

Posttraumatic Growth, Coping and Quality of Life in Stroke Carers

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ABSTRACT

Objective: this study examined variables associated with posttraumatic growth (PTG) in people caring for a spouse who had suffered a stroke. **Method:** A cross sectional study was conducted in which carers (n=71) completed questionnaires measuring PTG, coping style, social support, level of functioning (of the care-recipient) and carer quality of life. A systematic search of the literature was also conducted. **Results:** All carers who completed a measure of PTG (n=70) reported growth in at least one area of their experience and mean PTG score for the sample was significantly different from zero ($t[69] = 17.86, p < .001$). PTG was positively correlated with rumination coping, social support, avoidance coping and quality of life. Regression analyses showed that rumination coping, social support and level of functioning (of the care-recipient) explained the greatest proportion (46%) of variance in PTG scores and that rumination coping, alone, accounted for 37% of variance in scores. **Conclusions:** The findings add to the limited body of evidence suggesting that stroke carers experience personal growth as a result of their experiences. The findings also suggest a particular role for ruminative coping processing in predicting growth and support the use of the model of PTG proposed by Tedeschi and Calhoun (2004) over that of Schaefer and Moos (1998).

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Posttraumatic Growth, Coping and Quality of Life in Stroke Carers

1.1. Introduction

A stroke is a highly stressful experience for patients (Field *et al.*, 2008) and also for carers (Carek *et al.*, 2010). Carers may suffer acute effects due to the sudden, unexpected and life-threatening nature of a stroke (Carek *et al.*, 2010). Over the longer term, carers may face additional stressors such as changes to roles, disruptions to future plans and altered relationships due to changes in the survivor's personality (Greenwood *et al.*, 2009a).

The majority of the literature on caring for stroke survivors focuses on negative outcomes such as increased psychological difficulties (Ilse *et al.*, 2008) and decreased quality of life (Visser-Meily *et al.*, 2005). However, carers of stroke survivors have also described positive outcomes arising from their experience (Buschenfeld *et al.*, 2009; Bacon *et al.*, 2009; Haley *et al.*, 2009). Finding positives in response to stressful experiences is most commonly termed 'posttraumatic growth' (Tedeschi & Calhoun, 1996).

The current study aims to: (1) examine whether PTG occurs in a sample of stroke caregivers and (2) examine which variables (including coping style, social support, level of functioning) are associated with PTG in this sample. These are areas that have yet to be studied within this population using a correlational study. The research will have implications for theory and practice by identifying the factors that are associated with positive outcomes.

1.2. Stroke and Stroke Carers

1.2.1 Stroke

A stroke is the sudden death of brain cells caused by the interruption of the blood supply to the brain (WHO, 2012). There are two main sub-types of stroke (Royal College of Physicians, 2008): An ischemic stroke is where there is a blockage in the blood supply to the brain, and this accounts for 69 % of all strokes (Wolfe *et al.* 2002). A haemorrhagic stroke is where a major blood vessel ruptures and bleeds into the brain, and this accounts for approximately 13% of all strokes (Wolfe *et al.* 2002). A stroke can result in long term problems with: paralysis, speech and language, swallowing, memory and reasoning, loss of feeling, depression and death (de Haan 1995). Indeed, stroke is the main cause of severe disability in the UK (Adamson *et al.*, 2004) and, as a single cause of death, is second only to coronary heart disease as the biggest killer in the UK (Scarborough *et al.*, 2009).

1.2.2. Stroke Carers

Stroke carers provide unpaid care for family members and friends who need care, help or support due to their stroke (Welsh Government, 2012). Stroke carers often provide long term practical and emotional care for stroke survivors (Carek *et al.*, 2010) and a report by the audit office (DoH, 2005) found that over half of the 900 000 people living with the effect of a stroke (in England) were reliant on a carer for help with everyday activities.

In the UK, population surveys of stroke carers are lacking (Lincoln *et al.*, 2012). However, a survey of Australian stroke carers (Anderson, *et al.*, 1995) found that the majority of carers were spouses (59%), with the other 41% of carers being either adult children (32%) or other relatives (9%).

1.2.3 Benefits of stroke carers

Stroke carers have been shown to provide a wide range of benefits for survivors (Palmer and Glass, 2003). For example, Tsouna-Hadjis *et al.* (2000) assessed the role of family carers in providing emotional and practical support to a relative with a stroke. They found that survivors who received a high level of support improved more in terms of their functional status (i.e. they became less disabled by their stroke) compared to those survivors who received a low level of support. Stroke survivors who feel more supported by family members also report lower rates of depression compared to those who feel less supported (Morris *et al.*, 1991).

Informal carers also provide significant economic benefit and are 'estimated to have saved the UK government £87 billion pounds each year at 2009 levels' (Buckner & Yeandle, 2007). Specific data for the economic benefits of stroke carers do not exist. However, given that stroke is the leading cause of severe disability in the UK (Adamson *et al.*, 2004) it is likely that stroke carers contribute a significant amount to this £87 billion pound saving. The Department of Health has increasingly recognised the benefits that carers bring to the economy and recent reports such as 'New Approaches to Supporting Carers' Health and Well-being' (DoH, 2011) have been drawn up to help support carers in their role.

1.2.4. *Negative effects of caring on carers*

Despite the benefits to others, carers often suffer negative outcomes themselves (see Greenwood *et al.*, 2009a for a review). For example, stroke carers have been found to have increased levels of depression (Han & Haley, 1999), decreased quality of life (Visser-Meily *et al.*, 2005) and increased care-giver strain (Ilse *et al.*, 2008). Stroke carers have also reported themes of distress, feeling undervalued and feeling trapped in response to changes to the survivors' personality (Greenwood *et al.*, 2009a).

Negative outcomes for carers have been associated with the severity of the stroke (Dennis *et al.*, 1998), the survivor's functional disability (Ilse *et al.*, 2008), the survivor's level of dependence (Greenwood *et al.*, 2008a) and time spent caring (Van Puymbroeck, 2008 cited in Carek, 2010). Caregiver attributes such as gender and age (McCullagh *et al.*, 2005) and coping skills (Visser-Meily *et al.*, 2009) also impact on outcomes for carers. For example, Mackenzie *et al.* (2007) found that younger stroke carers (under 56 years old) experienced more lifestyle change and caregiver stress compared to older carers. Younger carers also found it more difficult to discuss problems with staff working in stroke services, a difficulty that may have been compounded by having to look after dependent children and sustain full-time employment (Mackenzie *et al.*, 2007).

Negative outcomes for carers have also been shown to impact on the survivor. For example, Grant *et al.* (2004 cited in Lincoln *et al.*, 2012) found that depressed carers of stroke survivors offered a poorer level of care, compared to carers who were not depressed. The mental health of a carer has also been associated with the mental health of the survivor and Carnwarth and Johnson (1987) found that stroke survivors were more likely to be depressed if their caregiver was depressed themselves. An increased carer burden also places stroke survivors at a higher risk of being placed in a residential home or hospital (McCullagh *et al.*, 2005 cited in Haley *et al.*, 2009).

Finally, as well as suffering negative effects due to the ongoing caring role, carers may also suffer negative outcomes in response to the sudden and acute nature of the stroke itself. Carek *et al.* (2010) investigated the prevalence of Posttraumatic Stress Disorder (PTSD) in a sample of stroke carers (n=51) and found that a preliminary diagnosis of PTSD could be applied to 20% of the sample. Qualitative research (e.g. Strudwick & Morris, 2009; Buchenfeld *et al.*, 2009) has also found that stroke carers report themes of trauma in response to their experience and that these effects often persisted over years. For example, one carer interviewed by Buchenfeld *et al.* (2009) reported intense and distressing memories of their partner's stroke some 5 years after it had occurred.

1.2.5. Positive effects of caring on carers

Whilst there is much evidence to suggest that carers experience detrimental effects due to their role, it is also important to note that stroke carers also describe positive outcomes arising from their role. For example, Greenwood *et al.* (2009a) reviewed the qualitative literature and found that carers reported several gains including: a sense of fulfilment in the caring role, improved relationships and a reappraisal of priorities.

The concept of PTG is described in more detail below:

1.3. Posttraumatic Growth

1.3.1. Posttraumatic Growth

PTG has been defined as “positive psychological change experienced as a result of the struggle with highly challenging life circumstances or traumatic events” (Calhoun & Tedeschi, 1999, p. 1). PTG refers to the idea that stressful events can cause fundamental and positive changes in people. It refers to the possibility that ‘in people’s lives there is something positively new...[an] additional benefit compared to pre-crisis level’ (Zoellner & Maercker, 2006, p628). Terms synonymous with PTG include: ‘thriving’, ‘benefit finding’, ‘stress related growth’ and ‘adversarial growth’ (for review see: Tedeschi & Calhoun 2004a; Zoellner & Maercker, 2006). However, the term ‘posttraumatic growth’ will be used in this paper as it is the most commonly used term to describe this phenomenon (Manne *et al.*, 2004).

The following extract illustrates how a person can grow from a traumatic experience. It comes from a woman who suffered severe injuries following an accident and had to give up work as a result:

It's not that I am glad that it [traumatic incident] happened and that it [life] is the way it is, but for the first time in my life, I take time for myself and for what is important to me. I attend meditation classes now and that gives a lot to me. I also appreciate life a lot more. I am more aware of every day's pleasures and I am thankful for what I still have. I am very thankful for my husband. I can fully rely on him. (Zoellner & Maercker, 2006, p627).

The extract illustrates some of the main areas of growth proposed by Tedeschi and Calhoun (1996), namely: a fuller appreciation for life, a changed sense of priorities and strengthened relationships with others. Other areas of growth reported by people include: spiritual development, a greater sense of personal strength and recognition of new possibilities and life trajectories (Tedeschi and Calhoun, 1996). The extract also underlines the importance of the husband who can be ‘fully’ relied on; possibly in a caring role.

1.3.2. Use of the term ‘trauma’

In the posttraumatic stress literature, the term ‘trauma’ refers exclusively to the stress-response caused by events which cause actual or threatened death or serious injury (APA, 1994). However, in the PTG literature the term ‘trauma’ refers to a reaction to any ‘highly stressful event’ (Tedeschi & Calhoun, 2004a). In this sense, the term ‘trauma’ and ‘posttraumatic growth’ can extend to events that do not necessarily threaten a person’s

mortality (such as the separation from a partner, see Tashiro & Fraiser, 2004; or caring for someone who has had a stroke, see Bacon et al, 2009).

It should also be noted that neither PTSD symptoms nor a diagnosis of PTSD is needed for posttraumatic growth to occur.

1.3.3. Importance of PTG

PTG is an important concept as it represents a general shift in the literature from a disease-focused approach towards an approach highlighting resilience and growth (Lincoln *et al.*, 2012). Indeed, focusing only on the negative consequences of trauma and adversity can lead to a biased understanding of posttraumatic reactions (Linely & Joseph, 2004) and several theorists (e.g. Park, 2010; Park and Folkman, 1997; Brennan, 2001) have suggested that understanding the positive reactions to trauma (in addition to negative reactions) is key to developing comprehensive models of stress and coping.

PTG has also been associated with various measures of wellbeing and adjustment. For example, Helgeson *et al.* (2006) conducted a meta-analysis of people reporting a variety of life crises and found a significant relationship between PTG and positive wellbeing and between PTG and lower levels of depression. However, it should be noted that associations between PTG and quality of life have been less consistent, with some studies reporting a small positive association and others a small negative association (see Helgeson *et al.*, 2006).

1.3.4. Critique of PTG

A recurrent criticism within the literature is the issue of whether reports of PTG can always be considered genuine (Zoellner & Maerker, 2006; Nolen-Hoeksema & Davis, 2004). It has been suggested that people suffering a traumatic event may resort to illusions, such as perceptions of growth in an effort to cope with the trauma (Taylor & Armor, 1996). In this sense a person may report that they have benefited from the experience when, objectively, they have not. The illusory or self deceptive side of PTG is generally associated with maladjustment (Zoellner and Maerker, 2006). Here, a person may deny important elements to themselves and be unable to fully process the experience.

In an effort to reconcile the concept of PTG, Zoellner and Maerker (2006) have proposed a model of PTG which incorporates a functional, self transcending side (associated with adjustment) and an illusory or self deceptive side (associated with maladjustment). They suggest that illusory reports of growth are more likely to occur in the early stages following

trauma, whereas the constructive side of PTG may become apparent in the longer term. Indeed, in a review of the literature, Zoellner and Maerker (2006) found that 'all longitudinal studies find mild positive relations between perceived growth and adjustment' (p.638). The idea that PTG takes time to develop certainly corroborates the work of Tedeschi and Calhoun (2004a) who suggest that PTG will develop in people following the stages of automatic and deliberate rumination and thus after a set amount of time.

Zoellner and Maerker (2006) also suggest that the illusory side of PTG may help explain some of the contradictory findings between PTG and adjustment (e.g. between PTG and quality of life as noted in 1.3.3 above). Specifically, that those studies that recruit in the early stages of trauma may report on lower levels of genuine growth (and lower levels of adjustment) compared to those studies that recruit in later stages.

1.3.5. Factors associated with PTG in the general literature

PTG has been associated with a range of factors (see Zoellner and Maerker, 2006; Helgeson *et al.*, 2006; Linley & Joseph, 2004) which can be broadly grouped into coping, social support, event-related and individual themes. The themes capture the range of findings within the literature whilst allowing for similar factors to be grouped together. They also align with the dominant models of PTG (see section 1.3.6 below).

1.3.5.1 Coping Factors

Coping has been described as cognitive and behavioural efforts to reduce the stressfulness of an event (Lazarus & Folkman, 1986). Coping can take a number of forms, including: consciously trying to accept what has happened (acceptance coping), avoiding thinking about an event (avoidance coping) or trying to make sense of an experience (ruminative coping). Coping forms a main role in models of PTG (see 1.3.6 below). For example, Tedeschi & Calhoun (2004a) point to the importance of deliberate rumination, a meaning-focused coping which allows for reanalysis, reappraisal and growth in the aftermath of trauma.

Within the general literature, PTG has been positively associated with: acceptance coping style (in college students, Park *et al.*, 1996), active coping (in a sample of cancer survivors, Morris *et al.*, 2007), positive reappraisal coping (in a sample of stroke survivors, Gangstad *et al.*, 2009) and deliberate rumination (in a sample of people describing a range of traumatic events, Taku *et al.*, 2009). PTG has also been both positively and negatively associated with avoidance coping (see Zoellner & Maerker, 2006). Here, it should be noted that positive associations between avoidance and PTG run counter to models of PTG as this infers that a

person is avoiding thinking about their experiences. This issue is discussed in more detail throughout the text.

1.3.5.2. Social Support Factors

Social support includes the support that a person receives from friends, family and significant others (Zimet *et al.*, 1988). Social support has been suggested to aid growth by helping the person gain access to models of schema change (i.e. learning how others coped with trauma) but also to provide comfort, reduce emotional distress, and allow for deliberate rumination (Tedeschi & Calhoun 2004a).

Social Support has been found to be positively related to growth in women suffering from multiple sclerosis (Mohr *et al.*, 1999 cited in Sears *et al.*, 2003) and in people suffering a variety of traumas (Park *et al.*, 1999). Social support also made a small but significant contribution to variance in PTG (4%) in a sample of spouses of people who had suffered a heart attack (Senol-Durak & Ayvasik, 2010).

However, no such association has been found in patients with heart disease (Sheikh, 2004) or with chronic illnesses (Abraido–Lanza *et al.*, 1998).

