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Coping and psychological well-being in  
informal carers of stroke survivors with aphasia

by

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## **Abstract**

This dissertation considers coping and psychological well-being in informal carers of stroke survivors with aphasia. Firstly, a literature review examines the main problems reported by this group of carers, the coping strategies they use to manage these problems, and the links between coping and psychological well-being. This is followed by an empirical paper which reports on a study investigating how informal carers of stroke survivors with aphasia cope with communication problems, and examining the links between coping and an aspect of psychological well-being - depressive symptoms. Further, this study also explores the question of how best to measure how carers cope with communication problems, by including questions specifically developed for this topic alongside a traditional coping inventory. As expected, the results demonstrated a relationship between coping strategies and depressive symptoms in this group of carers. The use of avoidant coping strategies was associated with increased symptoms of depression. No links were found between problem-focused coping strategies and depressive symptoms, however it was shown that coping by 'positive reframing' was linked with reduced levels of depressive symptoms. The study also found that a traditional style coping inventory gives a useful assessment of the pertinent coping strategies used by informal carers of stroke survivors with aphasia to manage communication problems. However this is usefully supplemented by more specific questioning about the use of avoidance and withdrawal. The study concludes with a discussion of the clinical implications of the results and where future research in this area would be beneficially directed.

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**Informal carers of stroke survivors with aphasia:  
A review of stressors and coping**

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(Appendix I)

## Abstract

**Background.** Research suggests that the burden of care for informal carers of stroke survivors with aphasia is higher than that for carers of stroke survivors in general. Models of the stress process in carers suggest that when considering carers' well-being it is important not only to take into account the problems they face, but also to look at coping. A previous review of problems for carers of stroke survivors with aphasia was criticised for not giving weight to the findings of better designed studies. The present review aims to overcome these limitations, as well as to incorporate recent findings and include a focus on coping.

**Aim.** To critically evaluate research on the problems faced by informal carers of stroke survivors with aphasia, how they cope with these, and links between coping and well-being.

**Main contribution.** 18 studies were reviewed, spanning both qualitative and quantitative methodologies. Most studies employed a cross-sectional design. Many of the quantitative studies were limited by small sample sizes, recruitment biases or by use of untested measures. The findings of qualitative and quantitative studies were considered together, with weighting given to the better designed studies. It was identified that the main areas of difficulty are: restricted social and leisure activities, role changes, communication difficulties with the stroke survivor, employment/financial problems, physical and emotional health problems, and family problems. Little research

was found on coping. Qualitative studies report that carers use a wide variety of problem-focused coping strategies tailored to the specific stressors that they face, and a smaller range of emotion-focused coping strategies. Quantitative research suggests that coping by venting emotions or by focusing overly on caring duties was detrimental to carers' psychological well-being.

**Conclusions.** This review builds on previous work, and suggests that informal carers of stroke survivors with aphasia experience problems specific to aphasia but are also disproportionately affected by other problems such as role changes and restricted social and leisure activities. Many questions regarding coping in this group of carers remain unanswered. Future research should look at coping in relation to specific stressors in order to provide more clinically relevant information. Consideration needs to be given to how best to assess coping in this group of carers as generic coping inventories may miss coping strategies that are specific to the situations and stressors of this group of carers.

## **Introduction**

### **Stroke and aphasia**

Every year in the UK, an estimated 150,000 people suffer a stroke (Stroke Association, 2008). Research suggests that around a third of stroke survivors are aphasic in the first few weeks after stroke (Bakheit, Shaw, Carrington, & Griffiths, 2007; Wade, Hewer, David, & Enderby, 1986). Aphasia is a communication disorder caused by damage to the brain, in which a person becomes impaired in their ability to use and/or understand language. As well as affecting spoken language, aphasia can also affect reading, writing, and the use and understanding of gesture. This means that everyday tasks such as making a telephone call, reading the paper, or watching television can become a source of frustration and anxiety. As communication is a fundamental aspect of human nature, the consequences of aphasia are far reaching. Taylor-Sarno (1993) writes that “The deep and unexpected changes associated with aphasia initiate a series of reactions that impact on every aspect of the individual”.

In many cases aphasia resolves in the first few months after the stroke, however around 12% of stroke survivors are left with significant aphasia at six months (Wade, Hewer, et al., 1986) and indeed research suggests that after 18 months the figures are similar (Laska, Hellblom, Murray, Kahan, & Von Arbin, 2001). In other words, for over a third of stroke survivors who have aphasia in the acute phase post-stroke, it persists long-term

and is likely to be considered a permanent impairment. It is estimated that there are 250,000 people living with aphasia in the UK (Connect, 2008), with stroke being the leading cause. Of course aphasia is not the only impairment that can follow a stroke. About half of all stroke survivors have some form of severe physical or cognitive disability for which they require support (Mant, Wade, & Winner, 2004). Emotional problems are also common among stroke survivors, with the prevalence of depression being estimated to be 30% (Hackett, Yapa, Parag, & Anderson, 2005), and possibly higher amongst stroke survivors with aphasia (Kauhanen et al., 2000). Physical, cognitive, emotional and social challenges may combine with communication problems and impact upon virtually all aspects of life for stroke survivors and their families (Alaszewski, Alaszewski, Potter, Penhale, & Billings, 2003).

### **Informal carers**

Support for stroke survivors is often provided by close family members such as spouses or adult children (Anderson, Linto, & Stewart-Wynne, 1995; Wade, Legh-Smith, & Hewer, 1986). This type of support is referred to as 'informal care', as it is provided by people who are not paid or trained by statutory bodies (Low, Payne & Roderick, 1999). Informal carers are an essential resource for many stroke survivors living in the community. The support that they provide enables stroke survivors, who may otherwise require residential care, to remain living at home. Because this support is provided free of charge it saves health and social services millions of pounds that otherwise would have to be used to provide paid care (Carers UK, 2002). The importance of the role of

family and carers for stroke survivors with aphasia both during and after rehabilitation is well documented in literature spanning over the last half-century (Glass, Matchar, Belyea, & Feussner, 1993; Herrmann & Wallesch, 1989; Malone, 1969; Mulhall, 1978; Turnblom & Myers, 1952).

Taking on the role of informal carer for someone who has had a stroke can impact considerably upon one's quality of life. There is evidence that informal carers of stroke survivors experience higher levels of perceived strain and psychological morbidity compared to the general population (Low, et al., 1999; Schulz, Tompkins & Rau, 1988). Research suggests that the factors that particularly impact on carers' psychological well-being are the level of dependence of the stroke survivor along with the cognitive, behavioural and communication difficulties caused by the stroke (Low et al., 1999; Visser-Meily et al., 2009).

### **The need to understand stressors and coping among informal carers of stroke survivors with aphasia**

Taylor-Sarno (1993) suggests that families of stroke survivors with aphasia experience particular stress. She writes that aphasia has been described as a disruption in normal family life, which affects the free-flowing verbal exchange of the family. Research looking at carers of stroke survivors with aphasia as a separate group suggests that the overall burden of care is higher than that of carers for stroke survivors in general (Servaes, Draper, Conroy, & Bowring, 1999). Whilst it is known that informal carers of

stroke survivors with aphasia share many of the same problems faced by carers of stroke survivors in general, it is not clear what are the main problems that contribute to the burden of care for this population. A previous review of the problems reported by this informal carers of stroke survivors with aphasia (Servaes et al., 1999) was criticised for not according greater weight to the findings of the better designed studies when drawing conclusions (Oddy, 1999). A further review of research in this area would be useful in order to overcome the limitations of the previous review as well as to incorporate more recent literature.

For clinicians and health professionals working to support informal carers of stroke survivors with aphasia it is useful to have an understanding not only of the problems they experience but also how they cope with these challenges. It is recognised that coping plays a crucial role in mediating the effect of stress on health and well-being of carers (Pearlin, Mullan, Semple, & Skaff, 1990; Pruchno & Resch, 1989). The role of coping by informal carers of stroke survivors with aphasia is an area deserving of greater attention. A focus on coping and well-being in carers of stroke survivors is timely in the current health service climate. The integrated community health and social care White Paper *Our Health, Our Care, Our Say* (Department of Health, 2006) emphasises well-being and devotes a section to support for carers. A better understanding of the coping strategies used by carers of stroke survivors with aphasia, together with knowledge about which coping strategies are more helpful, could be used to improve the information, training and interventions for this group of carers.



The next section will provide an overview of the most relevant theories of stress and coping, before going on to consider a model of the stress process in carers that helps to clarify how the focus of this review fits within a wider context.

### **A theoretical overview of coping**

Lazarus and Folkman (1984), two of the key theorists in stress and coping, propose that adaptation to stress is governed by appraisal of the stressor, and by the coping strategies used to deal with the stressful event. Appraisal refers to the individual's judgement of the event as presenting harm, threat or a challenge, and to their consideration of the coping resources available to manage the problem. Coping is defined by Lazarus and Folkman as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (1984, p.141). They are careful to distinguish coping from outcome, so that coping refers to anything that the individual does to manage the stressor, regardless of how effective it is. Lazarus and Folkman consider two main types of coping strategies: problem-focused and emotion-focused. Problem-focused strategies are similar to strategies used for problem-solving, and are directed at defining the problem and generating appropriate solutions to act upon. Emotion-focused coping strategies are aimed at reducing emotional distress and can involve cognitive processes, such as acceptance and avoidance, or behaviours such as drinking alcohol or engaging in physical exercise to take one's mind off a problem.

Lazarus and Folkman (1984) state that, in general, emotion-focused forms of coping are more likely to be employed when the individual judges that there is nothing that can be done to modify the stressful situation, whereas problem-focused coping strategies are used more when the situation is amenable to change. The different forms of coping are not mutually exclusive and indeed Lazarus (1999) states that in any single stressful encounter people use almost all the coping strategies available to them. Lazarus and Folkman's view stress and coping as a dynamic process that changes over time as the stressful situation unfolds and is reappraised. For example, in the context of caring for a stroke survivor with aphasia, the carer may initially show a period of denial or minimisation shortly after the stroke, which may be gradually replaced by problem-focused approaches aimed at finding the best ways to assist with rehabilitation and optimising communication with the stroke survivor despite the disability.

Other theorists have suggested alternative ways of categorizing coping. Roth and Cohen (1986) defined approach and avoidance as two basic styles of coping. Approach coping involves confronting the problem, gathering information and taking direct action. Avoidant coping involves trying to avoid or minimize the significance of the stressful event. Roth and Cohen state that in an ideal situation both modes of coping would operate as each can be advantageous: avoidance is more effective for dealing with short term events or if used for a limited time period, whereas an approach style of coping is helpful for long term stressors and stressors that are controllable.

Both Lazarus and Folkman (1984) and Roth and Cohen (1986) emphasize that coping should be assessed in relation to the nature of the stressful event, as people use different strategies to cope with different types of problem. Another key recommendation following from Lazarus and Folkman's theory is that research should ideally employ a longitudinal approach, in order to address causal relationships and be able to explore changes in coping strategies over time so as to identify which strategies are helpful at which stages in the caring process (Kneebone & Martin, 2003).

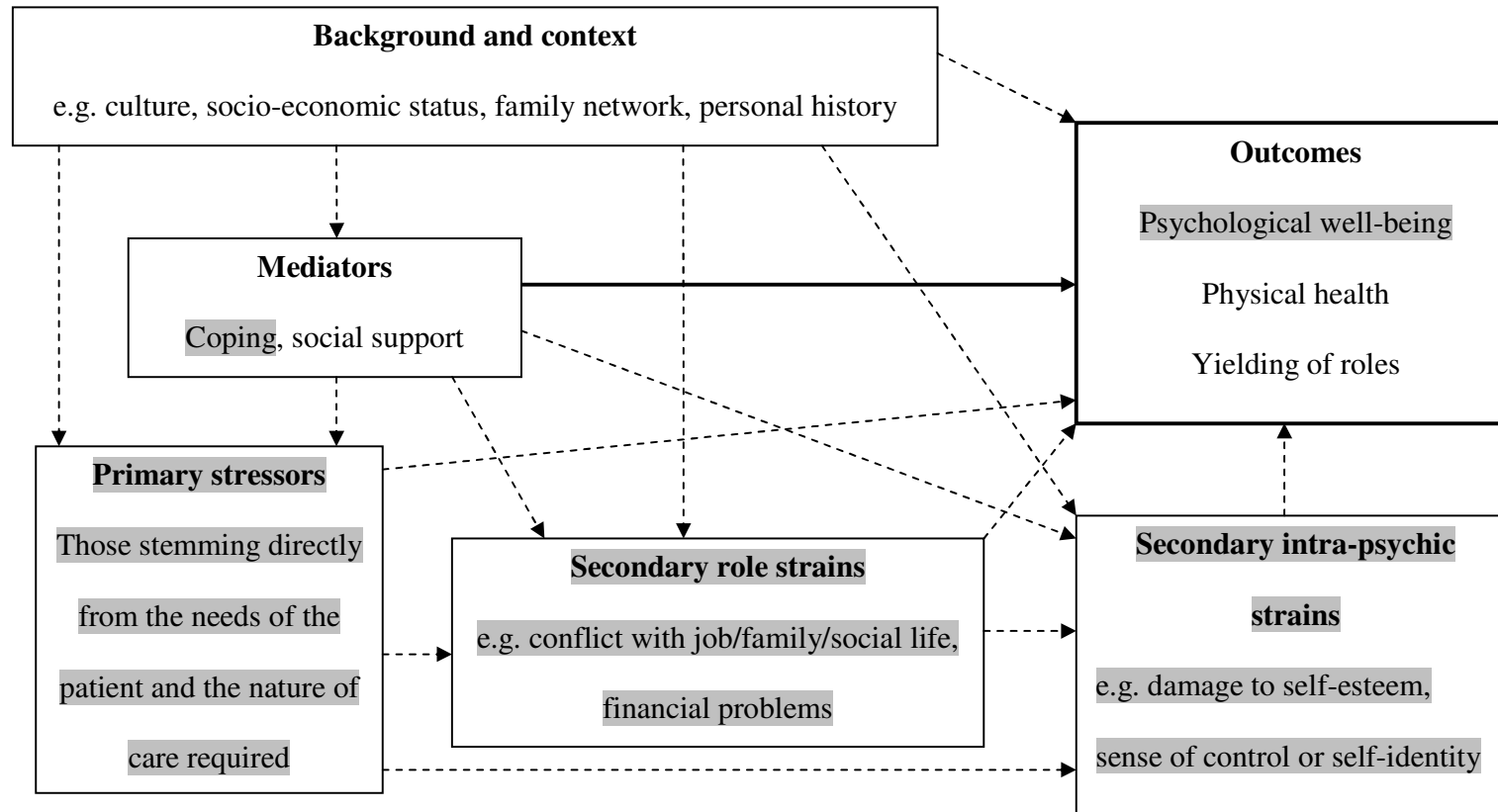
### **Links between coping and outcome**

In general, findings of research looking at coping in carers of those with a variety of illnesses suggest that the use of problem-focused coping strategies and the use of acceptance is beneficial for adjustment, and that the use of avoidant styles of coping and emotion-focused strategies (other than acceptance) are associated with a poorer outcome (Kneebone & Martin, 2003; Low et al, 1999; Pruchno & Resch, 1989). Research has highlighted the importance of distinguishing between different forms of emotion-focused strategies, for instance Almborg, Grafström and Winblad (1997) discuss research suggesting that a positive outlook can help the emotional adjustment of the carer, whereas wishfulness and avoidance are linked with poorer adjustment. Pruchno and Resch (1989) state that carers need to develop a range of coping strategies to enable them to defend against despair and respond to the multitude of demands made upon them.

### **A model of stress, coping and outcome for carers**

There are many different factors affecting stress and adaptation for carers, with coping being one important variable. Pearlin et al. (1990) developed a conceptual scheme for the study of caregiver stress (Figure 1). It can be seen that there are a number of inter-related variables that comprise what is referred to as 'the stress process'. The model describes how background and context variables, such as social and economic factors and the family network, directly influence the way that the stressors are experienced. These background variables also indirectly influence the adaptation process by affecting the social support and coping strategies available to the carer. Coping and social support are viewed as mediating the impact of the stressors on outcome (although unfortunately the model does not clearly depict this). Stressors are divided into two main types: primary and secondary. Primary stressors are those which arise directly from the needs of the care recipient. Secondary stressors arise as a consequence of the primary stressors, and include role changes, changes to the carer's social life, as well as changes to their sense of identity or their confidence in their ability to cope. All of these factors contribute to the outcome for the carer, which is seen in terms of a combination of their physical, emotional and mental health, and their quality of life. More recent models of stress and coping in carers acknowledge that emotional and physical health difficulties can in turn become a source of stress (Michallet et al., 2003).

Figure 1: Pearlin et al.'s (1990) model of the caregiver stress process



Pearlin's model gives a sense of the complexity of the carer stress process. It illustrates how coping is one of many different factors that potentially affect stress and outcome for carers. Pearlin et al. acknowledge that many of the pathways in the model are not well understood, and they intended the model to stimulate questions for further research. Having said this, there is evidence to support aspects of the model. Research has consistently shown that coping and social support affect the relationship between stress and outcome for carers (Rochette, Bravo, Desrosiers, St-Cyr/Tribble, & Bourget, 2007), although it appears that coping may exert not only a mediating effect but also a main effect (Pruchno & Resch, 1989) and a moderating effect on outcome (Goode, Haley, Roth, & Ford, 1998), and that social support is better described as a moderator than a mediator (Goode et al, 1998). There is less evidence for a direct relationship between caregiver stressors and outcome once coping and social support are controlled for (Goode et al., 1998; Schulz & Williamson, 1991), therefore this aspect of the model is less well supported, although Morrison (1999) in a research review concluded that certain types of stressor are related to carer distress and burden, for example an increase in the stroke survivor's emotional and behavioural problems was related to poorer outcome for carers. There is evidence to suggest that background variables such as socio-economic and demographic factors and stroke survivor characteristics exert an influence on outcome for carers (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Oyebode, 2003; Schulz et al., 1988), however much is yet unknown about which are the most salient variables and the pathways by which they operate.

### **Literature review: questions and focus**

Pearlin's model is used to illustrate the wider context in which the focus of this review sits. This review is concerned with a subset of the variables that are involved in the stress process for carers, namely stressors, coping, and outcome (but only outcome in relation to coping). The following questions will be addressed:

1. What are the main problems (stressors) reported by informal carers of stroke survivors with aphasia?
2. How do informal carers of stroke survivors with aphasia cope with these problems?
3. Which coping strategies are associated with a better outcome for the carer, and which coping strategies are less helpful?

A stress reaction occurs, according to Lazarus and Folkman (1984), when an individual appraises a situation or event as harmful or threatening and as exceeding their resources to cope. The notion of what constitutes a stressful experience is therefore subjective; however there are variables that can be classified as common stressors, i.e. many people would judge them to be harmful or threatening and difficult to cope with. In the present review a stressor is taken to be a variable that was either defined by the authors to be problematic or stressful, or was reported as such by carers. Outcome, in the context of research into carers, is viewed in multidimensional terms, including factors such as

psychological health, physical health, functional status and social health (Low et al, 1999). However, as Lazarus (1999) points out, each variable can play different roles. Outcome variables such as depression or health status can in turn become stressors. The nature of which variables are classified as stressors and which are classified as outcomes is open to interpretation, and varies between studies according to the focus of the research and the question being asked. Lazarus and Folkman (1984) acknowledge this potential ambiguity and state that it is important that the measures of stressor and outcome at any one time are made explicit. Therefore in the present review there is some overlap between variables that are reported as stressors and variables that are reported as outcome. The focus that is taken at any one time is dependent on how the variable was defined in the original study.

The review will examine outcome only in relation to coping. It will not include papers looking at other predictors of outcome, or papers looking at outcome in general.

Research looking at factors influencing appraisal of stress, such as the attitude of the carer towards the stroke survivor with aphasia (e.g. Croteau & Le Dorze, 2001; Malone, Ptacek, & Malone, 1970; Zraik & Boone, 1991) and the beliefs of the carer regarding the stroke survivor (e.g. Müller, Code, & Mugford, 1983) will not be covered. A particularly tricky issue is that of over-protectiveness on the part of the carer, which can be described both in terms of an attitude and a behaviour. Studies which focus on over-protectiveness as an attitude will not be included in the current review. However studies looking over-protective behaviours will be included, on the basis that this could be classed as a coping strategy. The review by Servaes et al. (1999) included papers that looked at the impact



of aphasia on marital satisfaction (Williams, 1993; Williams & Freer, 1986). These papers are not included in the current review, as marital satisfaction is judged by the author to be an outcome variable rather than a stressor in itself, however as mentioned above this is open to interpretation.

### **Method**

Empirical studies in AMED, CINAHL, EMBASE, MEDLINE, PsycINFO published up until 1<sup>st</sup> November 2008 were considered, with additional hand-searching of reference lists. The following search terms were applied: ‘carer’ and ‘stroke’ or ‘cerebrovascular disorders’ and ‘aphasia’ or ‘dysphasia’. These terms were exploded using the thesaurus option, where available, to obtain the initial pool of references. The following criteria were then applied:

#### *Inclusion criteria*

- The participants were informal carers of stroke survivors with aphasia<sup>1</sup>. Papers were accepted as relevant if the participants were described as spouses, partners, relatives, family, friends, or neighbours.
- The participants were adults (over 18 years of age).

