases such as coronary disease, diabetes and stroke 'were a natural part of the ageing process.' This broke down diseases of the elderly into two distinct categories; those which were due to 'wear and tear' and natural chemical changes within the body, and those which were more closely linked with the way in which people live and have lived their lives over the years. This second category is particularly interesting as it suggests that if lifestyle places people at a higher risk for serious diseases, then this risk could be reduced with appropriate changes to key risk factors. The two types of risk factor for illness, are those which are non-modifiable, for example, age, gender and family history, and those that are modifiable such as smoking frequency, healthiness of diet,

alcohol consumption and blood pressure (Pendlebury, Giles & Rothwell, 2009). In fact, in developed countries as many as 70% - 80% of deaths are thought to be due to diseases associated with lifestyle including modifiable risk factors (Dickey and Janick 2001). The WHO (2005) identified five aspects of modern lifestyle which they believe contribute the greatest risk towards preventable disease. These included; 1) poor diet, 2) being overweight, 3) insufficient exercise, 4) smoking tobacco and 5) drinking too much alcohol. Given that there are modifiable risk factors for stroke this suggests that stroke can be placed in the category for lifestyle affected illness; thus it is possible for people to reduce their risk of stroke by making lifestyle changes within their own lives and that in doing so clearly reduces the risk of first stroke (Rundek & Sacco, 2008). Pendlebury *et al.*, (2009) described the top 6 modifiable risk factors for stroke as the 5 previously identified by WHO, with high blood pressure making up the 6th.

### **2.1.2 Other Factors Affecting Modification of Risk Factors**

Whilst it may seem obvious, knowledge of the risk factors for stroke is necessary in order to predict risk and develop effective preventative strategies, (Pendlebury *et al.*, 2009). This was demonstrated by a study that found that 43% of patients did not know of a single risk factor for stroke at the time of the stroke, (Kothari, Sauerbeck, Jauch, Broderick, Brott, Khoury & Liu, 1997). Put simply, if someone did not know that their lifestyle impacted on their health risks it would be impossible to expect them to modify their behaviour to decrease the risk. However, these findings would suggest that 57% of people

did know at least one of the risk factors and therefore, there were other mediating factors involved in how likely they were to adopt health behaviours. Barriers to performing health behaviours have also been shown to include; psychological factors such as fear associated with illness prevention behaviours, and practical barriers such as time and expense (Abraham and Sheeran, 2005).

### **2.1.3 Gender Differences for Knowledge of Stroke Risk Factors**

Whilst being male carries a higher risk for stroke, the strokes experienced by women seem to be more serious with females being twice as likely to die from stroke, (The Stroke Association, 2008b). The research available seems to indicate that women are often unaware of the modifiable risk factors for stroke, for example, 60% of sampled women did not know their blood pressure and 67% were unaware of the optimal reading for blood pressure (Stroke Association, 2008). The same survey reported that whilst 22% of the women were prescribed blood pressure medication as many as half of these women did not take it. An additional study investigating risk factors found 83% of women were unaware that lack of exercise placed them at greater risk for stroke. Similarly, 72% of the sample did not identify poor diet as a stroke risk factor and 71% were reportedly unaware that alcohol consumption further increased the risk (Hairon, 2008). In a study of 28,090 German participants, men were found to be more likely than women to identify smoking, physical inactivity, alcohol consumption and poor diet as modifiable risk factors for stroke (Müller-Nordhorn, 2006). The same study indicated that women were up to 10% more likely to identify high blood pressure and 2% more likely to identify being overweight as modifiable risk factors for stroke.



#### **2.1.4 Health Belief Model and Self Efficacy**

According to Schroeder, Rosamond, Morris, Evenson & Hinn (2000), people who are knowledgeable about stroke do not always change their behaviour to reduce stroke risk. This study suggested an understanding of factors 'other than knowledge,' was necessary in order to understand when and how people modify their own stroke risk. Such a study was conducted to investigate predictors of intention to exercise in people at risk of stroke (Sullivan, White, Young, Ross, Scott & Clinton, 2008). For the first time in published stroke research they applied a Health Belief Model (HBM; Rosenstock, 1966) to a stroke research population. A HBM model incorporates beliefs about illness susceptibility, illness severity, the costs of, or barriers associated with undertaking healthy behaviours, and the perceived benefits of engaging in them. Broadly speaking, Sullivan *et al's* (2008) results demonstrated that people's pre-existing health beliefs affected how likely it was that they would engage in health behaviours to reduce the likelihood of stroke. It seemed their levels of self efficacy (Bandura, 1977), or self belief that engaging in a behaviour would prevent an illness impacted on how likely they were to engage in the health behaviour at all. Similarly, it has been demonstrated that individuals who believe they have some control over their health are more likely to engage in health behaviours (Norman & Brain, 2005; Pender, 1996). This perceived control over health has been referred to as having an internal health locus of control (Petersen & Lindström, 2010). Individuals with an internal health locus of control would be confident that engaging in health promoting behaviours would mediate health risks (Peterson & Lindström, 2010). Evidence suggests

individuals who have an internal health locus of control are more likely to engage in health promoting behaviours which also includes accessing appropriate health services (e.g. Roddenberry & Renk, 2010).

### **2.1.5 Rehabilitation and Support Following Stroke**

People who have had a stroke often engage in a period of rehabilitation, and with support, go on to live with the person they had resided with prior to their stroke. However, for this to be possible it can be necessary for these families to adopt roles as informal carers (carers). The National Audit Office Value for Money Report (2005) approximated that the informal care provided by families of stroke patients saved the NHS approximately £2.4 billion per year. Therefore, it would seem to be in the public interest to ensure that carers themselves remain healthy and free of stroke or other illness. However, the evidence base looking at stroke risk in carers seems scarce.

### **2.1.6 Health Impacts of Caring**

Studies have investigated stroke carer's psychological well being, and found them to be in need of emotional support, (e.g. Hodgson, Wood & Langton-Hewer, 1996; Wyller, Thommessen, Sodring, Sveen, Pettersen, Bautz-Holter & Laake, 2003). Evidence suggests that psychological support for carers is an important area for consideration because people caring for their partners demonstrate not only lower scores on wellbeing measures than the general population, but also lower rates than reported by those who are widowed (Stevens, 1989). Research has also investigated the physical demands of

caregiving and reported that the combination of loss, prolonged distress and physical demands of caregiving can increase carers risk for health problems (Vitaliano, 1997).

Swedish research indicated that when caring for close relatives, one's own health-related problems tend to be regarded as 'not important' compared to stroke and are therefore put to one side (Bäckstrom & Sundin, 2007). One participant indicated that they worried more for their own health than they had previously. However, their concern was borne out of fear about what would happen to their relative if something, like a stroke, happened to them too. Another of the emergent themes seemed to suggest that close relatives coped by living their lives hour-by-hour, day-by-day. This 'living in the present' helped foster feelings that they could cope. Additional Swedish research investigated the experience of offering advanced palliative home care for a close relative with severe, chronic heart failure, (Brännström, Ekman, Boman, & Strandberg, 2007). The three main themes which emerged were described as; being relieved of burden by staff, constant worry, and feeling worn out from being on constant alert to help. However, within their narratives, the women interviewed did not seem to mention any references to how this experience impacted on their own health or desire to remain healthy. However, 'Biographical Consequences' were described in research investigating healthy partners of people offering care to spouses with health conditions (Kuyper & Wester, 1998). These Biographical Consequences were those describing fear, not only for the life of their loved one, but also for the consequences of the disease for his or her own life. The participants sampled seemed to be

concerned about the changes in the amount of time they had to spend at home since their partner became ill, changes in role responsibility within the home and the ceasing of previously mutually enjoyed activities such as walking, holidaying and lovemaking. However, this concern did not seem to include a sense that observing the impact of illness upon their partner had led them to question their own fallible health and therefore the course of their own life. Indeed there does not seem to have been any published research investigating this area.

### **2.1.7 Aims and Research Questions**

The primary aim of the current study was to explore the experience of observing a stroke in a spouse and what effect this might then have had upon their own desire to remain healthy. It was hoped that some aspects of the Health Belief Model could be investigated and that a person's self efficacy and health locus of control might be explored. However, following the recommended guidance for conducting research to be analysed using grounded theory, the initial research questions were somewhat under developed and tentative (Robson, 2002).

## **2.2 Methodology**

### **2.2.1 Design**

In order to allow exploration of an area with a scarce knowledge base, a qualitative design and methodology was adopted. A semi-structured interview design was used. Grounded Theory analysis was chosen to allow the data collection and analyses to be conducted together and is recommended as especially helpful in areas of new or scarce research (Charmaz, 2006; Glaser & Strauss, 1967).

### **2.2.2 Participants**

### **2.2.3 Recruitment Procedure**

Ethical approval was granted by the researcher's University Ethics Panel, National Health Service (NHS) Research Ethics Committee and the NHS Research and Development Service (Appendix 2). The study was also approved by clinicians working in the centres used for recruitment. All participants gave their informed consent to take part in the study (Appendix 4), and were informed of their rights to withdraw from the study without need for reason. All potential participants were known professionally by members of staff working within community stroke rehabilitation settings and were informed about the study by these clinicians. Staff members received staff information sheets (Appendix 5) advising of the study aims and the inclusion and exclusion criteria. They also had an opportunity to meet the researcher to ask further questions. Individuals whom staff identified as meeting the inclusion criteria

were given Participant Information Packs<sup>14</sup>. Each pack contained a study information letter, initial questionnaire to confirm eligibility, a consent form, an opt-in sheet for completion of demographic details, and a reply paid envelope to return completed forms to the Researcher's University, (Appendices 4, 6, 7 & 9). If people did not wish to take part in the study they were asked to discard the information.

#### **2.2.4 Participant Details**

Eight married partners (carers) of stroke survivors<sup>15</sup> were interviewed between October 2010 and March 2011. So that the maximum numbers of participants were available, no age limits were applied to either the age of the participant or that of the stroke survivor. No limit was applied to the number of strokes experienced or the level of disability experienced by the stroke survivor. In order to be successfully recruited, it was asked that all participants confirm that they had not experienced either a Transient Ischemic Attack (TIA) or a stroke themselves. Eight women, aged between 49 – 85 years (mean 64.63) were interviewed once each using a semi-structured interview format. Their male partners / husbands had all experienced and survived a stroke and were aged between 56 – 89 years, (mean 69.63). The length of time couples had been in their relationships ranged from 12 – 70 years, (mean 42.5). The length of time elapsed since stroke, at the time of the interview ranged from 4 months – 42 months (14.13 mean). Individual partner's ability levels, as reported by

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<sup>14</sup> See Appendix 8, for Figure 2.2.3.1, flow diagram of recruitment procedure.

<sup>15</sup> One participant's husband requested that he and his compatriots be referred to as stroke survivors.

participants at the time of the interview ranged from being back at work and able to drive a car, being able to wash with assistance and climbing stairs, to requiring all personal care tasks to be performed and necessitating use of a wheelchair for mobilising. Seven of the eight participants reported that their husband's speech had been largely unaffected, the remaining participant reported that her husband experienced aphasia and apraxia which made communicating more challenging for them both.

## **2.2.5 Measures**

### **2.2.5.1 Semi-Structured Interview Schedule**

A semi-structured interview schedule was constructed (Appendix 10). Each question was based upon the literature and developed in discussion with co-authors and individuals working within stroke services to ensure the aims of the study could be met. To test for coherence and understanding, the schedule was piloted using a telephone interview; the results of this interview were not included within the final study. The first few interviews used each question of the schedule. However, in line with Grounded Theory methodology, as the study progressed, the exact delivery developed and changed and was slightly different for each participant. The researcher chose to investigate areas previously mentioned by participants and used questions that had previously elicited good responses from participants.

### **2.3.2 Demographic Data**

Demographic information was sought via an opt-in questionnaire (Appendix 9), and completed by participants when they opted in to the study; this information was verified at interview.



### **2.2.6 Procedure**

Once the researcher had received opt-in responses from potential participants the data provided was double checked against the inclusion criteria. In one case, a male participant's partner had experienced an aneurysm instead of a stroke, he was sent a letter thanking him for his interest and was sent a de-brief information sheet and offered a copy of the findings when they became available.

Interviews lasted between 20 minutes to 45 minutes. All participants were offered a choice of interview venues; 5 participants were interviewed within their own homes, 2 participants at clinic bases, and 1 at the researcher's university. Participants were guided by some questioning but otherwise encouraged to speak freely about their experiences. Participants who took part were reminded of the limits of confidentiality and their right to withdraw within 2 weeks of interview conclusion. No participants withdrew following interview. All Participants were given ethically approved debrief sheets (Appendix 11). All interviews were recorded using a digital dictaphone, and were transcribed verbatim for analysis.

### **2.2.7 Data Analysis**

The data collected at interview was analysed with a 'Grounded Theory approach' informed by Charmaz (2006). Theoretical coding, was adopted in full as part of the analysis process. However, other tenets of the grounded theory process, as specifically recommended by Charmaz were only partially adopted within the current study. These included; memo writing, constant comparison, an iterative approach to data collection and analysis, and theoretical sampling of interview focus. Theoretical sampling was demonstrated by the recruitment of two participants of working age, however, it was not possible to recruit male participants via this method, nor was it possible to recruit additional participants of a younger age. A full grounded theory analysis as recommended by Charmaz, would ordinarily include the testing of 'hunches' or hypotheses arising from the data, the development of properties for core categories, attention to 'process' issues to account for the triggering of categories, and looking for interactions between the main categories. These aspects of the process were not incorporated within the analysis of this study. Whilst it was generally the case that data from one interview was transcribed and coded before the next interview took place, this was not always possible due to some interviews occurring on the same day. Theoretical coding led to the coding structure detailed in section table 2.3.1, the grounded theory model presented in section 2.4.2 and the complete analysis of one theme example detailed within appendix 14. Grounded Theory was chosen above other methods of analysis due to the fact that it contributes a model or theory and this can be useful in

under researched areas<sup>16</sup>. Atlas Ti was employed to assist with the Grounded Theory analysis. In order to achieve familiarity with the data, all interviews, transcribing and coding<sup>17</sup> for the study were carried out by the Principal Researcher. The Grounded Theory coding process was double checked by co-authors to the project and two other professionals experienced in the use of grounded theory.