1.3.5.3. Event Related Factors

Event Related Factors refer to a range of factors associated with the traumatic event, including the severity of the event and the amount of time since the event occurred. Tedeschi and Calhoun (2004a) have suggested that more stressful events may afford more opportunity for growth. Some evidence to support this claim is provided by Lechner *et al.* (2003) who found that cancer patients with moderately severe symptoms reported more growth than those patients with early stage cancer and fewer symptoms. However, patients with moderately severe symptoms also showed more growth than patients with late stage cancer, making it difficult to make a simple association between increased severity and growth.

Longer time since the traumatic event may also allow for growth (Zoellner & Maerkner, 2006). Sears *et al.* (2003) found that longer time since a diagnosis of breast cancer made a unique contribution to increased PTG. However, Abraido–Lanza *et al.* (1998), Lechner *et al.* (2003), Park *et al.* (1996) found no relationship between the amount of time passed since the traumatic event and growth.

1.3.5.4. *Individual factors*

Idiosyncratic factors such as optimism, locus of control and self-esteem can render someone more likely to identify and experience growth (Tedeschi & Calhoun, 1995).

Locus of control refers to the extent that a person believes that they can control events in their lives (Carlson *et al.*, 2007) and a high internal locus of control has been associated with PTG. For example, Maercker *et al.* (1999) found that World War II bombing victims with a high internal locus of control (i.e. a sense that they can exert control over life events) reported higher levels of PTG compared to those with an external locus of control (i.e. a sense that life events are outside their control and due to outside influence).

Abraido–Lanza *et al.* (1998) also found that chronically ill patients who have high levels of self-esteem show more growth at 3 year follow up than those patients with low self-esteem. Age has also been associated with growth, with younger people reporting higher levels of growth compared to older people (Helgeson *et al.*, 2006).

1.3.6. *Models of PTG*

The two main models of PTG are that of Schaefer and Moos (1998) and Tedeschi and Calhoun (2004a). These models incorporate the factors associated with PTG as described above but differ in the emphasis they place on particular factors. For example, Schaefer and Moos (1998) suggest that PTG will be associated with approach coping, whereas Tedeschi & Calhoun (2004a) emphasise the role of deliberate rumination. These differences will be described in more detail in section 1.3.6.3, below.

1.3.6.1. *Schaefer and Moos (1998) model of PTG*

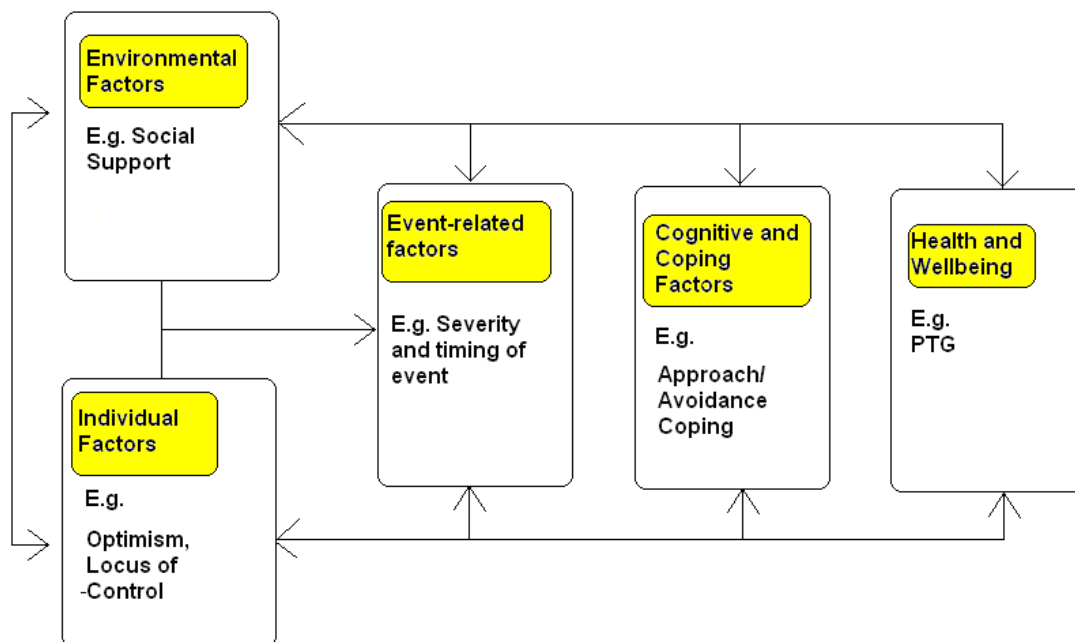
Schaefer and Moos (1998) suggest that a set of factors combine to influence the development of PTG within a person following a traumatic event. These factors include: 1) event-related factors 2) environmental factors 3) personal factors and 4) cognitive and coping responses (see Figure 1.1, below). These factors align with those factors described above (in section 1.3.5.) but are somewhat broader. For example, environmental factors include social support factors (as considered in section 1.3.5) but also the financial resources available to an individual.

Each factor is seen to make a unique contribution to PTG and a number of specific predictions are made. For example, the severity of the experience is seen to predict growth - but only when there is a successful outcome in the face of poor prognosis (Schaefer and Moos, 1998); severe events involving disfigurement and loss of bodily function are theorised

to be associated with less growth. Environmental factors and personal factors are also seen to combine to influence other factors. For example, social support (an environmental factor) may impact on how severe the person perceives the event to be and also the coping approach they use.

The model is dynamic in the sense that all factors feedback into one another. For instance, social support factors can enhance personal resources and vice versa. Schaefer and Moos (1998) also point to the importance of approach coping (i.e. rational analysis of the problem, positive reappraisal, active coping) over avoidance coping (denial, minimizing the problem); here, only approach coping is assumed to contribute to positive outcomes.

Figure 1.1 Model of PTG based on Schaefer and Moos (1998)



1.3.6.2. Tedeschi and Calhoun Model of PTG (1995; 2004a)

Tedeschi and Calhoun (1995; 2004a) offer another model for growth (see Figure 1.2) which was originally developed in 1995 but has since been updated (Tedeschi & Calhoun 2004a). This model is more cognitively orientated than the Schaefer and Moos (1998) model and is the most comprehensive model of PTG (Joseph & Linley, 2006). It is described in more detail below:

Traumatic events serve as 'seismic events' (Tedeschi & Calhoun 2004a) that shatter a person's assumptive world (i.e. their goals, beliefs and subjective sense of meaning). This leads to emotional distress and initiates a process of rumination in order to make sense out of the experience (Joseph & Linley, 2006). Rumination is defined using Martin and Tesser's (1996) description as 'thinking that (a) is conscious; (b) revolves around an instrumental theme; and (c) occurs without a direct cueing from the environment, but is easily and indirectly cued because it is connected with important goals, leading to recurrent thoughts' (Tedeschi & Calhoun 2004a, p.10).

Rumination, in this sense, can be distinguished from earlier usage of the term which refers exclusively to negative thinking and self-punishment (e.g. Nolen-Hoeksema *et al.*, 1997). Instead, rumination can be construed as a thinking process that can be 'constructive or destructive depending on whether rumination supports continued negative thoughts and emotions or helps move the person toward problem solving or finding meaning' (Calhoun *et al.*, 2010). Indeed, such a distinction is important given that studies that use rumination to refer to negative processes (such as self-punishment) have found that this predicts worse outcomes for people, especially in terms of increased levels of depression (see Nolen-Hoeksema *et al.*, 1997). Several approaches such as mindfulness have also been developed to ameliorate the risk of negative rumination and prevent relapses in depression (Deyo *et al.*, 2009).

In the literature on PTG, however, the term 'rumination' is used in the broader sense to include 'several varieties of recurrent [event related] thinking, including making sense, problem solving, reminiscence, and anticipation' (Martin & Tesser, 1996, p. 192). Constructive rumination processes are seen to be associated with growth (Tedeschi & Calhoun 2004a) and can occur both automatically and deliberately, as detailed below:

Automatic rumination – initially the ruminative process is more automatic than deliberate and consists of frequent and sometimes intrusive thinking around the experience. Such automatic rumination is consistent with the re-experiencing and avoidance processes found in PTSD (Joseph and Linley, 2006) and, although distressing, signifies an attempt to begin to reintegrate information into new cognitive schemas and an updated assumptive world.

Deliberate rumination - Automatic rumination gradually reduces emotional distress and allows for more deliberate rumination, characterized by a change in narrative and a search for meaning. It is this search for meaning, analysis of the new situation and re-appraisal that also allows for growth (Tedeschi & Calhoun 2004a).

Social support – support from friends and family is important in order to provide models for schema change (i.e. learning how others coped with trauma) but also to provide comfort, reduce emotional distress, and allow for deliberate rumination (Tedeschi & Calhoun 2004a) .

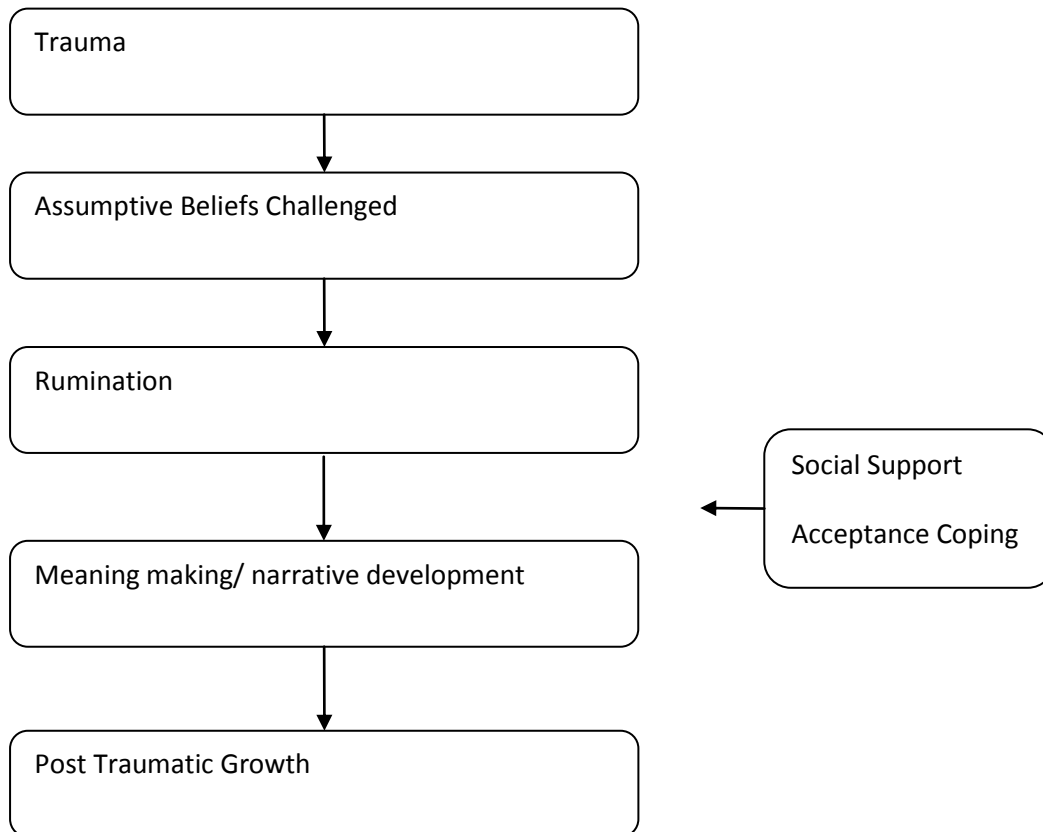
Coping - Calhoun *et al.* (2000) also see acceptance coping as important, particularly in the acute stages, in order to disengage from goals that are now unobtainable.

The model draws heavily on the work of theorists (e.g. Janoff Bulman, 1992; Neimeyer *et al.*, 2006) who suggest that people are guided through the world by a set of assumptions about themselves and their world and that challenges to these assumptions impact on the person's sense of predictability and control. The model also posits that PTG is more likely when assumptive beliefs are disrupted:

'Thus, the extent that [the event] disrupts core elements of the assumptive world, individuals experience more distress, show higher symptoms of posttraumatic stress disorder, and also have the potential for greater posttraumatic growth – it is the level of disruption of core beliefs which best predicts growth.' (Calhoun *et al.*, 2010, p.132).

In this sense, higher levels of stress and a more severe event should stimulate greater posttraumatic growth (Tedeschi & Calhoun 2004a).

Figure 1.2: Model of Post Traumatic Growth based on Tedeschi and Calhoun 2004a



1.3.6.3. Summary of models

Both models appreciate the importance of social support in helping the person begin searching for meaning and to successfully find positive meaning (Lechner & Antoli, 2004). Both models also agree that the severity of the event can afford opportunity for growth. However, the models differ in the mechanisms by which severity impacts on growth. Schaefer and Moos (1998) suggest that PTG may occur when a positive outcome follows a poor prognosis (i.e. a 'lucky escape') whereas Tedeschi & Calhoun (2004a) suggest that the level of disruption of core beliefs best predicts growth and, in this sense, PTG would be possible even in the face of poor prognosis. Both models also assume that individual factors such as extraversion and openness to experience affect the likelihood of PTG. However, these factors are less crucial in the Tedeschi & Calhoun (2004a) model. Neither model suggests that avoidance will be productive in fostering growth.

In terms of differences, Schaefer and Moos (1998) provide a generalized model utilising multiple factors whereas Tedeschi & Calhoun (2004a) see rumination, social support and acceptance coping as variables that hold 'most weight' in predicting growth (sic Tedeschi &

Calhoun, 2004b, p99). Schaefer and Moos (1998) also propose that approach coping (i.e. rational analysis of the problem, positive reappraisal, active coping) is key to growth, whereas Tedeschi & Calhoun (2004a) point to rumination coping. Here, rumination coping can be distinguished from approach coping in that rumination coping involves a reflection on events and on meaning making - often in response to indirect cues from the environment (see Tedeschi & Calhoun, 2004a; Martin and Tesser (1996) definition above) - rather than a proactive focus on a specific problem, as in approach coping.

1.3.6.4. Empirical support for models from literature

Both models emphasise the role of social support and, within the general literature, there is some evidence for an association between social support and PTG (see section 1.3.5.2.). Both models emphasise the importance of the severity of the event and there is limited evidence that severity predicts PTG, but in a curvilinear manner (such that only patients with moderately severe symptoms show heightened levels of PTG compared to those with low or high symptomatology, see section 1.3.5.3.). Both models also suggest that individual factors impact on growth and there is some evidence of a relationship between self esteem and perceived controllability and growth (see section 1.3.5.4.).

Few studies have compared the relative importance of the factors emphasised by different models. However, an exception is Senol-Durak and Ayvasik (2010) who assessed PTG in spouses of people with heart disease. They found that coping (including rumination and emotional coping) was positively related to PTG and explained 16 % of variance in scores. Social support, self esteem, perceived prognosis were also positively related to PTG but individually explained less variance (<4% per variable). Interestingly, problem focused coping did not make a significant contribution.

The findings of Senol-Durak and Ayvasik (2010) lend weight to the argument that certain factors (i.e. coping style) may be particularly important in predicting PTG and that rumination coping may be more influential than problem focused coping. These findings could be seen to support the model proposed by Tedeschi & Calhoun (2004a) over that of Schaefer and Moos (1998). However, it should also be noted that avoidance coping also positively predicted PTG, a finding that neither model would expect.

1.3.7. Summary of section 1.3

PTG refers to “positive psychological change experienced as a result of the struggle with highly challenging life circumstances or traumatic events” (Calhoun & Tedeschi, 1999, p. 1). PTG is an important concept as it represents a shift away from disease focused models of

stress and coping. It has also been associated with measures of wellbeing and adjustment (see section 1.3.3).