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<sup>1</sup> A liberal view of the method of determining aphasia was taken in order to include all the studies that were relevant. The majority of studies stated that aphasia was confirmed diagnostically, but there were others in which limited information was given about how aphasia was determined, however in such cases there were systems in place that meant the stroke survivor was likely to be suffering from aphasia, e.g. recruitment took place through aphasia support organisations or through local speech therapists.

- Informal carers of stroke survivors with aphasia were considered as a separate group (either alone or in comparison to informal carers of stroke survivors without aphasia).
- The paper included a focus either on stressors for informal carers and/or on coping by informal carers.
- The study was published in English.

#### *Exclusion criteria*

- No primary data (e.g. review and discussion papers)
- Personal accounts of caring for stroke survivors that did not contain any analysis.

### **Results**

A total of 18 studies were identified as meeting the criteria for inclusion in the review. 10 studies focused only on carers of stroke survivors with aphasia. The remaining 8 studies also included a group of carers of stroke survivors without aphasia. This research is reviewed in the following sections. Initially studies looking at the problems faced by informal carers of stroke survivors are discussed, beginning with cross-sectional studies and then considering longitudinal research. Qualitative and quantitative work is reviewed separately within each section. Research looking at coping strategies and associated outcomes is then considered using a similar format.

### **Problems reported by informal carers of stroke survivors with aphasia**

The majority of research in this section is comprised of cross-sectional studies. The studies cover a wide time period post-stroke, from the acute stage and up to 14 years post-stroke. Most studies focus on spouses of the stroke survivors, however some also include other relatives or 'significant others'. Where recruitment and sampling details were supplied, the studies in this section used convenience samples rather than employing purposive or random sampling methods. A table of the studies is reported in Appendix II.

#### ***Quantitative cross-sectional studies***

Herrmann and Wallesch's (1989) study is one of the few to look only at carers of stroke survivors with aphasia. Most other studies compared the problems of carers of stroke survivors with and without aphasia, which is useful but can minimise those areas where both groups report similar levels of difficulty. Herrmann and Wallesch developed a semi-structured interview schedule which they used to gather information from participants on psychosocial changes and stress occurring since the stroke. The items were generated on the basis of previous literature, and were classified into four groups: professional, social, familial and psychological. No information was provided on the literature that was used nor on how the questions were constructed and classified. It appears that the interview schedule was neither pilot-tested nor tested for face validity. The authors used a previously existing rating scale for categorising the participants'

answers to each question, which generated a rating between 1 and 5 depending on the degree of change experience in that area. Essentially therefore the interview schedule was used as a quantitative tool. They report that an analysis of inter-rater correlations and “stability” gave satisfactory results, however no details of the analysis or the results were reported. Although they refer to the interview schedule as “standardised” there appears to have been no tests for validity or for internal reliability of the aforementioned four groups.

Herrmann and Wallesch report that participants experienced changes in all four areas covered by the interview schedule. There was a downward progression of the standard of living for the families, partly due to the stroke survivor being unable to work and partly due to the carer reducing or discontinuing employment to care for the stroke survivor. Most of the participants reported decreased social contact and restricted leisure activities. Almost all the participants stated that they had to take over tasks previously belonging to the stroke survivor. Participants often reported physical problems and overtaxing responsibilities. Half of the participants reported suffering from depression and loneliness. Psychological changes in the stroke survivor were noted as difficult by almost all participants. Nearly half of the participants reported negative changes of communication within the family that were not related to the aphasic person’s language impairment. It is surprising that there appeared to be no questions about communication with the stroke survivor. This study was limited by the small number of participants (N=17), and lack of clarity about the psychometric properties of the interview schedule.

A further shortcoming is that it was not always clear whether something was a problem for the stroke survivor, for the relative, or both.

Four studies compared the problems experienced by informal carers of stroke survivors with aphasia to those experienced by informal carers of stroke survivors without aphasia. Where differences were found between these groups they were almost always in the direction of greater problems for carers of stroke survivors with aphasia. Informal carers of stroke survivors with aphasia were reported to experience significantly greater problems in the following areas: role changes (Christensen & Anderson, 1989), communication problems with stroke survivor (Artes & Hoops, 1976), reduced social life and leisure activities (Artes & Hoops, 1976; Kinsella & Duffy, 1979; Christensen & Anderson, 1989), and marital or relationship problems (Artes & Hoops, 1976; Kinsella & Duffy, 1979). Informal carers of stroke survivors with aphasia were also reported to experience greater impact on their physical and emotional well-being (Artes & Hoops, 1976; Bowling, 1977; Christensen & Anderson, 1989) and more temper outbursts and complaining/criticism from stroke survivor (Artes & Hoops, 1976), however no analysis was conducted to determine whether these differences were significant. Financial problems were similarly reported by both groups (Artes & Hoops, 1976).

One of the difficulties with the studies by Artes and Hoops, Christensen and Anderson, and Bowling was that they each developed their own questionnaire but did not explain how the areas for questioning were selected, nor did they report on psychometric properties. All of these studies were limited in terms of the quality of statistical analysis,

either because statistical tests were not consistently used to look at group differences (Artes & Hoops; Bowling; Christensen & Anderson), small sample sizes limited the power to detect a significant effect (Christensen & Anderson; Kinsella & Duffy), or multiple testing made a type I error more likely (Artes & Hoops). When considering the generalisability of the findings of these studies it should be noted that they only looked at spouse carers of stroke survivors, and one of the studies excluded stroke survivors with major physical problems (Artes & Hoops).

Of the four studies discussed above Kinsella and Duffys' was the most rigorous in terms of methodology. By comparing psychosocial adjustment between spouses of stroke survivors with aphasia alone, spouses of stroke survivors with aphasia plus hemiplegia, and spouses of stroke survivors with hemiplegia alone, they were able to begin to separate problems due to aphasia from problems due to aphasia plus other difficulties. Spouses of stroke survivors with aphasia showed evidence of significantly poorer overall social adjustment than spouses of stroke survivors without aphasia, this appeared to be especially so for spouses of stroke survivors with aphasia and hemiplegia together. Aphasia appeared to be particularly disruptive for marital relationships regardless of the presence of hemiplegia. Although overall social adjustment was related to presence or absence of aphasia, there did not appear to be a relationship between adjustment and severity of aphasia. Female spouses of stroke survivors with aphasia plus hemiplegia had significantly higher scores than the other groups on the *General Health Questionnaire* (a screening tool that identifies possible cases of minor psychiatric disorders, such as depression and anxiety) (Goldberg, 1978). A significant negative correlation was found

between the time since stroke and overall social adjustment, leading the authors to suggest that problems of adjustment grow worse over time. Unfortunately this study was limited by a lack of information on the psychometric properties of the measure used to assess social adjustment and by small numbers in the aphasia only group.

### *Qualitative cross-sectional studies*

Seven cross-sectional qualitative studies were identified that looked at the problems and needs of informal carers of stroke survivors with aphasia. In most cases these studies did not impose pre-selected areas for questioning, and therefore they reflect the experience of carers in a more holistic way than questionnaire studies. The standard of the research varied considerably across the seven studies. In terms of sample recruitment, where details were supplied, all the studies used a convenience sample rather than purposive sampling techniques. Sampling details were not supplied by Malone (1969), Michallet, Le Dorze and Tétréault (2001) and Michallet, Tétréault and Le Dorze (2003). All of the studies, with the exception of Bowling (1977) and Mykata, Bowling, Nelson and Lloyd (1976), gathered data using semi-structured interviews with participants. The data for the other two studies took the form of observations made by staff who attended a group for relatives of stroke survivors. Few of the studies used recognized methods of qualitative analysis. Le Dorze and Brassard (1995) used grounded theory to guide their analysis, Michallet et al. (2003) used a phenomenological approach, and Michallet et al. (2001) described a categorical method of analysis. Denman (1988) stated that common themes were identified from transcripts of the interviews, but no further information was given

regarding this. The remaining three studies presented their results in terms of themes, but no information was provided on how these themes were generated. Le Dorze and Brassard (1995) and Michallet et al. (2003) employed reliability checks on their coding, and Michallet et al. (2001, 2003) checked the validity of their analysis by conducting second interviews with participants to obtain feedback on the results. In terms of methodology, the studies by Le Dorze and Brassard (1995) and Michallet et al. (2001, 2003) were of a higher standard than the others.

The main themes arising from the qualitative studies (themes reported by two or more studies) were: role changes and new responsibilities (Bowling, 1977; Denman, 1998; Le Dorze & Brassard, 1995; Malone, 1969; Michallet et al., 2001 & 2003; Mykata et al., 1976), communication difficulties and problems arising from communication difficulties (Bowling; Le Dorze & Brassard; Michallet et al., 2001 & 2003; Mykata et al.), reduced social life and leisure activities, and the need to have better interpersonal relationships (including the relationship with stroke survivor) (Le Dorze & Brassard; Malone; Michallet et al., 2001 & 2003), family problems (e.g. oversolicitousness or rejection from family member, difficulties with children) (Malone; Michallet et al., 2003), employment difficulties and financial problems (Le Dorze & Brassard; Malone; Michallet et al., 2003), emotional problems (e.g. feelings of guilt, anxiety, irritability, sadness, loneliness) (Bowling; Malone; Michallet et al., 2003; Mykata et al.), physical health problems (e.g. disturbed sleep, fatigue) (Malone; Michallet et al., 2003), the need for a break and for time to themselves (Denman; Michallet et al., 2001), lack of support (both formal and informal) (Denman; Michallet et al., 2001), and lack of training and



information, and the need to be considered as a partner in the caring process (Denman; Michallet et al., 2001)

Many of these categories overlapped and were inter-related, and this review is not able to do justice to the richness of detail both within and between the themes arising from these qualitative studies. Although theirs was a cross-sectional study Michallet et al. (2001) spoke of how carers' needs interacted with one another and varied across time. For example during the acute hospital phase and the rehabilitation phase it was the stroke survivor's physical condition and uncertainty about the future that were the main worries. However after the stroke survivor came home, establishing an effective mode of communication became a major concern.

As with all qualitative research, these studies do not aim to interview a representative sample of carers, and while the results may provide an in-depth description of the experience of the participants, caution needs to be observed in transferring the findings to other informal carers of stroke survivors with aphasia.

### ***Longitudinal studies***

Both of the studies reviewed in this section focused on the experience of the carer in the first year post-stroke or post-rehabilitation. Herrmann Britz, Bartels and Wallesch (1995) assessed 25 stroke survivors with aphasia and 33 stroke survivors without aphasia and their relatives (mainly spouses) at the end of the first week post-stroke, and

then at 1, 6 and 12 months. The Severity of Psychosocial Change scale (Herrmann, Johannsen-Horbach, & Wallesch, 1993; Herrman & Wallesch, 1989) was used to look at changes in the following areas: job, work and household; social activities and recreation; family affairs; and psychological changes. No information was given on the standardization of this measure. Between the 6 and 12 month assessments both groups reported deterioration with respect to the job, work and household group of items. There were few differences found between families of stroke survivors with and without aphasia, although small group sizes limited the power to detect significant effects. Where significant differences were present the families of stroke survivors with aphasia were more affected by the changes. At six months post-stroke, relatives of stroke survivors with aphasia reported significantly more problems with 'household work' than relatives of stroke survivors without aphasia. There was significantly more pronounced social withdrawal and a more marked downward shift in social status and leisure activities in families of stroke survivors with aphasia compared to families of stroke survivors without aphasia at both 6 and 12 months. At 12 months there were also more problems for the families of stroke survivors with aphasia in terms of 'administration of income and property'. Unfortunately this study did not always clearly distinguish between whether the problems affected the stroke survivor, the relative, or both. People over the age of 75 were excluded, therefore the results may not be applicable to older carers of stroke survivors with aphasia. A significant loss to follow-up also affected the representativeness of the sample.

King and Shade-Zeldow (1995) compared the process of adapting to a partner's stroke in spouses of stroke survivors with and without aphasia. Data were collected prior to discharge, and at 6-10 weeks and 1 year post-discharge. This study contained both qualitative and quantitative elements. The carers' experience of the most difficult adaptive tasks was assessed through an open ended interview. The results were presented using descriptive statistics as well as qualitative examples.

The two groups were reported to be similar in terms of which tasks were identified as the most difficult. The main categories of difficult adaptive tasks were: maintaining emotional balance, managing role change/multiple responsibilities, and managing patient-focused care. At all time periods, role changes and patient-focused care were the most common difficulties reported by carers of stroke survivors with aphasia.

Communication problems were not specifically referred to in the results, however dealing with language deficits was subsumed under heading of patient-focused care. A greater percentage spouses of stroke survivors with aphasia identified role changes as difficult at each time period. At 1 year follow-up, 30% of the spouses of stroke survivors without aphasia identified no difficult adaptive tasks, compared with 13% of the spouses of stroke survivors with aphasia.

Although King and Shade-Zeldows' study used both qualitative and quantitative methodology, the advantages of neither were exploited. There was little in depth information about the difficulties described by the carers, and no statistical tests were

used to look at significant differences between the groups or to explore changes over time.

### *Summary*

The majority of research into the problems faced by carers of stroke survivors with aphasia is cross-sectional. There is a balance of qualitative and quantitative studies, which benefits the knowledge base, as there are advantages to each type of study and, to a certain extent, they compensate for each other's limitations. One of the main shortcomings of the quantitative studies was that, in most cases, the researchers designed their own questionnaires but inadequate information was given about how the areas for questioning were selected and the psychometric properties were not reported. A major area that was omitted from some of the questionnaires was difficulties in communicating with the stroke survivor (e.g. Christensen & Anderson; Herrmann et al.; Herrmann & Wallesch). Qualitative studies however suggest that communication problems with the stroke survivor are a major stressor for informal carers of stroke survivors with aphasia.

The qualitative studies, on the whole, did not make prior assumptions about the problems and needs of this group of carers, and so they had the potential to more accurately reflect the challenges they face. The findings of qualitative studies however cannot necessarily be transferred to other informal carers of stroke survivors with aphasia. Quantitative research, on the other hand, has the potential to produce

generalisable results, however most of the studies in this review had sample sizes that were too small and/or too restricted to be representative.

One of the aims of this review is to accord greater weight to the findings of the better designed studies. As there were problems with many of the studies, it is difficult to determine which findings should be given greater credit. One of the positive aspects of the overall body of research is that there was considerable overlap between the findings of the qualitative and quantitative studies. Where this occurs, the findings can be accepted with more confidence, as the problem in question was both spontaneously reported by carers, and affirmed by a larger group of carers when asked. Another area in which results can be accepted with more confidence is when a statistically significant difference was found between informal carers of stroke survivors with and without aphasia, indicating that the problem affects the former group to a greater extent. The shaded area in Table 1 shows the problems that were reported across both qualitative and quantitative studies. This shows that the most consistently reported problems for informal carers of stroke survivors with aphasia are: reduced social life and restricted leisure activities; role changes and new responsibilities; emotional health problems; difficulties in communicating with the stroke survivor; marital or relationship difficulties with the stroke survivor; employment and financial problems; physical health problems; and problems within the family. The weight of evidence is greatest for the first five problems in this list, as statistically significant differences were found in these areas between carers of stroke survivors with and without aphasia. The problems listed in the non-shaded area of Table 1 should not be dismissed, especially those that are

consistently reported in the qualitative literature. These areas warrant further investigation, as it may be that they present considerable problems for many informal carers of stroke survivors with aphasia but have not been sufficiently studied in quantitative research.

A note of caution should be applied to the terms used in the first column of Table 1. It should be acknowledged that there is no consistent means of measurement underlying these terms. Different studies used different means of assessing and measuring these problems. The quantitative studies relied on questionnaires which were purpose designed without adequate psychometric testing, and the results arising from these studies are therefore not based on a rigorous method of measurement. Table 1 represents a summary of a heterogeneous body of research, and the process of summarising this research has led to another level of abstraction being imposed on the data by the author. The terms used in the table are general headings which describe a range of findings. This table should be interpreted as a guide to the main areas in which informal carers of stroke survivors with aphasia experience difficulties.

Little is known about how the problems and needs of informal carers of stroke survivors with aphasia change over time. The few studies in this area suggest that, over the first year post-stroke, problems relating to employment, household changes, and social and leisure activities increase, but difficulties in other areas remain fairly constant. There is suggestion from cross-sectional retrospective research that in the acute stage post-stroke the main concerns for carers involve the stroke survivor's physical condition and

Table 1: *Problems and Needs of Informal Carers of Stroke Survivors with Aphasia: Consistency of Findings*

<b>The problem or need:</b>	Reported by quantitative study	Reported as a significantly	Reported
	looking at carers of stroke	greater problem for informal	consistently in
	survivors with aphasia <sup>a</sup> ?	carers of stroke survivors	qualitative
		with aphasia <sup>b</sup> ?	literature <sup>c</sup> ?
Reduced social life and/or restricted leisure activities	√	√	√
Role changes and taking on new responsibilities	√	√	√
Emotional problems	√	√	√
Communication difficulties with stroke survivor		√	√
Marital/relationship problems with stroke survivor		√	√
Employment and/or financial problems	√		√
Physical health problems	√		√
Family problems	√		√

Table 1 *continued*

<b>The problem or need:</b>	Reported by quantitative study looking at carers of stroke survivors with aphasia <sup>a</sup> ?	Reported as a significantly greater problem for informal carers of stroke survivors with aphasia <sup>b</sup> ?	Reported consistently in qualitative literature <sup>c</sup> ?
Psychological and/or behavioural changes in the stroke survivor	√		
The need for a break			√
Lack of support			√
Lack of training and information/the need to be considered a partner in the caring process			√

<sup>a</sup>Herrmann & Wallesch (1989).

<sup>b</sup>Artes & Hoops (1976), Christensen & Anderson (1989) or Kinsella & Duffy, (1979)

<sup>c</sup>Reported by at least two qualitative studies, including at least one of the higher quality studies (Le Dorze & Brassard (1995); Michallet et al. (2001, 2003)).



uncertainty about the future, however when the stroke survivor returns home the need to address communication problems becomes more important.

### **Coping by informal carers of stroke survivors with aphasia**

While there are a considerable number of studies describing the problems for informal carers of stroke survivors with aphasia, fewer studies have looked at coping, and there is even less research looking at the relationship between coping and outcome. As was the case in the previous section, most of the studies looking at coping use a cross-sectional design and were based on convenience sampling. A table of the studies is reported in Appendix III.

#### ***Quantitative cross-sectional studies***

McClenahan and Weinmans' (1998) study is unique in that it is the only study to use standardised measures of coping and psychological well-being. The study also stands out as the participants were specified to be unpaid, primary carers of stroke survivors, rather than described as spouses or relatives. The study included 33 carers of stroke survivors with aphasia and 53 carers of stroke survivors without aphasia. The aim was to investigate determinants of carer distress, and as such the study did not describe all of the coping strategies reported by the participants, but focused only on those that were related to distress. Coping was assessed with the COPE questionnaire (Carver, Scheier,

& Weintraub, 1989). The General Health Questionnaire (Goldberg, 1992) was used to measure psychological distress. No difference was reported in psychological distress between informal carers of stroke survivors with and without aphasia. Multiple regression analysis showed that use of the coping strategies 'Venting' (focusing on emotions and venting them) and 'Suppression' (suppressing one's attention to other activities, in order to concentrate more completely on dealing with the stressor) were positively associated with carer distress. A causal relationship between coping and distress cannot be assumed, as the cross-sectional design only permits associative findings. Although this was in many ways a well-designed study, the number of participants was too small to conduct a regression analysis with seven variables as this is sufficient to detect only a large effect size.

Oranen et al's (1987) study adds little to the understanding of coping strategies used by informal carers of stroke survivors with aphasia. Unfortunately the validity of their results are weakened by theoretical and methodological flaws (Appendix IV), and therefore it will not be considered further.

Croteau and Le Dorze (1999, 2006) conducted two studies, both looking at the use of a particular coping strategy, overprotection, by spouses of stroke survivors with aphasia. Croteau and Le Dorze (1999) refer to the concept of overprotection as 'an underestimation of the recipient's capabilities that is manifested in unnecessary help, excessive praise for accomplishments, or attempts to restrict activities'. They compared the level of overprotection reported by spouses of stroke survivors with aphasia to that

reported by spouses of healthy controls. They found that wives of stroke survivors with aphasia reported more overprotection than wives of men without aphasia, even when functional impairment of the person with aphasia was controlled for. Interestingly there was no difference between husbands of women with and without aphasia in reported use of overprotection.

Croteau and Le Dorze (2006) focused on the use of overprotection by spouses of stroke survivors with aphasia in the context of conversations. They found that the degree of reported overprotection was associated with the spouses' tendency to speak on behalf of the stroke survivor, and that this was not strongly associated with the severity of the aphasia.