### **2.5.1 Researcher's Own Position**

At the time of the study, the principal researcher was a Trainee Clinical Psychologist in the final year of training employed by a local NHS Trust. She first developed an interest in enabling people who have experienced strokes, and the people who care for them, whilst was working as a Home Carer in 2001. This interest developed further from 2004 onwards when working as a Rehabilitation Assistant for people with physical disabilities. These experiences left a fondness for this client group which could have impacted on the data analysis and interpretation. However, advisors to the project cross checked and verified these stages and therefore it is hoped that the impact was minimised. Having conducted the pilot interview with an adult of working age the researcher had hoped to interview participants who currently engaged in, or had previously engaged in health limiting past times. However, recruitment seemed to result in participants who led relatively healthy lives and engaged in few health risk behaviours.

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<sup>16</sup> For further information on Grounded Theory, please see Appendix 12.

<sup>17</sup> For a sample page of coded transcript please see Appendix 13 and for Theme example please see Appendix 14.

## Results

The study set out to examine the knowledge of modifiable risk factors for stroke and the impact on health in the married partners of people who had survived strokes. Using grounded theory, 3 core categories were identified within the data. These were; knowing, perceiving barriers to health behaviours and facilitators to health. Each of the core categories contained more than one subcategory and table 2.3.1 demonstrates the breakdown. The results section will talk about these categories using direct quotations<sup>18</sup> before going on to suggest a theoretical model depicting the barriers and facilitators associated with health change behaviours in this group (Figure 2.4.2).

Grounded theorists recommend that data collection is ceased when categories become 'saturated', meaning that "fresh data no longer sparks new theoretical insights, or reveals new properties of your core theoretical questions" (Charmaz, 2006, p. 113). The data collected for the present study reached the point of theoretical saturation although with a relatively homogenous sample and thus the findings presented are done so with caution. Due to small participant numbers it is possible that additional participant interviews may have added further weight to the existing categories or produced additional areas for consideration.

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<sup>18</sup> All names used are pseudonyms. All numbers in quotes refer to the Atlas Ti transcript phrase number.

**Table 2.3.1 - Breakdown of Core Categories**

<b>Core Category</b>	<b>Sub-Categories</b>
<b>Knowing</b>	Knowing about Stroke Knowing Risk Factors
<b>Perceiving Barriers to Health</b>	Putting Others First Self Efficacy and External Health Locus of Control Having to 'Fight' Perceiving Health Professional's Opinions Negatively Pre-existing Health Problems Lack of Support
<b>Facilitators to Health</b>	Motivation to Remain Healthy Self Efficacy and Internal Health Locus of Control Support to Remain Healthy

### 2.3.1 Knowing

One of the core areas in the analysis related to knowledge. This appeared to be in 2 particular areas, namely knowledge about stroke and knowledge about risk factors. In keeping with suggestions for grounded theory, the category has been called 'knowing,' so it keeps the active nature intended by participants (Charmaz, 2006).

#### 2.3.1.1 Knowing about Stroke

Many of the women had limited or no knowledge of stroke prior to their partner's stroke. It seemed however, that three of the women had gained their knowledge about stroke and stroke symptoms following a television campaign. The core category has been called 'knowing' as all 8 women had acquired extensive knowledge about stroke and the impacts of stroke as a result of witnessing the effects on their partner.

*I didn't actually know anybody who had strokes, so I didn't really know much about it only that sometimes if you have a stroke you can't move at all.*

*Judy, Line 7*

*Mmmmm, I don't know, I suppose because when you, you've not been very aware of stroke and people who've had them, then you tend to forget them, you know, cancer is in your face all the time isn't it? People are going on about cancer, and you know lots of people who've had it, but you don't hear of many people who have had a stroke.*

*Hilary, Line 150*

*Well, I've never met anybody who's had a stroke so really, very limited, I mean I've seen the adverts on the television and that's about as much as I know really.*

*Linda, Line 41*

*Well, as I said I was very grateful for the advertising campaign because it was so, explicit shall I say, that you can visualise it in your mind, you know, you start thinking about it, you know, the flaring on the forehead, that showed like, like a flame, and I thought it was very effective, very grateful for it.*

*Hilary, Line 162*

### 2.3.1.2 Knowing Stroke Risk Factors

It appeared the women sampled, not only had knowledge of the names of the six key modifiable risk factors for stroke, but with reference to blood pressure and cholesterol some were aware of their own measurements. All women reported they were aware of the health implications of smoking cigarettes. Whilst some had smoked prior to marriage, none of them had done so since. All were aware of the health protecting benefits of a healthy diet and generally tried to stick to it.

*I live healthily anyway, I don't exercise but I walk because I don't drive, so, urm, I don't smoke, I've never smoked and I don't drink, we eat healthily but I know when I need to, I watch my weight all the time, I'm not saying I'm skinny but I've always been quite conscious of my own health so that hasn't changed.*

*Anna, Line 37*

*I do try with our diet more, urm, I've always had cereals and whole wheat cereals, and I try to get Fred to eat them now.*

*Barbara, Line 27*

*Well, we both liked a glass of wine but neither of us were big drinkers at all I mean I haven't had a drink for 6 months you know, no, well, I mean Steve would perhaps have a glass of whisky occasionally but certainly not to excess, ever.*

*Linda, Line 113*

*I mean obviously we've got to think about the cholesterol, keep having it checked, keep checking blood pressure, that sort of thing and as I said of course diet and exercise as we can.*

*Hilary, Line 174*

*I did when I was younger for a few years when I was about 20, but when I had the children I stopped, and I haven't smoked since.*

*Linda, Line 105*

## 2.3.2 Perceiving Barriers to Protecting Own Health

The previous core category suggested the women had knowledge regarding the impacts and effects of stroke and that they were aware of the six key modifiable risk factors for stroke. However, whilst some of the participants were able to implement health promoting behaviours, others were not. The second core category related to the participants' perception of barriers which made it difficult for them to take steps to protect their own health. These perceived barriers were broken down into 6 further categories.

### 2.3.2.1 Putting Others First

Many of the women explained that they coped by putting the needs of their partner and their family before their own. For some, they had always lived this way, whereas for others this represented a change since their partner's stroke.

*That's how I am as a mum, you make everything, you want everything else to be fine don't you? You know, you want the kids to be fine, so you're last on the line really, and that's always suited me and I've never wanted to be anything other than that really.*

*Barbara, Line 61*

*Well if you think about it, it is, you know sometimes you're awake at night and you think 'oh what was that?' and 'what if I have got to have that done?' you know. Well I'll give you an example, I've got a prolapse, and they said: "don't worry about it unless it really affects you," but two of my friends have had the operation, and I think 'oh, should I do that?' And now I can't anyway, it's not worrying me, but you've got to think about that in the future. If you do go to have a check up, and it needs some kind of treatment what would happen?*

*Hilary, Line 226*

*It's, you just, your life is just taken over really, caring for Fred, just making sure that I can make his life as good as possible, if he needs me to be with him, I need to be with him.*

*Barbara, Line 31*

*If anything, I had low blood pressure and my cholesterol was fine and I've not had any worries with those things, I don't know now because I haven't had them tested while Mike has been in hospital, there hasn't been time to think about things like that, urm, but, I didn't have a problem beforehand.*

*Anna, Line 94*



### 2.3.2.2 Self Efficacy and External Health Locus of Control

There seemed to be differences in the levels of self efficacy held by the women, that is, how much they believed that they were able to create or maintain positive physical health by partaking in certain health behaviours. For 4 of the women there was evidence of external health locus of control, or poor self efficacy, for example;

*I think that a stroke is something that's just there just waiting to happen and I think that whoever you are, and whatever your age is, you could still have a stroke. If you tried everything not to have one you could still have one, it's an unseen thing inside your head.*

*Judy, Line 68*

*I mean we've got a friend who was that healthy and fit, I mean he walked, his diet was good, I mean he had a stroke one Sunday morning when he was getting ready to go on his holidays, and he died there and then, and yet he used to look that fit, he was slim and active.*

*Judy, Line 60*

*Urm, well, I've got quite high blood pressure, sometimes dangerously high, but somehow you feel it's never going to happen to you, you know so I'm not sort of that worried.*

*Beryl, Line 20*

*It would be to do more exercise, to lose weight, urm, I don't really know, I used to think, I used to think that you had strokes because you were like overweight or didn't do that, but it's not all, it isn't that, I mean David's Father died of stroke when he was 63, so did his Mother.*

*Judy, Line 21*

### 2.3.3.3 Having to 'Fight'

It seemed that many of the women spoke about having had to 'fight' for the appropriate care or treatment for their partners in the time following stroke. These women spoke of finding the experience exhausting. It seemed that the energy that might have otherwise been put into keeping themselves well had been diverted to fighting for appropriate services for their partner or encouraging their husband to lead a healthier life, for example;

*.....and I was also quite vocal enough to go with him with OT and fight his corner for him but there must be lots and lots and lots of people out there who either don't have the courage to do it, don't have the knowledge to do it.*

*Helen, Line 80*

*I've got a good level of education, I've got a good job, I've got a good understanding of people, I'm not afraid to use my voice, although I was surprised, because I am obviously stronger than I thought I was, I was able to go and fight for the services that Joseph needed, but the person, the people, that I felt sorry for was perhaps the little old lady who's suddenly plunged into the same position, hadn't got family around her, doesn't know who to ask, and just sits and meekly accepts what's there on the plate without having the support to go and fight for anything, or even the where withal to do it, and that's where the system falls down, I could fight for it and eventually got it, it should have been easier for me, it wasn't, I got it, but many many others will not of had that at all, but where's it left them?*

*Patricia, Line 103*

One woman also spoke about having to encourage or 'fight' her husband to lead a healthier life in order to prevent further strokes, she reported:

*So I've tried to encourage him to go swimming, to try and help this shoulder, but he won't, so I worry that when we don't have our dogs what he'll do about exercise. But I can't see our diet changing, urm, much. Urm, the only thing is Andrew very much took to heart when they said he had to rest and he does spend increasingly large amounts of time in bed and I sort of say to him whilst that's great, actually that on its own doesn't prevent stroke, he needs to do all the other bits as well.*

*Helen, Line 51*

#### 2.3.3.4 Perceiving Health Professionals Opinions Negatively

Three women felt that their perceptions of health professional opinions had, or would affect their own choices regarding accessing treatment, for example;

*Interviewer: Like you were saying, with cholesterol and blood pressure...what stops you from finding that out or pursuing it?*

*Barbara: When you're overweight it's difficult to go to the doctors because they will blame that on everything.*

*Barbara, Line 47 - 49*

*Urm, yes, so I, I, feel at times I have bothered the Doctor, because I was one never to bother them before, but I have perhaps I feel been a nuisance although they reassure me that I haven't been.*

*Patricia, Line 50*

Another participant also spoke of medication; namely fear of being prescribed more medication as a reason for not going to the doctors to talk about her own health, she reported;

*Well, I've been having very disturbed nights, you know, lie in bed and toss and turn and wake at 3 in the morning and think oh you know, wide awake and I haven't gone to the doctors because I don't want to go along the lines of sleeping tablets, it would just be another tablet to take wouldn't it? (laughs).*

*Linda, Line 177*

### 2.3.3.5 Pre-existing Health Problems

Three of the women had pre-existing health problems which they perceived placed barriers between them implementing health change behaviours:

*I have to use a mobility scooter now to take my dogs and everything because I've got a knee problem.*

*Barbara, Line 27*

*There wouldn't be that much, there wouldn't be any disadvantages, (to protecting own health) but at the moment I'm not very mobile, I've got two hip replacements I've had the one hip replaced twice, got arthritis, cervical spondilitis, lymphodaemia and all sorts of things that make it hard for me to do these things, I mean I could lose weight*

*Judy, Line 36*

*I've got (\*\*Health Condition\*\*<sup>19</sup>). So, urm, the risk of stroke and heart attack increases the longer you have the illness.*

*Helen, Line 43*

### 2.3.3.6 Perceiving a Lack of Support

Many of the women felt that the lack of support offered, not only made it difficult for them to focus on their own health, but in some cases actually had a detrimental effect upon it. They reported:

*There is no support for carers, and there is no focus on their health. There is just an expectation that they will cope and care, and you know, if there are consequences, well, it's almost too bad. And particularly when you have urm, a condition like mine which is progressive, it is degenerative, there is no cure for, so I know where it's heading, which is progressive disability. To actually then be forced into a situation which will exacerbate it and speed up that process is actually quite distressing.*

*Helen, Line 80*

*And ultimately, if the carer isn't supported then it's that person who's going to become ill so then there's two people totally dependent on hospital care so it is important that carers are given that support.*

*Patricia, Line 103*

*I worry about the physical impact on physically on my body, having to lug a 16 stone man around because I'm only little.*

*Anna, Line 37*

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<sup>19</sup> Name of health condition not given in order to protect participant's identity.

### **2.3.3 Facilitators for Protecting Own Health**

The final core category identified relates to factors which facilitate greater health. Three sub-categories were identified.