Within the literature various factors have been associated with PTG (see section 1.3.5). However the findings are mixed and not always conclusive, suggesting that more research is needed. In terms of models there is also some preliminary evidence supporting the model proposed by Tedeschi and Calhoun (2004a) over that of Schaefer and Moos (1998). However, given that few studies have compared the two models against each other, more research is needed.

The paper continues with a systematic search of the literature regarding PTG in carers of stroke but also carers of people with a range of physical illnesses.

1.4. Systematic search

1.4.1. Systematic search

The systematic search was originally conducted with a sole focus on PTG in carers of stroke survivors. However, given the paucity of research in this area the search was expanded to PTG in informal carers of people with physical health problems (other than stroke). Here, it was decided that carers of people with physical health problems would serve as a suitable population from which to draw inferences for stroke carers, with the caveat that caring for someone with a stroke is a distinct experience from other types of caring. For example, stroke carers have to cope with the sudden onset of the condition and may have to assist with difficulties such as paralysis and loss of speech that may not accompany other health conditions. The review begins with the results for carers in general and concludes with the results of PTG in carers of stroke survivors.

1.4.2. Carers in general

1.4.2.1 Search Strategy

The following databases were searched, from 1980 to 18th March 2012: PsychINFO, Embase, Medline and PsycARTICLES full text.

Key search terms relating to PTG were: posttraumatic growth, benefit finding, finding benefit*, stress related growth, perceived benefit* adversarial growth, thriving, positive psychological change*, identity reconstitution, and self transform*.

Key search terms relating to carers were: carer*, caregiver*

Terms with similar meaning were combined using Boolean operator 'OR' (e.g. carer* OR caregiver*) to give overall topic results for: PTG (Topic) and Carer (Topic). Topics were then combined using Boolean operator 'AND' - i.e. PTG (Topic) AND Carer (Topic)

All abstracts and titles identified during this process were reviewed. Where it was difficult to discern whether the paper met inclusion criteria from the abstract alone, the full article was reviewed. The bibliographies of all articles that met the inclusion criteria were examined for relevant studies, as were the reference lists of key review papers, book chapters and meta-analyses.

1.4.2.2. Inclusion and exclusion criteria

In reviewing the results, the following inclusion and exclusion criteria were applied:

Inclusion:

- informal rather than paid carers
- carers of people with a physical illness
- measures PTG in carers
- original articles
- quantitative studies
- peer reviewed papers
- studies published in English, between 1980 -2012

Exclusion

- carers of a person with severe and enduring mental health problems (e.g. schizophrenia)
- carers of people with a developmental disorder (e.g. autism)
- carers of children (with or without a physical illness)
- bereaved carers
- review papers
- papers that were not reviewed, such as dissertations

1.4.2.3. Search Results

Of the 212 papers identified, only nine papers met inclusion criteria (see Figure 1.3) and these papers are described in Table 1.1. After repetitions, the most frequent reasons to exclude papers were that they were: studies of carers of children (younger than 18 years old), review papers, unpublished research such as conference abstracts and dissertations, studies that did not measure PTG and studies that looked at paid carers (see Table 1.1.1). Papers were also excluded if the person cared for had no physical health issue (e.g. they had schizophrenia, autism or were veterans with no physical health problems).

Figure 1.3 Flowchart of review process (Carers in General)

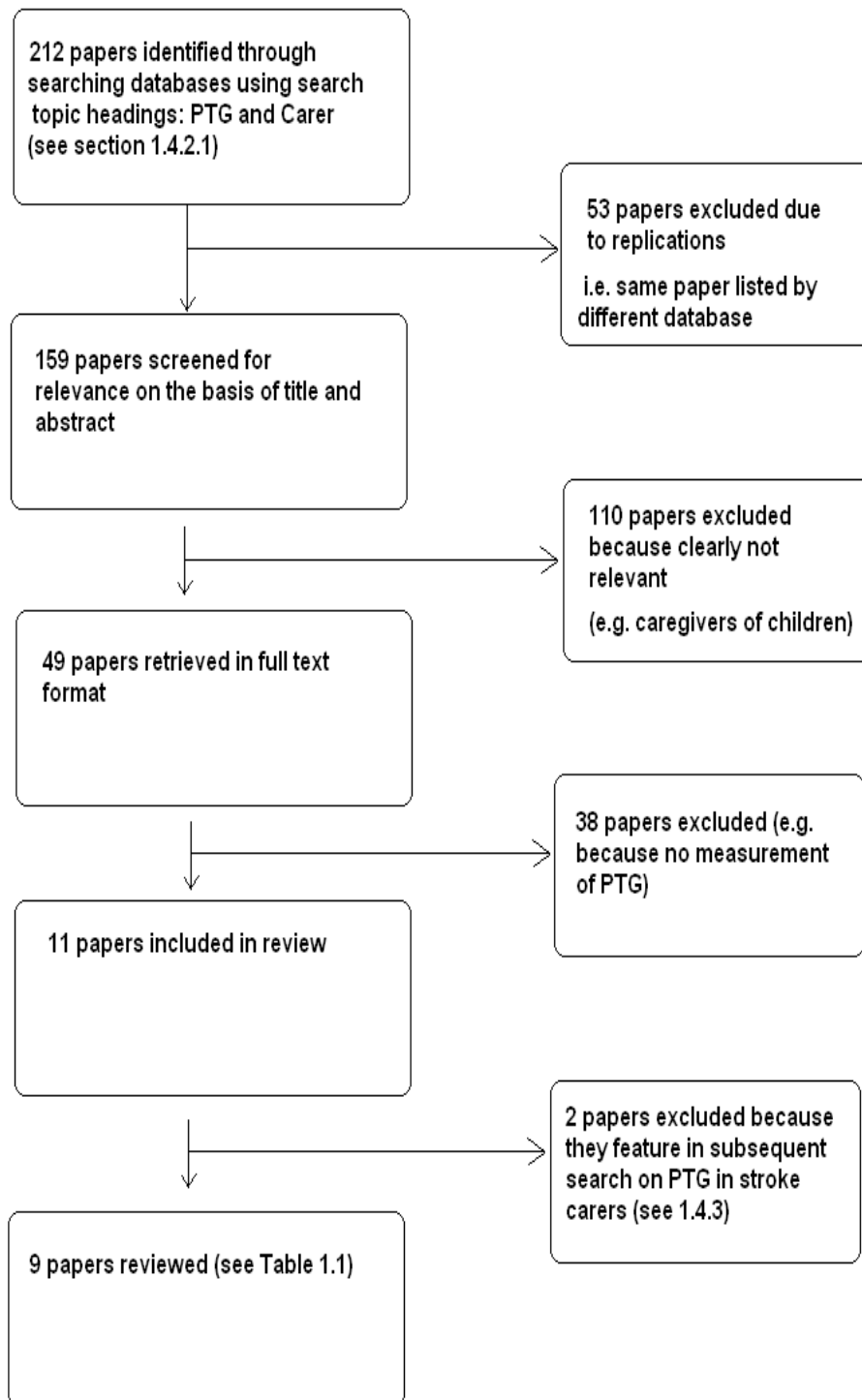


Table 1.1.1 Excluded papers (Carers in general)

Reason for exclusion	N
Replications	53
Qualitative Studies	7
Review Papers	35
Theoretical Papers	11
Caregivers of children (<18 years old)	26
Bereaved carers	5
Not peer reviewed (e.g. dissertations)	21
Does not measure PTG	18
No physical health condition	6
Carers of a person with schizophrenia or autism	5
Not informal carers	14
Included in subsequent search	2
<i>Retained</i>	9
Total	212

1.4.2.4. Prevalence of PTG

PTG was reported by at least some carers in all studies. McCausland and Pakenham (2003) found that 97 % of HIV carers reported benefits in their experience when asked the open question: 'What do you feel you have gained from caring for [care recipient's name]?'. Pakenham (2005a) found that 'most carers' (of a sample of 222 carers of people with MS) endorsed at least one area of benefit finding and 71% felt that they could now appreciate life more. However, reports of PTG were lower in carers of people with Amyotrophic Lateral Sclerosis (ALS) (Mock & Boerner, 2010). For example, when asked '...have you found anything positive in this experience?', 64% reported a benefit whereas 25% stated they had found no benefit. Here it is possible that, the ability to find positives is more difficult when faced with poor prognosis (see also Shaefer & Moos, 1998), particularly in ALS where the median survival time is only 3.5 years (see Table 1.1).

Several studies used validated scales to measure PTG. However, only Thombre *et al.* (2010) report on mean scores (mean = 95.13, SD, 18.73) when using the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1998; range 21-126) in carers of cancer sufferers in India.

1.4.2.5. Coping Factors

Several of the studies assessed the association between coping style and PTG in carers (Kim *et al.* 2007; McCausland & Pakenham, 2003; Pakenham, 2005b; Thombre *et al.*, 2010). Of these studies, some focused only on the impact of religious coping and used either the religious coping subscale of the Brief Cope (Carver, 1997) or the Religious Coping Scale (RCOPE, Pargament *et al.*, 2000). Some studies also investigated the role of social support coping on PTG but this will be considered below under a separate heading.

PTG was positively associated with positive reappraisal and avoidant coping in MS carers (Pakenham, 2005b) and positively associated with problem solving coping - but not associated with avoidant coping - in a sample of carers of people with HIV/AIDS (McCausland & Pakenham, 2003). PTG was found to be positively associated with overall religious coping scores cancer carers (Kim *et al.* 2007) and, when differentiated into factors, to be positively associated with increased use of positive religious coping and negatively associated with the use of negative religious coping (in cancer carers Thombre *et al.*, 2010). No association was found between PTG and wishful thinking and self-blame coping in a sample of MS carers (Pakenham, 2005b).

Associations between coping and PTG in carers seem to mirror those in the wider population in terms of associations with positive reappraisal and problem focused coping, and the mixed finding with regard to avoidant coping. Religious coping was positively associated with PTG, apart from when participants reported negative religious coping (e.g. 'decided that God was punishing me for my sins', see RCOPE, Pargament *et al.*, 2000). This finding is of interest because it suggests that people that make negative meanings out of their experience may not experience growth – i.e. that meaning making, per se, does not allow PTG to develop (contrary to Tedeschi & Calhoun, 2004a above).

Table 1.1: Post Traumatic Growth in Carers

Authors , Country	Design	Sample & recruitment location	n	Data collection (timing, location, etc.)	Carer details: gender, age, ethnicity & relationship to survivor	Theoretic al Model used	Measure of PTG	Results
Kilbourn <i>et al.</i> , 2011 U.S.A.	Longitudinal (to test efficacy of a 3 month telephone cognitive behavioural stress-management intervention)	Family carers of terminally ill people, living at home. Care recipient diagnosed with: Neurological condition (n=8), cardiorespirotary problem (n=4), cancer (n=11). 10 care recipients died during intervention 2 care recipients died between time 2 and time 3. 11 care-recipientents still living at home at time 3.	23	Data collected at three time points: T1 = baseline T2 = 3 months later T3 = 6 months later Mean length of time that care-recipient had received palliative care (at T1) = 86 days (range 8-676)	91% female Mean age = 60.63 years 48% spouses, 39 % adult children; 13 % other.	None used	Benefit Finding Scale (BFS, Antoni <i>et al.</i> , 2001)	PTG was reported in carers at baseline (mean BFS score = 68.0 , SD,12.1) Scores on BFS increased very slightly in response to intervention - e.g. from 68.0 at baseline to 68.9 (SD, 10.1) at 3 months and 68.5 (SD, 12.4) at 6 months
Kim <i>et al.</i> 2007 U.S.A.	Cross sectional	Family carers of people with cancer. Cancer Types: breast (28%), prostate (20%), colorectal (13%), lung (10%), non-Hodgkin's lymphoma (8%), ovarian (6%), skin (5%), and other (5%).	896	Mean length of time since care-recipient had received diagnosis = 2.2 years (SD . 0.6, range 1.3 to 4.7 years) The average duration of providing care was 19 months (SD, 16 months).	64.8 % female Mean age = 53.95 (SD=12.54)	None used	Benefit Finding Scale (BFS, Antoni <i>et al.</i> , 2001)	Social support and religious coping were positively associated with overall PTG scores (and both made significant contribution to regression equation) Higher levels of stress were associated with greater benefit finding in some domains, but the effects were generally small and inconsistent. No association between care recipient's physical functioning and PTG. Overall PTG scores were positively associated with life satisfaction

Table 1.1 (cont): Systematic Search: Post Traumatic Growth in Carers

Authors , Country	Design	Sample & recruitment location	n	Data collection (timing, location, etc.)	Carer details: gender, age, ethnicity & relationship to survivor	Theoretical Model used	Measure of PTG	Results
Kim <i>et al.</i> , 2008 U.S.A.	Cross sectional, SEM	Spouse carers of people with cancer. Cancer Types: breast (25%), prostate (24%), colorectal (11%), non-Hodgkin's lymphoma (11%), lung (9%), and other (5%)	314	Mean length of time since care-recipient had received diagnosis = 2.2 years (SD . 0.6)	51 % female spouse; 49% male spouse. White American (90.8%) Mean age= 56.50 (SD 10.62)	Attachment Theory	Benefit Finding Scale (BFS, Antoni <i>et al.</i> , 2001)	Attachment security related positively to finding benefit in carers Among wives (but not husbands), autonomous motives related to greater benefit finding.
McCausland & Pakenham, 2003 Australia	Cross Sectional	Carers of people with HIV/AIDS Recruited through HIV and gay outreach services; adverts in gay/lesbian magazines; HIV drop in centres	64	Mean number of months caring = 39.1 months (SD= 39.4, range 1-180 months)	41 % female Mean age = 43.1 (SD 11.2, range 19-70) 89 % white Australian 50 % Partner , 15.6% Mother, 34.4. % friend	TSM (Lazarus & Folkman, 1984)	Open ended question: 'What do you feel you have gained from caring for [care recipient's name]?'	97% of carers reported benefits in their experience $r = - 0.29^*$ between PTG and depression $r = 0.41^{**}$ between frequency of using social support and PTG $r = 0.59^{**}$ between seeking social support coping and PTG $r = 0.33^{**}$ between problem solving coping and PTG No significant association between PTG and: avoidant coping, wishful thinking coping, self blame coping, threat/ challenge/ controllability appraisals, level of distress about care-recipient symptoms, carers' health, impact of caring on carer (in terms of finances, family life, self esteem)

Table 1.1 (cont): Systematic Search: Post Traumatic Growth in Carers

Authors , Country	Design	Sample & recruitment location	n	Data collection (timing, location, etc.)	Carer details: gender, age, ethnicity & relationship to survivor	Theoretical Model used	Measure of PTG	Results
Moore <i>et al.</i> , 2011 U.S.A.	Prospective Study	Patients with severe cancer (n= 202) and a subsample of their carers (n=83) Recruited through outpatient clinics	83	Data collected at time patient diagnosed (T1) and then at 3 months (T2) and 6 months (T3)	Gender of carers not given; age of carers not given; ethnicity not given. 63 % spouses; 17 % aunt/uncle; 7 % siblings; 6 % parent; 3% son/daughter; 2 % other	None used	PTGI	Caregivers reported PTG as a result of patients' diagnosis of cancer. However, mean carer PTGI score; percentages of carers reporting PTG not given. (N.B. Given that the main focus of the study was on patients, only limited findings were reported for carers)
Mock & Boerner, 2010 Canada	Cross sectional	Carers of people with Amyotrophic Lateral Sclerosis (ALS) (ALS is a progressive neurological disease that causes severe physical disability and has a median survival time of 3.5 years)	52	Mean = 44 months since patients received their diagnoses (SD = 26.00).	71% female. Average age = 55.94 (SD, 12.70). Ethnicity not given	None used	Open ended question: 'Sometimes people who have a serious illness or disability find some positive aspect in the experience. For example, some people feel they learn something about themselves or others. Have you found anything positive in this experience?'	33 caregivers (64%) reported benefit, 13 caregivers (25%) reported they had not found benefit and six caregivers (11%) did not provide a response. Patient and caregiver pairs where neither found benefit had more depressive symptoms compared to pairs where at least one member found benefit. Benefit finding, but not sense making, was associated with fewer depressive symptoms for both patients and caregivers No assoc between PTG and : date of diagnosis, symptom severity, type of ALS onset (limb vs bulbar) or relationship type (spousal vs non-spousal)