### ***Qualitative cross-sectional studies***

Two qualitative studies were identified that looked at coping by spouses, relatives or friends of stroke survivors with aphasia. Both studies reported on stressor specific coping strategies. The stroke survivors in these studies were at least one year post-stroke. Both studies used recognised qualitative research methods (as detailed earlier). Le Dorze and Brassards' (1995) study looked at coping behaviours reported by nine relatives or friends of stroke survivors with aphasia in relation to a number of different problems. The Michallet et al. (2003) study took this one step further to also include 'indicators of adaptation' (the outcome of using a coping strategy to deal with a particular stressor). The results of these two studies are summarized in Table 2. A large

number of problem-focused coping strategies were reported in relation to each stressor and therefore only a sample of them could be provided. A potential contradiction in the results is that carers reported speaking for the person with aphasia in order to protect them, but they also reported trying *not* to do this. It is not clear whether the same carers reported using both of these coping strategies. The participants also reported using emotion-focused strategies, such as acceptance, rationalization and humour. The Michallet et al. study highlighted that negative outcomes, such as fatigue, loneliness and sadness, persisted despite the use of seemingly adaptive coping strategies. It would seem that in many situations the coping strategies were not able to offset the accumulation and the long duration of stressors faced by the carer.

The richness of detail produced by these qualitative studies provides a useful insight into how carers of stroke survivors with aphasia cope with a variety of stressors. The limitations of this research are that no indication was given of the frequency with which different coping strategies were used, and there were no links made between specific coping strategies and outcome.

### ***Longitudinal studies***

Only one longitudinal study considered coping by relatives of stroke survivors with aphasia. This study was reviewed earlier as it also reported on problems experienced by carers. Herrmann et al. (1995) used the short version of the *Freiburg Questionnaire on Coping with Illness* (Muthny, 1989) to assess coping by relatives of stroke survivors

Table 2: *Stressor Specific Coping Behaviours and Associated Outcomes for Carers of Stroke Survivors (Le Dorze & Brassard, 1995; Michallet et al., 2003).*

<b>The problem</b>	<b>Examples of coping strategies</b>	<b>Outcomes</b>
Communication difficulties	Asking the AP questions that can be answered with a 'yes' or a 'no'.	Fatigue
	Using forms of communication other than speech – e.g. gesture, facial expression.	Exhaustion
	Avoiding correcting the AP's speech.	Discouragement
	Choosing topics of interest to the AP.	Sadness
	Speaking for the AP in an attempt to protect him or her.	Worries about the
	Ensuring that others will speak to the AP in spite of his/her difficulties.	future
	Refraining from speaking for the AP.	
	Trying not to dwell on the AP's difficulties.	
	Using humour.	
Withdrawing when irritated.		

*Note.* AP = Aphasic Person.

Table 2 *continued*.

<b>The problem</b>	<b>Examples of coping strategies</b>	<b>Outcomes</b>
Interpersonal relationship problems (e.g. social isolation, family difficulties, difficulties with the stroke survivor)	<p>Making new friends amongst people familiar with aphasia.</p> <p>Informing friends about aphasia.</p> <p>No longer inviting friends over because it's too stressful.</p> <p>Making sure they have their own personal time to meet with friends.</p> <p>Accepting, rationalising, and justifying change in friendships.</p> <p>Encouraging communication among family members.</p> <p>Distancing oneself from the AP.</p> <p>Addressing problems through talking to the AP.</p> <p>Drawing on personal beliefs e.g. of moral responsibility and commitment</p>	<p>Feeling isolated, lonely and hurt.</p> <p>Sadness and regret family life.</p> <p>Dissatisfied with relationship with AP.</p>
Reduced leisure activities	<p>Organising their schedule so as to fit in time for personal activities.</p> <p>Finding new activities they can engage in as a couple.</p>	<p>Isolation</p> <p>Sadness</p>
Increased responsibilities	<p>Asking for help</p> <p>Praying and hoping.</p>	<p>Exhaustion</p> <p>Worried about future</p>

with and without aphasia, at 6 and 12 months post-stroke. No information was given on the standardization of this measure, however it has been described in other studies as well validated (e.g. Kraus, Schäfer, Csef, Scheurlen, & Faller, 2000). At six months post-stroke, the coping strategies 'religious belief/quest for sense' and 'active problem-oriented coping' were most frequently reported by relatives of stroke survivors with aphasia. Significant differences were found at six months between relatives of stroke survivors with and without aphasia with respect to 'active problem-oriented coping' and 'distraction and self-reorganisation'. Both styles were reported more frequently by relatives of stroke survivors without aphasia. Between 6 and 12 months post-stroke there was a significant increase in use of 'distraction and self-reorganisation' amongst the group of relatives as a whole. Otherwise, the coping strategies remained stable over time. At 12 months post-stroke there were no significant differences in coping strategies between relatives of stroke survivors with and without aphasia.

The study was limited by the small number of participants for whom a complete data set was obtained, thereby restricting power to detect significant changes in coping strategies over time, and possibly also affecting the representativeness of the sample (less than half of the couples in the aphasia group remained in the study at follow-up). Exclusion of people over the age of 75 also affects the generalisability of the findings to older carers.

### *Summary*

Much of our knowledge to date about coping by informal carers of stroke survivors with aphasia comes from qualitative studies, which have shown that carers use a wide variety of problem-focused strategies, tailored towards the specific stressors that they face, and a smaller range of emotion-focused strategies. A drawback of the qualitative studies is that no indication is given about the frequency with which different coping strategies are used. An important point to emerge from qualitative work is that, despite the use of a range of seemingly adaptive coping strategies, carers still report negative outcomes. The qualitative studies used convenience samples and therefore caution needs to be used in assuming the results can be transferred to the wider population of carers of stroke survivors with aphasia.

Both qualitative and quantitative studies have shown that some carers of stroke survivors with aphasia use overprotection as a coping strategy. Interestingly, the findings of qualitative research have highlighted that carers report both speaking for the person with aphasia in order to protect them, but also report trying *not* to do this. This is an issue deserving of further attention, as it is unclear whether the same people report both, or whether carers tend to do either one or the other. There is no data on the benefits, or otherwise, to the carer of using overprotection as coping strategy.



Few quantitative studies have looked at coping by informal carers of stroke survivors with aphasia. Only one used standardised measures to explore the links between coping and outcome, and this study was limited in statistical power. Nevertheless, the results of this study suggest that coping by venting emotions or by focusing too much on the problem at hand to the expense of other things, are both related to greater psychological distress for the carer.

The only study to take a longitudinal perspective on coping by this group of carers focused on the first year post-stroke, however a significant loss to follow-up limited the adequacy of the sample. Some differences were found in the early months between coping by relatives of stroke survivors with and without aphasia, with the former group using more meaning-making and religious ways of coping, and the latter using problem-oriented coping and 'distraction and self-reorganisation' to a greater degree. However by 12 months post-stroke there were no differences between the groups, and both groups had increased their use of 'distraction and self-reorganisation'.

There is scope for more research looking at coping by informal carers of stroke survivors with aphasia, in particular longitudinal studies. There is also a need for more research linking coping strategies with outcome, and to consider stressor specific coping. As with the previous section, there is little exploration of gender differences or culture issues in the literature on coping in this group of carers. These are both important areas for further investigation.

Whereas in the previous section of this review the findings from qualitative and quantitative studies dove-tailed fairly neatly, when it comes to looking at how carers cope with the challenges of supporting someone who has aphasia, qualitative and quantitative studies have produced quite different types of knowledge. Quantitative studies have used generic coping questionnaires, producing results grouped in terms of different types of pre-categorised coping strategies. Qualitative studies on the other hand have provided detailed information about coping strategies that are specific to the problems faced by informal carers of stroke survivors with aphasia. Whilst it might be possible to map the findings from qualitative studies onto the category headings used in quantitative research, much would be lost in the process, for example it would be difficult to know into which category to fit 'I try to refrain from speaking for the person with aphasia' or 'I explain to others the cause of the aphasic person's speech difficulties'. The different types of knowledge produced by qualitative and quantitative findings raises the question of how best to measure coping in this group of carers. Until such questions are answered attempts to look at links between coping and outcome will be hampered.

### **Discussion**

The aim of this review was look at the main problems reported by informal carers of stroke survivors with aphasia, to find out which coping strategies they use to deal with these difficulties, and to look at the relationship between coping and outcome.

Both qualitative and quantitative studies looking at the problems reported by informal carers of stroke survivors with aphasia were reviewed. Many of the quantitative studies were limited by small sample sizes, recruitment biases, assumptions made in the design of the questionnaires, and by lack of testing psychometric properties of the questionnaires. Nevertheless, the first aim was able to be reasonably well addressed by a method of triangulation, whereby findings of the more rigorous studies from different methodological approaches were compared, and were accepted as credible if they emerged from more than one type of study. In this way some of the weaknesses of any one methodological approach were overcome.

Using this method, it was established that the main problems reported by informal carers of stroke survivors with aphasia are: reduced social life and restricted leisure activities; role changes and new responsibilities; difficulties in communicating with the stroke survivor; emotional health problems; marital or relationship difficulties with the stroke survivor. Employment and financial problems, physical health problems, and problems within the family were also consistently reported. This review highlights that emotional and health difficulties, as well as being indicators of outcome, are experienced by carers as stressful in themselves. This second order distress is acknowledged in some models of carer stress, for instance Michallet et al. (2003) write that indicators of adaptation may in turn become stressors. Lazarus (1999) advocates a systems approach to the understanding of stress and coping, in which the same variable can be viewed sometimes as an independent variable or a cause, other times as a mediator, and at still other times as a dependent variable or effect, though never at the same instant. Although this is a

more complicated model, it seems to offer greater ability to capture the true nature of the caring process.

It must be remembered that the same problem can be experienced differently according to the individual. One of the key aspects of Lazarus and Folkman's (1984) theory is that a process of appraisal determines how a potentially stressful situation is experienced. For example, if a person did not place a great deal of value on socialising before they became a carer, then they are less likely to be concerned about reduced opportunities for socialising. Michallet et al. (2003) commented that, for their participants, the perception of stress related to marital relations with the stroke survivor depended, among other things, on the importance that communication held in their daily life pre-morbidly. The impact of potential stressors on carers also depends on other factors that influence appraisal, which Lazarus and Folkman term 'coping resources', for instance the carer's financial situation, the social support available, and their sense of self-efficacy (the belief that outcomes are controllable and that one has the ability to affect change).

This review aimed to provide an update of, and improve upon, Servaes et al.'s (1999) review into the stressors experienced by informal carers of stroke survivors with aphasia. As with this previous review, it was found that communication difficulties and role changes were two main problems experienced by this group of carers. However the current paper also emphasises a number of additional stressors. Although Servaes et al. mentioned other stressors, these tended to be minimized and labelled as 'problems non-specific to aphasia'. It is suggested here however that in order to understand the carer's

experience it may not be useful to separate problems specific to aphasia from other problems. Although carers of stroke survivors with and without aphasia experience an overlapping set of difficulties, it seems that some of these are augmented in carers of stroke survivors with aphasia. Aphasia may affect other problems which are not specific to caring for a stroke survivor with aphasia. For instance although reduced social life and restricted leisure activities are reported by carers of stroke survivors without aphasia, it appears that these problems are experienced by significantly more carers of stroke survivors with aphasia.

The remaining questions addressed by this review concerned coping. Qualitative research has provided most of the information on this subject to date. Carers report using a wide variety of problem-focused strategies tailored to specific stressors, along with a narrower range of emotion-focused coping strategies. This is consistent with Lazarus and Folkman's (1984) view that the more specific the research domain, the greater the proliferation of problem focused strategies. As discussed in the introduction, emotion-focused strategies are thought to be more useful when the stressor is outside of the person's control. Therefore it would be expected that carers of stroke survivors with aphasia use a range of problem focused strategies to cope with those aspects of their situation that they are able to influence, and use emotion-focused strategies to manage the less controllable aspects of their situation.

McClenahan and Weinmans' (1998) study was the only one to provide information about the relationship between coping and outcome. They found that greater use of

copied strategies involving focusing on and venting emotions, and/or focusing on caring duties to the exclusion of all else, were associated with reduced psychological well-being. No association was found between active coping and psychological well-being. A study by Visser-Meily et al. (2009) looking at psychosocial functioning of spouses of stroke survivors also failed to find evidence that active coping styles were beneficial for psychological health. They did however find that greater use of passive coping strategies was associated with increased depressive symptoms. They also found that coping by expressing emotion was related to fewer depressive symptoms, which seemingly contradicts McClenahan and Weinmans' findings. Interestingly, Visser-Meily et al. (2009) found that less expression of emotion was predictive of better social relations, which led them to comment that expressing emotions may reduce perceived burden and depression, but may adversely affect social relationships as others could lose interest in listening. Whereas active coping in Visser-Meily et al.s' study was unrelated to psychological well-being, it was predictive of better relationships with the stroke survivor and better social relationships, confirming findings in the wider caregiver literature that active problem-oriented coping is beneficial.

One of the findings from this review worthy of further discussion is the use of overprotection as a coping strategy. This has received most attention in qualitative literature, as it is not something that is covered by standard coping inventories. There is an apparent contradiction, whereby carers report both using overprotective behaviours, such as speaking for the person with aphasia, but also try to refrain from doing this. It is unclear whether both positions are reported by the same carers, or whether this is an

issue that separates groups of carers. Whereas there has been discussion of the effects of overprotection on the stroke survivor, there has been no research looking at the benefits (or otherwise) for the carer of behaving in an overprotective manner. Concerns have been raised that overprotection is unhelpful for the stroke survivor because it encourages them to remain in a 'sick role'. Croteau and Le Dorze (2006) however suggest that sometimes "speaking for" behaviours on the part of the carer may be helpful for people with aphasia who have difficulty expressing themselves. It would be useful to explore further the potential costs and benefits for both the carer and the stroke survivor of overprotective behaviours.

The review of coping by informal carers of stroke survivors with aphasia highlighted that different types of knowledge have come from qualitative and quantitative studies. It is not clear whether the general questions in standard coping inventories manage to elicit some of the more specific coping strategies used by this group of carers. The dilemma of whether to use problem-specific or general measures of coping is not new. Kneebone and Martin (2003) drew attention to this in a review of coping in carers of people with dementia. This issue has also been raised by Steed (1998), who discussed the advantages of using problem-specific measures in terms of capturing the complexity of individual coping repertoires, but also their disadvantage in producing results that are incomparable to other research. The use of generic measures of coping, on the other hand, offers the potential to produce comparable results, but risks lack of sensitivity to stressor specific coping strategies. It would be helpful, when planning future research, to know more

about the usefulness or otherwise of generic coping inventories with informal carers of stroke survivors with aphasia.

A lack of research into coping by informal carers of stroke survivors with aphasia made it impossible to satisfactorily answer the questions of the review that focused on coping and how it relates to outcome. More research is needed to understand coping by carers of stroke survivors with aphasia and to learn about adaptive ways of coping. In particular, research is required looking at stressor specific coping strategies so as to provide information that is most useful for clinicians working with this group of carers. Another area where more research is needed is longitudinal studies looking how the problems faced and coping strategies used by carers of stroke survivors with aphasia vary over time. Only two longitudinal studies were found, and both focused on the first year post-stroke or post-rehabilitation. A final recommendation on the basis of this review is for research on how the experience of caring for someone with aphasia is affected by the gender and culture, and whether these are relevant variables to be considered when exploring coping and adaptation.



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**Coping with communication problems by informal  
carers of stroke survivors with aphasia: Issues of  
measurement and links with depression**

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Article prepared based on author instructions for the journal Stroke

(Appendix V)

## Abstract

**Background and purpose.** National guidelines for stroke recognise the vital role of informal carers, and acknowledge their need for support, however research on which to base recommendations is lacking. The present study investigates how informal carers of stroke survivors with aphasia cope with communication problems, and examines links between coping and depressive symptoms. This study also explores how best to assess the coping strategies used to manage communication problems.

**Methods.** This was a cross-sectional, questionnaire study. Participants were 150 informal carers of stroke survivors with aphasia. The *Centre for Epidemiologic Studies Depression Scale* measured depressive symptoms. Coping was assessed with the *Brief COPE* plus specially designed questions. Multiple regression analysis explored the predictive role of coping in depressive symptoms. Bootstrapping was used to investigate whether coping mediated between communication impairment in the stroke survivor and depressive symptoms in the carer.

**Results.** Participants reported a wide range of coping strategies. The use of avoidant styles of coping were associated with increased depressive symptomology. Only one coping strategy, 'Avoidance', fulfilled conditions for mediation. The addition of questions specifically designed to assess coping with communications problems improved the amount of variance explained in the regression.

**Conclusions.** The results confirm associations between coping and depressive symptoms. A traditional coping inventory provides a helpful assessment of the coping strategies used by this group of carers to manage communication problems, and can be supplemented by more specific questions about avoidance. Clinical implications of the study are discussed and avenues for future research explored.

## **Introduction**

### **Stroke and aphasia**

Aphasia is a communication disorder in which a person has difficulty using and/or understanding language. It is one of the major impairments associated with a stroke, a disease that can also effect physical, cognitive and emotional functioning. Aphasia occurs in about a third of survivors in the early weeks post-stroke and persists long-term in about 12% of stroke survivors (Bakheit, Shaw, Carrington, & Griffiths, 2007; Laska, Hellblom, Murray, Kahan, & Von Arbin, 2001). As well as affecting spoken language, aphasia can also affect the ability to read, write, and to use and understand gesture. The National Clinical Guidelines for Stroke (Royal College of Physician, 2008) recognise that aphasia can have a significant impact on virtually all aspects of an individual's life.

### **Informal carers of stroke survivors with aphasia**

Aphasia effects not only the life of the stroke survivor, but also their family. Many stroke survivors with aphasia depend on the support of an informal carer. In most cases this type of care is provided by family members such as a spouse or adult child (Anderson, Linto, & Stewart-Wynne, 1995; Mant, Wade, & Winner, 2004). Informal carers provide valuable physical and emotional support, and play an important role in rehabilitation (Glass, Matchar, Belyea, & Feussner, 1993; Morris, Robinson, Raphael, &

Bishop, 1991). Research comparing the problems experienced by informal carers of stroke survivors with and without aphasia suggests that the former group experience more problems. This has led to the conclusion that the overall burden of caregiving is greater for carers of stroke survivors with aphasia (Servaes, Draper, Conroy, & Bowring, 1999a). Among the main problems reported by informal carers of stroke survivors with aphasia are communication difficulties and role changes, however they also report the same problems as carers of stroke survivors in general such as limitation of social and leisure activities, tiredness, and employment difficulties (Servaes et al, 1999a).

Research has shown that levels of psychological distress in carers of stroke survivors is higher than that of the general population. Schulz, Tompkins and Rau (1988), for instance, suggest that the prevalence of depressive symptoms is 2.5 to 3.5 times higher in primary carers of stroke survivors than among similarly aged peers. Findings are mixed as to whether carers of stroke survivors with aphasia differ in terms of psychological distress from carers of stroke survivors in general. Some studies report no difference between the groups (McClenahan & Weinman, 1998; Wade, Legh-Smith, & Hewer, 1986), whilst others report higher rates of psychological distress among carers of stroke survivors with aphasia (Kinsella & Duffy, 1979).

### **A theoretical overview of coping**

It is recognised that the health and well-being of carers is related to how they cope with the challenges associated with their role (Pearlin, Mullan, Semple, & Skaff, 1990).

Lazarus and Folkman (1984) define coping as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141). In viewing coping as a dynamic process, Lazarus and Folkman hypothesize that, at any one time, people may draw on a range of coping strategies, rather than show one particular style of coping. Two main types of coping are considered: problem-focused, which are attempts to tackle the problem, and emotion-focused, which are attempts to reduce the emotional distress caused by the problem. Lazarus and Folkman state that, in general, problem-focused coping strategies are more likely to be used when the stressful situation is amenable to change, whereas emotion-focused coping is used more often to deal with situations beyond the individual’s control. Others have argued that the division of coping into problem-focused and emotion-focused strategies is too simple, and that these should be further subdivided. Carver, Scheier and Weintraub (1989), for example, suggest that ‘denial’, ‘positive reinterpretation’ and ‘seeking social support’ are very different from each other, even though they are all forms of emotion-focused coping.

Steed (1998) offers an alternative conceptualization of coping whereby the two main types of coping strategies are further divided into approach and avoidant. Some examples of problem-focused approach strategies would be problem-solving and planning, whereas physically withdrawing oneself from the situation is an example of a problem-focused avoidant strategy. Emotion-focused avoidant strategies include denial, wishful thinking, and distancing, compared to emotion-focused approach strategies which include acceptance and positive reframing. Although not every coping strategy



can be nearly categorized into one of these four groups, this is one of the more comprehensive frameworks for classifying coping.

A key aspect of Lazarus and Folkman's (1984) theory is that coping should be assessed in relation to specific stressors. People use different coping strategies for different problems, and the success of any given coping strategy will depend on the problem. This has been confirmed in research with carers. Gottlieb and Gignac (1996), for instance, compared stressor-specific assessment of coping with more a more general coping assessment. It was found that assessing coping in relation to a specific stressor yielded a better understanding of the relationship between coping and outcome than the assessment that did not distinguish between different stressors. A number of researchers have called for more research looking at how carers cope with specific stressors (Kneebone & Martin, 2003, Williamson & Schulz, 1993). Pruchno and Kleban (1993) suggest that a better understanding of the links between stressors and coping would benefit the development of appropriate interventions for carers. Therefore when assessing the effectiveness or otherwise of different coping strategies it is recommended to focus on one type of stressor at a time.