#### **2.3.3.1 Motivation to Remain Healthy**

All but one of the participants spoke of a desire to remain healthy. The remaining participant, the eldest sampled, felt that she had led a long, healthy and happy life and that now she just wanted to relax:

*We've travelled, we've been on wonderful cruises, we've been to Japan and to China and everywhere, so in a way it's lovely to feel that we've done all this so that we can relax.*

*Beryl, Line 58*

For the remaining participants, the reasons for wanting to remain healthy varied. Some felt that having experienced the effects of stroke upon their partner they did not wish to experience that for themselves. Whereas for others it seemed the motivation to stay healthy was borne more out of the necessity to continue to offer care to their partner:

*It's a bit scary, cos you think 'I don't want a stroke,' because I find that quite a terrifying prospect.*

*Helen, Line 43*

*I don't think that it is a worry about what will happen to me in that respect, it's what does Mike do?*

*Anna, Line 46*

One participant described the effect of seeing how ill her husband was and how medication had affected him had been motivation for her to stay well:

*I've got this abhorrence of tablets, knowing that I'm approaching, well I consider it old age although I'm not into it yet, I think that the longer that I can stay healthy the better.*

Patricia, Line 81

Some of the women described their partner's stroke as having caused them to commence lifestyle changes which they regarded as beneficial for their own health, for example:

*It is important that I remain healthy and that I do tend to have things checked out far more so than I would have done in the past.*

Patricia, Line 50

*He makes me take it easy, keeps saying "are you coming to sit down?"*

Beryl, Line 103

*I do exercise, I did exercise reasonably well, since we've got the dog<sup>20</sup> I do even more so now, I get up, it's the first thing I do in the morning take the dog out.*

Patricia, Line 72

One participant described her partner's stroke as having caused a re-appraisal of her own health symptoms:

*But uh, I have had a couple of incidents with my, with chest pains which have turned out not to be anything, but, I know that things like heart attacks, you don't always get the classic symptoms, especially women, and I often wonder whether the fact Joseph did have symptoms but didn't recognise them or chose to ignore them and I can't afford to do the same thing.*

Patricia, Line 50

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<sup>20</sup> Dog acquired to keep her partner company whilst she is at work.

### 2.3.3.2 Self Efficacy and Internal Health Locus of Control

Whilst health locus of control and self efficacy were previously described as a barrier to taking care of their own health, some of the women demonstrated a clear belief that lifestyle creates or wards off health problems. This suggests that they had an internal health locus of control and felt reasonably confident in the efficacy of their health behaviours, for example:

*He smoked, this was going to happen.*

*Anna, Line 58*

*I used to tell him not to get so angry about things, I used to say that one day something will go pop.*

*Judy, Line 52*

*I thought we were leading a fairly reasonably healthy life, we don't eat a lot of red meat, I drain as much fat as possible, salt doesn't exist in this house apart from to put on the ice and the snow (laughs). We eat chicken, fish, we don't eat fried food, you know we eat lots of fruit and vegetables so you know, as far as I was concerned we eat a healthy diet.*

*Helen, Line 31*

*Well, obviously we're going to be more sort of careful about diet, hopefully we'll be able to get back to doing some exercise, and we like the routines as well, we tend to do that a bit more than perhaps, a bit more than we used to, you know. We'll have lunch at more or less lunch time and then a meal early evening because we've been told we mustn't eat too late at night.*

*Hilary, Line 133*

*I used, uh, you know, it was not a joke, I don't mean that flippantly but I always said 'you know if you don't change your lifestyle you'll end up having a stroke.'*

*Anna, Line 35*

### 2.3.3.3 Support to Remain Healthy

The final sub-category details how some of the women felt that some people had helped them to be able to focus on their own health, for example:

*My employer was happy for me to take whatever time I needed for appointments and to take him to the speech therapist the doctor's, blood tests, everything, they were absolutely marvellous and I have to say that that support from work and my work colleagues has probably done, had gone a great distance to me being as well in my mental and physical state as I am.*

*Patricia, Line 42*

*My cholesterol level was picked up as being high at one of the wellbeing days at work when they tested, did further tests, it showed that I had got a significant proportion of it was good cholesterol so I was within the acceptable limit but recently I have had my cholesterol checked again and apparently my cholesterol, my good cholesterol is extremely good for someone of my age.*

*Patricia, Line 66*

*A lady from urm, Warwickshire carer's came out and had a chat with me before ever David was discharged and she said Judy, you think your life is over, but believe me, you will be happy again, you'll have a different life but you will be happy and she was quite right.*

*Judy, Line 127*

*I was absolutely exhausted and my (\*health condition\*) flared up, urm, so my medication had to increase urm, my consultant wanted to admit me to hospital because I was so exhausted and my condition was spiralling out of control but I couldn't go into hospital because there was nobody to look after Andrew and nobody to look after the children and it was only my consultant intervening and saying this has to stop, and contacting the GP's who were wonderful who then got help.*

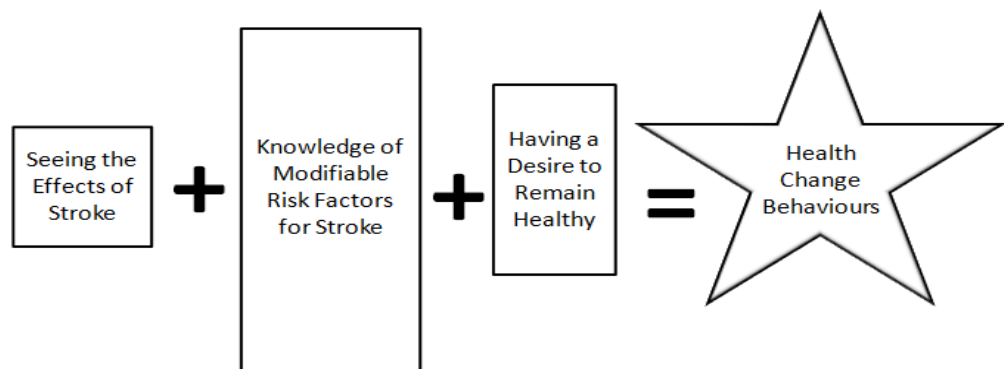
*Helen, Line 76*



## 2.4 Summary of Findings

The expected course of action for individuals with 1) knowledge of stroke effects, 2) knowledge of modifiable risk factors for stroke and 3) a desire to remain healthy is depicted below in Figure 2.4.1.

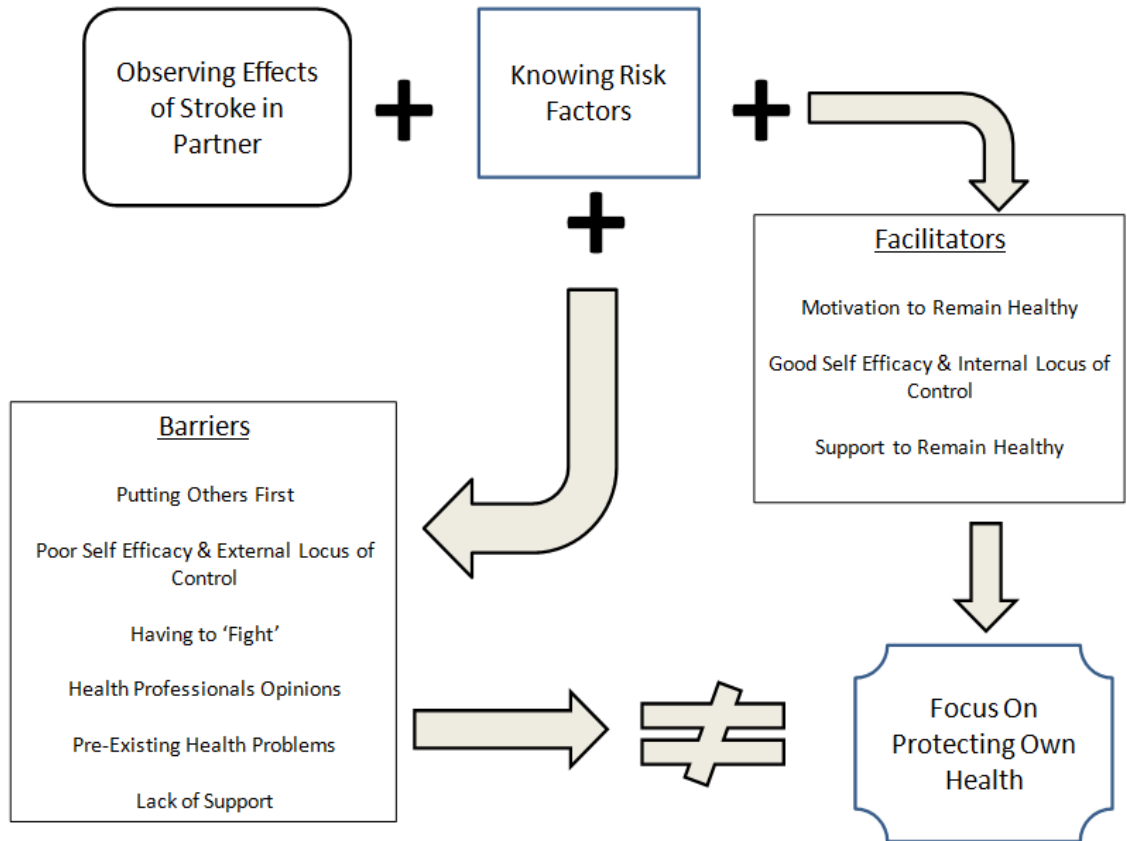
**Figure 2.4.1 Expected Course of Action for Individuals with Knowledge of Stroke**



However, the results of the current study did not show the linear pattern of events depicted within figure 2.4.1. The findings of the current study showed that despite having experience of observing the effects of stroke and knowing the 6 key modifiable risk factors for stroke, the women sampled did not always implement health change behaviours. Perceived barriers to the implementation of health change behaviours were identified as; Putting others first, Poor Self Efficacy and External Health Locus of Control, Having to 'Fight', Perceiving Health Professionals Opinions Negatively, Pre-existing Health Problems and Lack of Support. Factors which facilitated the women to implement health change behaviours included; Motivation to Remain Healthy, Good Self Efficacy and Internal Health Locus of Control and Support to Remain Healthy. Figure 2.4.2 demonstrates these findings in the form of a grounded theory model.

## 2.4.2 Grounded Theory Model

**Figure 2.4.2 A Grounded Theory Model of Barriers and Facilitators to Protecting Own Health in Female Partners of Stroke Survivors.**



## **2.5 Discussion**

### **2.5.1 Discussion of Findings in Relation to the Literature**

All participants had knowledge of the six key modifiable risk factors for stroke, (WHO 2005). This challenged Kothari, Sauerbeck, Jauch, Broderick, Brott, Khoury & Liu's (1997) findings which suggested 43% of their sample did not know of a single risk factor for stroke. Many of the participants within the current sample could be regarded as older adults and 7 out of 8 of them still had a desire to remain healthy and to avoid stroke, which demonstrated that they did not necessarily see diseases such as stroke as a natural part of the ageing process. This finding supports the WHO position (2005).

Barriers to performing health behaviours were not shown to include time, expense or fear as was demonstrated by Abraham and Sheeran, (2005). Approximately 40% of the sample knew of their blood pressure reading. This is the same figure as that identified within the Stroke Association report (2008b). However, at no point in the current study were participants directly asked whether they knew their blood pressure and therefore this figure may have been higher. All women were aware that 'not exercising' placed them at higher risk of stroke, as did having a poor diet and consuming alcohol. This was in contrast to the study by Hairon (2008), which detailed between 71 and 83% of women were unaware of this. Not all of the women in the current sample mediated their stroke risk via the implementation of health change behaviours. In that respect, it supported Schroeder, Rosamond, Morris, Evenson & Hinn's

findings (2000), that people knowledgeable about stroke do not always change their behaviour to reduce stroke risk.

It seemed that levels of self efficacy (Bandura, 1977), were important in determining whether or not the participants within the current study engaged in health protecting behaviours. The current research also found that when caring for close relatives, one's own health-related problems tend to be regarded as 'not important' compared to stroke and are therefore put to one side, (Bäckstrom & Sundin, 2007).

### **2.5.2 Methodological Limitations and Areas for Future Research**

Whilst no new categories or sub-categories emerged in the final few interviews, the sample for the present study was relatively small. As such, it would be expected that if recruitment had continued that new data may have arisen. Thus, whilst the study appeared to have reached the point of saturation with participants of retirement age, this may have been different had the sample been less homogenous.

The study resulted in a useful static grounded theory model which depicted the barriers and facilitators to participant's health behaviours. However, a potential limitation to the model is that it may have been more insightful for participants and clinicians were it to have offered a 'middle line theory.' For example, such a dynamic theory might have provided a tool to explain why

certain barriers or facilitators were apparent for each participant as a result of their experiences. Further incorporation of some of the principles of Grounded Theory Analysis may have facilitated the production of such a model. Similarly, as the hypotheses arising from the data were not tested out with subsequent participants, this suggests that there may have been a lack of depth within the analytic process.

Whilst this study adopted a positive methodology in trying to investigate the impact of observing the effects of stroke upon a person's own desire to remain healthy, it in no way sought to 'minimise the hardship associated with the event' (Tennen & Affleck, 2002, p585,). In fact, this is not the first study to use a positive methodology to explore the impact of neurological conditions upon family members and individuals, (e.g. Gillen, 2005; Pakenham & Bursnall, 2006; & Pakenham & Cox, 2009). Some studies have developed measures in order to specifically gauge 'benefit finding' and 'positive growth' in the families of people who have experienced neurological conditions (e.g. Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, & Goodkin, 1999 & Pakenham & Cox, 2008). Yet there are no apparent scales specifically aimed at measuring positive growth or benefit finding in the families of stroke survivors. Therefore, if handled sensitively, this would be an important area for future research.

The current study sought to interview the partners of people who had survived strokes. However, naturally, this sample therefore excluded those whose partners had passed away. The women interviewed for this study all seemed to

have very busy lifestyles following their partner's stroke and at times this made it difficult for them to focus on their own health. Therefore, it is possible that those who had lost their partner may have taken different meaning from their experiences; this may have impacted upon their own health in alternative ways than those reported in the present study. Therefore further research replicating the methodology in this study but sampling the partners of people who passed away as a result of stroke would serve to further the evidence base in this area.

Whilst two of the women within the current study were working full time, the majority of the participants were retired with the mean age being 65. Given that expected life course trajectories would suggest people are more likely to become ill as they age, it may have been helpful to have also sourced participants through the 'Different Strokes' organisation which offers support and advice to younger people affected by stroke. The impact on the health of partners of people in this age bracket may have been different to this study and thus sampling in this way in future could be helpful.

Data was obtained on length of time together as a couple and length of time since stroke. However, due to the relatively small number of people sampled within this study it was not possible to infer meaning from this. Therefore in a larger scale or quantitative study it may be pertinent to incorporate this data into the analysis.

Three of the women sampled declared pre-existing health conditions of their own; this could already have caused them to reflect on their own health behaviours prior to their partner's stroke. Details regarding 'type of stroke' were not taken. Therefore, in future research it is recommended that a more homogenous group could be sampled.