Table 1.1 (cont): Systematic Search: Post Traumatic Growth in Carers

Authors , Country, Quality Rating	Design	Sample & recruitment location	n	Data collection (timing, location, etc.) & data analysis	Participant details: gender, age, ethnicity & relationship to survivor	Theoretical Model used	Measure of PTG	Results
Pakenham, 2005a Australia	Cross sectional	Multiple Sclerosis (MS) carers	222	Mean number of months caring = 111.8 months (SD= 104.8, range 2-480 months) N.B. This study used data from the main study (Pakenham, 2005b) below.	64 % male Mean age = 51 years old (SD = 12.71; range 20-82) Ethnicity not given. 86% spouse, 10 % immediate family member, 4% close friend.	None used	Mohr <i>et al.</i> 's (1999) 19-item benefit finding scale Benefit finding spilt into: Personal Growth (PGrowth)(e.g. 'I am now more determined') Family Relations Growth (FRGrowth) (e.g. 'I better keep in touch with my family')	Most carers endorsed at least one area of benefit finding. E.g. 71% of carers endorsed item: '[care recipient's] MS has made me appreciate life more'. r= 0.24** time since diagnosis and FRGrowth r= 0.17* time since diagnosis and PGrowth r= 0.18* between PGrowth and dyadic adjustment (e.g. 'significant other and I share same interests') r= - 0.16* between FRGrowth and care-recipient positive affect No significant association between PTG and: age, gender, number of caregiving problems reported, number of care-recipient symptoms, stress appraisals and various outcome variables (global distress, negative affect, life satisfaction)
Pakenham, 2005b Australia	Prospective study	Multiple Sclerosis (MS) carers	222 (T1) 155 (T2)	Data collected at two time points: T1 = baseline T2 = 3 months later Mean number of months caring = 111.8 months (SD= 104.8, range 2-480 months)	64 % male Mean age = 51 years old (SD = 12.71; range 20-82) Ethnicity not given. 86% spouse, 10 % immediate family member, 4% close friend.	None used	Mohr <i>et al.</i> 's (1999) 19-item benefit finding scale	r= 0.22** between time since diagnosis and PTG r= 0.19* between avoidance coping (T1) and PTG (T2) r=0.22** between practical assistance coping (T1) and PTG (T2) r= 0.22** between positive reframing coping and PTG No significant association between PTG and: Supportive engagement and Criticism/coercion coping. avoidance coping, practical assistance coping, positive reframing coping predicted PTG in regression equation as a whole, but not individually.

Table 1.1 (cont): Systematic Search: Post Traumatic Growth in Carers

Authors , Country, Quality Rating	Design	Sample & recruitment location	n	Data collection (timing, location, etc.) & data analysis	Participant details: gender, age, ethnicity & relationship to survivor	Theoretical Model used	Measure of PTG	Results
Thombre <i>et al.</i> , 2010 India/ U.S.A.	Cross sectional, correlation design	Family caregivers of cancer patients in India Care recipient suffering from: breast cancer (46.5%), Head/neck cancer (20.7%), Lung cancer (32.8%).	58	Mean number of months since patient's initial diagnosis = 11.5 months (SD, 30.2)	58.6 % male Mean age = 39.8 years old (SD = 12.7) 62.1 % Maharashtrian; 37.9 % other 41.4% spouse, 31 % adult child, 20.7% close relative, 5.2% parents.	Pargament <i>et al.</i> (2000) model of religious coping	PTGI	Mean PTGI score = 74.13 (SD, 18.73) (range 0-105) ¹ r = 0.60** between PTGI and benevolent religious reappraisal r= 0.51** between PTGI and spiritual connection r= -0.48** between PTGI punishing god reappraisal r= -0.42** between PTGI and spiritual discontent In regression, only benevolent religious reappraisals and punishing God reappraisals predicted PTGI scores.

TSM = Transactional Model of Stress and Coping; SEM = Structural Equation Modelling; PTGI = Posttraumatic Growth Inventory; * p < 0.05; ** p < 0.01

¹ N.B. Thombre *et al.*, 2010 *et al.* report a mean score of 95.13 on the PTGI. However, on examination it was found that a Likert scale from 1-6 was used, resulting in a possible score range of 21-126. As the PTGI generally uses a Likert scale 0-5 and range 0-105, 21 points were subtracted from the mean score in order to give a new standardized mean score (=74.13).

1.4.2.6. Social Support Factors

Social support was positively associated with PTG in all papers that investigated such relationships: McCausland and Pakenham (2003) found a strong positive correlation between the frequency of using social support and PTG in HIV carers, when using two separate measures of social support (WOC, Vitaliano *et al.*, 1985; Social Support Measure, Zich & Temoshok, 1987, cited in McCausland and Pakenham, 2003). Kim *et al.* (2007) measured perceived availability of social support and found this to be positively associated to PTG in a sample of cancer carers. Pakenham (2005b) found PTG to be positively associated with practical assistance coping, a dimension of the Coping with MS Caregiving Inventory (Pakenham, 2002), which contains items such as 'I seek assistance from others' and 'I talk to others about the problem' as well as more generic items such as 'I offer [care recipient] physical assistance'.

1.4.2.7. Event related factors

The level of care-recipient functioning and symptom severity could be expected to impact on PTG in carers. However, three studies failed to confirm this; PTG was unrelated to: The number of care recipient symptoms in a sample of MS carers (Pakenham, 2005a), the severity of care recipient symptoms in carers of people Amyotrophic Lateral Sclerosis (Mock & Boerner, 2010) and the level of care recipient physical functioning in a sample of cancer carers (Kim *et al.*, 2007). McCausland and Pakenham (2003) also found PTG to be unrelated to carers' level of distress regarding care recipient problems in a sample of carers of people with HIV/AIDS. These findings are important as they suggest no straightforward connection between the severity of the illness and levels of PTG in carers. However, it would be of interest to investigate any curvilinear relationships between PTG and severity, whereby PTG in carers was associated with moderately severe symptoms but not mild or very severe symptoms (as in Lechner *et al.*, 2003 above).

Time since diagnosis was not found to impact on PTG in carers of people with Amyotrophic Lateral Sclerosis (Mock & Boerner, 2010). However Pakenham (2005a) found time since diagnosis to be positively correlated with higher levels of PTG in MS carers, both in terms of personal growth and growth related to relationships with others.

1.4.2.8. Individual factors

Kim *et al.* (2008) found PTG to be positively associated with attachment security and autonomous motives in carers of people with cancer. Autonomous motives for caring include:

'because it was something I deeply valued doing' (whereas externally motivated reasons include: 'because my family and friends expected me to do so') (Kim *et al.*, 2008). Age was not found to be associated with PTG in a sample of MS carers (see Pakenham, 2005a).

1.4.2.9. PTG and Adjustment

Several studies found that PTG was associated with improved adjustment. For example, PTG was found to be positively associated with: carer's life satisfaction (in a sample of cancer carers, Kim *et al.* 2007), dyadic adjustment (in a sample of MS carers, Pakenham 2005a) and positive affect in the person being cared for (in a sample of MS carers , Pakenham 2005a). Equally, PTG was found to be negatively associated with factors indicating maladjustment such as depression in carers of people with HIV/AIDS and in carers of people with ALS (McCausland & Pakenham, 2003; Mock & Boener, 2010, respectively). It should however be noted that, where given, the associations between PTG and measures of adjustment were generally small (ranging from $r = 0.16$ to 0.29). In addition, Pakenham found no association between PTG and global distress, negative affect and life satisfaction when assessing outcomes in carers of people with MS. However, this null finding may have been confounded by his choice to split PTG scores into two factors (Person related growth and Family Relationship growth, see Table 1.2). This resulted in no overall PTG score and possibly reduced the strength of a correlation between PTG and adjustment.

1.4.2.10 Methodological Issues

It should be noted that PTG was measured differently across studies. For example, some studies used validated scales, such as the PTGI (see Thombre *et al.*, 2010) whereas McCausland and Pakenham, (2003) used an open ended question and measured level of PTG in terms of the number of benefits spontaneously reported. It could be argued that the use of open questions leads to underreported levels of PTG as people may need prompting to report benefits. This problem may also impact on the strength of correlations between PTG and other factors. Indeed, in discussion of their findings, McCausland and Pakenham (2003) note: 'The absence of stronger relations between benefit finding and adjustment may be due to the way benefit finding was measured'.

Sample sizes also varied between studies (range 23-894) with smaller studies (e.g. Kilbourn *et al.*, 2011) being limited in the use of statistical methods and the conclusions that could be drawn. From examining the demographics and range of the sample it was also noted that participants were often recruited less than one year since taking on a caring role or receiving

a diagnosis. (see Moore *et al.*, 2011; McCausland and Pakenham, 2003; Pakenham, 2005). As previously noted, recruiting participants in acute stages may confound associations between PTG and related factors (see section 1.3.4.)

The comparisons that can be made between different populations of carers may also be an issue: for example, carers of people who are terminally ill may have very different experiences to cases where prognosis is better. However, the work of Kilbourn *et al.* (2011) suggests that carers still report PTG even when caring for people who are terminally ill and close to death.

1.4.3. Stroke carers

1.4.3.1. Search Strategy

The following databases were searched, from 1980 to 3rd March 2012: PsychINFO, Embase, Medline, and PsycARTICLES full text.

Key search terms relating to PTG were: posttraumatic growth, benefit finding, finding benefit*, stress related growth, perceived benefit* adversarial growth, thriving, positive psychological change*, identity reconstitution and self transform*. In comparison to the search on carers in general (see section 1.4.2 above), the search term positive outcome* was also included. This is a more general term for PTG that was included to ensure that the widest selection of results was obtained on this search.

Key search terms relating to stroke were: stroke, cerebrovascular accident, CVA, apoplexy, ischaemic stroke, ischemic stroke, haemorrhagic stroke, cerebral hemorrhage

Key search terms relating to carers were: carer*, caregiver*

Terms with similar meaning were combined using Boolean operator 'OR' (e.g. carer* OR caregiver*) to give three overall topic results for: PTG, Stroke and Carer. Topics were then combined with 'AND' to give results for: PTG (Topic), AND Stroke (Topic), AND Carer (Topic)

All abstracts and titles identified during this process were reviewed. Where it was difficult to discern whether the paper met inclusion criteria from the abstract alone, the full article was reviewed. The bibliographies of all articles that met the inclusion criteria were examined for relevant studies, as were the reference lists of key review papers, book chapters and meta-analyses.

1.4.3.2. Inclusion and exclusion criteria

In reviewing the results, the following inclusion and exclusion criteria were applied:

Inclusion:

- informal rather than paid carers
- stroke carers
- measures PTG in carers
- original articles
- quantitative studies
- peer reviewed papers
- studies published in English, between 1980 -2012

Exclusion

- carers of children
- bereaved carers
- review papers
- papers that were not reviewed, such as dissertations

1.4.3.3. Search Results

Of 59 studies only three studies met the inclusion criteria (see Figure 1.4) and these three studies are described in Table 1.2. The most frequent reasons to exclude papers were: PTG not measured, review papers, replications. Papers were also excluded if carers were bereaved or were caring for a child. Exact numbers of papers excluded by exclusion criteria are given in Table 1.2.1, below.

Figure 1.4 Flowchart of review process (Stroke Carers)

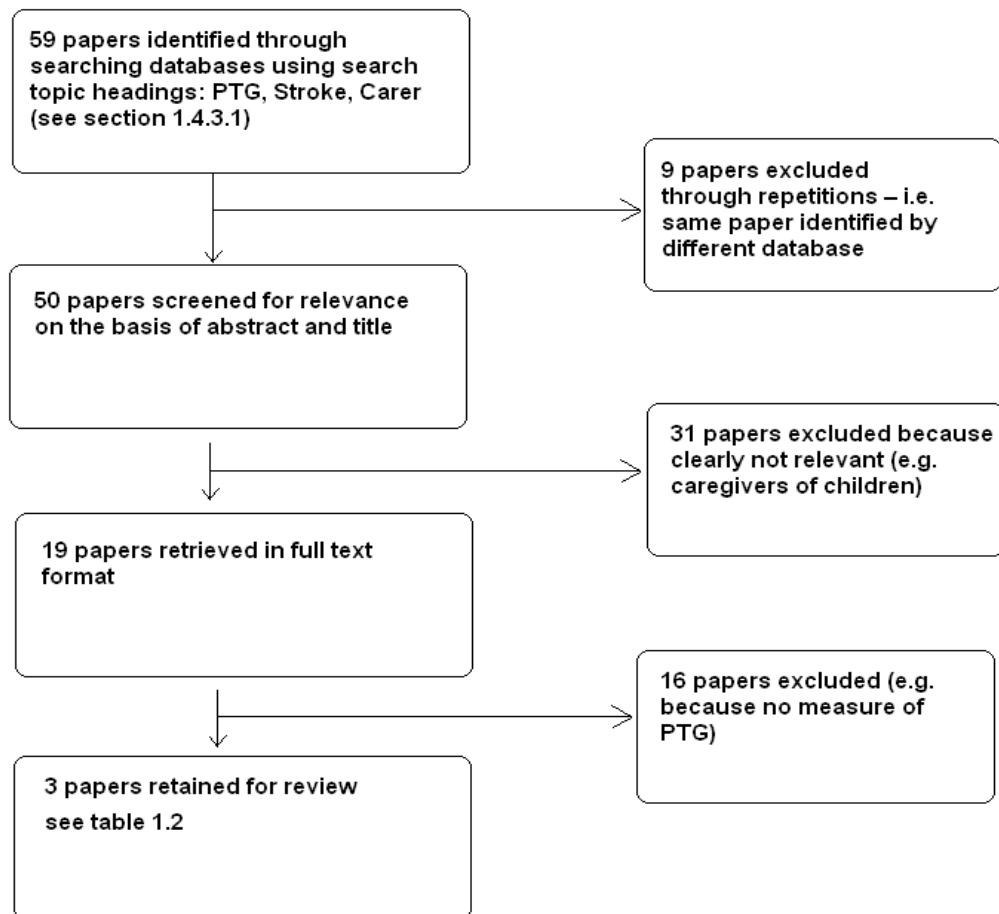


Table 1.2.1 Excluded Papers (Stroke Carers)

Reason for exclusion	N
Replications	9
Qualitative studies	6
Review Papers	12
Theoretical papers	7
Caregivers of children	4
Bereaved carers	1
Dissertation, not peer reviewed	1
Does not measure PTG	16
<i>Retained</i>	3
Total	59

1.4.3.4. Brief description of studies

Given the low number of papers retained (n=3) and the fact that PTG in stroke carers is the main focus of the review, each paper will be briefly described in turn:

In Bacon *et al.* (2009), four stroke carers were asked to respond on a day-to-day basis in relation to a bothersome event that had occurred during that day. Carers were then asked to report on a measure of coping strategies used and gains experienced. Here, it should be noted that PTG refers to a 'seismic' event that shatters assumptive beliefs (Tedeschi & Calhoun 2004a) and takes time to develop (Zoellner & Maerker, 2006). Therefore, it could be argued that gains reported on a day-to-day basis do not represent PTG. However, it was decided to retain this study given the paucity of research in this area. It was also of interest to examine what gains stroke carers reported, even on a day-to-day basis.