### **Coping in informal carers of stroke survivors with aphasia**

Coping strategies have been found to play a significant role in mediating the relationship between stress and well-being for carers (Pruchno & Resch, 1989). However there has as yet been little investigation of coping by informal carers of stroke survivors with

aphasia, despite calls over the last twenty years for more research (Ross & Morris, 1988; Servaes et al., 1999b). The literature in this area to date is comprised mostly of qualitative studies, which have shown that this group of carers report a wide range of problem-focused strategies tailored to deal with the different problems that they face, and a smaller range of emotion-focused strategies aimed at managing the ongoing and uncontrollable aspects of their situation (Le Dorze & Brassard, 1995; Michallet, Tétreault, & Le Dorze, 2003). Unfortunately qualitative studies cannot explore the role of coping in predicting outcome, although Michallet et al. (2003) highlighted that negative outcomes, such as fatigue, loneliness and sadness, persist despite the use of seemingly adaptive coping strategies.

Only one quantitative study has addressed coping in carers of stroke survivors with aphasia (McClenahan & Weinman, 1998). This study found no difference between carers of stroke survivors with and without aphasia on demographic or individual measures, and therefore the data from the two groups was merged for the main analysis. It was identified that coping by focusing on and venting emotions or by focusing too much on caring duties to the exclusion of other things was associated with a worse psychological outcome for the carer. The sample size was however too small for the regression analysis to be able to detect anything other than a large effect size. Further, these findings contradicted those of a larger and longitudinal study of coping in carers of stroke survivors, where greater expression of emotion was related to fewer depressive symptoms (Visser-Meily et al., 2009). The findings of the McClenahan and Weinman study are also of limited clinical use because coping was not assessed in relation to a

specific stressor but rather in relation to the caring role in general. The present study aims to improve on McClenahan and Weinmans' study by including a larger sample, and by focusing on coping in relation to a specific stressor.

### **Rationale for study**

The stressor focused on in the present study is how carers of stroke survivors with aphasia cope with communication problems. This was chosen because communication-related problems are one of the major difficulties reported by informal carers of stroke survivors with aphasia (Michallet et al., 2003; Servaes et al., 1999a), and they are arguably the main area that differentiates the problems experienced by informal carers of stroke survivors with aphasia from the problems experienced by carers of stroke survivors in general. In the National Stroke Strategy (Department of Health, 2007) it is recognised that carers are vulnerable to difficulties in coping and to depression, and it is recommended that carers are trained in methods for managing communication difficulties and in the use of coping strategies to promote emotional well-being. This is therefore a timely study that will provide valuable and clinically relevant results to contribute to a knowledge base for meeting these goals.

When examining specific stressors for carers there is a question regarding whether generic coping inventories can be adequately applied or whether they may miss some forms of coping (Gottlieb & Gignac, 1996; Pearlin et al., 1990). Generic measures of coping assess broad coping strategies, however qualitative research has shown that

informal carers of stroke survivors with aphasia use some very specific coping strategies to manage communication problems, which may not be captured by the questions on standard coping inventories. The present study will include both a validated generic coping questionnaire and also a set of questions looking specifically at coping with communication problems. In this sense the present study will not only improve upon McClenahan and Weinmans' study, by including a larger sample and by focusing on a specific stressor, but will also extend it by including questions on coping with aphasia. The benefits of including these additional questions will be investigated, in order to establish whether they add to an understanding of the links between coping and outcome for carers.

As mentioned earlier, coping is usually conceptualized as mediating the relationship between stress and outcome (Lazarus & Folkman, 1984). Although this is often assumed to be the case in models of caregiver stress (e.g. Pearlin et al., 1990), it has not been extensively tested. The present study will explore whether coping mediates the relationship between the level of communication impairment in the stroke survivor (the stressor) and the degree of depressive symptoms in the carer (an outcome).

## **Aims**

The aims of the study can be summarized as follows:

1. To describe the coping strategies used by informal carers of stroke survivors with aphasia to manage communication problems and associated stress.

2. To explore the relationship between coping and symptoms of depression.
3. To assess whether including specific questions on coping with communication problems improves the explained variance depressive symptoms, over and above that accounted for by a standard coping inventory.
4. To explore whether coping mediates the relationship between the severity of communication difficulties of the stroke survivor and levels of depressive symptoms in the carer.

## **Participants and Methods**

### **Design**

This study took the form of a postal questionnaire survey using a cross-sectional design.

### **Participants**

It was decided to focus the study on informal carers of stroke survivors who were at least one year post-stroke. This time frame was chosen because research suggests that the problems reported by informal carers of stroke survivors with aphasia differ according to the time since stroke (Michallet, Le Dorze, & Tétreault, 2001), with communication being particularly pertinent once the stroke survivor returns home from hospital. It was judged that by one year post-stroke, the stroke survivor would be likely

to be at home and that carers would have had time to adapt to the changes and to have developed some coping strategies.

Informal carers of stroke survivors with aphasia were recruited through adverts or articles placed in newsletters and on websites of the following support organisations: Chest Heart and Stroke Scotland, Connect, Different Strokes, Dyscover, Lothian Stroke Managed Clinical Network, Speakeasy, Speakability, Speechmatters, Talk Surrey, and The Stroke Association (Appendices VI & VII). In some cases the support organisation sent the advert to their members in a separate mail-out, rather than including it with the newsletter. Some organisations preferred to bring the study to the attention of their members by mentioning it at carers' meetings, and in two cases the researcher was invited to talk at a carers' meeting. Inclusion criteria were that:

- Participants were over 18 years of age.
- They were resident in Great Britain.
- They provided the main source of unpaid physical and/or emotional support for the stroke survivor (e.g. they were a partner, family member or friend).
- The aphasia was the result of a stroke occurring over one year previously.

People who received a state carer's allowance were eligible to participate. Only one carer per stroke survivor was included. The study was approved by the School of Psychology Ethics Committee at the University of Southampton and was sponsored by Research Governance at the same university (Appendices VIII & IX).

## Procedure

Before recruitment began, the information and questionnaires for the study were shown to two informal carers of stroke survivors (one had aphasia and one did not) in order to check that everything was clear and easy to understand and that the questionnaires were acceptable. As a result of this process some small grammatical changes were made, but otherwise the study material was found to be acceptable and easy to complete.

An opt-in approach was used for recruitment, whereby informal carers who were interested in participating requested an information pack, which included the questionnaires and a free-post return envelope. The information sheet (Appendix X) contained a free-phone number, which potential participants could call if they wanted to ask any questions about the study. If the questionnaires were not returned in 14 days a reminder was sent. If the questionnaires were completed and returned this was taken to imply informed consent to participate in the study<sup>2</sup>. If the questionnaires were not returned, then no more contact was made.

If the participant's responses on the measure of depressive symptoms indicated that they were at high risk for depression then, in accordance with the Code of Ethics and Conduct of the British Psychological Society (2006, p.19), the researcher wrote to the participant and advised them to talk to their GP if they were concerned (Appendix XI).

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<sup>2</sup> The reason that written consent was not obtained was to preserve the participants' anonymity for the return postage. The questionnaires contained sensitive and confidential information and it was judged to be in participants' interest that no identifying information was contained. This accorded with university ethics and research governance approved procedures.

The researcher offered to contact the participant's GP to inform them of the questionnaire results if the participant requested this.

Participants could contact the researcher at any stage by using a free-phone number, by email or in writing. Participants were offered a written summary of the results upon completion of the research.

## **Measures**

### ***Outcome Variable: Depressive Symptoms in Caregivers***

*The Centre for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977)* measured the presence and severity of depressive symptoms. This is a 20-item self-report scale designed to identify individuals at risk for depression. It has been widely used for the evaluation of depression in primary care and community dwelling samples (Beekman et al., 1997; Lewinsohn, Seeley, Roberts, & Allen, 1997; Williams, Pignone, Rameriz, & Stellato, 2002) and has been used successfully with both older and younger adults (Radloff & Teri, 1986). Responses are scored 0 to 3, with higher scores indicating higher levels of depressive symptoms. A cut-off score of 16 or more discriminates well between the general population and psychiatric service-users (Radloff, 1977), shows good concurrent validity (Radloff, 1977), and is predictive of future diagnosis of depression (Lewinsohn, Hoberman & Rosenbaum, 1988). Radloff (1977) reported high



internal consistency (0.85) and moderate test-retest correlations (0.51 to 0.67 for intervals from two to eight weeks), which the authors deem acceptable given that the measure is designed to assess current state. Beekman et al. (1997) report a weighted<sup>3</sup> sensitivity and specificity of 100% and 88% respectively. The *CES-D* has been used effectively in previous studies looking at adaptation in carers of stroke survivors (e.g. Schulz et al, 1988; King & Shade-Zeldow, 1995).

### ***Characteristics of stroke survivors***<sup>4</sup>

Participants were asked to provide data on the age and gender of the stroke survivor, and the length of time since the stroke that caused the aphasia.

The level of dependence of the stroke survivor was measured using the *Nottingham Extended Activities of Daily Living Index* (*Nottingham Extended ADL*; Gladman, Lincoln & Adams, 1993; Nouri & Lincoln, 1987). This index was developed for stroke survivors living in the community. It consists of 22 questions divided into three scales: mobility, household, and leisure. Each question asks how independently the stroke survivor managed a particular activity, and is answered using the response categories:

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<sup>3</sup> Beekman et al. stratified their study sample so that 50% of participants scored above the cut-off point on the *CES-D* and therefore they needed to weight the calculation of sensitivity and specificity when extrapolating from their findings.

<sup>4</sup> Consideration was given to whether consent should be sought from the stroke survivor for obtaining this information. This involved discussion in supervision as well as correspondence with the British Psychological Society (Appendix XII). There were arguments both for and against seeking consent from the stroke survivor. Practical issues about the feasibility of getting consent from stroke survivors with aphasia had to be taken into account. Ultimately it was decided that it would be permissible, in the absence of consent from the stroke survivor, to ask the informal carer for their opinion on questions concerning the stroke survivor. This was approved by the School of Psychology Ethics Committee.

‘on their own’, ‘on their own with difficulty’, ‘with help’ and ‘not at all’. Activities performed by the stroke survivor on their own or on their own with difficulty are scored 1, and activities that they are unable to perform or for which help is needed are scored 0. The scales have been demonstrated to be valid and unidimensional, with the exception of leisure (Gladman et al., 1993)<sup>5</sup>. As recommended by Gladman et al., one question was omitted from the ‘household’ scale in order to improve the validity of this scale, leaving 21 remaining items. Almost all questions show excellent test-retest reliability (Nouri & Lincoln, 1987).

The degree of communication impairment was assessed using the *Communicative Effectiveness Index (CETI)* (Lomas et al., 1989). The *CETI* is a short measure, developed in conjunction with people with aphasia and their relatives, which focuses on communication in everyday situations. It consists of 16 questions, covering topics such as the stroke survivor’s ability to understand writing and to participate in different types and levels of conversation. A visual analogue scale is used to rate current ability between ‘not at all able’ (0) and ‘as able as before the stroke’ (10). The authors report good internal reliability ( $\alpha = 0.9$ ), and good test-retest reliability ( $r = 0.9$ ). The *CETI* was shown to correlate significantly with the *Western Aphasia Battery* (Kertesz, 1982), a traditional measure of language ability.

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<sup>5</sup> The authors commented that leisure is an area of lifestyle that would not necessarily be expected to form a unidimensional construct. However they argue that the ‘leisure’ scale is of use as it discriminated between those in institutional care and those who were not, and between those receiving services and those who were not.

### ***Background characteristics of caregivers***

Participants were asked to provide data on age, gender, marital status, ethnicity, level of education, relationship to the stroke survivor, whether they lived in the same household as the stroke survivor, and other significant commitments (such as a job, young children, or other caring commitments). Participants' post-codes were used to obtain a score on the *Index of Multiple Deprivation (2007) (IMD)* (Department of Communities and Local Government, 2007). The *IMD* is the UK government's official measure of multiple deprivation. The *IMD* combines a number of indicators, chosen to cover a range of economic, social and housing issues, into a single deprivation score for the area in which the person lives. The higher the *IMD* score the more deprived the area.

### ***Coping***

The *Brief COPE* (Carver, 1997; Appendix XIII) was used to assess the coping strategies that participants used to manage communication difficulties. The *Brief COPE* is a shortened and adapted form of the *COPE* (Carver et al., 1989). The *COPE* and the *Brief COPE* have predicted clinically relevant outcomes across a variety of stressors and populations, including use with carers of stroke survivors (McClenahan & Weinman, 1998). The *Brief COPE* consists of 14 scales of two items each. Response options range from 0 (I haven't been doing this at all) to 3 (I've been doing this a lot). As with the *COPE*, the *Brief COPE* can be used to assess situational coping or dispositional coping. This study used the former method of assessing coping, and the instructions were

worded accordingly. Carver (1997) reported that alpha reliabilities of the *Brief COPE* scales all met or exceeded 0.5<sup>6</sup>, and all but three exceeded 0.6 ('Venting', 'Denial', and 'Acceptance'). Test-retest reliability has yet to be documented for the *Brief COPE* but research with the *COPE* indicates that the coping tendencies measured are reasonably stable (ranging from 0.5 to 0.9, with most over 0.6) (Carver et al., 1989). Carver et al. (1989) found the expected associations between selected scales of the *COPE* and personality dimensions such as trait anxiety, self-esteem, and optimism, thereby providing evidence of construct validity.

An additional set of questions was constructed to assess in more detail the coping strategies used for managing communication problems. These questions were informed by qualitative literature on how carers of stroke survivors with aphasia cope with communication difficulties. This preliminary investigation tool was termed the *Coping with Aphasia Questionnaire (CAP)* (Figure 1). Information on development and psychometric properties is provided in Appendix XIV.

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<sup>6</sup> Carver states that 0.5 is the minimum acceptable value for alpha, referencing Nunnally (1978). This is not usually regarded as an acceptable value for alpha, normally any value below 0.7 is less than ideal (Field, 2005). However Field (2005) points out that one also needs to consider the number of items in the scale, as scales with a small number of items can have acceptable reliability with alpha values of less than .7. The scales in the *Brief COPE* consist of two items each, and therefore it is possible that they are reliable at lower values of alpha, however without access to further information (such as the corrected item-total correlations) this cannot be confirmed.

Figure 1. The *Coping with Aphasia Questionnaire*.

### COPING WITH APHASIA

The following items are specifically designed to look at how people deal with communication problems that arise when caring for someone who has aphasia.

Use the same response format as the last questionnaire. Again, don't answer on the basis of whether it seems to be working or not—just whether you do it.

	0	1	2	3
1. I pay close attention to what the person with aphasia is saying				
2. I take time to listen to the person with aphasia				
3. If the person with aphasia is struggling to say something then I say it for them				
4. I make phone calls on behalf of the person with aphasia				
5. I check what I think they have said to make sure I have understood correctly				
6. I try to guess what they mean				
7. I ask them questions that can be answered with a 'yes' or a 'no', or give them simple choices				
8. I use different ways of helping the person with aphasia to understand what I am saying (e.g. gesturing, drawing, writing, etc)				

9. I withdraw when I get irritated by communication problems			
10. I avoid talking about certain topics that might annoy or frustrate the person with aphasia			
11. I accept that it's not their fault that communication is so frustrating			
12. I choose topics of conversation that I think they are interested in			
13. I make sure that the person with aphasia uses as much language as possible			
14. I explain to other people why the person with aphasia has a communication problem			
15. I make sure that other people speak to the person with aphasia			
16. I avoid correcting the aphasic person's speech			
17. I use humour to cope with the communication problems			
18. I try not to dwell on the aphasic person's difficulties			
19. I give up trying to communicate with the person with aphasia			
20. I talk to other people at different stages post-stroke to gain a sense of what to expect or to appreciate how far we have come			
21. I accept the aphasia as a disability			

### *Social support*

The following subscales from Krause's (1999) measure of social support were used:

'Informational Support', 'Practical Support', 'Emotional Support', 'Anticipated Support', 'Satisfaction with Informational Support', 'Satisfaction with Practical Support' and 'Satisfaction with Emotional Support'. Response options for indicating the amount of support range from 1 (never) to 4 (very often). Satisfaction with support is assessed by asking whether the amount support was about right, too much or too little. Krause's (1999) measure of social support is a shorter version of a scale developed by Krause and Markides (1990). The present study included three questions from this longer scale as they were pertinent to this study ('How often did someone tell you who you should see for assistance with a problem that you were having?', 'How often did someone provide you with a place where you could get away for a while?', and 'How often did someone look after a family or household member while you were away?'). Krause and Markides reported acceptable internal reliability for the subscales 'Informational Support', 'Practical Support', and 'Emotional Support' ( $\alpha \geq 0.7$ ), and also demonstrated predictive validity of the scale. Krause (1999) reported Cronbach's alpha of 0.8 for the more recently added subscale of 'Anticipated Support'.

### **Missing Values**

Table 1 describes the missing data. Where possible, a prorating (mean substitution) system was used to calculate missing values. Any measure missing more than one item was excluded from the analysis. For measures scored according to subscales (e.g. the *Brief COPE* and the measure of social support), prorating was used if one item was missing from the subscale, and subscales missing more than one item were excluded. The *CETI* is scored using the mean value of the ratings, if only one item was missing then a mean rating was calculated for the remaining 15 items, otherwise the measure was excluded.

### **Statistical Analyses**

The characteristics of the sample were investigated using descriptive statistics for all variables. Associations between the dependent variable and the other variables were explored using Mann-Whitney tests and Spearman's correlations. Non-parametric tests were chosen because the data for the dependent variable, and many other variables, was skewed.



Table 1.

*Missing data*

<b>Measure</b>	<b>Number of participants with missing data</b>	<b>Number of participants with missing data after prorating</b>
Background characteristics of stroke survivor	1	N/A
<i>Nottingham Extended ADL</i>	6	2
<i>CETI</i>	16	6
<i>Brief COPE</i>	27	3 <sup>a</sup>
<i>CAP</i>	24	5 <sup>a</sup>
<i>CES-D</i>	17	5
Social support measure	36	25 <sup>a b</sup>
Background characteristics of participants	15	N/A

*Note.* N = 150.

<sup>a</sup> Data was prorated at the level of subscales. Participants may have had one or more subscales prorated.

<sup>b</sup> Much of the missing data was from items assessing satisfaction with each form of support, which were single questions and not able to be prorated.

Hierarchical regression was used to explore associations between coping and depressive symptoms. Based on previous literature (McClenahan & Weinman, 1998), it was estimated that a maximum of 10 of the independent variables would correlate significantly with the *CES-D*. In order to have a high level of power (0.8) to detect a medium effect size with 10 predictor variables it was determined that 150 participants would be required (Field, 2005).

The mediation analysis was guided by Holmbeck (1997), who outlined a set of four conditions that must be met in order for a variable to be considered a mediator: 1) the stressor must be significantly associated with the hypothesized mediator, 2) the stressor must be significantly associated with the outcome variable, 3) the mediator must be significantly associated with the outcome variable, and 4) the impact of the stressor on the outcome measure must be less after controlling for the mediator. Conditions 1 to 3 were tested using correlations. The variables that met these conditions were entered into a multiple regression to test condition 4.

## Results

### Participants

182 people contacted the researcher to request an information pack, 170 of which met the inclusion criteria and were sent questionnaires. 153 questionnaires were completed and returned. Three people were subsequently deemed non-eligible, and were excluded. The total number of participants was therefore 150.

Table 2 summarises the characteristics of the participants. The majority of the participants were female (81%), and most were aged between 50 and 69. The participants were mainly the spouse or partner of the stroke survivor, approximately 10% were the child of the stroke survivor, and the remainder were siblings, friends, neighbours or a parent of the stroke survivor. Most of the participants (91%) lived in the same household as the stroke survivor. Approximately half of the participants had other significant commitments aside from caring for the stroke survivor. A substantial minority (17%) of the participants had two or more additional significant commitments. Nearly all of the participants were ethnically white British. Participants spanned a range of educational backgrounds.

### **Characteristics of stroke survivors**

Most of the stroke survivors were male (69%) and aged between 60 and 79 years (64%), although 7% were under 49. Approximately one third (32%) were one to two years post the stroke that caused the aphasia. Around one tenth (11%) were 10 or more years post-stroke, and the remainder were fairly evenly divided between 3-4 years and 5-9 years post-stroke. The mean score on the *Nottingham Extended ADL* was 7.6 (*SD* 5.8, median 7, interquartile range 2 – 12). This score is comparable to that obtained by Gladman et al. (1993), where a median score of 5.5 (interquartile range 2-8<sup>7</sup>) was obtained for aphasic stroke survivors and a median score of 9 (interquartile range 5-14) was obtained for the overall group of community dwelling stroke survivors. The overall mean rating on the *CETI* was 3.5 (*SD* 1.9, possible range 0-10, higher scores indicating greater communicative ability).

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<sup>7</sup> Gladman et al. had only 44 stroke survivors with aphasia in their sample compared to 150 in the present study, therefore one would expect some difference between the studies in the descriptive results for the *Nottingham Extended ADL* scores.