One of the evident limitations of this study was that it featured only the voices of women. Whilst the study planned to interview both sexes, on this occasion it was not possible to recruit men. This could have been affected by the researcher being female. Therefore, in order to start to build the knowledge base in this area it would be helpful if future research, either incorporated men within the sample and / or included males within the research team.

Participants of the current study were interviewed at their choice of 3 different locations. The locations may have affected how easily participants felt they were able to talk about their experiences. This may be especially true of the 3 participant's husbands who were present in the same house, albeit in a different room at the time of the interview. Given that all participants were talking about their experience of observing their partner they may also have experienced feelings of guilt. Whilst the methodological arrangements of the current study allowed the participants to have choice over interview location it may be helpful if future research standardised the location and interviewed all participants at the same location.

Lastly, it is important to acknowledge that biases may have occurred as a result of the recruitment process. Firstly, it is possible that the staff may have been biased in who they approached with participant packs. Secondly, there could have been a bias in the types of people who wanted to take part in the research after they had received the participant packs. Whilst this recruitment method protected participant confidentiality, further research, if undertaken on a larger scale or using different recruitment methods, may redress any response bias.

### **2.5.3 Clinical Implications for Findings**

Some of the participants said they were unaware of stroke prior to their partner's stroke, with one feeling that this was because they were not spoken about nearly as much as cancer. Three of the 8 participants spoke freely of an awareness of the NHS Act FAST campaign, which raises awareness of the 4 important factors for stroke; 'Face, Arm, Speech, Time to call 999'. The evidence from the current study seems to suggest that television is an effective educative medium. Perhaps in future, television could be used to raise awareness of the types of health protecting behaviours which could be undertaken in order to protect carer's own health.

One participant suggested an idea for conducting a group for the partners of stroke survivors whereby the group would run at the same time as their partner's therapy so that carers could have the opportunity to share experiences and learn from one another. A group such as this may provide an



excellent opportunity to offer the support which participants in the current study felt was so lacking from professionals. This group could also serve as an aid to health promotion and education on the types of health behaviours which counteract the modifiable risk factors for stroke. The same participant also felt that at the time immediately following her partner's stroke she wanted to do all sorts of things for herself and for her partner. However, as time elapsed and she grew used to the effects of her partner's stroke she felt that the time had passed and she never got round to doing these things. This would suggest there may be a discrete window of time where it is possible to engage this group with health change behaviours, but once this window has passed it may become more difficult. Therefore, there is clinical importance for staff to not only offer emotional support but also practical support and education in this area.

Participant's perceptions of health professionals were shown to be an important factor affecting whether or not they took care of their own health. Therefore it would seem important for health services to go out of their way to include this group and help to reduce any prejudices which may exist. Similarly, it seemed that much time and energy was spent by participants in 'fighting' for adequate care and services for their partner. Thus if there was greater equality and ease of access to services perhaps more time would be freed up for the partners of stroke survivors to focus upon their own health.

## **2.6 Conclusion**

This is the only study to have investigated the impact of a partner's stroke on a person's own desire to remain healthy and implement health change behaviours. Despite limitations within the research, a number of preliminary findings and implications arose from the data. The study identified that participants had knowledge of modifiable risk factors for stroke. The perceived barriers and facilitators to implementing health change behaviours as identified by participants were also discussed and a model proposed. Clinically, this is an important area for consideration as many of the women sampled did not feel supported by health professionals and despite their knowledge of what they 'should be doing,' it was often difficult for them to do this. Further research in this area is recommended so that the knowledge base can be developed further.

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## **Chapter 3: Reflective Account**

### **To Send or Not to Send? That is the Question: A Reflective Account of Therapeutic Letter Writing in Clinical Research**

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**Word Count - 2604**

**(Excluding Abstract and References)**

## **Abstract**

This reflective account introduces and reflects upon the research process using therapeutic letters. This chapter also explores the dual purpose of therapeutic letters and includes two letters; one to the research participants and one to the principal researcher. The usefulness of each letter is assessed in terms of the functions identified for therapeutic letters. Finally the author reflects and decides upon whether to send the letter to participants.

## **3.0 Reflective Paper**

### **3.1 Introduction**

This reflective paper uses therapeutic letters and linking discussions to present and reflect upon the issues arising during the research process. It starts with a brief overview of the evidence for therapeutic letters and then the letters serve to offer insight into the evaluative and reflexive processes arising as a result of ethical, professional and personal considerations. The chapter concludes with a discussion addressing the usefulness of the letters based on how well they achieve their intended function as discussed within the introduction.

#### **3.1.1 Therapeutic Letters**

Therapeutic letters are a tool often used by Narrative Therapists (White & Epston, 1990), Solution Focused Therapists (Nunnally & Lipchik, 1989; Shilts & Ray, 1991), Family Therapists (Nau, 1997), and Cognitive Analytic Therapists<sup>21</sup> (Ryle, 1995). Letters are regarded as therapeutic when they are client-centred, future-oriented, hopeful, and realistic (Goldberg, 2000).

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<sup>21</sup> In Cognitive Analytic Therapy Therapeutic letters are usually referred to as Reformulation Letters.

### **3.1.1.1 Functions of Therapeutic Letters**

The reasons for writing therapeutic letters can be numerous. This section will split the reasons in terms of uses for client and uses for clinician.

### **3.1.1.2 Function of Letters - Clients**

One of the main functions of a therapeutic letter is to provide a tangible reminder of a session for a client. This can help clients to remember and reflect upon the content of the session and can help them to see how far they have come (Epston, 1994). In some cases, therapeutic letters have been shown to be of even greater importance to clients than the therapy sessions themselves. In fact, a single letter has been shown to offer the equivalent therapeutic value to clients of up to four therapy sessions (White & Epston, 1990). Letters can also act as a way of letting a client know their clinician has heard their story accurately and can help the therapeutic relationship to develop (Parry & Doan, 1994). Evidence suggests that therapeutic letters also help clients to feel understood and borne in mind by the clinician outside of the therapeutic session (Rodgers, 2009).

### **3.1.1.3 Function of Letters - Clinicians**

The process of writing therapeutic letters is not entirely altruistic as the process of writing them and later reading them can also be beneficial for clinicians. Research has demonstrated that letters serve as a useful way for clinicians to reveal some details about themselves in order to help establish an appropriate transparency and ensure a mutually empowering relationship (Rodgers, 2009).

The process of letter writing can allow therapists to reflect, to slow their thinking down and to reiterate comments or important shifts made during sessions (Nau, 1997).

The evidence base looking at the function of letter writing from a clinician's perspective seems to be scarce. However, as a personal testimony, I have found that the process of writing therapeutic letters has helped my feelings of empathy for clients to develop quicker, have served as an important space in aiding my client formulations and have allowed me time to let the client know that I think of them outside of sessions. I have also found re-reading them prior to therapy sessions more helpful than clinical notes in enabling me to quickly capture the feelings of previous sessions and consider the progress made by clients from session to session.

### **3.1.2 Therapeutic Letters 1 & 2**

Letter 1 is two pages long and is written to all of the research participants from me, the principal researcher they met at interview. It is followed by a short passage which explains how letter 2, also 2 pages long, was first thought of as a concept.

### 3.2.1 Letter 1, Page 1, Letter to Participants

Dear [Helen, Barbara, Linda, Patricia, Hilary, Beryl, Anna and Judy,]

I wanted to write to you to once again thank you for making the time to take part in my research study. I was impressed with the way you were able to speak openly and honestly about your experiences and with the ways you have coped with the difficult experiences that life has put your way lately.

I thought that I would let you know a little more information about the way I used the data that arose from our conversations together. You may remember the participant sheet you received, which explained that I was going to transcribe our conversation to enable me to analyse it in more detail. For me, the single most challenging aspect of the research was following this transcription, when I looked at these conversations on paper and realised that in order to complete my research I would not be able to use some of the data. Much of what you had said was especially moving and emotive, both at the time when spoken, and when seen in black and white. However, as the purpose of the study was to look at the way in which your partner's stroke affected your own desire to remain healthy I was unable to include data which did not relate to this area. This felt incredibly difficult, as due to the highly charged emotional content, this was the very data that I wanted most to include. I wondered why I might have found this, and I reflected that it was likely to have been because I wanted your words to not have been in vain. I wanted people to understand what a difficult process it is to care for and offer support to a partner after they have had a stroke. However, I hope that the data I have been able to include still shows the difficulties that you have encountered and that my work still does your words justice. I also hope that the results serve to offer support and guidance to you and to others who may find themselves in a similar position in future.

As we discussed at the end of the interview, with this letter I have also included a copy of the main findings of the research. These findings take the form of a copy of a poster that I will be presenting as part of my qualification. Whilst you all mentioned that you would like to receive copies of the findings I have chosen to offer these to you in this format as I did not want to overburden you with pages of literature that you may not have wanted. However, if you find the poster interesting and would like to see more of the findings then please do not hesitate to get in touch.

### **Letter One, Page Two**

If our meeting evoked feelings that you might wish to explore in a therapeutic context it is possible to self-refer for therapy through the Improving Access to Psychological Therapies (IAPT) Service which your GP or local health authority will be able to provide more information on.

I would like to take this opportunity to thank you once again for the warmth you extended to me when we met and for your willingness to participate in this research. I would also like wish you and your family all the best for the future.

Best wishes,

Marianne Durran

**Trainee Clinical Psychologist and Principal Researcher**

### **3.3 Idea for Letter Two**

Letter one was originally longer, however, when I read it back later that same day I realised some of the paragraphs seemed to be exploring my own dilemmas and anxieties about the research process. This led me to reflect upon whether it was appropriate for me to do this within a letter to research participants. I decided that this was not the best outlet for these types of concerns. However, because the content of these paragraphs still felt important I chose to include them within a 'letter to self'.

### 3.2.3 Letter Two, Page One, Letter to Self

Dear Marianne,

I felt compelled to write to you to allow a space for you to reflect upon the impact your thesis and training has had upon you over the last few years. I hope that you will find this letter to be a helpful resource to help process some of the difficult feelings that may have arisen. I wonder if in future you find yourself requiring a space for reflection whether you might be able to use some of the methods that you have found so helpful over the last few years, namely; an open and honest stance within supervision, keeping a reflective journal, swimming, practicing pilates and of course, your favourite – talking and laughing with friends and family? How would you know when it was time to take a break and implement some of the self care that you speak about so often with clients?

At the beginning of training you found yourself worrying and feeling intimidated about seeing a client who was slightly younger than you and in a highly skilled occupation. You wondered what you could possibly have to offer her which she might find helpful. I wonder whether you were able to apply any of the answers you reached on this occasion when you began to worry about the prospect of interviewing older people about their own health behaviours for this research? In most cases you felt that you were the age of participant's own children and in other cases you felt that you were young enough to have been their granddaughter. Do you remember the therapeutic role plays from the first few weeks of your training? You and your fellow trainees were horrified that somebody might ask to see someone else who 'wasn't a student,' or 'had more experience.' However, in reality, you found nobody said this to you. What might this tell you about the skills you possess as both a therapist and a researcher? What might this tell you about what clients think of you and whether your age matters to them? How might this have helped you at the time when you were worried that your questioning for the empirical paper may have been interpreted by participants as 'health preaching,' or 'teaching your grandmother to suck eggs?' Now that you are just a few months away from your 30<sup>th</sup> birthday how might you expect this to affect you in future?

The recruitment and interviewing for the empirical study occurred at a difficult time of



## Letter Two, Page Two

training for you. Consequently, the interviewing required reflexive 'juggling' for you to convey a professional face at a time when this felt especially challenging to do so. I know that at the time you felt that this may have impacted upon the data that you were able to gain from each interview.

How might your judgements of yourself as a researcher have differed if you had not been going through this difficult stage of training? Have you considered that the data arising from the study was likely to have been the same regardless of the way that you were feeling on the day of interview? Despite the inherent challenges of training and of the last year, you have managed to produce a thesis which you are proud of and which ultimately, at times you enjoyed writing. What might this tell you about yourself and this difficult time in your life? How might this help you in the future?

You have chosen to write your reflective paper in the form of therapeutic letters as this was something that you have found to be especially beneficial for both yourself and for clients within your last placement. I know that you are currently committed to letter writing and that you are keen to continue to do this in future. I hope that you are able to incorporate this practice within your eventual post qualifying job as I know that you welcome the reflecting and formulating time which the process affords you. However, you are also aware that the clients you have previously written to have opted in to receive therapeutic letters. Whilst all participants wanted to hear results of the findings you did not explain that you would write them a letter. I wonder if that is why you are wondering whether you should actually send the letter to participants? I know that whatever your eventual decision about whether or not to post the letter that it will have been thought about and justified accordingly.

I would like to take this opportunity to wish you all the best for the future and to congratulate you on being able to enjoy the journey of clinical training and conducting research as well as anticipating the eventual goal.

Be kind to yourself,

Marianne

### **3.5 Reflections on the Intended Functions of the Letters**

Within this process I was the author of both letters in this chapter and also the recipient of my letter to self. I will use this final part of the chapter to reflect upon whether these letters achieved the functions of therapeutic letters as identified within the introduction section.

Each letter was client-centred, future-oriented, hopeful, and realistic as recommended by Goldberg (2000). In writing the participant letter I wanted the participants to feel borne in mind by me (Rodgers, 2009), and to have a tangible reminder of our interview (Epston, 1994). I felt this was important as they had given their time to me and I had not been able to compensate them for theirs. I wanted them to feel it had been time well spent and for them to know that I had appreciated it. I was also mindful that one clinician I approached to ask for assistance with recruitment had declined, citing the reason that they had been disappointed by previous researchers who had not let participants know of the results of a study they had taken part in.

When writing letter 1, I carefully considered whether to include information which related to specific participants or perhaps whether to write them individual letters so that the client-centred nature was maximised. Whilst this may have increased participants feeling that I had heard their story accurately (Parry & Doan, 1994), I was also mindful that this would have cemented a therapeutic relationship that I was unable to continue. Therefore, upon reflection, now that both letters are written, I think that it was best to write a

joint letter, especially given that the participants had not been asked if they wished to receive such a letter.