Haley *et al.* (2009) conducted telephone interviews with 75 family stroke carers, 8-12 months post stroke. Carers were asked to report on a measure of the stroke survivor's impairments. Carers were also asked about any gains via the Positive Aspects of Caregiving Scale (an 11

Table 1.2: Post Traumatic Growth in Carers of Stroke Survivors

Authors , Country, Quality Rating	Design	Sample & recruitment location	n	Data collection (timing, location, etc.) & data analysis	Participant details: gender, age, ethnicity & relationship to survivor	Theoretical Model used	Measure of PTG	Results
Bacon <i>et al.</i> , 2009 UK	Small sample, longitudinal design	Purposive sampling - i.e. only carers who had described positive experiences at interview were recruited. Potential participants were identified via local (NHS) stroke teams	4	3 to 10 months post stroke Carers filled in a daily diary of stresses and perceived benefits	2 male; 2 female. 62- 65 years old. Ethnicity not reported. 2 Husbands; 2 Wives.	TSM (Lazarus and Folkman, 1984)	6 item self-report scale of positive experiences following 'bothersome' event.	Carers reported high levels of positive experiences. PTG was associated with emotion-focused coping in one carer and with problem-focused coping in another
Haley <i>et al.</i> , 2009 USA	Cross-sectional, observational design	Family stroke caregivers Family carers identified through epidemiological survey of 30214 Americans, of which 230 had suffered a stroke. Of these 230 stroke survivors, 95 survivor-carer dyads were contacted; of these 95, 75 were recruited (79 %)	75	8 to 12 months post stroke	79 % female. Mean age, 63.69 years (SD = 13.62). 56 % white American; 44 % black American. All family caregivers: 53 % spouse; 31 % child; 16 % other (e.g. sister)	None reported	Positive Aspects of Caregiving Scale (Schulz <i>et al.</i> 1997)	Caregivers reported many benefits from care-giving, with over 90% reporting that care-giving enabled them to appreciate life more

Table 1.2 (Cont): Systematic Search: Post Traumatic Growth in Carers of Stroke Survivors

Authors , Country, Quality Rating	Design	Sample & recruitment location	n	Data collection (timing, location, etc.) & data analysis	Participant details: gender, age, ethnicity & relationship to survivor	Theoretical Model used	Measure of PTG	Results
Thompson, 1991 U.S.A.	cross-sectional design	stroke caregivers Carers recruited through survivor attending an outpatient appointment	40	Average of 9 months after stroke (range 1-60 months)	13 male; 27 female Mean age, 56.0 years (range 21-81) Ethnicity not reported. 80% spouses; 10 % relatives other than an adult child; 5% adult children; 5 % not related to the patient.	Attribution theory, with attributions linked to: why stroke happened; what caused stroke; feelings of responsibility	Open-ended question of perceived benefit	45 % of carers reported benefits in their experience $r=0.29^*$ between adjustment and PTG $r=0.30^*$ between finding a cause for the stroke and PTG Regression analysis (using the <i>combined</i> data of $n=40$ carers and $n=40$ stroke patients) found: <ul style="list-style-type: none"> - PTG predicted adjustment (when controlling for severity of stroke) - Finding a cause predicted adjustment (when controlling for severity of stroke) (N.B. adjustment score = composite of depression and meaningfulness in life scales) (N.B. severity of stroke = composite score of: ability to care for self scale; physical limitation scale; interviewer ratings of degree of patient physical functioning)

TSM = Transactional Model of Stress and Coping; PTGI = Posttraumatic Growth Inventory; * $p < 0.05$; ** $p < 0.01$

item scale that asks carers to report on perception of benefits using a 'yes'/no' scale, Schulz *et al.*, 1997) and about their overall strain and levels of depression.

Thompson (1991) interviewed 40 stroke carers using a measure of meaning making processes (e.g. 'have you searched for a cause of the stroke?') and a measure of the meaning made (i.e. the extent that carers had made meaning out of their experience). However, all participants that found meaning in their experiences also described positive outcomes (such as appreciating life more) - so the measure of meaning made is ostensibly a measure of PTG. The severity of the stroke was also measured through a composite score of carer, patient and interviewer ratings and levels of carer adjustment through a composite of a depression scale and a scale 'tapping a sense of order, of fairness and of purpose in life' (Thompson, 1991 p.85).

1.4.3.5. Prevalence of PTG

Haley *et al.* (2009) found that of 75 stroke carers, 90% reported benefits from the care-giving experience. Gains included: appreciating life more (in 90% of carers), feeling needed (in 88% of carers) and strengthened relationships with others (in 86% of carers). Bacon *et al.* (2009) also found carers reported gains on a six item measure of positive experiences. Here, the most common gain was 'felt appreciated'.

Thompson (1991) found that 45 % of stroke carers reported benefits when asked the open question: 'have you found any meaning in your experience with a stroke?' Reported benefits included appreciating life more and appreciating the survivor more. However, use of an open-ended question may have resulted in under-reporting of benefits. Indeed, the question is vague and it could be argued that some carers may not have spontaneously reported benefits, even if they had experienced them.

1.4.3.6. Coping factors

Bacon *et al.* (2009) visually inspected graphs and found a positive association between challenge appraisals and positive experiences in all cases (n=4). Here, challenge appraisals were measured by asking: 'were you excited about thinking about the outcome of the event or situation?' However, conclusions about how coping style interacts with benefits in stroke carers were less conclusive. For example, benefits were positively associated with emotion-focused coping in one carer and with problem-focused coping in another (Bacon *et al.*, 2009 p12).

Thompson (1991) used attribution theory in structuring the research question and discussing findings and, although not explicitly linked to PTG, attribution theory can be useful in the importance it places on searching and attributing causes to events. Indeed, searching for and finding a cause for the stroke was correlated with higher PTG ($r=0.30$); a cognitive process that could somewhat be compared to the ruminative process and the search for meaning described by Tedeschi & Calhoun (2004a).

1.4.3.7. Social Support factors

Of the three studies, Bacon *et al.* (2009) was the only study to ask stroke carers about social support. Specifically, carers were asked: 'to what extent did you seek emotional support from loved ones, friends or professionals?' However, this item was later grouped into a meta-variable (problem focused coping) so the individual contribution of seeking support on finding benefits cannot be evaluated.

1.4.3.8. Event related factors

Bacon *et al.* (2009) recruited carers 3-10 months post stroke and found that reported benefits increased over the 6-weeks study period. Although carers were responding to gains on a day-to-day basis, such findings suggest that carers may be more able to find benefits in their experience over time. This tentatively corroborates the stance of Zoellner and Maerker (2006) who suggest that authentic PTG rarely develops in the acute stages following a crisis; rather that PTG takes time to develop.

None of the studies directly assessed the impact of physical functioning on PTG. However, Thompson (1991) found that PTG remained a significant predictor of adjustment when controlling for level of physical functioning. This is an important finding as it suggests that the impact of PTG on wellbeing is not simply mediated by physical functioning. Rather, PTG has an independent effect on adjustment.

1.4.3.9. Individual factors

Thompson (1991) examined the impact of age on PTG and found a negative relationship between PTG and age ($r= - 0.36, p<0.01$) – i.e. caregivers were more likely to report growth if they were younger. However, as noted previously, reports of PTG may have been confounded by use of a vague question, a confound that may be magnified in older participants.

1.4.3.10. Wellbeing and adjustment

Thompson (1991) found that PTG was positively correlated with adjustment in stroke carers ($r=0.29$, $p<0.05$). Haley *et al.* (2009) also found that only 13.7 % of stroke carers scored at or above criterion for depression. However, as no comparisons were made in the study it is unknown whether depressed carers were able to identify benefits in their experience, or not.

1.4.3.11. Methodological issues

A strength of the Bacon *et al.* (2009) study was the prospective design which allowed for the finding that reported gains increased over time. A weakness was whether Bacon *et al.* (2009) actually assess PTG in its true sense. The small sample size ($n=4$) and recruitment on the basis that participants reported some gains at initial interview also confounded the generalizability of the results.

A strength of the study by Thompson (1991) was the focus on meaning making and PTG and, if we discount the Bacon *et al.* (2009) as not studying PTG in its true sense, then the study by Thompson (1991) also represents the only correlational study of PTG in stroke carers. However, there were several weaknesses to the study. For example, Thompson (1991) made no indication as to whether data was parametric, yet she used parametric statistics, namely Pearson's correlation. Thompson (1991) also combined data for patients and carers in the regression analysis, making interpretation difficult. Indeed, when combining data, it was found that asking oneself 'why me?' significantly predicted adjustment. However, this was not found to be a predictor of adjustment when this was analysed in carers only. It should also be noted that, although some correlations are reported between variables and PTG, the focus of Thompson's (1991) study was on the predictive nature of adjustment, rather than growth. This means that relationships between certain variables and growth –i.e. of particular interest to this study- were not analysed. This was particularly so for the regression analysis which set adjustment, rather than PTG, as the dependent variable.

A strength of the study by Haley *et al.* (2009) was the fact that they recruited from a community population rather than a service-based sample. Indeed, combined with the results of Thompson (1991) and Bacon *et al.* (2009), who recruited through stroke teams and rehabilitation settings, it can be confirmed that both community and service-based samples of stroke carers report benefits in their experience. A weakness of the Haley *et al.* (2009) study was that various statistical tests (e.g. correlation/ regression) were not used.

This made it difficult to draw conclusions of relevance to the current study (e.g. whether the reported stressfulness of patients' problems correlated with PTG in carers).

1.4.3.12 Summary

In summary there was evidence that stroke carers report PTG and that gains may increase over time. Factors that may be associated with PTG in stroke carers include: younger age of carer and searching and finding a cause for the stroke. Thompson (1991) also found that PTG predicted adjustment, even when controlling for level of physical functioning. However, many methodological issues were also noted. For example, sample sizes in correlation studies were low (range, 4-40), correlations between PTG and relevant factors were not conducted (see Haley *et al.*, 2009) or not reported when the dependent variable was set as adjustment rather than PTG (see Thompson, 1991). Further research is therefore needed and specific outstanding questions regarding PTG in stroke carers listed in section 1.5.3.

1.4.4 Summary of review: section 1.3 and section 1.4

The following review summarises the findings of the generic and systematic search of the PTG literature:

Prevalence of PTG – PTG has been reported following a wide range of events including: illness, bereavement and accidents (see Helgeson *et al.*, 2006 for a review). PTG has also been reported in carers of people with physical health issues (e.g. Mock & Boener, 2010) and in carers of people with stroke (e.g. Haley *et al.*, 2009). Given these findings it is assumed that PTG will be reported in the sample of stroke carers recruited for the study (see **H1**). Additionally, it is expected that growth scores on a standardized measure will not differ from other carers (see **H2**).

Coping factors –there was strong evidence from the general literature that coping style impacts on PTG (see Table 1.3). There was also a small body of evidence that coping style impacts on PTG in stroke carers. This study will focus on the coping processes indentified in the models of Tedeschi & Calhoun (2004a) and Schaefer and Moos (1998) – namely, whether rumination, acceptance coping and active coping are associated with PTG in stroke carers (see **H3**, **H4**, **H6**,**H11** respectively). The study will not assess the impact of positive appraisal on growth, given its large overlap with PTG (Siegel *et al.*, 2005) or religious coping, given that a religious belief in the UK is relatively low (You Gov, 2012)². However, the impact of avoidance coping on PTG will be assessed (see **H5**) as this has been both positively and negatively associated with PTG within the general literature (see Table 1.3).

Social Support - Social Support was found to be positively related to growth in the general literature, and in carers (see Table 1.3). However, as no study has reported on the impact of social support on PTG in stroke carers, this is investigated in the current study (see **H7**).

Event-related factors –there was some evidence that cancer patients with moderately severe symptoms show heightened growth (see Table 1.3). However, there was little evidence to suggest that the level of physical functioning or number of care-giving problems impacts on growth in carers (e.g. McCausland & Pakenham, 2003). Thompson (1991) also found that survivor’s level of functioning had no impact on the relationship between PTG and adjustment in carers. However, given that the *direct* impact of the survivor’s functioning has

² A recent YouGov poll found that, of 1828 adults aged between 18 and 60+ years in the UK, 74 % stated they were either ‘not very religious’ or ‘not religious at all’ (YouGov, 2012).

not been assessed in stroke carers this is an area worthy area of further investigation (see **H8**).

Time since event has been shown to be associated with growth in the general literature and in some studies of carers, but not others (see Table 1.3). However, in an effort to keep the number of factors to a minimum, the impact of time on PTG will not be investigated within the current study.

Individual factors –within stroke carers, Thompson (1991) found that younger age was associated with PTG. However, Pakenham (2005a) found no such association between age and PTG in a sample of MS carers. Given the mixed findings it is worthwhile to assess the impact of age on PTG in carers, specifically whether younger age is associated with growth (see **H9**).

Outcome –PTG was associated with adjustment in stroke carers and with lower levels of depression in MS carers (see Table 1.3). Kim *et al.* (2007) also found PTG to be associated with life satisfaction in cancer carers. However, associations between PTG and improved quality of life within the general literature have been inconsistent (see 1.3.3). Additionally, it is unknown whether a relationship between PTG and quality of life becomes apparent when measured using a questionnaire specifically designed for carers. This will therefore be tested in the current study (see **H10**).

Models - preliminary evidence supports the model proposed by Tedeschi & Calhoun (2004a) over that of Schaefer and Moos (1998) (see section 1.3.6.4.). However, more research is needed in this area. In this study, the predictive value of factors identified by Tedeschi and Calhoun (2004a) (i.e. rumination; social support, acceptance coping, level of functioning³) are compared to factors identified by Schaefer and Moos (1998) (i.e. active coping, level of functioning, social support, age) (see **H11**).

³ N.B, in terms of the Tedeschi & Calhoun model (2004), level of functioning is used as an indirect measure of the stressfulness of the event (i.e. the stroke), with the assumption that those survivors that are less independent suffered a more debilitating and stressful stroke experience.