Table 2.

*Characteristics of Participants*

		N (%)
Gender:	Male	29 (19%)
	Female	121 (81%)
Age:	Less than 50	22 (15%)
	50-69	89 (59%)
	70 or more	38 (25%)
Relationship to stroke survivor (SS):	Partner or spouse	127 (85%)
	Child of SS	16 (11%)
Other significant commitments:	Children under 18 yrs	8 (5%)
	Other caring commitments	29 (19%)
	Full-time/part-time job	56 (37%)
	Other	7 (5%)
Education:	None	16 (11%)
	GCSE/ O level	40 (27%)
	A level/vocational qualification	49 (33%)
	Degree or above	41 (27%)
Ethnicity:	White British	145 (97%)
	White – other	3 (2%)
	Mixed ethnicity	1 (1%)

*Note.* Because of missing data N may not equal 150 and percentage may not total 100%.

### **The Brief COPE: Descriptive statistics**

Table 3 summarizes the descriptive statistics for the *Brief COPE*. There was considerable variation in the frequency with which the different subscales were reported. ‘Acceptance’ was the most frequently used coping strategy, followed by ‘Active Coping’ (taking action and exerting efforts to remove or ameliorate the stressor) and ‘Planning’ (thinking about how to cope with the stressor). ‘Positive Reframing’ (looking for something good in the situation) and ‘Self-Distraction’ (doing something to take one’s mind of the stressor) were also commonly used. The least used coping strategies were ‘Denial’, ‘Substance Use’ and ‘Behavioural Disengagement’ (giving up the attempt to deal with the stressor).

### **CAP: Descriptive statistics**

Following testing of the psychometric properties of the *CAP*, four subscales were accepted as having sufficient internal reliability to be considered as meaningful and specific coping strategies (Appendix XIV). These are shown in Table 4, along with descriptive statistics. It can be seen that ‘Attentiveness to the Stroke Survivor’ was the most frequently used coping strategy for managing communication problems. ‘Proactively Facilitating Communication’ and ‘Keeping a Positive Focus’ were also frequently used. ‘Avoidance’ was less often used on average, however the relatively large standard deviation shows that there was considerable individual variation.

Table 3.

*Descriptive Statistics for the Brief COPE*

<b>Type of coping</b>	<b>Mean score<sup>a</sup></b>	<b>SD</b>
	( )	
Acceptance	5.2	1.4
Active coping	4.3	1.6
Planning	4.3	1.6
Self-distraction	3.4	1.8
Positive Reframing	3.3	1.9
Use of Instrumental Support	2.6	1.8
Humour	2.5	1.9
Use of Emotional Support	2.2	1.6
Venting	2.0	1.4
Self-Blame	1.9	1.7
Religion	1.7	2.1
Substance Use	0.9	1.7
Behavioural Disengagement	0.9	1.4
Denial	0.7	1.4

<sup>a</sup> possible range 0-6.

Table 4.

*Descriptive statistics of subscales from the CAP*

<b>Subscale title and associated items</b>	<b>Brief description of subscale</b>	<b>Range of possible scores</b>	<b>Mean score</b>	<b>Standard Deviation</b>
Proactively Facilitating Communication. Items: 3, 4, 5, 6, & 8	Proactively involved in facilitating communication for the stroke survivor	0 - 15	11.5	2.7
Keeping a Positive Focus Items 12, 16, 17, & 18	Focusing on positive aspects of communication and not dwelling on difficulties	0 - 12	8.4	2.5
Attentiveness to the Stroke Survivor. Items: 1 & 2	Paying close attention to the stroke survivor and taking time to listen	0 - 6	5.6	1.0
Avoidance. Items: 9, 10 & 19	Trying to avoid upsetting the stroke survivor. Withdrawing when things get too difficult.	0 - 9	3.2	2.1



### **Depressive symptoms: Descriptive statistics**

The mean score on the *CES-D* was 16.2 ( $SD = 11.5$ ). 46% of the participants ( $N=69$ ) scored equal to or above 16 on the *CES-D* (the cut-off point for high levels of depressive symptoms (Radloff, 1977)).

### **Relationships with depressive symptoms**

Associations between the dependent variable and all other variables were explored using Mann-Whitney tests and Spearman's correlations. Multiple measurement was controlled by using  $p < .01$  as the cut off point for accepting a significant result<sup>8</sup>.

Significant associations were found between participants' *CES-D* score and the degree of communication impairment of the stroke survivor, with more severe communication impairment associated with a higher level of depressive symptoms ( $r = -.3$ ,  $p$  (two-tailed)  $< .01$ ).

Seven scales of the *Brief COPE* correlated significantly with *CES-D* score (Appendix XV). Greater use of 'Active Coping' and 'Positive Reframing' were significantly associated with lower levels of depressive symptoms, whereas greater use of 'Self-

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<sup>8</sup> Applying Bonferroni's correction would entail using a level of  $p < .001$  to determine significance. However Field (2005) states that Bonferroni's correction is a conservative test that lacks statistical power, thereby increasing the probability of a Type II error, which is not desirable at an exploratory stage of the analysis.

Distraction', 'Denial', 'Substance Use', 'Behavioural Disengagement', and 'Self-Blame' were significantly associated with higher levels of depressive symptoms. Only one scale of the *CAP* significantly correlated with *CES-D* score: the 'Avoidance' scale ( $r = .3$ ,  $p$  (two-tailed)  $< .01$ ). Greater use of 'Avoidance' was associated with higher levels of depressive symptoms.

*CES-D* score significantly correlated with all forms of social support, apart from 'Practical Support' ( $r = -.3$  ('Informational Support'),  $r = -.2$  ('Emotional Support'), and  $r = -.3$  ('Anticipated Support'),  $p$  (two-tailed)  $< .01$ ). Participants who were satisfied with the amount of 'Informational Support' and 'Emotional Support' reported lower levels of depressive symptoms (Mann-Whitney,  $U = 1633$  and  $1564$  respectively,  $p$  (two-tailed)  $= < .01$ ). In 99.9% of cases dissatisfaction with support meant that the participant wanted more of this type of support rather than less. Satisfaction with 'Practical Support' was not related to *CES-D* score.

No significant associations were found between participants' *CES-D* score and the gender, age-group, level of dependency of the stroke survivor, or the time since the stroke. Neither were significant associations were found between *CES-D* score and characteristics or circumstances of participants. As 97% of the participants were White-British, it was not possible to look at differences associated with ethnicity.

### **Regression analysis of the role of coping strategies in predicting level of depressive symptoms**

A hierarchical multiple regression was used to examine the association between coping and depressive symptoms. Only those variables that correlated significantly with *CES-D* score in the previous section were included in the regression<sup>9</sup>.

Usually, when performing hierarchical regression, the known predictors are entered into the model first, in order of their importance in predicting the outcome (Field, 2005).

After known predictors have been entered, any new predictors are added to the model. Models of stress and coping in carers (Pearlin et al., 1990; Schulz et al., 1988) suggest that, when assessing the association between coping and outcome, it is important to account for the effects of the stressor and of social support. The stressor (*CETI* score) was entered in the first block. Social support variables were entered in the second block in order to account for variance due to social support before entering coping variables, thus making it a more stringent test of the role of coping in predicting depressive symptoms. In the third block the variables from the *Brief COPE* were entered. In the last block, the 'Avoidance' scale from the *CAP* (the new predictor) was entered. Within each block the variables were entered using a forced entry method (they were entered into the model simultaneously).

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<sup>9</sup> If Bonferroni's correction had been used in the previous section when exploring associations between the dependent variable and the other variables, then the following variables would not have been significantly associated with *CES-D* score, and would not have been included as predictors in the regression: *CETI*, 'Self-Distraction', Informational Support, Emotional Support. However none of these variables were significant predictors in the final model. Therefore the application of Bonferroni's correction would not have changed the outcome.

The change in  $R^2$  at each step of the regression was significant. The final variance accounted for by the model was 55%. Table 5 shows the parameters of the final model (for the parameters at all four steps of the regression see Appendix XVI). The following variables were significant predictors in the final model:

- ‘Anticipated Social Support’;
- ‘Positive Reframing’, ‘Substance Use’, ‘Behavioural Disengagement’, and ‘Self Blame’ from the *Brief COPE*.
- The ‘Avoidance’ scale from the *CAP*.

### **Mediation analysis**

In order to test for condition 1 of Holmbeck’s (1997) conditions for mediation, the correlations between the stressor (*CETI*) and the hypothesized mediators (those coping strategies previously shown to be significantly associated with *CES-D* score) were explored. *CETI* score correlated significantly only with the ‘Avoidance’ scale from the *CAP* ( $r = -.2, p < .05$  (two-tailed)). Holmbeck’s conditions 2 and 3 for mediation were tested in the previous section.

Table 5.

*Summary of Final Step of Heirarchical Regression Analysis for Variables Predicting Depressive Symptoms (N = 134)*

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	Correlations		Collinearity Statistics	
					Zero-order	Partial	Tolerance	VIF
Constant	18.87	4.29		4.4**				
CETI	-0.34	0.39	-.06	-.87	-.26	-.08	.82	1.22
Informational Support	0.17	0.35	.04	.50	-.21	.05	.66	1.52
Emotional Support	0.29	0.33	.07	.86	-.19	.08	.51	1.95
Anticipated Support	-0.91	0.37	-.20	-2.43*	-.34	-.22	.54	1.87
Satisfaction with Informational Support	-0.97	1.57	-.04	-.62	-.26	-.06	.75	1.34
Satisfaction with Emotional Support	-2.01	1.80	-.09	-1.12	-.28	-.10	.57	1.74
Active Coping	-0.94	0.55	-.12	-1.71	-.30	-.16	.72	1.39
Positive Reframing	-0.90	0.44	-.15	-2.05*	-.28	-.19	.69	1.45

Table 5 continued.

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	Correlations		Collinearity Statistics	
					Zero-order	Partial	Tolerance	VIF
Self-Distraction	0.06	0.42	.01	.15	.24	.01	.83	1.21
Denial	0.24	0.60	.03	.40	.33	.04	.73	1.37
Substance Use	1.38	0.46	.22	3.00**	.42	.27	.72	1.38
Behavioural Disengagement	1.44	0.57	.17	2.52**	.27	.23	.82	1.22
Self-Blame	2.28	0.49	.33	4.67**	.48	.39	.74	1.35
Avoidance (from <i>CAP</i> )	0.92	0.39	.16	2.38*	.40	.21	.79	1.27

Note.  $R^2 = .07$  for Step 1;  $\Delta R^2 = .12$  for Step 2 ( $ps = \leq .01$ );  $\Delta R^2 = .36$  for Step 3 ( $ps = \leq .01$ );  $\Delta R^2 = .02$  for Step 4 ( $ps = < .05$ ).

\*  $p \leq .05$       \*\*  $p \leq .01$

In order to meet condition 4 for mediation, the impact of the predictor on the dependent measure must be less after controlling for the mediator. A regression analysis was performed to test this (Table 6). It can be seen that the value of  $\beta$  for the predictor (CETI score) decreased after controlling for 'Avoidance', thereby fulfilling conditions for a mediating role of this coping strategy in predicting the relationship between degree of communication impairment in the stroke survivor and level of depressive symptoms in the carer. CETI score remained a significant predictor of depressive symptoms, therefore 'Avoidance' can only be described as a partial mediator.

Table 6. *Summary of Hierarchical Regression Analysis for Mediating Role of 'Avoidance' in Predicting Depressive Symptoms*

	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>R</i> <sup>2</sup>
Step 1:					
CETI score	-1.47	.47	-.26	-3.11**	.07
Step 2:					
CETI score	-1.01	.45	-.18	-2.27*	
'Avoidance'	2.13	.44	.38	4.83**	0.2

\*  $p < .05$

\*\*  $p < .01$

It is recognised that Holmbeck's method for determining mediation (which is based on the Baron and Kenny (1986) method) suffers various limitations. These include an increased possibility of a Type II error (see Appendix XVIII), and not addressing

whether the indirect effect of the mediator differs significantly from zero (Preacher & Hayes, 2004). Bootstrapping is a way to overcome the latter, and this was used to test the significance of the mediating effect. Bootstrapping is a non-parametric procedure that involves repeatedly taking random samples from the data and calculating the size of the indirect effect of the mediator in the resamples. Confidence intervals for the indirect effect are estimated over many bootstrap resamples. In order to accept that the mediating effect is significant, the confidence intervals should not contain zero. Using bootstrapping with 2000 samples, the mean indirect effect for 'Avoidance' was -.45 and the true indirect effect was estimated to lie between -1.13 and -.05 with 99% confidence<sup>10</sup>, and therefore was significantly different from zero at  $p < .01$  (two-tailed). The indirect effect of 'Avoidance' explained 4% of the variance in depressive symptoms.

## Discussion

### Summary of findings

This is, as far as the author is aware, the largest quantitative study to look at coping by informal carers of stroke survivors with aphasia, and to explore the association between coping with communication problems and symptoms of depression.

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<sup>10</sup> 99% confidence intervals were selected to control for the effect of multiple testing because a further seven bootstrapping tests were carried out with other coping strategies (Appendix XVIII)



The first aim of the study was to describe the coping strategies used by informal carers of stroke survivors with aphasia to manage communication problems. Considering the results of the *Brief COPE* and the *CAP* together, the findings showed that participants most frequently used problem-focused approach strategies (particularly ‘Active Coping’ and ‘Planning’ from the *Brief COPE*, and ‘Attentiveness to the Stroke Survivor’ and ‘Proactively Facilitating Communication’ from the *CAP*) and emotion-focused approach strategies (particularly ‘Acceptance’ and ‘Positive Reframing’ from the *Brief COPE*, and ‘Keeping a Positive Focus’ from the *CAP*). The coping strategies used least to manage communication problems were the avoidance strategies of ‘Denial’, ‘Substance Use’, ‘Behavioural Disengagement’ from the *Brief COPE* and ‘Avoidance’ from the *CAP*.

It is interesting that participants in this study frequently used acceptance as a way of coping with communication problems. The use of acceptance as a coping strategy has been reported in previous literature on coping by informal carers of stroke survivors with aphasia (Greenwood, Mackenzie, Cloud, & Wilson, 2009), however the paucity of studies in this area makes it impossible to ascertain whether the level of acceptance reported in this study is unusually high. There is no normative data for the *Brief COPE*, however Carver, Scheier and Weintraub (1989) present data on the *COPE* from a large sample of undergraduates and this also showed a high use of acceptance. The participants in this study were not, to the authors knowledge, in receipt of any services that aimed to increase their level of acceptance (such as Acceptance and Commitment Therapy), and indeed there is a recognised need for more support and services for carers

of stroke survivors (Department of Health, 2007). Therefore if the level of acceptance in the present study materialises to be unusually high, then one could speculate that this is something specific to coping with communication problems, or that high levels of acceptance are more common in carers who are members of support groups, which was how the participants for the present study were recruited.

The second aim of the study was to explore the relationship between coping and symptoms of depression, and to describe which coping strategies were associated with increased or reduced symptoms of depression. The regression model showed that the level of 'Anticipated Social Support' was negatively related to symptoms of depression: as 'Anticipated Social Support' increased, depressive symptoms decreased. This adds credence to Krause's (1999) argument that anticipated support (the belief that significant others would be willing to provide assistance in the future should the need arise) is an important aspect of social support. Krause demonstrated this with respect to older adults, but as far as the author is aware, this is the first study to show this relationship in a carer population. A significant negative relationship was also found between the coping strategy 'Positive Reframing' and depressive symptoms. The use of the coping strategies 'Substance Use', 'Behavioural Disengagement', 'Self Blame' and 'Avoidance' were positively associated with depressive symptoms: more frequent use of these coping strategies to manage communication problems was related to higher levels of depressive symptoms.

The results of this study suggest that the level of communication impairment of the stroke survivor is not a significant predictor of depressive symptoms in informal carers after controlling for the effect of coping. This finding is concordant with previous literature showing that the level of impairment of the stroke survivor has a lesser effect on carers' longer term psychosocial functioning compared to that of coping (Forsberg-Wärleby, Möller, & Blomstrand, 2004; Visser-Meily et al., 2009).

The third aim was to ascertain whether including questions designed specifically for coping with communication problems improved the explained variance in depressive symptoms, beyond that accounted for by a traditional coping inventory. Only one of the scales from the *CAP* was significantly associated with depressive symptoms – the 'Avoidance' scale. The information from this scale added an extra 2% to the variance accounted for in depressive symptoms. Although this was statistically significant, it is small compared to the amount of variance already accounted for by the *Brief COPE* (36%). This suggests that a generic coping inventory, such as the *Brief COPE*, is an adequate assessment of how carers of stroke survivors with aphasia cope with communication problems. Additional questioning however may be useful in eliciting more information about avoidance, withdrawal and giving up. It would seem that the questions in the *CAP* that asked specifically about withdrawal and avoidance in relation to communication problems were able to draw out extra information that was not gained from the more general questioning in the *Brief COPE*.

The final aim of the study was to look at whether coping mediated the relationship between the severity of communication difficulties of the stroke survivor and depressive symptoms in informal carers. Of all the coping strategies that were assessed, only 'Avoidance' satisfied the conditions for (partial) mediation. Use of 'Avoidance' was associated with a poorer level of functional communication in the stroke survivor, and with a greater level of depressive symptoms in the carer.

### **Limitations and issues to consider when interpreting the results**

A post-hoc power analysis for the multiple regression showed that, as intended, there was a high power (0.8) to detect a medium effect size for the change in variance at each step (Appendix XIX). It was not possible to calculate power for the individual predictors where more than one predictor was entered simultaneously (i.e. the subscales of social support, and the subscales of the *Brief COPE*). It should be noted that the power of the regression analysis to detect small effect sizes was limited, and therefore it is possible that Type II errors may have occurred and individual predictors may have been falsely rejected as not predictive of the variance in depressive symptoms.

Bootstrapping was used to test significance for the mediation analysis. Although no power calculations were performed for this, bootstrapping is a powerful strategy for testing mediation (Preacher and Hayes, 2004), and confidence intervals are produced around the effect size of the mediator, thereby quantifying uncertainty in the results.

It should be emphasised that the associations reported in this study between coping and depressive symptoms do not imply a causal relationship. Coping by avoidance, substance use, and self-blame could be argued to be a consequence of high levels of depressive symptoms. Similarly one might expect carers who experience more depressive symptoms to believe that others are not likely to help them in the future, and therefore the direction of causality between 'Anticipated Social Support' and depressive symptoms is unclear. Having said this, longitudinal studies, which are able to explore causal associations, have showed that active styles of coping appear to lead to a better psychosocial outcome, and passive styles of coping to a worse outcome (Visser-Meily et al., 2009).

It is important to remember that the index of depression used in this study does not imply a diagnosis, but rather gives information about the level of depressive symptoms. The cut-off score identifies people at high risk for depression. The figure of 46% of informal carers reporting a high number depressive symptoms is similar to that found by Visser-Meily et al. (2009), who reported that 50% of spouses of stroke survivors (not just those with aphasia) had high levels of depressive symptoms. Others however have reported lower figures, for example Schulz et al. (1988) reported that 34% of primary support persons of stroke survivors scored above the cut-off point for likely depression. There is variation in the literature regarding the prevalence of depression among informal carers of stroke survivors. Comparison between studies is hampered by use of different measures, different sampling methods, and variations in time post-stroke.

None of the background variables of the carer or the stroke survivor were related to level of depression in the carer. This is not a consistent finding in the literature. Some studies looking at carers of stroke survivors have reported that caregiver depression is associated with the age and income of the carer (Schulz et al., 1988), whether or not they live with the stroke survivor (Franzén-Dahlin et al., 2007), or with gender of the carer (Visser-Meily et al., 2009). Other literature looking at carers more generally has commented on the significance of the carer's gender in relation to stress and outcome (Oyebode, 2003; Pruchno, Kleban, Michaels, & Dempsey, 1990). Possible reasons why gender was not found to be a significant factor in this study are firstly that, whilst the gender of the carer may affect outcome for some types of stressor, it may not be relevant for coping with communication problems. Secondly gender may have a moderating effect on the relationship between communication problems and depressive symptoms in the carer. The analysis for this study did not include pathways for moderating variables.

Caution must be applied to accepting a significant mediating role for 'Avoidance', because the psychometric properties of the *CAP* (from which this subscale came) have not been fully established. It is perhaps surprising that none of the coping strategies from the *Brief COPE* were found to be significant mediators. On closer consideration however, the *Brief COPE* can be criticized for the low item number per subscale, and the internal reliability of some of the subscales is questionable. There were weaknesses in the psychometric properties of both the *Brief COPE* and the *CAP*, and this may have affected the findings. The *Brief COPE* was selected because it is a theoretically

grounded instrument that provides information about a wide range of coping behaviours and because it can be used to assess stressor specific coping. It was chosen over the full *COPE* because of its acceptable length, but the trade-off is that its psychometric properties are weaker. Possibly the use of the full *COPE*, with its more robust subscales, would have revealed that more coping strategies fulfilled a mediating role.