I think both letters served as a helpful way for me to reveal some details of myself to the recipient (Rodgers, 2009). Whilst I can appreciate that only a few people will know about the difficulties I encountered during my final year of training, letter 2 showed me the first hand importance of letting a client know you understand a situation that was difficult for them whilst also maintaining their privacy in case other people have access to the letter. I am now especially pleased that I have done this in previous therapeutic letters and that I did so within both of these therapeutic letters.

I wished both letters to be warm and empathic especially given the time and the consideration that the participants gave, and I certainly feel that this has been achieved. Letter 2 was my first experience of receiving a therapeutic letter and certainly my first experience of writing to myself! However, after reading it following completion of my thesis, I felt considered, understood and enthusiastic about my future, so I would say that it achieved its purpose. Whilst I understand that the difficulties in my participant's lives will not be erased with a letter, I would like them to feel considered and borne in mind and therefore I have chosen to send them a copy of letter 1 when I send them the summary of findings document.

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# Appendices

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## **Appendix 1- Guidelines for Authors**

Journal of Positive Psychology

Psychology, Health & Medicine

## Advice to authors on preparing a manuscript

**NB: Please follow any specific instructions for authors provided by the Editor of the journal**

**Font:** Times New Roman, 12 point. Use margins of at least 2.5 cm (1 inch).

**Title:** Use bold for your article title, with an initial capital letter for any proper nouns.

**Authors' names:** Give the names of all contributing authors on the title page exactly as you wish them to appear in the published article.

**Affiliations:** List the affiliation of each author (department, university, city, and country).

**Correspondence details:** Please provide an institutional email address for the corresponding author. Full postal details are also needed by the publisher, but will not necessarily be published.

**Anonymity for peer review:** Ensure your identity and that of your co-authors is not revealed in the text of your article or in your manuscript files when submitting the manuscript for review. Advice on anonymizing your manuscript is available here.

**Abstract:** Indicate the abstract paragraph with a heading or by reducing the font size. Advice on writing abstracts is available here.

**Keywords:** Please provide five or six keywords to help readers find your article. Advice on selecting suitable keywords is available here.

**Headings:** Please indicate the level of the section headings in your article:

First-level headings (e.g. Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.

Second-level headings should be in bold italics, with an initial capital letter for any proper nouns.

Third-level headings should be in italics, with an initial capital letter for any proper nouns.

Fourth-level headings should also be in italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

**Tables and figures:** Indicate in the text where the tables and figures should appear, for example by inserting [Table 1 near here]. The actual tables and figures should be supplied either at the end of the text or in a separate file as requested by the Editor. Ensure you have permission to use any figures you are reproducing from another source. Advice on artwork is available here.

**Running heads and received dates** are not required when submitting a manuscript for review.

If your article is accepted for publication, it will be copy-edited and typeset in the correct style for the journal.

If you have any queries, please contact us at [authorqueries@tandf.co.uk](mailto:authorqueries@tandf.co.uk), mentioning the full title of the journal you are interested in, or see our Author Services homepage.



## GUIDE FOR AUTHORS INTRODUCTION

Click [here](#) for guidelines on Special Issues.

*Social Science & Medicine* provides an international and interdisciplinary forum for the dissemination of social science research on health. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health and healthcare from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and the organization of healthcare. We encourage material which is of general interest to an international readership.

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The journal publishes the following types of contribution:

- 1) Peer-reviewed original research articles and critical analytical reviews in any area of social science research relevant to health and healthcare. These papers may be up to 8000 words including abstract, tables, and references as well as the main text. Papers below this limit are preferred.
- 2) Peer-reviewed short reports of findings on topical issues or published articles of between 2000 and 4000 words.
- 3) Submitted or invited commentaries and responses debating, and published alongside, selected articles.
- 4) Special Issues bringing together collections of papers on a particular theme, and usually guest edited.

## BEFORE YOU BEGIN

### *Ethics in Publishing*

For information on Ethics in Publishing and Ethical guidelines for journal publication see

<http://www.elsevier.com/publishingethics> and  
<http://www.elsevier.com/ethicalguidelines>.

### *Conflict of interest*

All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. See also <http://www.elsevier.com/conflictsofinterest>.

### *Submission declaration and verification*

Submission of an article implies that the work described has not been published previously (except in the form of a conference abstract or as part of a published lecture or thesis for an academic qualification), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder. To verify originality, your article may be checked by the originality detection software iThenticate. See also <http://www.elsevier.com/editors/plagdetect>

## **Appendix 2 - Ethical Clearance Documentation**

Coventry University Ethics

NHS Ethics

NHS Research and Development

**REGISTRY RESEARCH UNIT  
ETHICS REVIEW FEEDBACK FORM**  
(Review feedback should be completed within 10 working days)

**Name of applicant:** Marianne Durran **Faculty/School/Department:** HLS

**Research project title:** Health change behaviours of people whose spouses have had strokes

Comments by the reviewer

<b>1. Evaluation of the ethics of the proposal:</b>	<p>The protection of the informants seems to be in place, but as the central feature of the informant's life of interest to the study is the experience shared with a stroke patient partner, I would like to see an indication that the patient has also given informed consent to their partner discussing possibly painful experiences of his/her life, even only as the stimulus to which the informant's discussed response is made. The patient is not irrelevant here, even if he/she is never spoken to or seen by the researcher. He/she is very much a participant in the overall conduct of the study, perhaps more potently so in his/her absence. Indeed, contributions of the patient to the investigation could provide crucial insights once the data are collected. It is perhaps not helpful in adjusting to a possibly debilitating event to know one may be talked about officially without giving consent. Does he take sugar, and all that. The longer proposal form states why the patient's consent is not going to be sought, but I think under the circumstances, the patient may already feel marginalized in the informant's life in some aspects, while feeling uncomfortable about being central to it in others. Even an initialing or countersignature on the consent form would be respectful to the patient, if that is possible for him/her to do, spoken witnessed consent if writing is not possible.</p>
<b>2. Evaluation of the participant information sheet and consent form:</b>	<p><b>Principal</b> Researcher, not Principle Researcher, here and wherever else it is written. If anything goes wrong: cancelling an interview may not be the only thing that can go wrong in a potentially sensitive interview. There is information at the end for additional support, but it might well be signposted in the early part of the information sheet. On page 5 [and anywhere else these descriptions are given], the descriptions of the potential people need to be clarified - I copy here: "Husband / Wife / Common Law partner of a person who has had a stroke who consents to taking part in the research and to the potential publication of anonymised data arising from the said research." The referent for "who" after "stroke" is not clear - is this the one who has had the stroke, to whom the "who" refers, or is it the carer? The first "who" only has one clear referent, the second has two, and a comma might clarify, or rewording. "Can you tell me" questions are legitimately answerable by "yes" or "no". "What can you tell me" can't, although they could be difficult and say "nothing". Rewording these interview questions would be useful.</p>
<b>3. Recommendation:</b>	<p>(Please indicate as appropriate and advise on any conditions. If there any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).</p> <p><input type="checkbox"/> Approved - no conditions attached</p> <p><input checked="" type="checkbox"/> Approved with minor conditions (no need to resubmit) but please discuss the question of patient consent to be discussed with your supervisor. The questions aren't aimed at the patient, but he/she is not irrelevant in the discussion.</p> <p><input type="checkbox"/> Conditional upon the following – please use additional sheets if necessary (please re-submit application)</p> <p><input type="checkbox"/> Rejected for the following reason(s) – please use other side if necessary</p> <p><input checked="" type="checkbox"/> Further advice/notes - please use other side if necessary - just a small note. Be sure that apostrophes are used in possessive forms. It is only a small thing, but it can affect the credibility of a writer when trying to get important findings seen.</p>

**Name of reviewer:** Beverly Plester .....

**Signature:** BP via email .....

**Date:** 25 February 2010 .....

# NHS Ethical Approval Information



## National Research Ethics Service

### Birmingham, East, North and Solihull Research Ethics Committee

REC Offices  
Osprey House  
Albert Street  
Redditch  
B97 4DE

Telephone: 01527 587528  
Facsimile: 01527 587501

19 May 2010

Miss Marianne J Durran  
Trainee Clinical Psychologist  
Coventry and Warwickshire Partnership Trust  
Clinical Psychology Department  
St Michael's Hospital  
Warwick  
CV34 5QW

Dear Miss Durran

**Study Title:** An investigation of whether a spouse having a stroke affects whether the healthy spouse implements health behaviour changes in their own lives in an attempt to mediate the risk of key modifiable stroke risk factors.

**REC reference number:** 10/H1206/35

**Protocol number:** 2

The Research Ethics Committee reviewed the above application at the meeting held on 12 May 2010. Thank you for attending to discuss the study.

#### **Ethical opinion – Record of Ethical Issues Discussed**

##### **The time to consent does not appear to be very long.**

Clinicians will approach families and if they are interested their information will be passed on to the researcher. They will have a few days after expressing an interest to consider consenting to the study.

##### **Is it possible to pay travel expenses for participants?**

There is no funding available for this. It is hoped to co-ordinate the study appointment with a routine appointment so that there will be no additional visits.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority  
*The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England*

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**Other conditions specified by the REC**

- Information sheet – include a telephone number for PALS.
- Consent form – include a tick box for consent to audio-tape the interview.

**It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		26 March 2010
REC application		26 March 2010
Protocol	2	24 March 2010
Investigator CV		26 March 2010
Supervisor CV [REDACTED]		
Clinical Supervisor CV [REDACTED]		
SSI supervisor CV [REDACTED]		
Participant Information Sheet: Appendix 1	2	23 March 2010
Participant Information Sheet: Staff Information Sheet Appendix 3	2	23 March 2010
Evidence of insurance or indemnity		01 August 2009
Letter from Sponsor		24 March 2010
Participant Consent Form: Appendix 5	1	15 February 2010
Questionnaire: Initial questionnaire Appendix 2	1	15 February 2010
Participant opt in form	1	15 February 2010
Ineligibility letter Appendix 7	2	23 March 2010
Interview Schedules/Topic Guides	2	23 March 2010
Summary of changes since review by Coventry University Ethics		25 February 2010
Referees or other scientific critique report		25 February 2010
De-brief information sheet Appendix 10	1	15 February 2010
Waiting list letter Appendix 9	1	23 March 2010

Invitation to interview letter appendix 8	1	15 February 2010
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**Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

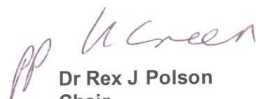
The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

10/H1206/35	Please quote this number on all correspondence
-------------	--

With the Committee's best wishes for the success of this project

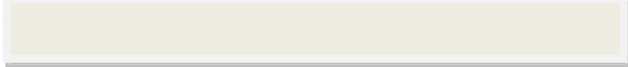
Yours sincerely



**Dr Rex J Polson**  
**Chair**  
Email: [Karen.Green@westmidlands.nhs.uk](mailto:Karen.Green@westmidlands.nhs.uk)

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

*"After ethical review – guidance for researchers"*

Copy to: 

**Birmingham, East, North and Solihull Research Ethics Committee**

**Attendance at Committee meeting on 12 May 2010**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr S George	Consultant Psychiatrist	Yes	
Mrs Lynne Gray	Senior Biomedical Scientist	No	
Mrs Rosemary Harris	Lay Member	Yes	
Mrs Theresa Hyde	Lay Member	Yes	
Mrs Irene Linder	Lay Member	Yes	
Ms Veronica Morgan	Midwife	Yes	
Dr Richard Mupanemunda	Consultant Paediatrician	Yes	
Dr David O'Brien	GP	Yes	
Dr Rex J Polson	Consultant Physician	Yes	
Dr Timothy Priest	Consultant in Anaesthesia & Pain Management	No	
Mr Rajeshwar Singh	Lay Member	Yes	
Mrs Margaret Sparrey	Lay Member	Yes	
Ms Gill Tomlinson	Head of Radiology, Solihull Hospital	Yes	

# Additional REC Clearance



National Research Ethics Service

## Birmingham, East, North and Solihull Research Ethics Committee

REC Offices  
Prospect House  
Fishing Line Road  
Enfield  
Redditch  
B97 6EW

Tel: 01527 582534  
Fax: 01527 582540

02 February 2011

Miss Marianne J Durran  
Trainee Clinical Psychologist  
Coventry and Warwickshire Partnership Trust  
Clinical Psychology Department  
St Michael's Hospital  
Warwick  
CV34 5QW

Dear Miss Durran

**Study title:** An investigation of whether a spouse having a stroke affects whether the healthy spouse implements health behaviour changes in their own lives in an attempt to mediate the risk of key modifiable stroke risk factors.

**REC reference:** 10/H1206/35

**Amendment number:** AM01

**Amendment date:** 21 December 2010

Thank you for your letter of 21 December 2010, notifying the Committee of the above amendment.

The amendment has been considered by the Chair.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

### Documents received

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment		21 December 2010

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and  
Research Ethics Committees in England



**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H1206/35:

Please quote this number on all correspondence

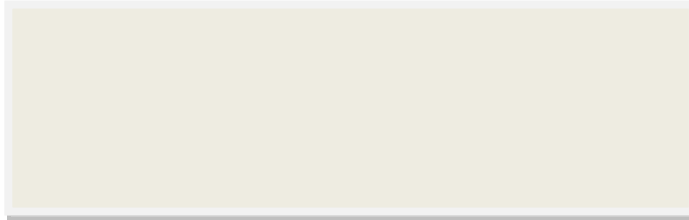
Yours sincerely



**Mrs Karen Green**  
**Committee Co-ordinator**

E-mail: [Karen.Green@westmidlands.nhs.uk](mailto:Karen.Green@westmidlands.nhs.uk)

Copy to:



# Research and Development Approval Information



University Hospitals  
Coventry and Warwickshire



NHS Trust

## Research & Development Department

R&D Services Manager: Ceri Jones - Tel: 024 7696 6196  
R&D Divisional Finance Manager: Chris Moore - Tel: 024 7696 6198  
Deputy Divisional Finance Manager: Reena Savani - Tel: 024 7696 6197  
Deputy Divisional Finance Manager: Elena Edwards - Tel: 024 7696 6069  
Assistant Research & Development Manager: Natasha Wileman - Tel: 02476 966197  
Research & Development Assistant: Isabella Petrie - Tel: 02476 966202  
Research & Development Assistant: Claire Bacon - Tel: 02476 964495  
Post Doctoral Research Grant Writer: Deborah Griggs - Tel: 02476 96 6195

University Hospital  
Clifford Bridge Road  
Walsgrave  
Coventry  
CV2 2DX

Tel: 024 7696 4000  
Fax: 024 7696 6056  
www.uhcw.nhs.uk

12<sup>th</sup> July 2010

Our Reference: MD072410  
MREC number: 10/H1206/35

Miss Marianne J Durran  
Trainee Clinical Psychologist  
Coventry Psychology Department  
St. Michael's Hospital  
Warwick CV34 5QW

Dear Marianne,

**Study Title:** **An Investigation of whether a spouse having a stroke affects whether the healthy spouse implements health behaviour changes in their own lives in an attempt to mediate the risk of key modifiable stroke risk factors**

Thank you for submitting the above study for consideration by the Research & Development Office, in line with new regulations governing R&D approval of local sites from 1<sup>st</sup> April 2009. I am pleased to inform you that the study has been approved and your research is covered by NHS indemnity as set out in HSG(96)48. For reference, the approval number is: MD072410 and it would be appreciated if you could quote the R&D reference in all future correspondence.