Table 1.3: Factors Associated with Growth

	General	Carers	Stroke Carers
Coping Factors	Deliberate rumination (+) <i>(Taku et al., 2009)</i>		Rumination (+) <i>(Thompson, 1991)</i>
	Avoidance coping (+/-) (see Zoellner & Maerker, 2006)	Avoidance coping (+) <i>(Pakenham, 2005b)</i> Avoidance coping (N.S) <i>(McCausland & Pakenham, 2003)</i>	
	Positive re-appraisal (+) <i>(Gangstad et al., 2009)</i>	Positive Appraisal (+) <i>(Pakenham, 2005b)</i>	
	Active Coping (+) <i>(Morris et al., 2007)</i>	Problem solving coping (+) <i>(McCausland & Pakenham, 2003)</i>	
	Acceptance Coping (+) <i>(Park et al., 1996)</i>		
			Challenge appraisals (+) <i>(Bacon et al., 2009)</i>
		Religious coping (+) <i>(Thombre et al., 2009; Kim et al., 2007)</i>	
Social Support	Social Support (+/-) <i>(Park et al., 1999; Sheikh, 2004)</i>	Social Support (+) <i>(McCausland & Pakenham, 2003)</i>	
Event related Factors	Moderate severity of symptoms (+) <i>(Lechner et al., 2003)</i>	Level of physical functioning (N.S) <i>(Pakenham, 2005a)</i> Symptom severity (N.S.) <i>(Mock & Boener, 2010)</i>	
		Number of care-giving problems (N.S) <i>(Pakenham, 2005a)</i>	
	Time (+) <i>(Sears et al., 2003)</i>	Time (+, N.S) <i>(Pakenham, 2005a; Mock & Boener, 2010)</i>	Time (+) <i>(Bacon et al., 2009)</i>
Individual Factors	Internal locus of control (+) <i>(Maerker et al., 1999)</i>		
		Attachment security (+) <i>(Kim et al., 2008)</i>	
	Age (-) <i>(Helgeson et al., 2006)</i>	Age (N.S) <i>(Pakenham, 2005a)</i>	Age (-) <i>(Thompson, 1991)</i>
	Self esteem (+) <i>(Abraido-Lanza et al., 1998)</i>		
Outcome	Depression (-) <i>(Helgeson et al., 2006)</i>	Depression (-) <i>(McCausland & Pakenham, 2003; Mock & Boener, 2010)</i>	
		Dyadic Adjustment (+) <i>(Pakenham, 2005a)</i>	Adjustment (+) <i>(Thompson, 1991)</i>
		Life satisfaction (+) <i>(Kim et al., 2007)</i>	

(+/- refers to a positive or negative association, respectively; N.S = Non Significant association)

1.5. Rationale for the study

The following section outlines why it is important to study PTG in stroke carers, how likely PTG is in stroke carers and what questions remain outstanding:

1.5.1. Why study PTG in stroke carers?

Reasons to study PTG in stroke carers include:

The need to develop integrated models - As previously discussed (see section 1.3.3.), several theorists (e.g. Park, 2010; Park and Folkman, 1997; Brennan, 2001) suggest that understanding the positive and negative reactions to trauma is key in developing comprehensive models of stress and coping. Indeed, within the literature on stroke carers, the positive of caring have largely been ignored (Lincoln *et al.*, 2012) and, although some studies examine PTG in stroke carers (see Table 1.2), further research is needed.

The possible adaptive significance of PTG – it is possible that PTG is associated with increased well being and lower levels of distress. Indeed, within stroke carers (and carers in general), multiple findings suggest that PTG is associated with adjustment in terms of lower levels of depression, higher levels of life satisfaction and higher levels of marital satisfaction (see Table 1.3).

Finding benefits may increase the quality of care giving – Hilgeman *et al.* (2007, cited in Halyley *et al.*, 2009) studied dementia carers over a 12 month period and found that carers who found benefits in their experience responded better to a caregiving intervention (based on helping carers deal with problems such as wandering, incontinence etc). It is possible that such gains related to PTG would also be found in stroke carers.

The transmission of PTG – preliminary results also suggest that PTG in female survivors of breast cancer is associated with PTG in their husbands (Weiss, 2004). Thus it is possible that PTG in carers may also facilitate growth in stroke survivors.

1.5.2. How likely is PTG in stroke carers?

Studies have found that between 45 -90% of stroke carers reported benefit from the caregiving experience (see section 1.4.3.). Thus it is likely that PTG will be reported by stroke carer in the current study. However, benefits may have been more widely reported in some studies (e.g. Thompson, 1991) if a validated scale was used. In the current study the PTGI was used (see section 2.6.2 for a detailed description of this measure).

1.5.3. *What questions are outstanding?*

From the review of the literature on PTG in stroke carers a number of questions appear to be outstanding.

- Is PTG reported by stroke carers when using the Post Traumatic Growth Inventory (PTGI)?
- How will scores on the PTGI differ from those reported by stroke survivors and carers of people with other health conditions?
- How do the factors: social support, level of functioning, rumination and age impact on PTG in a sample of stroke carers?
- Is PTG associated with quality of life when using a specific measure for carers?

From the review of the literature on PTG in general some additional questions appear to be outstanding:

- What factors better account for PTG in a sample of stroke carers - those predicted by Tedeschi and Calhoun (2004a) or Schaefer and Moos (1998)?
- Is avoidance coping related to growth?

1.6. Aims and Hypotheses

1.6.1. Aims

In summary, this study aims to:

- 1) Assess PTG in a large sample of stroke caregivers
- 2) Utilise a correlational approach to identify specific variables (including coping style, social support, level of functioning) associated with PTG across the sample
- 3) Compare the relative contribution of the factors proposed by Tedeschi and Calhoun (2004a) in predicting PTG to the more general factors proposed by Schaefer and Moos (1998).
- 4) Investigate the association between PTG and Quality of Life (particularly as a quality of life scale specifically designed for carers has not been used before)

1.6.2. Hypotheses

Based on the aims of the study and the literature to date, the following hypotheses will be tested:

H1: PTG will occur in a sample of stroke carers, with scores significantly greater than zero on the Post Traumatic Growth Inventory (PTGI)

H2: PTGI scores in this sample will not differ significantly from that of carers of other health conditions (two-tailed)

H3: PTG in stroke carers will be positively associated with higher levels of rumination (one-tailed)

H4: PTG in stroke carers will be positively associated with active coping style (one-tailed)

H5: PTG in stroke carers will be positively associated with acceptance coping style (one-tailed)

H6: PTG in stroke carers will be negatively associated with avoidance coping style (one-tailed)

H7: PTG in stroke carers will be positively associated with higher levels of social support (one-tailed)

H8: PTG will be associated with the level of functioning of the stroke survivor (two-tailed)

H9: PTG will be negatively associated with age (one tailed)

H10: PTG in stroke carers will be positively associated with quality of life in carers (one-tailed)

H11: Variance in PTG will be explained by two significant regression models - one based on factors identified by Tedeschi and Calhoun (2004a) (i.e. rumination; social support, acceptance coping, level of functioning) and the other based on factors identified by Schaefer and Moos (1998) (i.e. active coping, level of functioning, social support, age).

METHOD

2.1 Design

The study used a cross-sectional questionnaire design. Correlation and regression analysis were used to determine relationships between PTGI scores (dependent variable) and the independent variables (e.g. rumination coping, active coping, acceptance coping, avoidance coping, social support, level of functioning, age).

2.2. Participants and recruitment

2.2.1. Participants

The final sample was made up of 71 people who cared for a spouse who had suffered a stroke.

2.2.2. Recruitment

Carers were recruited from the following sources:

1. Voluntary stroke clubs in Wales and the South West of England
2. Communication groups in Wales
3. Internet adverts placed on the web pages of two nationwide stroke charities: Different Strokes and the Stroke Association

(For a fuller description of recruitment sources see Appendix 2.1 and for a breakdown of participants recruited by source see Appendix 2.2).

2.3 Procedure

The stages of the study are set out in Figure 3 and described in detail below:

Stage 1: The study was approved by the Psychology Research Ethics Committee, Cardiff University (see Appendix 2.3) and Cardiff and Vale UHB agreed to sponsor the study (see Appendix 2.4). However, before recruiting at each source, approval was also sought from all group facilitators, the regional directors of the stroke association, the director of the Bristol Area Stroke Foundation and from the web administrators (at Different Strokes and Stroke Association). An application was not made to an NHS ethics committee as there was no need to access patients, patient records or NHS staff.

Stage 2: Potential participants were alerted to the study via the on-line advert (see Appendix 2.5) or via their group facilitator in accordance with the participant information sheet (see Appendix 2.6).

Stage 3: Potential participants indicated interest in the study by contacting the researcher directly by email, or via their group facilitator.

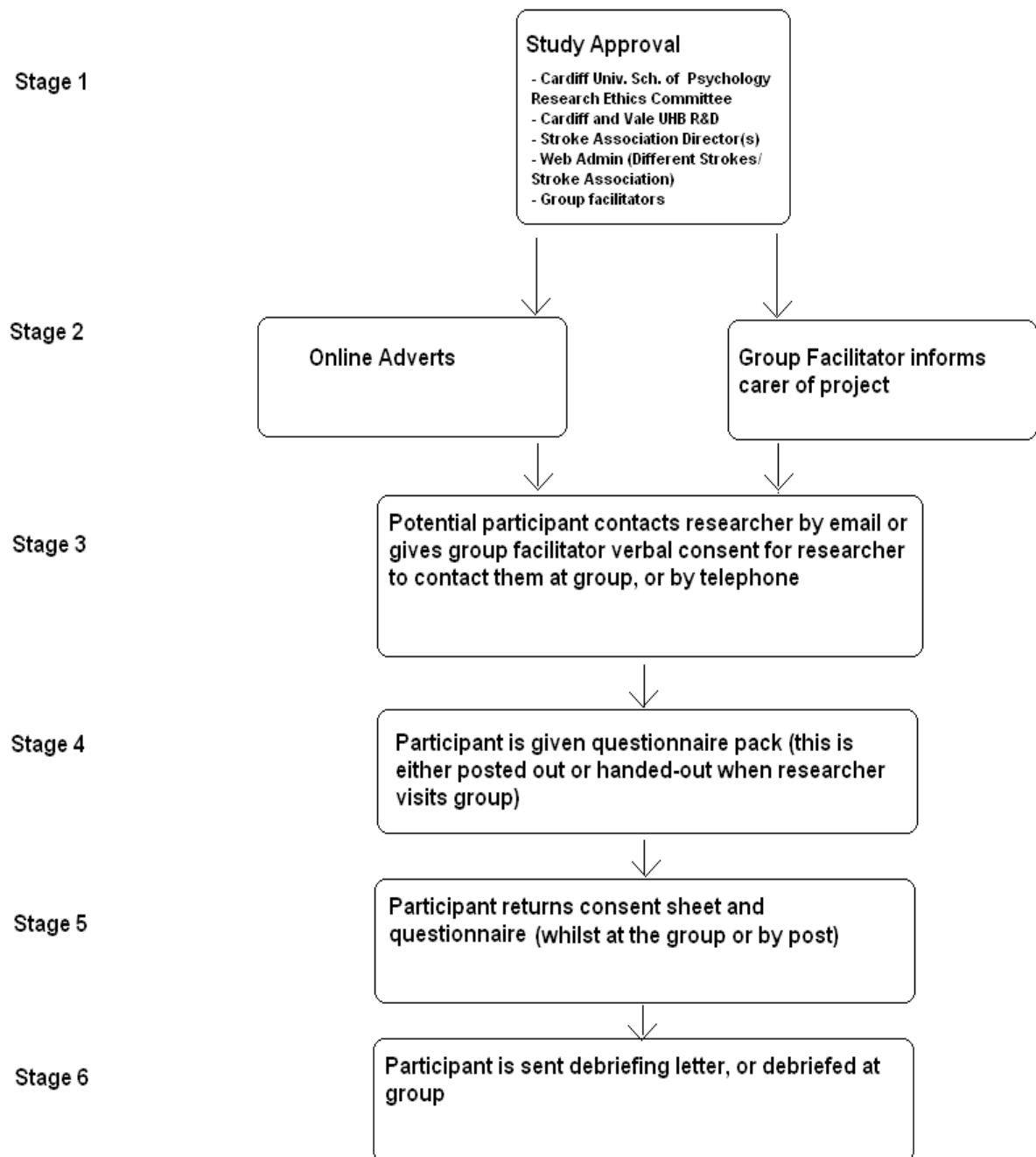
Stage 4: Participants who met inclusion criteria (see section 2.5 below) were given a questionnaire pack, including:

1. A Participant Information Sheet (Appendix 2.6).
2. A Consent Form, on which they could also indicate whether they would like a summary of the research findings (Appendix 2.7).
3. A questionnaire battery (Appendix 2.8).
4. A pre-paid envelope for those who wanted to return their questionnaire and consent sheet by post.

Stage 5: Participants returned their consent sheet and questionnaire (whilst at the group or by post).

Stage 6: Participants were sent a thank you and debriefing letter, or debriefed at the group (according to the debriefing letter, see Appendix 2.9).

Figure 2.1: Research Procedure



2.4 Ethical Considerations

2.4.1. Informed Consent

Participants were asked to complete a consent form (see Appendix 2.7) before they answered the questionnaire. In signing the consent form, participants were also asked to confirm they had read the participant information sheet (Appendix 2.6).

Informed consent was not requested from the stroke survivor as it was felt that it should be the carers' choice to participate or not. However, it was appreciated that spouses may have been curious as to the nature of the research. In the participant information sheet (see Appendix 2.6) it was therefore suggested that carers may like to share the information about the project with their spouse.

2.4.2. Inducement

Potential participants were first alerted to the study through the on-line advert (see Appendix 2.5) or their group facilitator; and only participants who had shown interest in the study were then contacted by the researcher. It was also highlighted that carers' participation was entirely voluntary (see participant information sheet, Appendix 2.6). It was hoped that these measures ensured that there was no undue pressure on people to participate.

2.4.3. Confidentiality

Questionnaires were coded and participants were asked not to write their names or any personal identifiable information on questionnaires. Consent forms were kept separately from questionnaires in a locked cabinet in South Wales Doctoral Course in Psychology, Archway House, Cardiff. Participants were informed of these confidentiality arrangements on both their consent form (Appendix 2.7) and debriefing letter (Appendix 2.9)

2.4.4. Demands on participants

The questionnaire was trialed with two Trainee Psychologists (South Wales Doctoral Course in Psychology, Archway House, Cardiff) and deemed to be comprehensible and sufficiently brief. It was also reviewed by the Assistant Regional Manager for Stroke Association Cymru.

There was a small risk that the questionnaire would be upsetting as it required participants to reflect on the experience of caring for a spouse who had had a stroke. In order to safeguard against this risk, participants were notified that they could omit items or stop the questionnaire at any time they wish (see front cover of the questionnaire, Appendix 2.8) and that their participation was entirely voluntary (see Participant Information sheet, Appendix 2.6). This information was also iterated verbally if the researcher met the participant in a group setting. Participants were also advised to contact their stroke club facilitator if they found any of the material upsetting (see back cover of questionnaire, Appendix 2.8).

2.4.5. Attending a group

By entering a group setting there was a risk of disrupting routine activities and dynamics. In order to minimise such a risk the researcher took several precautions, including:

- advertising the visit in advance, in order to alert both participants and non-participants that the researcher would be attending the club
- introducing themselves to the whole group on arrival
- advising participants to complete a questionnaire at a time that caused least disruption to the rest of the group
- feeding back on the project aims to all group members (i.e. those who had participated, or not) at the end of the visit

2.5. Inclusion/ Exclusion criteria

2.5.1. Inclusion criteria

Participants were recruited if they met the following inclusion criteria:

- 1) Their spouse or partner had suffered a stroke
- 2) They were an informal carer for their spouse/ partner
- 3) Their spouse/partner⁴ had their stroke at least 18 months previously

The decision to focus on informal spouse carers was based on the fact that spouses make up the majority of the stroke carer population (Lincoln *et al.*, 2012) and that by recruiting only spouses it was possible to increase the homogeneity of the sample.

⁴ the term 'spouse' is used rather than 'spouse/ partner' throughout the document for simplicity.

The decision to specify that the stroke must have occurred at least 18 months previously was based on the idea that PTG may take time to develop following trauma (Tedeschi and Calhoun, 1995). Indeed, research shows that, at one year post-stroke, carers are still coming to terms with the dramatic changes in their lifestyles (Smith *et al.*, 2004 cited in Buschenfeld *et al.*, 2009). Thus, by setting a lower limit of 18 months since stroke, carers would have had sufficient time to adjust to life changes. Setting a lower limit also reduced the chance of masking by 'emergency' coping strategies that may be used in the immediate aftermath of trauma (Zoellner & Maercker, 2006).