It must be emphasized that this study only considered coping as a mediator. Although traditionally it is theorized that coping mediates the effect between stressor and outcome, research suggests that it also operates through other pathways. Pruchno and Resch (1989), for example, found that different coping strategies affect outcome in different ways, some through a main effect and some through a mediating effect. Holmbeck (1997) argues that coping could plausibly act as a moderator of stress, i.e. certain types of coping may act as a buffer against the negative effects of stress. To test this one would need to explore the interaction between stressor and coping in order to assess whether the causal relationship between stress and outcome changed as a function of coping.

It is acknowledged that the method of recruitment used in this study biased the sample towards inclusion of informal carers who were in contact with support organisations. Therefore a representative sample cannot be claimed. The present sample is similar to that of other studies in terms of predominance of females and of spouse carers (Greenwood, MacKenzie, Cloud, & Wilson, 2008; Low et al., 1999). The geographical spread of the sample covered most regions of England, and included some participants

from Wales, Northern Ireland and Scotland. A comparison of the *IMD* scores for the present sample with the data for England (Department of Communities and Local Government, 2007) however suggests that the participants were, on average, less deprived than the wider population, and therefore were not representative of informal carers from areas of higher deprivation. It should also be noted that the sample were almost totally of white British ethnicity. In addition to the issue of representativeness, there was also concern over whether all of the variables in the regression met the assumptions of homoscedasticity, which means that the results of the study need to be verified in other populations before they can be accepted. For these reasons, extreme caution must be applied to generalising from the results of this study.

It was not possible in this study to obtain a formal diagnosis of aphasia. The *CETI* was used as a measure of the severity of the stroke survivor's communication impairment. This is not a measure of aphasia, however it does correlate with such measures. Some research implies that carers do not accurately estimate the communication skills of aphasic stroke survivors (Helmick, Watamori, & Palmer, 1976), however others have argued that ratings from a significant other are equally valid to those of professionals (Holland, 1977; Taylor-Sarno, 1993).

### **Wider discussion of results and considerations for future research**

The focus of this study was how informal carers of stroke survivors with aphasia cope with a specific stressor, and how this is related to depressive symptomology. There are



many other factors, in addition to coping, that may influence the relationship between stressor and outcome. The present study was able to consider only some of these. Other factors that would have been interesting to include are the quality of the premorbid relationship between the informal carer and the stroke survivor (Oyebode, 1993), and the impact of personality changes in the stroke survivor (Stone et al, 2004). There are also additional factors to take into account when considering outcome, apart from depressive symptomology. Previous literature has highlighted the importance of including positive aspects of mental health (Steed, 1999), and it has been shown that different coping strategies are related to different aspects of mental health (Pruchno & Resch, 1989). Low et al. (1999) call for a multi-dimensional approach to outcome assessment for carers of stroke survivors, which includes psychological health, physical health, functional status and social health. Having said this, the inclusion of too many variables can make the analysis unwieldy, and depression is one of the key factors to assess as it is predictive of other outcome variables, such as health decline (Pruchno et al., 1990).

The decision was made in this study to look at stressor-specific coping. The advantages of this approach are that it follows closely from a theoretical model of stress and coping, and that it provides clear and clinically relevant information. However, carers of stroke survivors with aphasia have to cope with the whole impact of the stroke, not only with communication problems. It is also likely different problems interact with each other, and that the coping strategies used to manage these problems are not targeted at individual problems but rather directed at a range of problems that present concurrently.

This study raises the question of how easy, and even how valid, it is for carers to separately report on the coping strategies they use to manage communication problems. This may be a further reason why this study did not find strong evidence that coping mediated the relationship between communication problems and symptoms of depression. It is arguably useful to look at stressor specific coping however, as Lazarus (1999) writes, in order to truly understand how individuals cope it is important to use a broad spectrum of methods and to be able to move between levels of abstraction, sometimes considering component parts and other times looking at the whole picture. This necessitates an outlook of methodological pluralism, where the findings from multiple and diverse research procedures are converged, and the respective values and strengths of each are optimised (Steed, 1998).

### **Clinical applications**

In the National Stroke Strategy (Department of Health, 2007) it is recommended that carers are trained in methods for managing communication difficulties and in the use of coping strategies to promote emotional well-being. The results of this study provide information that usefully contributes to a knowledge base for the implementation of these guidelines.

The results emphasize that measures of stress are not a good predictor of which carers are vulnerable to high levels of depressive symptoms, and are therefore not a sound basis for deciding where to target interventions. The results suggest that a stress-coping

model, such as Lazarus and Folkman's (1984), can be helpful in deciding where to aim resources. It was shown that carers who reported a high frequency of coping by avoidance, disengagement, self-blame, or substance use had a greater level of depressive symptoms, and this could help to identify those carers who may benefit from additional support. The present study showed that the *Brief COPE* provides a useful assessment of the coping strategies used for managing communication problems, and this can be supplemented by additional, more specific, questions on avoidance and withdrawal such as those in the *CAP*.

Visser-Meily, van Heugten, Post, Schepers, and Lindeman (2005), in a critical review of intervention studies for caregivers of stroke survivors, found that counseling-based interventions gave the highest chance of a positive outcome. These were programmes aimed at teaching coping strategies to reduce the negative effects of stress. Published clinical guidelines for carers of stroke survivors suggest that counselling interventions aimed at increasing active problem-solving behaviour and support-seeking behaviour have a positive effect on emotional well-being and on the capacity to maintain social support, and it is recommended that such interventions should be offered to vulnerable carers (van Heugten, Visser-Meily, Post, & Lindeman, 2006). Eldred and Sykes (2008) conducted a systematic review of psychosocial interventions for carers of stroke survivors and recommended that interventions designed to promote problem-solving and coping should be offered to primary carers. The results of the present study link well with the findings from these reviews, and suggest that counselling and educative interventions with carers could usefully also aim to decrease the use of unhelpful coping

strategies such as avoidance. Interestingly the present study did not find an association between active, problem-solving coping and lower levels of depressive symptoms. It was found, however, that positive reframing (an emotion-focused, approach style of coping) was related to fewer depressive symptoms. The stressor in the present study was communication problems caused by aphasia, which is a chronic and largely uncontrollable form of stress. Lazarus and Folkman's (1984) theory suggests that emotion-focused coping strategies are often used to deal with stressors that are beyond the individual's control. The results of this study therefore imply that interventions with carers should not focus totally on active problem-focused coping at the expense of teaching helpful emotion-focused coping strategies.

This study also highlighted the importance of considering anticipated social support when designing interventions for carers of stroke survivors. Anticipated social support refers to the individual's perception of whether or not help would be there in the future should the need arise, for instance someone who could provide support if the carer was taken ill. This is an understandable concern for carers, who may worry that if something should happen to them there would be no-one else to take over caring responsibilities. More work needs to be done to establish a causal link between anticipated social support and depressive symptoms, and also to determine what kind of anticipated social support carers are most concerned about (i.e. emotional support, practical support, or both). However, the findings of this study tentatively indicate that it would be beneficial for interventions to address carer's concerns about where they could access more support in the future should they need it.

## **Conclusion**

This study has built on and improved previous work, and has gone some way to answering calls for more research looking at coping by informal carers of stroke survivors with aphasia. Further research is needed, particularly with samples that are diverse in terms of ethnicity and levels of social deprivation. There is scope for both qualitative and quantitative studies, and for research employing multidimensional assessments of outcome, so as to expand understanding of coping by informal carers of stroke survivors with aphasia. Ideally future studies would employ a longitudinal design to capture the dynamic nature of stress and coping, and to explore causal relationships. Given the importance of establishing the theoretical basis for mechanisms of action, more attention needs to be paid to evaluating the mechanism through which coping operates, and consideration should be given to the likelihood that different forms of coping operate via different pathways. Ultimately more understanding is needed so that guidelines such as the National Stroke Strategy (Department of Health, 2007) can provide more specific recommendations about the delivery of high quality and effective care for informal carers of stroke survivors.

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## **Appendix I**

### **Aphasiology: Instructions for authors**

## GENERAL GUIDELINES

*Aphasiology* is concerned with all aspects of language impairment and related disorders resulting from brain damage. The journal encourages papers which address theoretical, empirical, and clinical topics from any disciplinary perspective; cross disciplinary work is welcome. *Aphasiology* publishes peer reviewed clinical and experimental research papers, review essays, theoretical notes, comments, and critiques. Research reports can take the form of group studies, single case studies, or surveys, on psychological, linguistic, medical, and social aspects of aphasia. Ideas for Clinical Fora are welcome.

*Aphasiology* publishes several kinds of contribution:

- review articles - peer-refereed, reflective theoretically based papers exploring existing thinking, methodologies, and presenting new perspectives.
- research reports - accounts of qualitative and quantitative enquiries, including implications for future practice and directions for future research.
- clinical forums - discussion and exchanges of views on key clinical issues.
- research notes - short reports on work of a preliminary nature.
- book reviews - concise and critical insights into newly published books.

### **Submitting a paper to *Aphasiology***

Please read these Guidelines with care and attention: failure to follow them may result in your paper being delayed. Note especially the referencing conventions used by *Aphasiology* and the requirement to avoid gender-, race-, and creed-specific language, and for adherence to the Ethics of Experimentation.

*Aphasiology* articles have a maximum limit of 7,500 words. This 7,500 words is to include main text only. It excludes title, author's contact details, abstract, references, figures, tables, captions and footnotes.

- Please write clearly and concisely, stating your objectives clearly and defining your terms. Your arguments should be substantiated with well reasoned supporting evidence.
- In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the journal, and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.
- For all manuscripts, gender-, race-, and creed-inclusive language is mandatory.
- Ethics of Experimentation: Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.
- Abstracts are required for all papers submitted, they should be between 150 and 400 words and should precede the text of a paper; see 'Abstracts'.
- Manuscripts should be **double-spaced** throughout, including the reference section.
- Authors should include telephone and fax numbers as well as e-mail addresses on the cover page of manuscripts.

## **ABSTRACTS**

### **Structured Abstracts:**

Authors submitting papers should note that from Volume 16 Issue 1 (2002), the journal is introducing Structured Abstracts. There is good evidence that Structured Abstracts are clearer for readers and facilitate better appropriate indexing and citation of papers.

The essential features of the Structured Abstract are given below. Note in particular that any clinical implications should be clearly stated.

### **Review Abstract:**

*Background:* Outline the background to the review.

*Aims:* State the primary objective of the paper; the reasons behind your critical review and analyses of the literature; your approach and methods if relevant.

*Main Contribution:* The main outcomes of the paper and results of analyses; and any implications for future research and for management, treatment or service delivery.

*Conclusions:* State your main conclusions.

## **CODE OF EXPERIMENTAL ETHICS AND PRACTICE**

Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

When experimental animals are used, state the species, strain, number used, and other pertinent descriptive characteristics.

For human subjects or patients, describe their characteristics.

For human participants in a research survey, secure the consent for data and other material -- verbatim quotations from interviews, etc. -- to be used.

## **FORMAT**

Papers should be prepared in the format prescribed by the American Psychological Association. For full details of this format, please see the *Publication Manual of the APA* (5th edition).

Authors and referees please note that *Aphasiology* requires that the word 'aphasic' is written as an adjective, not a noun. There are two reasons for this. The first is the grammatical one and the second is that it is perceived as offensive by some to describe an aphasic person as 'an aphasic'. The first reason is trivial but adds support to the second, which is important. So the word 'aphasic' should always be qualified by 'participants, speaker, subject, client, patient, person', whichever is appropriate for the field of study (e.g., 'patient' in the context of a medical study, 'speaker' for linguistic and phonetic studies).



**Appendix II**

**Studies looking at problems for  
informal carers of stroke survivors with aphasia**

<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant results</b>
Artes & Hoops (1976) USA	Cross-sectional. Quantitative: questionnaire-based interview.	Wives of SS with (35) and without (30) aphasia, identified from hospital records.	Three months to five years.	Wives of SS with aphasia reported more problems than wives of SS without aphasia with: economic difficulties, social limitations, temper outbursts and complaining/criticism from the SS.
Bowling, (1977) Australia	Cross-sectional. Part 1. Qualitative: observation of issues raised by group members Part 2. Quantitative: questionnaire	Part 1: 60 relatives of SS attending a group. 25% had aphasic partners. Part 2: 22 from above sample	Not stated.	Part 1: Main issues were: communication problems, lifestyles changes, role difficulties, and emotional concerns. No separation of issues for relatives of aphasic and non-aphasic SS. Part 2: Wives of SS with aphasia reported more emotional problems, depressive complaints, and sleep problems than wives of SS without aphasia.

<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant results</b>
Christensen & Anderson (1989) USA	Cross-sectional. Quantitative: questionnaire.	Spouses of SS with (11) and without (11) aphasia, identified from hospital records.	1 to 1.5 years	Spouses of SS with aphasia reported significantly greater role changes, more emotional and/or health problems, and more social adjustment problems than spouses of SS without aphasia.
Denman (1998) UK	Cross-sectional. Qualitative: semi- structured interview	9 spouses of SS with aphasia. Convenience sample.	At least one year	Problems identified were: lack of support, lack of training, lack of information, challenges associated with role changes, and the need to have a break.

<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant results</b>
Herrmann, Britz, Bartels, & Wallesch (1995) Germany	Longitudinal. Quantitative: questionnaire.	25 relatives of SS with aphasia and 33 relatives of SS without aphasia, recruitment details not supplied.	First year post- stroke	Families of SS with aphasia were more severely affected by professional and social changes than families of SS without aphasia.
Herrmann & Wallesch (1989) Germany	Cross-sectional. Quantitative: questionnaire	20 relatives of SS with aphasia, recruitment details not supplied.	15 to 108 months	Changes reported in each area covered by questionnaire: professional, social, familial, and psychological.

<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant results</b>
King & Shade- Zeldow (1995)  USA	Longitudinal.  Mixed  quantitative and qualitative	Spouses of SS with (15) and without aphasia (20)	First year post- rehabilitation.	Problems identified were: emotional difficulties, role changes/multiple responsibilities, and managing care of SS.
Kinsella & Duffy (1979)  UK	Cross-sectional.  Quantitative: semi-structured interview and questionnaires.	Spouses of SS with aphasia (8), aphasia plus hemiplegia (28), and hemiplegia (43), identified through rehabilitation centres.	3 months to 3 years	Spouses of SS with aphasia were lonelier and reported more marital problems than spouses of SS with hemiplegia. Spouses of SS with aphasia plus hemiplegia were more bored, had poorer overall social adjustment, and (females) had higher prevalence of minor psychiatric disorder than spouses of SS with hemiplegia alone.

<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant results</b>
Le Dorze & Brassard (1995) Canada	Cross-sectional. Qualitative: semi-structured interview.	9 relatives or friends of SS with aphasia, convenience sample.	2 to 14 years	Problems reported with: communication, interpersonal relationships, increased responsibilities, behavioural changes in the SS, restricted activities, and stigmatization.
Malone (1969) USA	Cross-sectional. Qualitative: semi-structured interview.	25 family members of SS with aphasia. Recruitment details not supplied.	Not stated.	Problems identified with: role changes, irritability and guilt, social life, job and finances, health (mental and physical), and family problems.
Michallet, Le Dorze, & Tétreault (2001) Canada	Cross-sectional. Qualitative: semi-structured interview.	6 spouses of SS with severe aphasia, recruitment details not supplied.	Not stated	Problems identified with: lack of information, communication with SS, interpersonal relationships, being considered as a partner in the caring process, lack of support and respite.

<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant results</b>
Michallet, Tétreault, & Le Dorze (2003) Canada	Cross-sectional. Qualitative: semi-structured interview.	5 spouses of SS with aphasia, recruitment details not supplied.	At least one year post-discharge.	Problems reported with: communication, interpersonal relationships, responsibilities, leisure activities, and finances.
Mykata, Bowling, Nelson, & Lloyd (1976) Australia	Cross-sectional. Qualitative observational study.	Attendees of a support group for relatives of SS. Two-thirds had aphasic partners.	Post-inpatient rehabilitation.	Problems identified were: communication difficulties, role changes, fear that the SS would have another stroke, anxiety about leaving SS alone, preoccupation over cause of stroke, feelings of guilt.
Salonen (1995) Finland	Cross-sectional. Quantitative: questionnaire	274 SS with aphasia and their family members. Identified from hospital records.	3 to 4 years	Problems identified with: employment, leisure and social activities, and lack of information.

### **Appendix III**

**Studies looking at coping by informal carers of stroke survivors with aphasia  
and links between coping and outcome**



<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant measures</b>	<b>Relevant results</b>
Croteau & Le Dorze (1999) Canada	Quantitative. Cross- sectional: questionnaire based interview.	21 spouses of SS with aphasia, and 13 controls.	From 1 year to 12.7 years post-onset	The overprotection-dependency scale of the Questionnaire on Resources and Stress (QRS). The Functional Status Index.	Wives of SS with aphasia reported more overprotection than control group. No difference between for husbands of SS with aphasia and control group.
Croteau & Le Dorze (2006) Canada	Quantitative. Cross- sectional: questionnaire	18 couples including a SS with aphasia.	1 to 12 years	The overprotection-dependency scale of the QRS.	Reported overprotection was positively associated with “speaking for” behaviours by spouses.

<b>Authors, etc</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period</b>	<b>Relevant measures</b>	<b>Relevant results</b>
Herrmann, Britz, Bartels, & Wallesch (1995) Germany	Longitudinal. Quantitative: questionnaire survey.	See table in previous appendix	First year post- stroke	Freiburg Questionnaire on Coping with Illness.	Six months post-stroke: the coping strategy “religious belief/quest for sense” was most commonly reported by relatives of SS with aphasia. Use of the “distraction and self- organisation” strategy had increased in both groups at 12 months.
Le Dorze & Brassard (1995) Canada	Cross- sectional. Qualitative semi- structured interview.	See table in previous appendix	2 – 14 years post- stroke	None	Coping behaviours related to communication problems, interpersonal relationship difficulties, and increased responsibilities were reported.

<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant measures</b>	<b>Relevant results</b>
McClenahan & Weinman (1998) UK	Cross-sectional. Quantitative: questionnaire survey.	86 carers of SS with aphasia (53) and without aphasia (33). Recruitment details not supplied.	At least 11 months	General Health Questionnaire, COPE	Use of the coping strategies 'Venting' and 'Suppression' were positively associated with carer distress.
Michallet, Tétreault, & Le Dorze (2003) Canada	Cross-sectional. Qualitative: semi-structured interview.	See table in previous appendix	See table in previous appendix		Coping strategies grouped into those aimed at directly tackling the problem, those aimed at controlling the meaning of the problem, and those aimed at managing stress.

<b>Authors, date &amp; country</b>	<b>Design</b>	<b>Sample and recruitment</b>	<b>Time period post-stroke</b>	<b>Relevant measures</b>	<b>Relevant results</b>
Oranen, Sihvonen, Äystö, & Hagfors (1987) Finland	Cross- sectional.  Quantitative: questionnaire survey.	101 spouses of SS with aphasia, identified through aphasia association or health professionals.	1 month to 23 years	Unclear.	Five 'coping patterns' identified: 'Depressive', 'Nervous', 'Optimistic', 'Protective', and 'Guilt'. The best adjusted families showed an 'Optimistic' coping pattern, and the least adjusted a 'Depressive' or 'Nervous' coping pattern. Spouses self-rated their own family adjustment which may have confounded results.

**Appendix IV**

**Theoretical and Methodological Flaws in Oranen et al. (1987) study**

The aims of the Oranen et al. (1987) study were: to investigate the changes occurring in the lives of families of aphasic people (as experienced and expressed by the spouse), to examine the coping mechanisms of the families; and to consider these mechanisms as a function of family adjustment and the duration of aphasia.

The authors state that “questionnaires” were sent to 126 spouses of aphasic people identified via speech therapists or via the regional aphasia association. Hardly any information on the questionnaire was provided, other than that it included 112 items covering various areas relating to the study aims. No information was given on whether the questionnaire was developed specifically for this study, or whether items were borrowed from pre-existing measures. No information was given on the psychometric properties of the questionnaire.

Although one of the main aims of the study relates to coping, there is no discussion of the literature on coping and no reference to theoretical models of coping. The authors do not offer a definition of what they considered coping to be. Coping was assessed by a factor analysis of items on the questionnaire relating to “attitudes and moods”. A five factor solution was identified, and the resulting factors were termed “coping patterns”. The labels they use do not pertain to any recognised theoretical understanding of coping, and seem to confuse emotional states with coping (e.g. “depressive”, “nervous”, “protective”, “optimistic” and “guilt”).

Family adjustment was rated by the spouses on a scale from 1 to 5. Again no discussion

was given of the validity or reliability of this measure of family adjustment. The authors correlated the coping patterns with family adjustment. It was found that the best adjusted families were characterised by an optimistic coping pattern, and the least well-adjusted families by a depressive or nervous coping pattern. This would seem to be a circular pattern – arguably an individual prone to optimism would rate their family adjustment as better and would also report more optimistic answers, and conversely an individual experiencing low mood or depression would arguably rate their family adjustment as worse and would report answers resonant with low mood or anxiety.

It was considered that this study did not share the same theoretical understanding of coping as that which is widely recognised in the literature. The “coping patterns” overlap with emotional states, and it is arguably not meaningful that they correlate with self-rated family adjustment. It was considered that it would be confusing and misleading to include this study in the main body of the review.