May I take this opportunity to remind you that, as a researcher, you must ensure that your research is conducted in a way that protects the dignity, rights, safety and well-being of participants. Trust R&D Approval assumes that you have read and understand the Research Governance Framework and accept that your responsibilities as a researcher are to comply with it, the Data Protection and Health & Safety Acts.

Your project may be subject to ad hoc audit by our department to ensure these standards are being met.

The Trust wishes you every success with your project.

Yours sincerely

**Ceri Jones**  
Research and Development Services Manager

CC



Chief Executive: Malcolm Stamp CBE      Chairman: Philip Townshend

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Missed appointments cost our hospitals nearly £4 million a year. Please help us reduce this by ensuring you attend yours or call 0800 252060 to change your date/time.

**Appendix 3 - Table 1.2.3.1 - Further Details of Reviewed Studies**

Order in Review	Authors	Design	N	Measures Used	Brief Procedure / Main Findings
1	Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, & Goodkin (1999)	Mixed Methods	Time 1: 50 F: 33 M: 17  Time 2: 94 F:70, M:24	Demographics, Physical Functioning Assessment, The Short Word List Delay (Beatty & Paul, 1995), The Controlled Oral Word Association Test, (Lezak, 1995), POMS, (McNair <i>et al.</i> , 1981), Ways of Coping Questionnaire, (Folkman & Lazarus, 1988)	<p><b>Time 1:</b> Sampled 50 people with open ended questions to gauge experiences of MS.</p> <p><b>Time 2:</b> Responses collated into 67 statements and a further 94 participants asked to rate statements on likert scales.</p> <p>First study of its kind to highlight psychosocial benefits in MS. Benefits reported at a rate of almost 3:1 compared to deficits.</p>
2	Pakenham (2007)	Qualitative.  (Data taken from mixed methods study)	404	Demographics. Cognition subscale of Mayo-Portland Adaptability Inventory (MPAI), (Malec & Thompson, 1994), Benefit Finding Scale (BFS), Mohr <i>et al.</i> , (1999).	Responses demonstrating 7 themes of PG including 2 already represented by BFS, 3 not reflected by BFS and 2 partially represented by BFS.

Order in Review	Authors	Design	N	Measures Used	Brief Procedure / Main Findings
3	Phillips & Stuifbergen (2008)	Longitudinal Study	433 (F: 362 M: 71)	Demographic and disease related information.  The Incapacity Status Scale (Kurtzke, 1981)  The Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977)  The Quality of Life Index (QLI) MS version (Ferrans & Powers, 1992).  The Positive Experiences Scale	Correlational Study. 7 <sup>th</sup> year of Longitudinal Study looking at quality of life in community dwelling people with MS.  Higher number of positive experiences associated with lower levels of depressive symptoms, fewer functional limitations and better quality of life.
4	Finlayson, Van Denend & Dalmonte (2005)	Qualitative	27 older adults with MS; 23 F, 4 M	Demographic Information  Quality of Life Interview (Ritvo <i>et al.</i> , 1997),  SF-36 Functioning Subscale (Stewart <i>et al.</i> , 1988)  The Medical outcomes study modified social support scale (Sherbourne & Stewart, 1991,)  The Mental Health Inventory (Veit & Ware 1983)	Examining positive and negative aspects of being an older adult with an MS diagnosis.  The positive aspects of MS included; social benefits, becoming a better helper, realising potential, strengthening family, and discovering resources.

Order in Review	Authors	Design	N	Measures Used	Brief Procedure / Main Findings
5	Mazur (2006)	Qualitative	50 (18 Adolescents, 15 Physically Disabled Parents, 7 Well Spouses, 10 Professionals)	World Health Organisation, 2001 Classification for Illness Severity.  Hendershot, Colpe & Hunt, (1999) classification for illness severity.  Parental Disability Events Profiles.  Demographic Information.	49, Telephone Interviews, 1 in person. Examining positive and negative experiences of: parenting with illness, being parented by an ill parent, spouse to an ill parent and professionals observing a family affected by illness.  Samples of meaningful positive and negatively appraised events that shape future research.
6	Barker-Collo, Cartwright & Read (2006).	Qualitative	16 (M:5, F:11) 8 in 5 Year Group, 8 in 15 Year Group	Demographics	Telephone Interviews. Examining narratives of the journey from feeling unwell, being diagnosed and beyond.  Both negative and positive consequences of diagnosis process and living with MS.
7	Reynolds & Prior	Qualitative	27 Females	Demographics	1: 1 Semi-Structured Interviews. Interpretive Phenomenological Analysis. Described various ways that women negotiated quality of life including positive consequences of MS.

## Appendix 4 – Participant Consent Form

**Coventry University**  
 Priory Street, Coventry CV1 5FB  
 Telephone 024 7688 8328  
 Fax 024 7688 8702

**Programme Director**  
**Doctorate Course in Clinical Psychology**  
 Dr Eve Knight  
 BSc Clin.Psy.D., CPsychol

Version 2 – 04/06/2010

THE UNIVERSITY OF  
**WARWICK**



### **B** Consent Form for Participants

**Title of project:** An investigation of partner's experience post stroke.

**Principal Researcher:**  
 Marianne Durran (Trainee Clinical Psychologist)

**Instructions:**  
 Please read the following points and tick each box to indicate that you agree, then please sign and date at the end of the form and return to the Principal Researcher.

- |   |                          |  |                          |
|---|--------------------------|--|--------------------------|
| 1. I confirm that I have read & understood the participant information sheet produced by Marianne Durran.   | <input type="checkbox"/> | 4. I understand that my comments will not be identifiable within any published findings, and that I can receive a copy of the findings.  | <input type="checkbox"/> |
| 2. I understand that should I require any further information I can contact Marianne Durran or her supervisor [REDACTED]  | <input type="checkbox"/> | 5. I understand that my participation is voluntary.  | <input type="checkbox"/> |
| 3. I understand that unless I disclose information which could lead to harm for myself or others, that any information I provide will be treated as confidential. | <input type="checkbox"/> | 6. I understand that I have the right to change my mind about participating in the study. In order to withdraw from the study I should quote my participant number within two weeks of the interview date. | <input type="checkbox"/> |

I consent to the audio recording and analysis of my interview:

**Please sign and date:**

Signature: \_\_\_\_\_

Print name: \_\_\_\_\_

Date: \_\_\_\_\_

Witness Signature: \_\_\_\_\_

Witness name: \_\_\_\_\_

Date: \_\_\_\_\_

Principal Researcher's Signature: \_\_\_\_\_

Participant Number: 43

**Dean of Faculty of Health and Life Sciences**

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Chair of Department of Psychology**

Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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## Appendix 5 – Staff Information Sheet

**Coventry University**  
 Priory Street, Coventry CV1 5FB  
 Telephone 024 7688 8328  
 Fax 024 7688 8702

**Programme Director**  
**Doctorate Course in Clinical Psychology**  
 Dr Eve Knight  
 BSc Clin.Psy.D. CPsychol

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### Staff Information Sheet

**Title of project: An investigation of partner's experience post stroke**

As part of my doctorate in Clinical Psychology at the University of Warwick and Coventry University, I am researching people's experiences following their partner's stroke. This research is supported and supervised [REDACTED] and with the approval of [REDACTED]. The study has been reviewed and approved by the Universities of Coventry and Warwickshire Ethics Committee, NHS Ethics Committees in Coventry and Warwick and for [REDACTED].

The aim of the study is to explore how people live their own lives after their partner has had a stroke. It is hoped that findings from the study will aid future practice; training and support of people who have strokes and those that care for them.

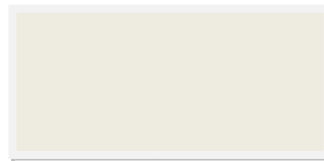
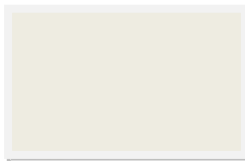
I am asking staff who work in services to help me identify people who may like to take part in the study. To try and make sure that I am able to talk to people who have had similar experiences, I have set certain criteria for those that are able to take part:

- Husband / Wife / Common Law partner of a person who had a stroke AND:
- Was living as a couple with their partner when their partner had a stroke.
- Consents to taking part in the research.
- Consents to the audio recording of any interview or portion of interview between themselves and the Principal Researcher.
- Consents to the potential publication of anonymised data arising from the said research.

If you feel that you know someone who may wish to take part, please pass a copy of the participant pack to them when you next see them.

Marianne Durran, Principal Researcher & Trainee Clinical Psychologist

Marianne Durran  
 Clinical Psychology Doctorate,  
 James Starley Building,  
 Coventry University,  
 CV1 5FB  
 Tel: (024) 76 888 328  
[durranm@uni.coventry.ac.uk](mailto:durranm@uni.coventry.ac.uk)



#### Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

#### Chair of Department of Psychology

Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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## Appendix 6 - Participant Study Information Letter

**Coventry University**  
 Priority Street, Coventry CV1 5FB  
 Telephone 024 7688 8328  
 Fax 024 7688 8702

**Programme Director**  
**Doctorate Course in Clinical Psychology**  
 Dr Eve Knight  
 BSc Clin.Psy.D. CPsychol

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### Participant Information Sheet

#### Title of project:

An investigation of partner's experience post stroke.

#### What is the Purpose of the study?

Supporting a partner who has had a stroke is a complex and demanding role and is probably one you had never expected or planned for. The purpose of this study is to find out more about you, the person who supports their partner after they have had a stroke. Your partner may still be in hospital / rehabilitation or they may be back at home with you, either way, we would like to meet with you so that we can hear more about what you have learnt as a result of the stroke, and what might have helped to make things easier for you.

#### Why have I been chosen?

You have been chosen because someone currently involved in the support of yourself and / or your partner has identified that you are in a relationship with someone who has had a stroke.

#### Do I have to take part?

No, you don't have to take part if you don't wish to. Participation is entirely voluntary. If you decide not to take part it will not affect the services you currently receive.

#### What will I have to do if I take part?

If you agree to take part in the study you will be invited to meet with the **Principal Researcher** to take part in what is known as a research interview. It is hoped that you will find this interview to be a warm and friendly experience. It is not intended to assess or test you in any way, we just want to find out more about you and how you have lived your life, before the stroke, and after the stroke, and how you see yourself living your life in future.

#### Where will it take place?

It is expected that the interviews will take place at the hospital base where you currently receive support. It is likely that this will be either [redacted] or [redacted]. These bases have been chosen because it can often be easier to talk about your experiences when you are not at home. If for any reason you would be unable to travel to the site nearest to you, it is possible that the Principal Researcher would be able to meet you in a place which is more convenient. If this affects you, please let us know when you send your consent form and preliminary questionnaire back to us.

#### How long will it last?

It is expected that each interview will last approximately forty five minutes to an hour although this will depend on how much you wish to talk about. The interview will be between Marianne Durran, Principal Researcher / Trainee Clinical Psychologist and you; no one else will be present.

#### Will what I say be confidential?

The interview will be audio taped, however all information will be treated as confidential (i.e. not passed to any other person or party,) and you will not be identifiable in any published findings. However, if any risks of harm to you or another person are highlighted, then it is likely that this information would have to be

Continued.....

**Dean of Faculty of Health and Life Sciences**  
 Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priority Street Coventry CV1 5FB Tel 024 7679 5805

**Chair of Department of Psychology**  
 Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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shared although this would be discussed with you at the time of the disclosure. You will not be identifiable in any published findings and your recording will be deleted as soon as Marianne has listened to the interview again and typed up what you have both said. Before the interview commences you will be asked to sign a consent form which advises that you are happy to take part and to being interviewed, the interview audio taped, and to the audio tape being used for analysis. The only people to listen to the recordings will be immediate members of the research team and the Principal Researcher who will conduct the interview with you. Signing the consent form also confirms that you are aware that you can change your mind about taking part in the research at any point up to two weeks after the interview.

#### **What will I be asked?**

It is difficult to tell you in advance exactly what the questions will be because they are going to be asked within a 1:1 interview which will be slightly different for each participant because the Principal Researcher will respond to what each participant says and tailor the interview accordingly. However, they will focus on your knowledge and experience since the time of your partner's stroke.

#### **Who will know if I decide to take part?**

The staff who gave you this information sheet would know about the study but they would not know that you had chosen to take part in the study unless you chose to tell them. If you wished to tell your partner about your participation in the study you would be free to do so, although you do not have to. Any information you gave would remain anonymous and confidential, therefore you would not be identifiable in any of the findings, nor will any feedback about the interview process or interviewees be provided to services you use. In line with all NHS professionals and research, the only time that this would be breached would be if during the course of the interview you disclosed that you intended to cause harm to yourself or others.

#### **What if something goes wrong?**

If an interview has to be cancelled Marianne will attempt to contact you on the telephone number you have provided. If you feel that any other support would be beneficial, Marianne can discuss possible services where you may be able to seek this assistance. All people taking part in the interviews will be given an information sheet which identifies support groups.