Participants were required to be proficient in English. In accordance with NHS Research and Development approval, the information sheet and consent form were available for translation into Welsh if participants requested this. However, the questionnaire could not be translated into Welsh as it contained measures only validated in the English language.

2.5.2. Exclusion Criteria

Participants were excluded if they were under 18 years of age.

2.6. Measures

The questionnaire consisted of a demographic survey and a battery of validated questionnaires (see Appendix 2.8):

2.6.1. Demographic survey

Participants were asked to complete a demographic survey concerning:

- a) Themselves (e.g. their gender, attendance at stroke club).
- b) Their partner (e.g. years since stroke, level of communication difficulty).

Items were included to give an overview of the sample and an indication of issues of interest. For example, carers were asked if they felt their spouse had changed in personality since having a stroke (Question 12) as this can have an impact on carer wellbeing (Smith *et al.*, 2004 cited in Buschenfeld *et al.*, 2009). Items were identified via the literature search and through consultation with research supervisors, who have expertise in stroke and caring.

2.6.2. Posttraumatic Growth

The Post Traumatic Growth Inventory (PTGI, Tedeschi & Calhoun, 1996) is a self report measure of positive outcomes following traumatic experiences. It consists of 21 items, scored on a Likert scale from 0 ('I did not experience this change') to 5 ('I experienced this change to a very great degree'). Five factors measure a different aspect of growth and include: Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and, Appreciation of Life. Total scores range from 0- 105, with higher scores representing more growth (however, any score above zero represents some degree of PTG).

The PTGI is widely used and has been shown to have excellent internal consistency (Cronbach's alpha = .92) when used with a sample of stroke survivors (Gangstad, 2009). It has also been shown to have adequate test-retest reliability in a sample of undergraduate students ($r = .71$, Tedeschi & Calhoun, 1996) and was found to be unrelated to a measure of social desirability (i.e. the Marlowe–Crowne Social Desirability Scale, Crowne & Marlowe, 1960; see Tedeschi & Calhoun, 1996).

2.6.3. Coping

The COPE scale (Carver *et al.*, 1989) is a 60 item inventory of coping responses with 15 distinct subscales (for their psychometric properties see Carver *et al.*, 1989). However, as with other research (e.g. Sears *et al.* 2003), it was decided to reduce the length and burden of the COPE by only using subscales that were of interest to this study. These include the Active Coping, Denial and Acceptance subscales.

The Active Coping, Denial and Acceptance subscales have been shown to have adequate internal consistency in a range of people suffering a variety of crises (Cronbach's alpha = 0.63 and 0.93, Park *et al.*, 1996; Armeli *et al.*, 2001) and adequate test-retest reliability in a sample of college students ($r = .54$ to $r = .69$, Carver *et al.*, 1989).

2.6.4. Social Support

The Multi Dimensional Scale of Social Support (MSPSS, Zimet *et al.*, 1988) is a 12 item scale assessing the extent that a person perceives that they receive social support from

others. Questions are scored on a Likert scale from 1 ('very strongly disagree') to 7 ('very strongly agree'). It can be split into subscales that relate to perceived support from family, friends and a significant other. A higher score indicates a greater perceived support. The MSPSS has been shown to have excellent internal consistency (Cronbach's alpha = 0.87-0.94) and good test-retest reliability ($r=0.73$) when tested in both a clinical and normal sample of older adults (Stanley *et al.*, 1998).

For the purposes of this study, a clarifying statement was added to the instructions to explain that the term 'special person' could refer to anyone, e.g. a spouse, friend or professional.

2.6.5. Rumination

The Rumination Scale (Calhoun *et al.*, 2000) is a self report measure that assesses rumination style following a stressful experience. Fourteen items are scored from 1 ('not at all') to 4 ('often'). Items reflect intrusive rumination (e.g., "I thought about the event when I didn't mean to") and deliberate rumination (e.g., "I decided to think about the experience to try and make sense out of what happened"). For each item, participants are asked to reflect on level of rumination shortly after the event and level of rumination more recently. A higher score indicates a greater level of rumination.

Internal consistencies, as measured in a general United States population, were as follows: intrusive rumination soon after the event (Cronbach's alpha = .85) and recently (Cronbach's alpha = .83); deliberate rumination soon after the event (Cronbach's alpha = .72) and recently (Cronbach's alpha = .74) (Taku *et al.*, 2009). Test-retest reliability for total scores have also been found to be acceptable ($r=0.71$, Calhoun *et al.*, 2000).

2.6.6. Level of functioning

The Barthel Index (Mahoney & Barthel, 1965) measures a person's functioning on a range of different day-to-day or 'activities of daily living' (Collin *et al.*, 1988). It is scored on the basis of whether the person can do the task independently or with the help of others and it is a tool that is commonly used to assess the level of functioning of stroke survivors (see Kwakkel *et al.*, 2010).

The index consists of 10 items that cover various activities including feeding, toilet use and mobility. It is scored using a scale: 0,5,10, 15 giving a total score of 0-100 (Mahoney & Barthel, 1965) or on a scale: 0, 1, 2, 3 to give a total score from 0 to 20 (see Collin *et al.*, 1988), with higher scores indicating increased functioning and independence (Kwakkel *et al.*, 2010). Both versions have been shown to be reliable and valid (see Kwakkel *et al.*, 2010 for a review). However, it was decided to use the Collin *et al.* version due to the clearer format for scoring items.

The measure is traditionally administered by a professional who observes the patient. However, it is also possible to interview the patient or a relative to obtain scores (Kwakkel *et al.*, 2010). Interviewing a relative (such as a spouse) has been found to be a reliable method of assessment, particularly when the patient is confused (Collin *et al.*, 1988). Indeed, scores on the Collin *et al.* version were shown to correlate highly between relatives, a trained nurse and occupational therapist (Kendall's coefficient of concordance $W= 0.93$, $p < 0.001$, Collin *et al.*, 1988). A self-report version - as used in this study - has also been shown to be reliable and practical (Gompertz *et al.*, 1994).

2.6.7. Quality of Life

The AC-QOL (Elwick *et al.*, 2011) is a measure of quality of life that is specific to carers. It consists of eight subscales designed to tap different aspects of quality of life important to carers including: Support for Caring, Caring Choice, Caring Stress, Money Matters, Personal Growth, Sense of value, Ability to Care and Carer Satisfaction. Items are scored from 1 ('Never') to 4 ('Always') and, with adjustment for reversed items, higher scores indicate greater quality of life.

Although tests of internal consistency and reliability are not reported upon, the subscales were determined using 'statistical analysis' and can be used separately (see Elwick *et al.*, 2011). All subscales were used in the current study, bar Personal Growth, Money Matters and Sense of Value. These subscales were excluded in order to: a) reduce replication of similar questions asked within the questionnaire and b) reduce burden. This gave a maximum score of 25 and a minimum of 0.

2.7 Statistical analysis and considerations

2.7.1 Sample Size

Within the reviewed literature (see Table 1.3), correlations between measures of PTG and the independent variables (rumination, active coping, acceptance coping, avoidance coping, social support, age, adjustment/ quality of life) ranged from between 0.29 and 0.46. Based on Cohen (1988, p 101-102), at least 69⁵ respondents was needed to detect similar correlations in the current study with the array of one and two tailed hypotheses used in this study (see Hypotheses), alpha set at 0.05 and power set at 0.80. The exception was level of functioning which only showed a correlation of 0.15 (Abraido-Lanza *et al.*, 1998). However, it was decided to retain this variable as studies have only investigated the effect of physical impairment on PTG in patients and not carers.

Multiple regression techniques were used with 1 dependent variable (PTG) and 7 independent variables (acceptance coping, active coping, avoidance coping, rumination, social support, level of functioning, age). Based on VanVoorhis and Morgan (2007), who suggest a minimum of 10 participants per independent variable⁶, a sample of 70 was therefore required.

Taken together this indicated that a sample size of at least 70 respondents was needed.

2.7.2 Methods of Analyses

The methods of analyses were as follows:

1. A one sample t test - to establish whether mean PTGI scores (dependent variable) differed significantly from zero (independent variable)
2. An independent t-test – to establish whether mean PTGI scores (dependent variable) differed from previously reported scores for a sample of carers (independent variable; see Thombre *et al.*, 2009)

⁵ N= 69 when tested on G Power: correlation t-test, $r=0.29$, $p = 0.05$, power = 0.80

⁶ N.B. VanVoorhis and Morgan (2007) also state that there should be a medium sized relationship between the predictor and dependent variable; based on Cohen (1988), all independent variables have shown a medium sized relationship with PTG (range $r=0.29-0.56$).

3. Pearson Product-moment correlation - to determine the relationship between PTGI scores (dependent variable) and independent study variables (rumination, active coping, acceptance coping, avoidance coping, social support, level of functioning, age, quality of life)

4. Linear regression (using three separate regression models) - to assess the amount of explained variance in PTGI scores.

- In Regression 1, factors identified by the Tedeschi and Calhoun (2004a) model (i.e. rumination, social support, acceptance coping and level of functioning) were entered into the model in blocks using the Enter method on SPSS (ver.18) according to their simple correlation with PTG (see Results section, Table 2.6).

- In Regression 2, Factors identified by the Shaefer and Moos (1998) model (i.e. social support, active coping, level of functioning and age) were entered into the model in blocks using the Enter method and according to their simple correlation with PTG (see Results section, Table 2.6).

- In Regression 3, a stepwise regression was used ('stepwise function', SPSS ver. 18) to assess the impact of all variables when using objective, mathematical criteria (i.e. predictors were not entered in terms of a specific model). It also allowed for the impact of avoidance coping on PTG to be assessed, a factor not included in any model of PTG.

It was expected that all three models would significantly contribute to variance in PTG. R-Squared values were also compared to determine which model best accounts for variance in PTG.

2.7.3. Bonferroni Correction

Bonferroni Correction was not used as this test is highly conservative and may miss significant relationships, particularly when assessing the relationship between variables in a questionnaire survey (Bland, 1996). Indeed, statistical correction did not feature in any of the studies reported in the systematic search (see Table 1.1 and Table 1.2). For this reason, correction was not applied to the multiple tests of significance of Pearson's correlations in the current study.

RESULTS

3.1. Results

This chapter is divided into 3 main parts (preliminary data analysis; descriptives and analysis). It begins with preliminary data analysis to check for errors and account for missing data within the dataset:

3.2. Preliminary data analysis

3.2.1. Error analysis

Minimum and maximum values for each categorical and continuous variable were screened in order to test whether data fell within the possible range on an item. Four data points were identified as input errors using this method and subsequently corrected after referring back to the raw data⁷.

3.2.2 Missing Data

Missing data was relatively low and accounted for only 1.8% of the data set.

On visual inspection, missing data was also found to be evenly spread through the data set with three notable exceptions: one participant did not complete the PTGI, one participant did not complete the Barthel Index and another participant completed less than 50% of the Active, Avoidance and Acceptance coping variables. Data for these participants were excluded using a pairwise technique from correlation and regression analysis.

All other participants provided data for at least 50% of each variable. Missing data for continuous variables were replaced using the mean of all responses from other participants on that variable.

⁷ 3 cope items were incorrectly coded as '5'; one cope item was incorrectly coded as '11'

3.3. Descriptives

3.3.1. Response rate

Out of 102 questionnaires given out, a total of 75 (or 73%) were returned. However, four datasets were excluded as the carer was caring for a spouse less than 18 months post stroke (see exclusion criteria, section 2.5). The final sample therefore consisted of 71 stroke carers.

3.3.2. Demographics of carer

Mean age for carers was 66.5, range 33-86 and standard deviation of 11.4 (see Table 2.1, below). This meant that the majority of carers were between 55 and 75 years old. Carers had also been caring for a mean of 9.2 years (SD 7.0), range 1 year and 6 months to 31 years. This matches mean years since stroke (see Table 2.3) but differs slightly in terms of standard deviation, suggesting that a small proportion of carers started caring sometime before or after their spouse had a stroke.

Table 2.1 Carer age and years caring ^a

	(N)	Mean	SD	Range
Age	(70)	66.5	11.4	33-86
Years caring	(71)	9.2	7.0	1 yr, 6 months - 31 yrs

^a N=number of carers; where N < 71, data was missing from the dataset.

In terms of carer demographics, most were female (73.2%), white British (97.2 %) and attended a stroke club at least once a month (62.2 %, see Table 2.2, below). However, a proportion of carers (28.2 %) never attended a stroke club or group. Sixty-two percent of carers spent over 50 hours a week caring for their spouse and a small proportion (15.5%) received support from a professional carer. When a professional carer was involved they visited an average of 8.6 times per week (SD, 5.3).

One carer (1.4%) did not report on their gender or ethnicity and 3 carers (5.2 %) did not report on the time spent caring per week. Missing data in Table 2.2 was not replaced as it not required in subsequent statistical analysis.

Table 2.2 Carer demographics ^a

		N	%
Gender	Male	18	25.4
	Female	52	73.2
	Missing	1	1.4
Ethnicity	White British	69	97.2
	White Irish	1	1.4
	Missing	1	1.4
Stroke club attendance	Never	20	28.2
	Less than once a month	4	5.6
	Once a month	10	14.1
	Once a fortnight	10	14.1
	Once a week	23	32.4
	More than once a week	4	5.6
Hours Caring	0-10	7	9.9
	11-20	3	4.2
	21-30	7	9.9
	31-40	5	7.0
	41-50	2	2.8
	>50	44	62.0
	Missing	3	4.2
Support from professional carer	Yes	11	15.5
	No	60	84.5

^a N=number of carers ; %=percentage of total sample.

3.3.3. Demographics of survivor

Carers were asked to respond on several demographic questions regarding their spouse (results given in Table 2.3 and Table 2.4). As can be seen from Table 2.3, all spouses had suffered a stroke at least 18 months ago (or 1 year, 6 months).

Table 2.3 Years since stroke ^a

	(N)	Mean	SD	Range
Years since stroke	(71)	9.2	7.2	1 yr, 6 months - 31 yrs

^a N=number of carers; SD = Standard Deviation.

Over 59.2% of survivors were reported to have mild or severe communication and memory problems (see Table 2.4). Seventy-six percent of carers reported that their spouse had

changed in personality since their stroke, a change which has been noted in other research (e.g. Stone *et al.*, 2004) and which can often be stressful for the carer (Greenwood *et al.*, 2009a). Eighteen percent of carers also reported that their spouse often suffered from depression and anxiety and 14% of carers reported that their spouse was unable to show them affection. In terms of the latter, it would be of interest to determine what characteristics of the survivor are associated with an ability to show affection. However, this is outwith the remit of the current study.

Table 2.4 Survivor demographics ^a

		N	%
Communication Difficulties	None	8	11.3
	Mild	42	59.2
	Severe	21	29.6
Memory Problems	None	14	19.7
	Mild	42	59.2
	Severe	15	21.1
Get upset, angry or 'difficult'	Yes	55	77.5
	No	14	19.7
	Missing	2	2.8
Know that they have had a stroke	Yes	70	98.6
	No	1	1.4
Seem to have changed in personality since their stroke	Yes	54	76.1
	No	15	21.1
	Missing	2	2.8
Suffers from depression or anxiety	Never	9	12.7
	Sometimes	47	66.2
	Often	13	18.3
	Missing	2	2.8
Can clearly communicate their needs and wishes to	Yes	53	74.6
	No	18	25.4
Able to show [carer] affection	Yes	59	83.1
	No	10	14.1

^a N=number; %=percentage of total sample.