**Appendix V**

**Stroke: Instructions for authors**



Stroke: A Journal of Cerebral Circulation publishes reports of clinical and basic investigation of any aspect of the cerebral circulation and its diseases from many disciplines, including neurology, internal medicine, radiology, nuclear medicine, neuropathology, neurosurgery, epidemiology, vascular surgery, rehabilitation, anesthesiology, critical care medicine, vascular physiology, neuropsychology, speech pathology, and neuro-ophthalmology.

### **Instructions to Authors**

*Original Contributions.* For preparation, see "General Instructions." Maximum length for manuscripts is 4000 words. Please note, that the 4000-word limit **includes** title page, abstract, main body of text, references, and figure legends. Authors should eliminate redundancy, emphasize the central message, and provide only the data necessary to convey that message. **Please note, that accepted manuscripts received after December 1, 2008 exceeding the 4000 word count limit, will incur excessive word count penalty charges, and be published ONLINE ONLY.** The total number of figures and/or tables is limited to 6. A maximum of an additional 2 figures or 2 tables or 1 of each may be submitted for publication online only, at the discretion of the editor. They must be clearly labeled as "online only" on the title page and in references throughout the paper and should be placed at the very end of the manuscript. No other text will be considered for "online-only" publication. There should be no more than 1 figure or 1 table for every 750 words.

### **General Instructions**

- Type manuscripts double-spaced, including references, figure legends, and tables, on one side of the page only.
- Leave 1-inch margins on all sides. Number every page, beginning with the abstract page, including tables, figure legends, and figures.
- Cite each figure and table in text in numerical order.
- Cite each reference in text in numerical order and list in the References section. In text, reference numbers may be repeated but not omitted.
- Use SI units of measure in all manuscripts. For example, molar (M) should be changed to mol/L; mg/dL to mmol/L; and cm to mm. Units of measure previously reported as percentages (eg, hematocrit) are expressed as a decimal fraction. Measurements currently not converted to SI units in biomedical applications are blood and oxygen pressures, enzyme activity, H<sup>+</sup> concentration, temperature, and volume. The SI unit should be used in text, followed by the conventionally used measurement in parentheses. Conversions should be made by the author before the manuscript is submitted for peer review.
- Consult the *American Medical Association Manual of Style*, 9th ed, Baltimore, Md, Williams & Wilkins, 1997, for style.
- When reporting randomized controlled trials, please adhere to the CONSORT (Consolidated Standards of Reporting Trials) statement (<http://www.consort-statement.org>)
- Please provide sex-specific and/or racial/ethnic-specific data, when appropriate, in describing outcomes of epidemiologic analyses or clinical trials; or

specifically state that no sex-based or racial/ethnic-based differences were present. See the [Uniform Requirements](#) for more details.

- Assemble manuscript in this order: (1) author information page, (2) acknowledgments and funding page, (3) title page, (4) abstract page, (5) text, (6) references, (7) tables, (8) figure legends, (9) figures.
- Specify the number of words on your title page. Word count should include all parts of the manuscript (abstract, manuscript text, references, figure legends, etc). Over-length manuscripts will **NOT** be accepted for publication.
- Consult current issues for additional guidance on format.

#### **4. Abstract**

- Do not cite references in the abstract.
- Limit use of acronyms and abbreviations.
- Be concise (250 words, maximum). The abstract should have the following headings: Background and Purpose (description of rationale for study), Methods (brief description of methods), Results (presentation of significant results), and Conclusions (succinct statement of data interpretation).

#### **5. Text**

- Follow the instructions in "General Instructions."
- The following are typical main headings: Materials and Methods, Results, Discussion, and Summary.

- Abbreviations must be defined at first mention in the text, tables, and figures.
- *Methods section.* For any apparatuses used in Methods, the complete names of manufacturers must be supplied. For animals used in experiments, state the species, strain, number used, and other pertinent descriptive characteristics. For human subjects or patients, describe their characteristics. When describing surgical procedures on animals, identify the preanesthetic and anesthetic agents used, and state the amount or concentration and the route and frequency of administration for each. The use of paralytic agents, such as curare or succinylcholine, is not an acceptable substitute for anesthetics. For other invasive procedures on animals, report the analgesic or tranquilizing drugs used. If none were used, provide justification for such exclusion. Generic names of drugs must be given. Manuscripts that describe studies on humans must indicate that the study was approved by an institutional review committee and that the subjects gave informed consent. Reports of studies on both animals and humans must indicate that the procedures followed were in accordance with institutional guidelines.

**Appendix VI**

**Advert for study**

## **Coping and well-being among informal carers of stroke survivors with aphasia**

### **A research study is looking for people to take part**

If you care for a partner, friend or family member who has had a stroke resulting in aphasia, if they had the stroke over one year ago, and if you are over 18 years old, then we invite you to take part in a postal questionnaire study



### **Why should I do it?**

- **To improve understanding of how carers cope with communication problems and associated stress**
- **To improve the quality of future services for informal carers of stroke survivors with aphasia**

### **For an information pack**

#### **Contact:**

**Rhona McGurk, Trainee Clinical Psychologist**

**Department of Clinical Psychology,**

**34 Bassett Crescent East, Southampton, S016 7PB**

**Freephone 0800 7833 011**

**or Email: [rm306@soton.ac.uk](mailto:rm306@soton.ac.uk)**

## **Appendix VII**

**Articles about study that appeared in the newsletters of support organisations**

## Do you care for someone with aphasia?

If you care for someone who has aphasia as a result of a stroke which happened over a year ago, then we'd like to invite you to take part in our postal survey. The survey is being run by Southampton University and hopes to improve understanding of how carers of stroke survivors with aphasia cope with the challenges of this role, and to improve future services for such carers. If you're over 18 and would like to help us with this survey, contact Rhona McGurk, Trainee Clinical Psychologist for an information pack on freephone 0800 7833 011, or email [rm306@soton.ac.uk](mailto:rm306@soton.ac.uk)





### Coping and well-being amongst informal/family carers of stroke survivors with aphasia

People are being sought for a postal survey looking at the relationship between coping and psychological well-being in family/informal carers of stroke survivors with aphasia. Research suggests that carers of stroke survivors with aphasia experience greater levels of strain than carers of stroke survivors who do not have aphasia. Unfortunately to date there is little research that tells us how informal carers, such as partners and other family members, cope with the challenges of caring for someone who has aphasia. This is a study that seeks to answer this question. We are focusing on the ways in which informal carers cope with the communication problems that arise when you care for someone who has aphasia, and how carers deal with the stress these problems can cause. The study will also look at which coping strategies are associated with greater well-being in carers. It is hoped that the results of the study will be used to improve the quality of information and therapeutic interventions offered by health professionals to people with aphasia and their families.



If you care for a partner, friend or family member who had a stroke more than one year ago that resulted in aphasia and you would like to find out more about this study, please contact Rhona McGurk, trainee clinical psychologist, by calling freephone 0800 7833 011, e-mailing [rm306@soton.ac.uk](mailto:rm306@soton.ac.uk), or writing to the Department of Clinical Psychology, 34 Bassett Crescent East, Southampton, SO16 7PB (mark letters for the attention of Rhona McGurk, Trainee Clinical Psychologist). She will send you an information pack. Potential participants should be 18 years of age or older.

## **Appendix VIII**

### **Emails confirming ethical approval**

**Your Ethics Form approval**

Psychology.Ethics.Forms@ps1.psy.soton.ac.uk  
[Psychology.Ethics.Forms@ps1.psy.soton.ac.uk]

You forwarded this message on 7/14/2008 9:18 AM.

**Sent** Saturday, July 12, 2008 12:12 PM  
:

**To:** [mcgurk r. \(rm306\)](#)

This email is to confirm that your ethics form submission for "Understanding carers coping with aphasia: are generic coping inventories good enough?" has been approved by the ethics committee

Project Title: Understanding carers coping with aphasia: are generic coping inventories good enough?

Study ID : 517

Approved Date : 2008-07-12 12:12:45

[Click here to view Psychobook](#)

If you haven't already submitted the Research Governance form for indemnity insurance and research sponsorship along with your ethics application please be aware that you are now required to fill in this form which can be found online at the link below.

Research Governance Form:

[http://www.psychology.soton.ac.uk/psyweb/psychobook/admin/ethics/research\\_governance.doc](http://www.psychology.soton.ac.uk/psyweb/psychobook/admin/ethics/research_governance.doc)

This will need to be returned to the address provided on the form.

Please note that you cannot begin your research before you have had positive approval from the University of Southampton Research Governance Office (RGO). You should receive this by email in a maximum of two working weeks. If you experience any delay beyond this period please contact Pippa Smith.

More information about Research Governance can be found at the link below. (You will be prompted to log into sussed.)

<http://www.resource1.soton.ac.uk/legalservices/rgo/regprojs/whatdocs.html>

**Amendment approved****Your Ethics Form approval**

Psychology.Ethics.Forms@ps1.psy.soton.ac.uk  
[Psychology.Ethics.Forms@ps1.psy.soton.ac.uk]

**Sent:** Monday, October 13, 2008 9:20 PM

**To:** [mcgurk r. \(rm306\)](#)

This email is to confirm that your ethics form submission for "Understanding carers coping with aphasia: are generic coping inventories good enough?" has been approved by the ethics committee

Project Title: Understanding carers coping with aphasia: are generic coping inventories good enough?

Study ID : 517

Approved Date : 2008-10-13 21:20:19

[Click here to view Psychobook](#)

If you haven't already submitted the Research Governance form for indemnity insurance and research sponsorship along with your ethics application please be aware that you are now required to fill in this form which can

**Appendix IX**

**Letters of approval from Research Governance**

Mrs Rhona McGurk  
34 Bassett Crescent East  
Southampton  
SO16 7PB

17 July 2008

Dear Mrs McGurk

RGO Ref: 5926

**Project Title Understanding Carers Coping with Aphasia: Are Generic Coping Inventories Good Enough?**

I am writing to confirm that the University of Southampton is prepared to act as sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care (2nd edition 2005).

The University of Southampton fulfils the role of Research Sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the Principal Investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Research Governance Office on this basis.

I would like to take this opportunity to remind you of your responsibilities under the terms of the Research Governance Framework, and the EU Clinical Trials Directive (Medicines for Human Use Act) if conducting a clinical trial. We encourage you to become fully conversant with the terms of the Research Governance Framework by referring to the Department of Health document which can be accessed at:

<http://www.dh.gov.uk/assetRoot/04/12/24/27/041224>

In this regard if your project involves NHS patients or resources please send us a copy of your NHS REC and Trust approval letters when available.

Please do not hesitate to contact me should you require any additional information or support. May I also take this opportunity to wish you every success with your research.

Yours sincerely

A handwritten signature in black ink, appearing to read "M. Prude".

Dr Martina Prude  
Head of Research Governance  
Tel: 023 8059 5058  
email: rgoinfo@soton.ac.uk

**Appendix X**

**Information sheet**

16 April 2010

Dear

**Coping and psychological well-being among informal carers of stroke survivors with aphasia.**

Thank you for responding to my advert and expressing interest in this research. My name is Rhona McGurk, and I am a trainee clinical psychologist at the University of Southampton. I am inviting your participation the above study. This research is being supervised by Dr Ian Kneebone, Visiting Senior Fellow, University of Surrey and Dr Tony Brown, Lecturer in Clinical Psychology, University of Southampton.

**What is the reason for doing this study?**

Informal carers play a major role in the lives of stroke survivors and they also save the nation billions of pounds with the unpaid care that they provide. Despite this, carers can feel neglected and unsupported in their role. Research suggests that informal carers of stroke survivors with aphasia experience higher levels of strain than carers of stroke survivors who do not have aphasia. Little is known about how carers cope with the communication difficulties that arise as a result of caring for someone with aphasia and how they deal with the stress that these can cause. My study aims to understand this, and also to look at which ways of coping are associated with better outcomes for the informal carer in terms of their psychological well-being. It is hoped that the results of this study will be able to improve future services for informal carers of stroke survivors with aphasia.

**Who can take part in the study?**

I am looking for informal carers, by which I mean the person who is the main source of un-waged physical and/or emotional support for the stroke survivor (e.g. a partner, family-member, or friend). To take part in this study you must be over 18 years of age. The person you care for should be at least one year post-stroke and should have aphasia. Aphasia is a language problem, resulting from a brain injury, which affects the ability to speak, read, write, understand and use gesture.

**What will happen if I decide to take part?**

If you decide to take part then it will involve completing the enclosed questionnaires. The questionnaires ask about the following topics:

- The level of ability of the stroke survivor, and the degree of the communication



difficulty.

- The coping styles and strategies that you use to cope with problems resulting from communication difficulties.
- Your psychological well-being (in other words how you are feeling).
- Background information about yourself and about the stroke survivor, such as age group, gender, etc. This includes asking about things which are nothing to do with your caring role such as your level of education and your ethnicity. The reason for asking this is so that I can describe the sample of people who took part in the research to see if they are representative of the wider population, and also so that I can look for patterns in the results.

It takes about 40 minutes to fill in all of the questionnaires. You may find it helpful to take a break, in which case I have put a half-way mark in the pack of questionnaires. Personal information will not be made available to anyone other than researchers involved in this project. The results of this study will not include your name or any other identifying characteristics.

#### **Is there anything else I need to be aware of?**

One of the questionnaires asks about symptoms of depression. Caring for someone who has had a stroke can be stressful, and it is not uncommon for carers to feel low or depressed at times. It is my responsibility to inform anyone who reports high levels of depressive symptoms that they may be suffering from depression. In such cases, I will write to you to say that your answers suggest that you may be suffering from depression, and I will advise you to talk to your GP about this if you have not already done so. Of course, the choice of whether you talk to your GP is entirely up to you and I will not disclose this information to anyone else.

#### **What will happen to the results of the research?**

It is planned to publish the results in a relevant academic journal, and also to present at conferences attended by health professionals. It is hoped that what is learnt will improve the quality of future therapeutic interventions with informal carers of stroke survivors with aphasia. If you would like a written summary of the results please contact me on freephone 0800 7833 011 or email [rm306@soton.ac.uk](mailto:rm306@soton.ac.uk), and leave your name and address (or attach a note along with the returned questionnaires). I will send a summary to you when the study is completed.

#### **What shall I do now?**

If you are willing to take part in this research study please complete the questionnaires and return them to me in the enclosed Freepost envelope. If I do not hear from you within 14 days I will send you a reminder note. If I do not receive the questionnaires after that I will assume that you do not wish to take part in the study. If you have any questions, or if you are concerned as a result of anything to do with this study, please contact me on freephone 0800 7833 011 or email [rm306@soton.ac.uk](mailto:rm306@soton.ac.uk). I can also be contacted at the address on the bottom of the first page (mark letters for the attention of Rhona McGurk, Trainee Clinical Psychologist).

Completion and return of the questionnaires will be taken to indicate that you have given your informed consent to be included as a participant in this study. This means that the data you supply can be used for the purposes of this research, with the understanding that published results of this research project will maintain your confidentiality. Your participation is completely voluntary. You do not need to answer every question and you may withdraw your participation at any time.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 5578.

Once again many thanks for expressing interest in my study. I am extremely grateful to those people who give up their valuable time to take part.

With best wishes

Rhona McGurk  
Trainee Clinical Psychologist  
University of Southampton

**Appendix XI**

**Letter to participants scoring above the cut-off point on the *CES-D***

16 April 2010

Dear

Thank you for completing the questionnaires for my study considering coping and well-being in informal carers of stroke survivors with aphasia.

Your score on one of the questionnaires suggests that you may be experiencing depression. If you are concerned by this I suggest you talk to your GP who may be able to help. Or alternatively, if you would like me to, I can write to your GP to inform them of this.

As previously, you may contact me with any queries about this or any other aspect of the study on freephone 0800 7833 011 or email [rm306@soton.ac.uk](mailto:rm306@soton.ac.uk) . I can also be contacted at the address at the bottom of this page (mark letters for the attention of Rhona McGurk, Trainee Clinical Psychologist).

With best wishes

Rhona McGurk  
Trainee Clinical Psychologist  
University of Southampton

**Appendix XII**

**Correspondence with the British Psychological Society  
regarding whether to seek consent from the stroke survivor**

-----Original Message-----

From: mcgurk r. (rm306) [<mailto:rm306@soton.ac.uk>]

Sent: Monday, May 05, 2008 12:36 PM

To: Reception External

Subject: enquiry about seeking informed consent

Hello

I am a member of the BPS (no. 205754), and I am a trainee clinical psychologist at the University of Southampton.

I have a query about seeking informed consent from potential research participants, which I would be grateful if you could forward to someone on the research board or ethics committee.

I am planning to carry out a piece of research as part of my DPsych looking at coping among informal carers of stroke survivors with aphasia. I will be seeking informed consent from the informal carers who participate. However, I plan to ask the carers some questions about the stroke survivor (e.g. level of independence in activities of daily living, level of functional communication, gender, age-band, and time since the stroke). What I am unsure of is whether this means that I should also ask for consent from the stroke survivor for this information to be shared, even though they are not participating in the study. I am unsure where I stand ethically, and would be grateful for your guidance.

With many thanks

Rhona McGurk

Reply received from BPS on 19/05/2008:

Dear Rhona,

Many thanks for your enquiry. After consulting with our ethical enquiry team they gave the following responses:

There are two views to consider from the panel:

- 1) A suggestion that you only need consent from the interviewee and the information you are requesting can only be the interviewee's opinions on independence etc., rather than explicit facts, but the researcher needs to employ delicacy when asking about these issues.

2) That there may be arguments that the stroke survivor has a right to decide what personal information is given or withheld by a third party. The view could be that it would only be if there is no way of communicating with the stroke survivor that consent would not be sought from them.

The more general recommendation would be for this issue to be considered by the relevant Southampton Uni school ethics committee.

We hope this helps with your research,

**Appendix XIII**

**The *Brief COPE* (Carver, 1997)**

The *Brief COPE* is available freely online

<http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>

Downloaded 10<sup>th</sup> November 2008



### The Brief COPE

These items ask about the way you cope with the communication difficulties that arise from caring for someone who has aphasia. Different people deal with things in different ways. I'm interested in what *you* do. Each item says something about a particular way of coping. I want to know to what extent you do what the item says. Don't answer on the basis of whether it seems to be working or not—just whether or not you do it. Use these response choices and tick **ONE** box per question:

- 0 = I don't do this at all
- 1 = I do this a little bit
- 2 = I do this a medium amount
- 3 = I do this a lot

	0	1	2	3
1. I turn to work or other activities to take my mind off things.				
2. I concentrate my efforts on doing something about the situation I'm in.				
3. I say to myself "this isn't real."				
4. I use alcohol or other drugs to make myself feel better.				
5. I get emotional support from others.				
6. I give up trying to deal with it.				
7. I take action to try to make the situation better.				
8. I refuse to believe that it has happened.				
9. I say things to let my unpleasant feelings escape.				
10. I get help and advice from other people.				
11. I use alcohol or other drugs to help me get through it.				
12. I try to see it in a different light, to make it seem more positive.				
13. I criticise myself.				
14. I try to come up with a strategy about what to do.				
15. I get comfort and understanding from someone.				
16. I give up the attempt to cope.				
17. I look for something good in what is happening.				
18. I make jokes about it.				
19. I do something to think about it less, such as go to the movies, watch TV, read, daydream, sleep, or shop.				
20. I accept the reality of the fact that it has happened.				
21. I express my negative feelings.				
22. I try to find comfort in my religion or spiritual beliefs.				
23. I try to get advice or help from other people about what to do.				
24. I learn to live with it.				

<b>25.</b> I think hard about what steps to take.			
<b>26.</b> I blame myself for things that happened.			
<b>27.</b> I pray or meditate.			
<b>28.</b> I make fun of the situation.			

**Appendix XIV**

**Information about the development and testing of the *CAP***

### **Development of the items in the CAP**

A literature search was conducted to find qualitative papers on coping by carers of stroke survivors with aphasia. The references were read to ascertain whether they reported coping strategies used specifically to manage communication problems.

Through this process the following references were selected: Bowling (1977), Le Dorze and Brassard (1995), Michallet, Tétreault and Le Dorze (2003), Montgomery-West (1995) and Nienaber (2007). Using these papers, a list was made of coping strategies that carers of stroke survivors with aphasia reported using or coping strategies that they were observed to use to manage communication problems (see Table I below).

Therefore the questionnaire reflected what carers do or what they say they do, rather than reflecting professional advice on how to manage communication problems. The list was checked for redundancy and where a similar coping strategy was listed more than once the clearest example was selected. A large number of problem solving type strategies were reported and it was not possible to include all of these in a short questionnaire. Therefore a range of problem solving type strategies were included but not an exhaustive list. The items that were included in the questionnaire were phrased as closely as possible to the original text to avoid changing the meaning. Rephrasing was used only for clarification or simplification. The final questionnaire consisted of 21 coping strategies and participants were asked to indicate whether they used these strategies. The response format was the same as that in the *Brief COPE*. There was space left at the bottom of the questionnaire for participants to list any additional coping strategies.

Table I.