#### **What are the potential disadvantages of taking part?**

Given that this might be a hard topic to talk about, it is understandable that it could feel difficult at times. However, it is hoped that taking part in the research will be an experience which participants find to be compassionate, warm and empathic. It is hoped that you will find that the Principal Researcher treats you respectfully and with understanding at all times.

Taking part in a research interview may require travel to hospital; unfortunately, any costs incurred as a result of this cannot be reimbursed by the research team.

#### **What are the advantages of taking part?**

You may find that you enjoy talking about your experiences. Any subsequent findings could help shape future research into stroke care and the services offered to the family of people who have had strokes.

#### **What if I agree to take part and later change my mind?**

You can withdraw from the study at any time by contacting one of the researchers on the numbers below. You will not have to give any reasons for this and deciding to do so will not affect the NHS services that you or your partner already receive. If you take part, you will be given a participant information number. Please make a note this and if you wish to withdraw your data, simply contact the research team, let them know, and quote your participant number within two weeks of completing your interview. If you decide to withdraw, all of your data will be destroyed and will not be used in the study.

#### **Ethical approval and confidentiality**

This study has been approved by NHS research committees, and Coventry and Warwick Universities. All information collected through the study will be treated as confidential and anonymous. It will not be possible for anyone other than yourself and the Principal Researcher to identify you from the completed research, although you may of course remember some of the comments that you made so you could recognise yourself that way. A copy of the final research report will be made available on its completion in September 2011. All participants will be able to receive a summary of the results if requested. The recordings of the

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interview will be destroyed once typed. The typed documents of the interview will be retained and stored securely by Coventry University for a period of 5 years, your name will not appear on this data. After this time it will be destroyed as confidential waste.

#### Who is organising and funding the research?

The Principal Researcher is Marianne Durran, who is undertaking a Doctorate in Clinical Psychology at The University of Warwick and Coventry University. Marianne is employed by the NHS by Coventry and Warwickshire partnership trust. She is supervised by [REDACTED]

[REDACTED] The research is not externally funded.

#### Who has reviewed the study?

The research proposal has been approved by Coventry University. It has also been granted ethical approval by Coventry University, the NHS research ethics panel and Research and Development Networks for Coventry and Warwickshire.

#### What will happen to the findings?

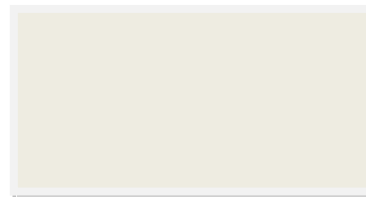
The results will be written up and presented as part of the qualification for a Doctorate in Clinical Psychology. It is anticipated that the anonymous findings may also be written up for publication in an academic journal.

#### What do I do now?

If you would like to take part in the study you will need to read the information, complete and return; the initial questionnaire, (A) the consent form, (B) and the Participant opt in form (C). You will then be contacted by Marianne Durran in order to arrange a time and date for interview. It is hoped that the Interview will be held at the NHS hospital where you or your partner usually receive your support. If you do not wish to take part you do not need to do anything and you will not be contacted by us again.

#### Contact for further information:

Marianne Durran (Trainee Clinical Psychologist)  
Clinical Psychology Doctorate,  
James Starley Building,  
Coventry University,  
CV1 5FB  
Tel: (024) 76 888 328  
[durranm@uni.coventry.ac.uk](mailto:durranm@uni.coventry.ac.uk)



It may not be possible for us to take your call immediately but please give details of how we may contact you and we will return your call as soon as possible.

Many thanks in advance,

Marianne Durran  
Trainee Clinical Psychologist and Principal Researcher

## Appendix 7 – Initial Questionnaire for Participants

**Coventry University**  
 Priory Street, Coventry CV1 5FB  
 Telephone 024 7688 8328  
 Fax 024 7688 8702

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**Programme Director**  
**Doctorate Course in Clinical Psychology**  
 Dr Eve Knight  
 BSc Clin.Psy.D. CPsychol

### A Initial Questionnaire for Participants

**Title of project:** An investigation of partner's experience post stroke.

**Principal Researcher:**  
 Marianne Durran (Trainee Clinical Psychologist)

**Instructions:** Please read the following points and tick each box to indicate that this describes you, and to indicate what your relationship is to your partner. Then please sign and date below and return to the Principal Researcher in the pre-paid envelope with your completed opt-in form and consent form.

- |  |   |
|--|---|
| <p>1. My husband, wife, common law partner had a stroke. <input type="checkbox"/></p> <p>2. I was living with my partner at the time that they had their stroke. <input type="checkbox"/></p> <p>3. I have never had a stroke myself. <input type="checkbox"/></p> | <p>4. <i>(Tick relevant answer)</i><br/>                 I am: Male..... <input type="checkbox"/><br/>                 Female... <input type="checkbox"/></p> <p>5. <i>(Tick relevant answer)</i><br/>                 My relationship to my partner who had a stroke is that I am their:<br/>                 Husband..... <input type="checkbox"/><br/>                 Wife..... <input type="checkbox"/><br/>                 Common Law.. <input type="checkbox"/><br/>                 Partner <input type="checkbox"/></p> |
|--|---|

**Please use this space to include any other information which you feel is relevant:**

---



---



---



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**Please sign and date:**

Signature: \_\_\_\_\_  
 Print name: \_\_\_\_\_  
 Date: \_\_\_\_\_

43

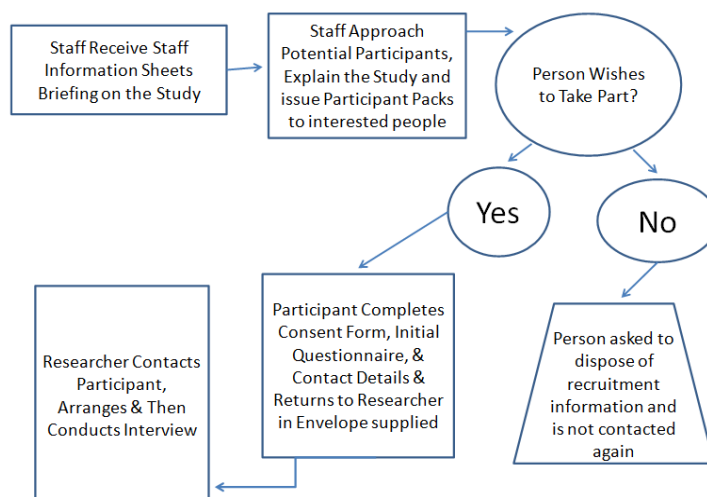
**Dean of Faculty of Health and Life Sciences**  
 Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Chair of Department of Psychology**  
 Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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## Appendix 8

Figure 2.2.1: Recruitment Procedure Flow Diagram



## Appendix 9 - Demographic Details Opt-in Form

**Coventry University**  
 Priory Street, Coventry CV1 5FB  
 Telephone 024 7688 8328  
 Fax 024 7688 8702

**Programme Director**  
**Doctorate Course in Clinical Psychology**  
 Dr Eve Knight  
 BSc Clin.Psy.D. CPsychol

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### **C** Participant Opt in Form

Yes, I have read the participant information sheet and I would like to take part in the study investigating my experience of my partner's stroke.

- I have listed my contact details below.
- I consent to the Principal Researcher contacting me to organise an interview using these details
- I enclose my completed 'Initial Questionnaire for Participants' A
- I also enclose my signed consent form B
- I have made a note of my participant number for my own reference. Ref: 43

Now please send completed documents, A, B, & C back to the researcher using the pre-paid envelope which should have been enclosed with your information pack. If you require a pre-paid envelope please contact the researcher using the details below.

#### Contact details:

Name: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

Address: \_\_\_\_\_

e-mail: \_\_\_\_\_

#### Please sign and date:

Signature: \_\_\_\_\_

Print name: \_\_\_\_\_

Date: \_\_\_\_\_

Marianne Durran  
 Trainee Clinical Psychologist  
 Clinical Psychology Doctorate  
 James Starley Building  
 CV1 5FB  
**Tel: (024) 76 888 328**  
[durranm@uni.coventry.ac.uk](mailto:durranm@uni.coventry.ac.uk)

#### Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

#### Chair of Department of Psychology

Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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## Appendix 10 - Semi-Structured Interview Schedule

**Coventry University**  
 Priory Street, Coventry CV1 5FB  
 Telephone 024 7688 8328  
 Fax 024 7688 8702

**Programme Director**  
**Doctorate Course in Clinical Psychology**  
 Dr Eve Knight  
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Date: ..... Length of Time in  
 Name:..... Relationship:.....  
 Age:..... Gender:..... When partner had 1<sup>st</sup> stroke:.....  
 Spouse Age:..... Gender:..... Partner's level of ability:.....

- 1) Can you tell me about what your knowledge or experience of stroke was before your partner had their stroke?  
**Prompt: For example did you know anyone who had previously had a stroke?**
- 2) Can you tell me about how serious you think your partner's stroke was for them?
- 3) Can you tell me about how observing the affects of stroke on your partner has / or does influence your own behaviour?

**There are two types of risk factors for illness, modifiable and non-modifiable.**

**Modifiable risk factors are changes that we can make in our own lives to make it less likely that we will become ill. Non-Modifiable risk factors would be age for example.**

- 4) Could you tell me about the benefits to you if you were to make health / did make changes to your own lifestyle?
- 5) Could you tell me about the disadvantages if you were to make health changes in your life?

**Risk Factors: Diet, exercise, smoking, alcohol, blood pressure, cholesterol**

**Prompt: Health Warning Signs. Prompt: What did you make of them?**

- 6) Motivation? Future?
- 7) What were you told at the time? What might have been helpful?
- 8) That is all of the formal questions I have for you today, but I wonder whether you feel that there is anything else that you would like to say?

**Copy of Findings Required? YES NO address?**

**Dean of Faculty of Health and Life Sciences**

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

**Chair of Department of Psychology**

Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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## Appendix 11 – De-Brief Sheet

**We have spoken about a number of lifestyle factors today which can affect stroke risk. You might find it helpful to talk to your GP about what changes you could make which might benefit your health. We have also spoken about a number of issues which may have felt difficult to discuss. If you feel that it would be helpful to speak further to someone about these issues you can find support in a number of places**

Patient Advice and Liaison Service (PALS) offer advice about the NHS and can help you with any other health related enquiry. They can help to resolve complaints or concerns which you have which may be related to the NHS. They can also and signpost you to other support groups and agencies outside the NHS. [www.pals.nhs.uk](http://www.pals.nhs.uk) Warwickshire PALS: 0845 423 8903. UHCW PALS: 0800 028 4203.

- Coventry Carers Centre offer support over the phone, via email or in person. Telephone: 024 7663 2972 Email: [contactus@coventrycarers.org.uk](mailto:contactus@coventrycarers.org.uk) Drop in: (Mon, Wed, Thurs, & Fri 9:30am – 4pm). City Arcade, Coventry, CV1 3HX.
- The Samaritans provide confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair. Whatever you're going through, whether it's big or small, don't bottle it up. If you're worried about something, feel upset or confused, or just want to talk call 08457 90 90 90.
- Re-Think, a national charity offer practical advice and support for people affected by mental illness. You can contact them by telephone on: 0845 456 0455.
- If you think that it might be helpful to speak to a counsellor you could speak to your GP to ask about being referred to a counselling service.
- Alternatively, if you have any further questions about the research that you have taken part in please telephone the research team on either (02476) 887 806 or (02476) 785 66.

**The Stroke association have a number of affiliated stroke clubs which run in The West Midlands area. For more information on The Stroke Association stroke clubs and support groups contact their Helpline on 0845 3033 100 or email [info@stroke.org.uk](mailto:info@stroke.org.uk)**

<p><b>Coleshill Stroke Club</b> Meets on Thursdays from 10am-3.30pm at the Community Centre, Hudson Avenue.</p>	<p>Meets every Thursday from 12pm-2pm at Quinborne Community Centre, 80 Ridgacre Road.</p>	<p>Herbert Street, Wolverhampton</p>
<p><b>Dudley Stroke Association</b> Meets on the second Tuesday of each month from 7pm-10pm at Dudley Employees Social Club, High Ercal Avenue, Brierley Hill.</p>	<p><b>Solihull Stroke Club</b> Meets on <b>Mondays</b> from 10am-2pm at <b>Whar Hall Community Centre</b>, Whar Hall Road. Offering games, exercises &amp; outings. Meets on <b>Wednesdays</b> from 10am - 2pm at the <b>United Reformed Church Hall</b>, Faulkner Road.</p>	<p><b>Sutton Coldfield Stroke Club</b> Meets on the second and fourth Wednesday of the month from 10.30am-3.15pm at the United Reformed Church, Brassington Avenue. Activities include games, outings, crafts, cooking and speakers.</p>
<p><b>Northfield Stroke Club</b> Meets Wednesdays from 10am - 12pm at 81 Church Road, Northfield.</p>	<p><b>Stourbridge Stroke Club</b> Meets on the second and fourth Friday of the month from 12pm-3pm at New Road Methodist Church Hall.</p>	<p><b>Womborne Stroke Club (Wolverhampton)</b> Meets on Fridays 2pm-4pm at the Hand in Hand Centre, Church Road. Painting, games &amp; social chat.</p>
<p><b>Northfield Stroke Group</b> Meets on Wednesday 10am-12pm at Pocklington Place, Chatham Road.</p>	<p><b>Stroke Support West Midlands (Wolverhampton)</b> Meets on Saturdays from 11am-1pm at The Maltings,</p>	
<p><b>Quinborne Stroke Club (Quinton)</b></p>		

## **Appendix 12 - Further Information on Grounded Theory**

The term 'Grounded Theory' was described by Strauss and Corbin (1990) as "one that is derived from the phenomenon it represents. That is, it is discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon." This means that it allows data collection and analyses to be conducted together in order to develop a model or theory from the data; therefore it is considered of beneficial use in areas of new or scarce research (Charmaz, 2006; Glaser, 1967). Given that one of the main aims of this research is to generate a theory or model about what carers know, and do about risk factors for stroke, the limited research in this area makes grounded theory a valid methodology to use within this research. Grounded theory allows the generation of categories which are 'grounded' in the data.

The constant comparative method is a method for analysing data in order to develop a grounded theory. Glaser and Strauss (1967) suggest that when used to generate theory, the comparative analytical method they describe can be applied to social units of any size. As Glaser and Strauss (1967, pp. 28-52) describe it, this process involves:

- Identifying a phenomenon, object, event or setting of interest. (Partners of stroke survivors).
- Identifying a few local concepts, principles, structural or process features of the experience or phenomenon of interest. (The impact on own health within this population).
- Making decisions regarding initial collection of data based one's initial understanding of the phenomenon. Further data collection cannot be planned in advance of analysis and the emergence of theory. (Initially Sampling through 2 stroke clinics and latterly through a community team, consideration that a non-NHS setting may have led to younger participants).
- Engaging in theoretical sampling (attempting to recruit male participants and successfully recruiting 3 participants of working age).



When using Charmaz' method for grounded theory the data is broken down at 3 different stages of coding:

- Initial coding is detailed coding of data line by line or phase by phase.
- Focused coding works around the initial coding to find over-arching concepts, it also discards some of the earlier coding.
- Theoretical coding is where core categories are selected and related to other categories until the list of emerging categories is exhausted and a coherent picture is gained of how the coding represents what the participants have said.

Categories are refined and arranged in relation to each other so that a theory or schematic representation of the data can be produced. Throughout all stages of data collection and analysis, notes and 'memo's'<sup>22</sup>, (Charmaz, 2006, p72 - 95), are made concerning important issues or possible relationships between categories. These notes are incorporated into the emerging theory and once the analysis is complete the findings are compared to previous literature and discussed in terms of the initial research questions / aims.

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<sup>22</sup> For examples of memo writing please see Appendix 15.

**Appendix 13 - Portion of a Transcript and Examples of Coding<sup>23</sup>**

**Original Grounded Theory Analysis utilised Atlas Ti**

**'Helen<sup>24</sup>'**

<p>and there was that stroke campaign on the television which is actually very good but it's misleading because urm, you know Andrew took it to heart and it didn't explain that you don't always get all the symptoms but as regards risk factors I know it's sort of hereditary and it's to do with high blood pressure and it's diet and alcohol and those other things so I felt I was fairly well informed. Yeah</p>	<p><b>Knowing about Stroke / TV</b></p> <p><b>Knowing Risk Factors</b></p>
<p>Ok, and how did you come to understand or make sense of why Andrew had his stroke</p>	
<p>Actually that was the hardest thing because when we went to the hospital he didn't have any of the risk factors, he didn't have a high cholesterol count, although his blood pressure was elevated it wasn't to the point where you would have thought he was a candidate for stroke, he wasn't overweight, he walks the dogs every day and so he gets at least an hour of sort of brisk sort of</p>	<p><b>Knowing Risk Factors</b></p> <p><b>Examples of Risk Factors</b></p> <p><b>Not seeing partner as candidate for stroke – internal locus of control</b></p>

<sup>23</sup> For ease of comprehension within this thesis document this has been shown in a table format. However, original coding and analysis was performed using Atlas Ti.

<sup>24</sup> All names used are pseudonyms.

exercise every day, doesn't smoke, so you know, we looked at all the risk factors and yes he did drink but not to the point that he was in the red zone of sort of risking his health and the only thing was the sort of hereditary factor and of course that's the one you can't control and the other thing that as I mentioned before we started the interview was the stress that we were under. So it was only really the stress and the hereditary factors

Can you tell me a little bit more about the stress?

Oh my lord! Yes, we'd decided to have some extension work done because of my medical condition and we employed a builder who turned out to be the builder from hell. He'd start one job and then stop it, we had holes in walls, we had that horrendously cold weather, work he was doing wasn't satisfactory, he was leaving, coming at 8 in the morning, leaving at ten and not coming back, Christmas was looming, we had no kitchen, we were living in just this one tiny living room and it went, it was supposed to take 8 weeks and we were 16 weeks into and we were still nowhere near completion, they'd put the foundations in wrong, it was just a nightmare and you know you cope with it for so long but as the weeks went into months and there was no progress and we were looking at sort of having to take legal action, the stress was just horrendous and we had sort of no family here it was just Andrew and I and the children sort of

**Knowing Risk Factors**

**Identifying stress and hereditary as risk factor**

**Describing stress prior to stroke**

trying to sort it out and so yeah, the stress was really bad.

Ok, so it sounds like the stress and the blood pressure were possible

Yes, but as I say, the blood pressure wasn't particularly elevated you expect it to be 180, 190 Andrew's was 160 so and the, the, the diastolic was 90, 95 well that's not really what you consider a risk factor, okay you like it lower but you wouldn't expect that on its own.

You mentioned family history, tell me a little bit more about that

Well, Andrew's mum who is now deceased she had quite a lot of TIA's, transient ischemic attacks and had 2 strokes, she made very good recoveries but then Andrew also mentioned that she had seven brothers and all except one died of heart attacks so although um, one would argue a heart attack isn't the same as a stroke, actually the mechanism is the same it's a blood clot and when we mentioned it at the hospital they said it was the fact that on his mother's side there was this strong history, yeah,

Yeah, you sort of hit the nail on the head really, there's the modifiable risk factors for stroke and the non modifiable, so non modifiable would be age, gender, family history those kinds of

**Knowing stroke risk factor, BP**

**Not seeing partner as likely to have a stroke**

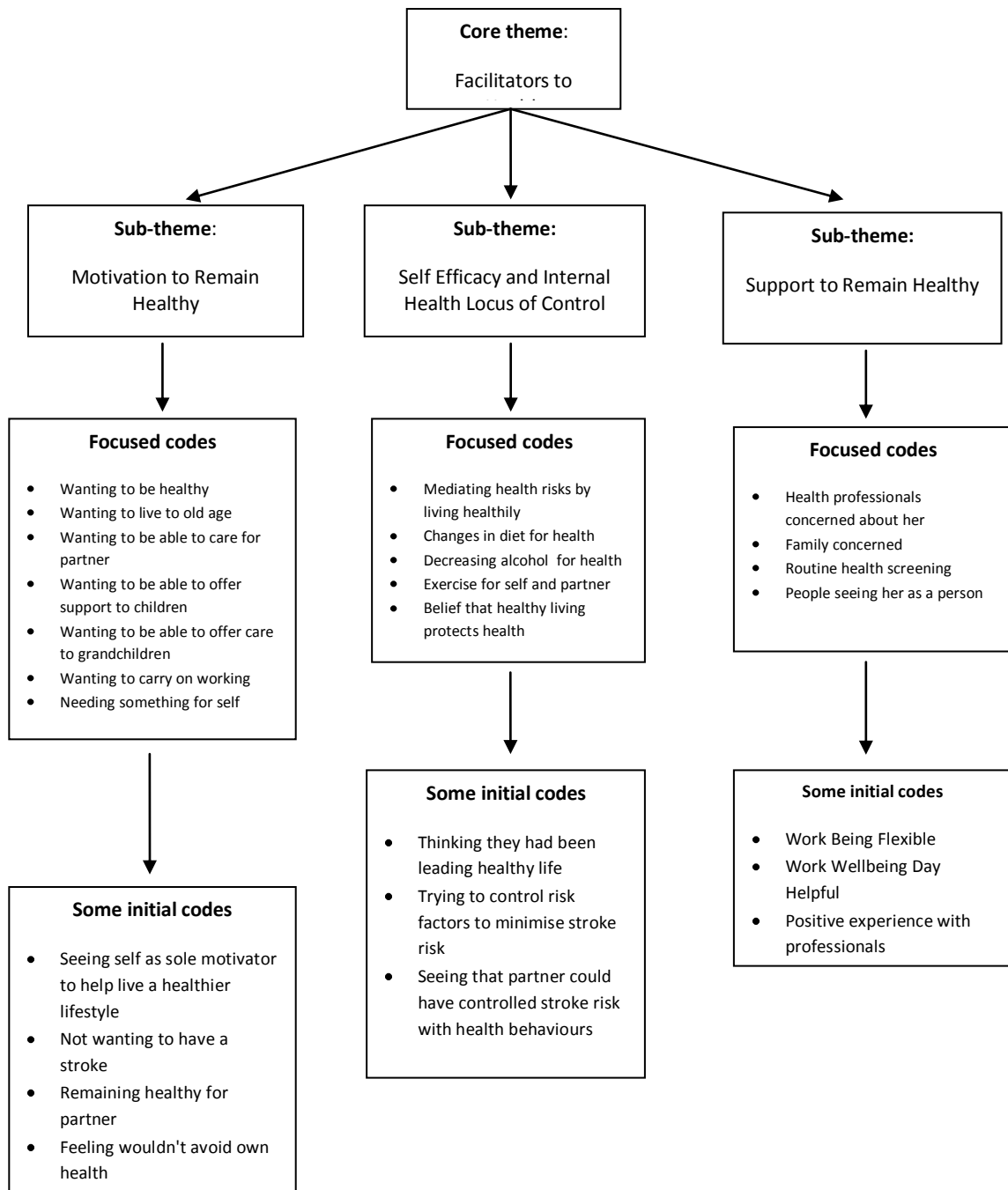
**Family History**

<p>things and as you'd mentioned yourself the modifiable would be cholesterol, blood pressure,</p> <p>Diet, alcohol, exercise, stress, so yeah..... I thought we were leading a fairly reasonably healthy life, we don't eat a lot of red meat, I drain as much fat as possible, salt doesn't exist in this house apart from to put on the ice and the snow (laughs) we eat chicken, fish, we don't eat fried food, you know we eat lots of fruit and vegetables so you know, as far as I was concerned we eat a healthy diet.</p> <p>So how's that impacted on your ability to make sense of your own health?</p> <p>Urm, well, you become a bit fatalistic particularly as I've got an auto immune disease, you accept that you try to live a healthy life but if it's genetic there's actually not a lot that you can do about it, I mean my own disease came on really, really suddenly, I had a flu jab and I fully accept that immunisations don't cause all the illnesses that people claim and my dissertation for my degree was on MMR and I proved without a shadow of diet that Wakefield was talking nonsense and I firmly believe in Imms but I also accept that it can trigger the immune system into overdrive which is what happened to me, so I think if it's genetic you can control all the factors that can increase the risk but to an extent</p>	<p><b>Examples of risk factors</b></p> <p><b>Internal health Locus</b></p> <p><b>Diet (Knowing Risk)</b></p> <p><b>External Health Locus</b></p> <p><b>Pre-existing health Problem</b></p> <p><b>Own Health</b></p> <p><b>Own health</b></p> <p><b>External locus</b></p>
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## Appendix 14 - Example of complete analysis for one theme

A theme from the final analysis broken down into sub-themes, theoretical codes and focused codes. Some initial coding is also included.



## **Appendix 15 - Examples of memo's arising in analysis process**

**Event: I asked her about her own health and she replied with details about her partner's health.**

**Memo:** Perhaps she didn't hear me properly? But I think that she did, she seems to have heard everything else that I have said accurately and responded accordingly so something else must have gone on when I asked this question. Perhaps it is too painful to focus on her own health? Perhaps she is so used to focusing on her husband's health since his stroke that she is not used to being asked about herself by a health professional. Perhaps the pain of not being able to focus on herself anymore is too much to bear and therefore a defence to cope with this pain is to discuss her husband. Perhaps she misunderstood the nature of the interview and that in fact when I asked about her own health she assumed that I was referring to her husband's health. Dynamically, this could have been an unconscious desire not to focus on herself or it could have simply been a misunderstanding regarding the nature and purpose of the interview. I must listen out for any future references for this within subsequent interviews and be aware of it within the analysis of the remainder of this and other interviews.

How could this be used as part of a core category? Does it demonstrate that in order to cope that women put other people's needs before their own or perhaps that they cope because they put other people's needs before their own?



### **Event: Use of Humour in Interviews**

**Memo:** Many of the participants appear to laugh quite frequently. Perhaps they are just fun loving, laugh easy women. However, of late they have been through difficult experiences and perhaps this is worth further investigation. Perhaps the laughter and finding humour in a situation has come about as a coping mechanism for dealing with these challenging times. Adopting humour as a coping strategy is free! It is portable and comes with you wherever you go. There would be distinct advantages to this. However, perhaps this use of humour is used as a defence to mask painful feelings of loss, guilt and anger at how their life has turned out and how they now have been put into a role that they did not choose. It does not seem appropriate to explore the use of humour with participants as a method for coping, especially if they have nothing to replace it with and it serves them well.

**Event: Anger from participant**

**Memo:** One of the participants seems to be angrier about her situation than the others. It is likely that this is because her husband was the most seriously affected by the stroke and as such her life is also more affected. However, it seems that she sees health behaviours as mediating health risk (an internal health locus of control perhaps?) and it seems that much of the anger seems to be evident when she discusses her husband having had a heart attack a number of years before the stroke and that her husband had not heeded this warning. It seems that perhaps empathy is more difficult to achieve if health professionals, family and even your partner have warned about unhealthy lifestyle and it has not affected life choices / health behaviours. I don't feel that there will be room within the model to address anger as there is no clear evidence to suggest that it was used as a coping strategy or to help her to focus on herself. Therefore I will not pursue anger as a theme or intentionally set out to delve deeper into participant's anger if it crops up again. I am aware that I do not want participants to feel worse when they have met me than they did before.

**Event: Health professionals helping / not helping**

**Memo:** It was difficult at times within the interviews when participants made reference to help from health professionals being lacking. I wanted more for the participants and their partners so as a health professional this was difficult to hear. One participant specifically said that the services of a clinical neuropsychologist would have been helpful which difficult as this is an area I have received some training in. She felt that this would have helped her husband considerably and perhaps taught him new ways of coping. Perhaps this service may have led her to feel that she had done all she could and also help her to cope too?

**Event:** Pre-Existing Health Problems

**Memo:** Some participants have so far disclosed pre-existing health problems for themselves. This may have caused them to reflect on their own health change behaviours prior to their husband having a stroke and prior to the interview with me taking place. However, I did not specifically ask people whether they had any pre-existing condition themselves and so of course this number could in fact be higher. If I am able to recruit further participants and they disclose a health history of their own I could investigate how this impacted on their own health choices and helped or hindered them at the time of their partner's stroke and subsequent rehabilitation.