*List of coping strategies reported in qualitative literature that carers of stroke survivors with aphasia use to manage communication problems*

PAPER	COPING STRATEGY
Bowling (1977)	<ul style="list-style-type: none"> <li>• To cease trying to communicate with the patient</li> </ul>
Le Dorze &	<ul style="list-style-type: none"> <li>• Paying more attention to what the aphasic person is saying.</li> </ul>
Brassard (1995)	<ul style="list-style-type: none"> <li>• Taking time to listen.</li> <li>• Checking their answers, verifying the content.</li> <li>• Trying to protect the aphasic person by speaking for them.</li> <li>• Making the aphasic person's phone calls.</li> <li>• Avoiding certain topics that might annoy the aphasic person.</li> <li>• Explaining to others the cause of the aphasic person's speech problems.</li> <li>• Withdrawing when irritated.</li> </ul>

- 
- Trying not to dwell on the aphasic persons difficulties.
  - Trying to guess what the aphasic person means.
  - Avoiding correcting the aphasic person's speech.
  - Refraining from speaking for him/her.
  - Ensuring that others will speak to the aphasic person in spite of his/her withdrawal from conversation.
  - Correcting the aphasic person's mistakes.

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Michallet, Tétrault

& Le Dorze (2003)

- Proceed by deduction, trial and error, guessing.
  - Using cues on the aphasic person's face.
  - Offering choices. Asking questions that could be answered with a 'yes' or 'no'.
  - Asking the aphasic person to supply them with a key word.
  - Asking the aphasic person with to give a hint, proceeding by enumeration in order to know what was being talked about (e.g. going through names of children in order).
  - Using humour.
  - Using different strategies to make themselves understood, e.g. reformulating sentences, using simple
-

---

words, explaining several times where necessary.

- Choosing conversational topics that were of potential interest to the aphasic person.
- Using different means of communication, e.g. writing, gestures, mime.
- Letting the aphasic person manage as far as possible when talking to others before stepping in to help. Or alternatively, letting aphasic person do things on their own.

---

Montgomery-West

(1995)

- Ensuring that the person with aphasia uses as much language as possible
- Waiting while they struggle to produce words rather than say it for them
- Accepting the aphasia as a disability
- Talking to others at different stages post-stroke to gain a sense of what to expect or how far you have come

---

Nienaber (2007)

- Trying to accept that it's not the person with aphasia's fault that communication is so frustrating
-

### **Principle component analysis and testing psychometric properties**

The 21-item correlation matrix was scanned to check for variables that did not correlate with any other, as such variables should be eliminated for principle component analysis (Field, 2005). It was not necessary to eliminate any variables at this stage. A preliminary analysis of the data showed that the determinant of the correlation matrix was 0.001, indicating that there was no problem with multicollinearity. The KMO measure of sampling adequacy statistic was .72. Field (2005) reports that values of the KMO statistic between .7 and .8 can be considered 'good', and indicate that the data are appropriate for principle component analysis. The KMO values for the individual variables were all above the minimum value of .5. Bartlett's test of sphericity was highly significant ( $p < .001$ ), thereby confirming that the *R*-matrix was not an identity matrix.

The items were entered into a principle components analysis. An oblique rotation was used to start with, as it was thought that some of the components may correlate, however this was not found to be the case, and so an orthogonal rotation (varimax) was selected. Seven components with eigen-values greater than 1.0 were obtained. Kaiser's criterion suggests retaining factors with eigen-values greater than 1.0, however in order to accept Kaiser's criterion the communalities should all be .7 or above (Field, 2005), and this was not the case (Table II). The scree plot (Figure 1) was therefore used to decide how many factors to extract. Examination of the scree plot showed that retaining four or five factors would be justified. Both of these solutions were tried, and it emerged that a five factor



solution provided a clearer structure to the data. In total the five factors explained 55% of the variance in the data.

A cut-off for component loadings of 0.4 was considered appropriate for interpretation (Field, 2005). The component loadings after rotation are shown in Table III. Item 21 did not load onto any of the components, and items 7, 14 and 15 all loaded onto more than one component, therefore these items were not retained. Further exploration of the fit of the model using the reproduced correlation matrix (not shown here), found that 49% of the residuals had a value greater than .05. Field (2005) states that the percentage of residuals with absolute values greater than .05 should be less than 50%, therefore the present model represents an adequate fit of the data.

Table II.

*Communalities*

	Initial	Extraction
I pay close attention to what the person with aphasia is saying	1.00	.81
I take time to listen to the person with aphasia	1.00	.74
If the person with aphasia is struggling to say something then I say it for them	1.00	.52
I make phone calls on behalf of the person with aphasia	1.00	.44
I check what I think they have said to make sure I have understood correctly	1.00	.69
I try to guess what they mean	1.00	.51
I ask them questions that can be answered with a yes or a no, or give them simple choices	1.00	.62
I use different ways of helping the person with aphasia to understand what I am saying	1.00	.59
I withdraw when I get irritated by communication problems	1.00	.66
I avoid talking about certain topics that might annoy or frustrate the person with aphasia	1.00	.53
I accept that it's not their fault that communication is so frustrating	1.00	.43

Table II continued

	Initial	Extraction
I choose topics of conversation that I think they are interested in	1.00	.35
I make sure that the person with aphasia uses as much language as possible	1.00	.52
I explain to other people why the person with aphasia has a communication problem	1.00	.66
I make sure that other people speak to the person with aphasia	1.00	.56
I avoid correcting the aphasic person's speech	1.00	.47
I use humour to cope with the communication problems	1.00	.55
I try not to dwell on the aphasic person's difficulties	1.00	.57
I give up trying to communicate with the person with aphasia	1.00	.44
I talk to other people at different stages post-stroke to gain a sense of what to expect or to appreciate how far we have come	1.00	.51
I accept the aphasia as a disability	1.00	.37

Table III.

*Rotated Component Matrix*

<b>Item from CAP</b>	<b>Component</b>				
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Item 5. I check what I think they have said to make sure I have understood correctly	.66				
Item 6. I try to guess what they mean	.63				
Item 3. If the person with aphasia is struggling to say something then I say it for them	.62				
Item 4. I make phone calls on behalf of the person with aphasia	.62				
Item 7. I ask them questions that can be answered with a yes or a no, or give them simple choices	.58	.47			
Item 8. I use different ways of helping the person with aphasia to understand what I am saying	.47				

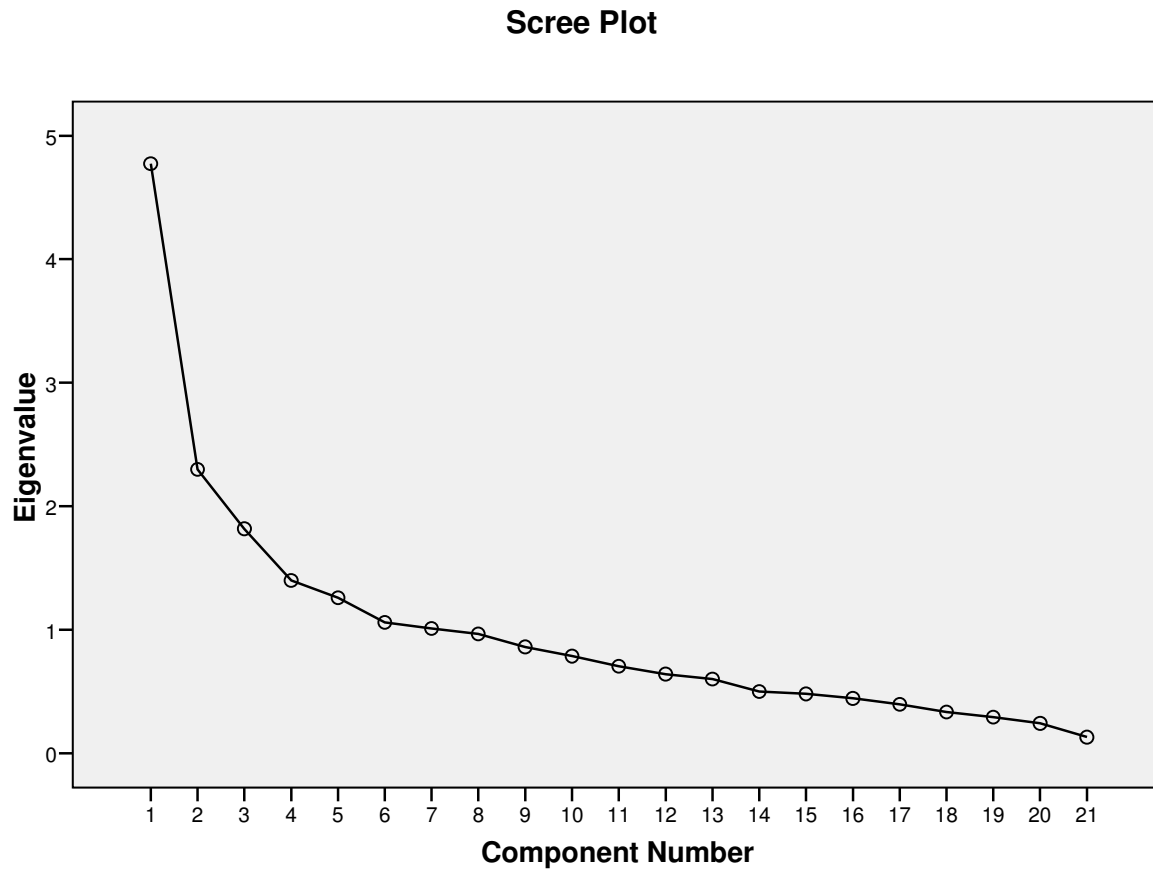
Table III *continued*

Item from <i>CAP</i>	Component				
	1	2	3	4	5
Item 18. I try not to dwell on the aphasic person's difficulties		.74			
Item 17. I use humour to cope with the communication problems		.69			
Item 16. I avoid correcting the aphasic person's speech		.62			
Item 12. I choose topics of conversation that I think they are interested in		.50			
Item 20. I talk to other people at different stages post-stroke to gain a sense of what to expect or to appreciate how far we have come			.69		
Item 13. I make sure that the person with aphasia uses as much language as possible			.64		
Item 14. I explain to other people why the person with aphasia has a communication problem	.46		.63		

Table III *continued*

Item from <i>CAP</i>	Component				
	1	2	3	4	5
Item 15. I make sure that other people speak to the person with aphasia		.40	.59		
Item 1. I pay close attention to what the person with aphasia is saying					.82
Item 2. I take time to listen to the person with aphasia					.80
Item 11. I accept that it's not their fault that communication is so frustrating					.47
Item 9. I withdraw when I get irritated by communication problems					.79
Item 10. I avoid talking about certain topics that might annoy or frustrate the person with aphasia					.65
Item 19. I give up trying to communicate with the person with aphasia					.58
Item 21. I accept the aphasia as a disability					

Figure I.



The content of the items loading onto each component was examined to identify common themes, where possible. These are shown in Table IV along with Cronbach internal reliability for each component. Usually values of  $\alpha$  equal to or above .7 are regarded as acceptable, however Field (2005) states that this guideline should be used with caution because the value of  $\alpha$  depends on the number of items in the scale, and for scales with a small number of items it will be more difficult to achieve an acceptable value of  $\alpha$ . Field (2005) therefore suggests also checking the corrected item-total correlations, to ensure that they are all equal to or above around .3. As most of the components in the *CAP* had a small number of items it was harder to achieve a value of  $\alpha \geq .7$ , and therefore the corrected item-total correlations were also checked. Using Field (2005) as a guide it was decided that if any of the corrected item-total correlations were less than .3 then consideration would be given to either rejecting the scale or to dropping items from the scale to improve reliability. It can be seen in Table IV that reliability for component 4 could be improved by deleting item 11<sup>11</sup>. The internal reliability for component 3 was problematic, and therefore this component was not used any further. In total, four components from the *CAP* were accepted as subscales to be used in the study: ‘Proactively Facilitating Communication’, ‘Keeping a Positive Focus’, ‘Attentiveness to the Stroke Survivor’, and ‘Avoidance’.

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<sup>11</sup> The principle component analysis was rerun without item 11 in order to check that the structure still held.



Table IV.

*Cronbach reliability calculations*

<b>Component:</b>	<b>Perceived common theme in component</b>	<b>Cronbach's</b>	<b>All corrected item-total</b>	<b>Subscale accepted</b>
		<i><math>\alpha</math></i>	<b>correlations <math>\geq .3</math>?</b>	
1	Proactively involved in facilitating communication for the stroke survivor	.6	Yes	Yes
2	Focusing on positive aspects of communication and not dwelling on difficulties	.6	Yes	Yes
3	Getting support from others, and encouraging language use in the stroke survivor	.4	Borderline	No
4	Being attentive to the stroke survivor and accepting it's not their fault that communication is difficult	.6 Increases to .9 if item 11 deleted	No Item 11 < 3	Yes, without item 11

Table IV *continued*.

<b>Component:</b>	<b>Perceived common theme in component</b>	<b>Cronbach's <i>α</i></b>	<b>All corrected item-total correlations <math>\geq .3</math>?</b>	<b>Subscale accepted</b>
5	Avoiding upsetting the stroke survivor, and withdrawing when communication gets too difficult	.6	Yes	Yes

Preliminary validity testing was conducted on the subscales from the *CAP* by correlating them, where possible, with scales from the *Brief COPE* that assessed similar (or opposed) forms of coping. Spearman's correlations were used as the data were not parametric. All of the correlations were in the predicted direction, however only two reached significance (Table VI).

Table VI.

*Preliminary validity testing of subscales from the CAP using subscales of the Brief COPE*

<b>Subscale from <i>CAP</i></b>	<b>Subscale from <i>Brief COPE</i></b>	<b>Spearman's <i>r</i></b>
Proactively Facilitating Communication	Active Coping	.09
Keeping a Positive Focus	Positive Reframing	.21**
Attentiveness to the Stroke Survivor <sup>a</sup>	Behavioural	-.13
	Disengagement	
Avoidance	Behavioural	.15*
	Disengagement	

<sup>a</sup>Negative correlation expected

\*  $p < .05$  (one-tailed). \*\*  $p < .01$  (one-tailed).

**Appendix XV****Correlation between *CES-D* score and scales of the *Brief COPE***

## Total CES-D score

Active Coping	-.26**
Planning	-.18*
Positive Reframing	-.27**
Acceptance	-.20*
Humour	-.21*
Religion	-.09
Use of Emotional Support	-.19*
Use of Instrumental Support	-.17*
Self-Distraction	.22**
Denial	.35**
Venting	.21*
Substance Use	.34**
Behavioural Disengagement	.30**
Self-Blame	.39**

\* $p < .05$  (two-tailed) \*\* $p < .01$  (two-tailed).

**Appendix XVI****Multiple Regression Analysis: Model Parameters**

Step		$\beta$	$t$	$p$	Correlations		Collinearity Statistics	
					Zero-order	Partial	Tolerance	VIF
1	Constant		10.82	.00				
	CETI	-.26	-3.08	.00	-.26	-.26	1.00	1.00
2	Constant		7.39	.00				
	CETI	-.15	-1.74	.08	-.26	-.15	.87	1.15
	Informational Support	-.05	-.58	.56	-.21	-.05	.74	1.34
	Emotional Support	.06	.60	.55	-.19	.05	.56	1.77
	Anticipated Support	-.24	-2.25	.03	-.34	-.20	.56	1.80
	Satisfaction with informational support	-.12	-1.37	.17	-.26	-.12	.82	1.22
	Satisfaction with emotional support	-.08	-.81	.42	-.28	-.07	.64	1.57

Step		$\beta$	$t$	$p$	Correlations		Collinearity Statistics	
					Zero-order	Partial	Tolerance	VIF
3	Constant		5.80	.00				
	CETI	-.09	-1.34	.18	-.26	-.12	.86	1.17
	Informational Support	.02	.22	.83	-.21	.02	.67	1.50
	Emotional Support	.06	.69	.49	-.19	.06	.52	1.94
	Anticipated Support	-.19	-2.24	.03	-.34	-.20	.54	1.86
	Satisfaction with informational support	-.06	-.78	.44	-.26	-.07	.75	1.33
	Satisfaction with emotional support	-.07	-.87	.38	-.28	-.08	.58	1.73
	Active Coping	-.14	-1.97	.05	-.30	-.18	.73	1.37
	Positive Reframing	-.16	-2.18	.03	-.28	-.20	.69	1.44
	Self-Distraction	.03	.46	.65	.24	.04	.84	1.19
	Denial	.03	.40	.69	.33	.04	.73	1.37



3					Correlations		Collinearity Statistics	
		$\beta$	$t$	$p$	Zero-order	Partial	Tolerance	VIF
	Substance Use	.21	2.80	.01	.42	.25	.73	1.38
	Behavioural Disengagement	.18	2.54	.01	.27	.23	.82	1.22
	Self-Blame	.38	5.46	.00	.48	.45	.81	1.24
4	Constant		4.4	.00				
	CETI	-.06	-.87	.39	-.26	-.079	.82	1.22
	Informational Support	.04	.50	.62	-.21	.045	.66	1.52
	Emotional Support	.07	.86	.39	-.19	.078	.51	1.95
	Anticipated Support	-.20	-2.43	.02	-.34	-.217	.54	1.87
	Satisfaction with informational support	-.04	-.62	.54	-.26	-.056	.75	1.34
	Satisfaction with emotional support	-.09	-1.12	.27	-.28	-.102	.57	1.74
	Active Coping	-.12	-1.71	.09	-.30	-.155	.72	1.39
	Positive Reframing	-.15	-2.05	.04	-.28	-.185	.69	1.45

4

				Correlations		Collinearity Statistics	
	$\beta$	$t$	$p$	Zero-order	Partial	Tolerance	VIF
Self-Distraction	.01	.15	.88	.24	.014	.83	1.21
Denial	.03	.40	.69	.33	.037	.73	1.37
Substance Use	.22	3.00	.00	.42	.265	.72	1.38
Behavioural Disengagement	.17	2.52	.01	.27	.225	.82	1.22
Self-Blame	.33	4.67	.00	.48	.393	.74	1.35
Avoidance (from <i>CAP</i> )	.16	2.38	.02	.40	.213	.79	1.27

## **Appendix XVII**

### **Information on multicollinearity**

One of the assumptions of multiple regression is that there is no perfect multicollinearity, meaning that there should be no perfect linear relationship between two or more of the predictors. If there is perfect collinearity between predictors it makes it very difficult to assess the individual importance of a predictor. Low levels of collinearity are, however, manageable (Field, 2005). Multicollinearity can be identified by scanning a correlation matrix of all the predictor variables for correlations of above .8 (Field, 2005). The variance inflation factor (VIF) can also be used to indicate whether a predictor has a strong linear relationship with the other predictors. Field (2005) suggests that a VIF value of 10 or above can be used as a guide for problematic multicollinearity. Also, the tolerance statistic is useful, with values below .1 indicating serious problems, and values below .2 giving cause for concern (Field, 2005). Using these methods, there was no indication that multicollinearity was a problem for the variables in the regression (see Table 5 for values of the VIF and tolerance statistic).

## **Appendix XVIII**

### **Bootstrapping Results**

The Holmbeck method of determining mediation can lead to an increased risk of Type II errors. In order to check that no coping strategies had been erroneously rejected as mediators, bootstrapping was performed on the other seven coping strategies that were significantly associated with depressive symptoms. 99% confidence intervals were selected in order to control for the effect of multiple testing. All of the confidence intervals included zero (see table below), and therefore the bootstrapping analyses confirmed that no other coping strategies were significant mediators.

<b>Coping strategy</b>	<b>Lower confidence interval for effect size<sup>a</sup></b>	<b>Upper confidence interval for effect size<sup>a</sup></b>
Behavioural Disengagement	-.49	.24
Denial	-.80	.08
Self Blame	-.79	.46
Self Distraction	-.54	.13
Substance Use	-.97	.12
Positive Reframing	-.50	.24
Active Coping	-.67	.33

*Note.* Bootstrapping was carried out with 2000 samples

<sup>a</sup> 99% confidence intervals

## **Appendix XIX**

### **Post-Hoc Power Calculations for the Regression Analysis**

Thomas (1997) states that one of the more helpful methods of analysing post-hoc power is to calculate the detectable effect size for a prescribed level of power. Post-hoc power calculations were performed using GPower (version 3), which enables a calculation of effect size, given the value of  $\alpha$ , the power, the sample size, the number of predictors and the degrees of freedom. Cohen's (1988) level of .8 was used as the accepted benchmark for high power. The effect size detectable at each step of the multiple regression analysis is shown in the table below. GPower describes effect sizes using Cohen's (1988)  $f^2$ . Cohen specifies that a value of  $f^2 = .02$  is conventionally accepted as a small effect size, a value of  $f^2 = .15$  is accepted as a medium effect size, and a value of  $f^2 = .35$  is accepted as a large effect size.

<b>Step of regression</b>	<b>Degrees of freedom</b>	<b>Number of predictors</b>	<b>Value of <math>f^2</math></b>	<b>Effect size detectable</b>
1	1	1	.06	Small to medium
2	5	6	.10	Medium
3	7	13	.11	Medium
4	1	14	.06	Small to medium

*Note.* N = 134,  $\alpha = .05$