3.3.4 Descriptive Statistics

PTG was evident in the current population with mean PTGI score at 52.6 for the sample (see Table 2.5). Scores on the PTGI also ranged from 6-104 indicating that all respondents that completed the PTGI reported growth in at least one area of their experience. However, it should be noted that one respondent did not complete the PTGI so it is unknown whether this particular carer experienced growth.

Mean scores on active and acceptance coping scales (mean = 12.2, SD 3.4; mean = 13.8, SD 2.6 respectively) suggested that most carers positively endorsed these items. However, scores for avoidance coping were lower (mean = 6.6, SD 3.3). Dependency scores (mean = 14.2, SD 4.8) indicated that most stroke survivors required assistance in numerous activities of daily living, including feeding, washing and mobility. Total quality of life score (mean = 63.2) also indicates a 'high level of quality of life for carers' on the rating scale devised for this scale (see Elwick *et al.*, 2010)⁸.

Table 2.5 Descriptive statistics

	N	Mean	Max. Range Poss.	Actual Range	Std. Deviation
PTGI	70	52.6	0-105	6-104	24.7
Active Coping	70	12.2	4 - 16	4-16	3.4
Acceptance Coping	70	13.8	4 - 16	4-16	2.6
Avoidance Coping	70	6.6	4 - 16	4-16	3.3
Rumination	71	34.7	14 -56	14-55	10.5
Social Support	71	64.7	12 - 84	26-84	13.9
Level of functioning	70	14.2	0 -20	2-20	4.8
Quality of Life	71	63.2	25 - 100	38-90	8.7

^a N=number of carers; where N < 71, data was missing from the dataset.

⁸ when adjusted for the three subscales (money matters, personal growth, sense of value) not used (see Measures, section 2.6.7)

3.4. Comparison of means

A one sample t-test was used to examine hypotheses H1 and H2 - i.e. whether PTGI scores differed significantly from zero and whether PTGI scores differed significantly from that of carers of other health conditions.

3.4.1. Assumptions

A t-test requires data to be normal. The distribution of PTGI scores was tested using the Kolmogorov- Smirnov test in order to test normality. As the test was non-significant ($D(70) = 0.08, p = N.S$) this assumption was met⁹.

3.4.2 Results

H1: PTG will occur in a sample of stroke carers, with scores significantly greater than zero on the Post Traumatic Growth Inventory

A one sample t-test found PTGI scores (mean = 52.6, SD 24.7) to be significantly different from zero ($t(69) = 17.86, p < .001$). This confirms our first hypothesis and it can therefore be concluded that PTG occurred in this sample of stroke carers.

H2: PTGI scores in this sample will not differ significantly from that of carers of other health conditions (two-tailed)

For this comparison it was hoped to draw on the mean PTGI scores from a range of health conditions. However, few papers investigating PTG in carers used the PTGI measure (see Table 1.1) and of those only Thombre *et al.* (2011) reported on mean scores.

Mean PTGI scores for the sample of stroke carers were therefore compared to mean PTGI scores reported by Thombre *et al.* (2011) who investigated PTG in a population of Indian cancer carers. A one sample t-test found PTGI scores in this sample (mean = 52.6) to be significantly lower than mean PTGI scores reported by Thombre *et al.*, 2011 (mean = 74.13,

⁹ df= 70 rather than 71 for this test as one participant did not complete PTGI so excluded from analyses (see Missing data, section 3.2.2)

$t(69) = -7.31, p < .001$). This finding was unexpected and disconfirms our second hypothesis. The issue will be discussed in more detail in section 4.2, below.

3.5. Correlational analyses

Correlational analyses were conducted to test hypothesised associations between PTG and the identified factors: active coping, acceptance coping, avoidance coping, rumination, social support, level of functioning, age and quality of life (see H3 to H10, section 1.6.2).

3.5.1 Assumptions

For parametric correlation to be used a number of assumptions should be met (Field, 2009). These include, normally distributed scores on variables, a linear relationship between variables, homoscedasticity and an absence of outliers. These are considered below:

Normality – normality was assessed through visual use of the Kolmogorov- Smirnov test for each variable. Only PTG, Rumination and quality of life scores were found to be non-significant and therefore normally distributed ($D(70) = 0.075$, $p = N.S$; $D(71) = 0.12$, $p = N.S$; $D(71) = 0.09$, $p = N.S$, respectively). Scores from all other variables (active coping, acceptance coping, avoidance coping, level of functioning, age) were found to deviate from the normal distribution.

Linearity – scatter plots of PTGI scores against each variable (appendix 3.1) were visually inspected to check for linearity. All scatter plots showed a linear distribution.

Homoscedasticity – the assumption of homoscedasticity (or equal scatter) requires similar variance at each level of the predictor variable. Scatter plots of PTGI scores against each variable (appendix 3.1) were visually inspected and appeared homoscedastic.

Outliers – outliers can bias correlations so are important to identify. Boxplots of each variable were inspected and a number of outliers were identified, particularly for the avoidance coping variable.

Conclusion (re. assumptions) – scatter plots showed linearity and homoscedasticity between PTGI scores and other variables. However, several variables were shown to deviate from the normal distribution and a number of outliers were also identified.

Field (2009) suggests that data be normally distributed in order to determine the significance of parametric tests, including Pearson's correlation coefficient (r). However, Havlicek and Peterson (1977) have found that r is a robust measure and probability statements for r accurate even when there is extreme deviation from normality.

Given the robustness of the test, it was decided to report on correlations in terms of Pearson's correlation coefficient (r). However, as a failsafe these results are also compared with non-parametric analysis (i.e. Kendall's tau¹⁰) in Appendix 3.2.

Use of Kendall tau also meant that correlations between the ranked data (containing no outliers) and the original data (containing outliers) could be compared. Outliers were therefore retained in the analysis.

3.5.2 Results

The results of the correlational analysis are shown in table 2.6. It is noted whether significance is tested at the one or two-tailed level and all correlations are given in terms of Pearson's correlation coefficient (r). The array of significant correlations using Pearson's r exactly matched that of non-parametric correlations (see Appendix 3.2).

¹⁰ Kendall's tau was used over Spearman's coefficient as the data set had a large number of tied ranks (see Field 2009, p181)

Table 2.6 Correlations between PTGI and independent variables ^a

		PTGI
Level of functioning	<i>r</i>	-.09
	Sig (2 tailed)	.480
	N	69
Active Coping	<i>R</i>	.17
	Sig (1 tailed)	.077
	N	69
Acceptance Coping	<i>R</i>	.07
	Sig (1 tailed)	.273
	N	69
Avoidance Coping	<i>R</i>	.21*
	Sig (1 tailed)	.04
	N	69
Social Support	<i>R</i>	.34**
	Sig (1 tailed)	.002
	N	70
Rumination	<i>R</i>	.62***
	Sig (1 tailed)	.000
	N	70
Quality of Life	<i>R</i>	.20*
	Sig (1 tailed)	.045
	N	70
Age	<i>R</i>	.04
	Sig (1 tailed)	.383
	N	70

*p<0.05; ** p <0.01; *** p<0.001

^a N=number of carers; where N < 71, data was missing from the dataset and excluded from correlation.

H3: PTG in stroke carers will be positively associated with active coping style (one-tailed)

PTGI scores were not found to correlate with active coping scores ($r = 0.17$, $p=N.S$). This disconfirmed hypothesis three and suggested that active coping style (e.g. 'I do what has to be done one step at a time') was unrelated to PTG in this sample of stroke carers. However, it should be noted that although small and non-significant, the correlation was positive as expected.

H4: PTG in stroke carers will be positively associated with acceptance coping style (one-tailed)

Acceptance coping was assumed to be associated with PTG as it may allow the person to disengage from unobtainable goals and undertake a process of meaning making (Tedeschi and Calhoun, 2004a). However, PTG was not found to be related to acceptance coping in this sample ($r= 0.07$, $p=N.S$). This disconfirmed hypothesis four.

H5: PTG in stroke carers will be positively associated with avoidance coping style (two-tailed)

Avoidance coping was correlated weakly, but positively, with PTG ($r = 0.21$, $p<0.05$). This finding disconfirmed hypothesis five as a negative correlation between avoidance coping and PTG was expected.

Other positive correlations between avoidance coping and growth have been noted within the general literature (see Table 1.3). These findings run contrary to all models of growth and suggest that defence mechanisms such as denial may be beneficial (an issue discussed in more detail in section 4.2).

H6: PTG in stroke carers will be positively associated with higher levels of rumination (one-tailed)

Rumination was found to be positively related to PTGI scores ($r = 0.62$, $p<0.01$). This finding confirmed hypothesis six and supported the work of Tedeschi and Calhoun (2004a), who propose that rumination is a key mechanism in enabling growth to occur.

It should also be noted that total rumination score was also associated with PTGI score, when item 2 and item 4 for of the rumination scale were excluded ($r = 0.63$, $p < 0.01$). This association is not described in Table 2.6 but is important to note as, compared to other items that represent adaptive rumination, these two items represent maladaptive rumination which is recent and intrusive (e.g. 'recently, thoughts about the experience came into my mind and I could not get rid of them'). This type of rumination is not associated with growth (Calhoun *et al.*, 2000) and, as could be expected, the association between PTG and rumination was strengthened from $r = .62$ to $r = .63$ when these items were excluded.

H7: PTG in stroke carers will be positively associated with higher levels of social support (one-tailed)

PTGI scores were associated with social support ($r = 0.34$, $p < 0.01$). This confirmed hypothesis seven and suggested that those carers who reported a high level of social support also reported growth.

H8: PTG will be associated with the level of functioning of the stroke survivor (two-tailed)

PTGI scores were not found to correlate with the level of functioning of the stroke survivor ($r = -0.09$, $p = \text{N.S.}$). This finding disconfirmed hypothesis eight which predicted that PTG would be associated with growth either positively or negatively. From visually inspecting the scatter plot (see Appendix 3.1), there was also no evidence of a curvilinear relationship between PTG and level of functioning (c.f. Lechner *et al.*, 2003). Taken together, these findings are important as they suggest that level of functioning does not impact on a carer's ability to experience PTG.

H9: PTG will be negatively associated with age (one tailed)

Age was not found to be associated with PTG ($r = 0.04$, $p = \text{N.S.}$). This disconfirmed hypothesis nine and ran contrary to findings that suggest people of younger age, be they carers or not, report higher levels of growth (see Thompson, 1991; Helgelson *et al.*, 2006). However, it should be noted that the population was skewed and consisted mostly of carers aged around a mean of 66.5 years old (SD, 11.4). Had the sample been more representative in terms of younger age then a stronger relationship between age and PTG may have been found.

H10: PTG in stroke carers will be associated with quality of life in carers (two-tailed)

PTG was positively associated with quality of life ($r = 0.20$, $p < 0.05$). This confirmed hypothesis ten.

3.5: Regression Analyses

Regression analyses were carried out in 3 stages. In stage 1, factors identified by the Tedeschi and Calhoun (2004a) were entered into a regression model (Regression 1). In stage 2, factors identified by the Shaefer and Moos (1998) were entered into Regression model 2 and, in stage 3, the predictive value of all factors was assessed, regardless of model (Regression 3).

3.5.1 Assumptions

Linear regression analysis requires that a number of a priori and post hoc assumptions are met. A priori assumptions include: absence of multicollinearity, predictors uncorrelated with external variables and a linear relationship between the outcome variable (i.e. PTG) and predictors (i.e. other variables), an assumption that has already been met (see section 3.5.1, above). Post hoc assumptions include homoscedasticity of residual terms, independent errors and model fit (Field, 2009, p220). These were tested separately for each separate regression model after conducting the analyses.

It should also be noted that predictors themselves do not need to be normally distributed (Field, 2009, p221; Tabachnik & Fidell, 2007). However, other assumptions are less likely to be met if this is the case (Tabachnik & Fidell, 2007).

A priori assumptions

Absence of multicollinearity – this assumption refers to there being no perfect relationship between predictor variables (for example, between social support and rumination); correlations above $r = .80$ are generally unacceptable (Field, 2009). Looking at Appendix 3.3, correlations between predictors ranged from $r = .01$ (between Age and Active Coping) to $r = .69$ (between Acceptance Coping and Active Coping), thus no predictors correlated too highly.

Predictors uncorrelated with external variables – this assumption requires that no external variables are excluded that are correlated with predictor variables. It is outside the scope of this project to assess how predictor variables are correlated with all other factors that may

predict PTG. However, for the purposes of this regression analysis, all predictors that were shown to be correlated with each other were included.

Post hoc assumptions

Homoscedasticity of residual terms – residual terms are the differences between those values of the outcome predicted by the regression model compared to those actually observed. Therefore if a model predicts observed outcomes very well, then residual terms will be minimal. Homoscedasticity of residual terms requires that variances of residual terms are equal at each level of the predictor variable. Standardized residuals were plotted against standardized predicted values for each regression analysis (see Appendix 3.1) and, when visually inspected, found to be homoscedastic.

Independent errors – this assumption requires that residual terms should be uncorrelated. The Durbin-Watson statistic was used to test for independent errors in each of the three separate regression analyses. Test values for the separate regressions ranged from 2 to 2.33 which is close enough to criterion value of 2 to conclude that this assumption was met (see Field, 2009 p229).

Model fit –in order to ensure that large residuals do not have an excessive effect on a model several tests can be conducted, including Cook's distance and Mahalmobis Distance. When inspected on a case-by-case level no residuals were found to exceed criterion set by these tests and it can therefore be concluded that no residuals had an excessive effect on the three separate regression analyses (see Field, 2009 p245).

3.5.2 Regression 1: Factors identified by Tedeschi and Calhoun model

3.5.2.1 Method of regression

Factors identified by the Tedeschi and Calhoun model (i.e. rumination, social support, acceptance coping and level of functioning) were entered into the model in blocks using the Enter method on SPSS (ver.18). Factors were entered according to their simple correlation with PTG (Table 2.6). The exception was Level of Functioning which correlated slightly higher than Acceptance Coping, but was entered last as it was less significant at the two-tailed level (Table 2.6).

It should also be noted that Level of Functioning was used as an indirect measure of the stressfulness of the event (see section 4.2; 4.5 for more on this issue).

3.5.2.2 Results

Table 2.7 Multiple Regression: Predictors of PTG (Tedeschi and Calhoun model)

	Adjusted R ²	B	Std. Error B	β
Model 1	.37			
Constant		2.10	8.23	
Rumination		1.46	0.23	.62***
Model 2	.43			
Constant		-24.0	12.40	
Rumination		1.40	0.22	.58***
Social Support		0.45	0.17	.25**
Model 3	.42			
Constant		-16.71	17.12	
Rumination		1.41	0.23	.60***
Social Support		0.44	0.17	.25**
Acceptance Coping		-0.60	0.90	-0.06
Model 4	.45			
Constant		-6.81	17.21	
Rumination		1.50	0.22	.62***
Social Support		0.46	0.16	.26***
Acceptance Coping		-0.48	0.89	-0.05
Level of functioning		-1.10	0.47	-.20*

*** p<0.001, ** p<0.01, *p<0.05; Std Error B = standard error of B; β = standardized beta.

Note: R² = .38 for Model 1 (p<0.001); R² change = .06 for Model 2 (p<0.01); R² change = .003 for Model (p=N.S.); R² change = .04 for Model 4 (p<0.05)

With the exception of acceptance coping, all variables significantly added to the model (i.e. changes in R^2 were significant). Rumination was entered first and explained 37% of the variance in total PTG scores. Social support was entered second and explained an additional 6% of variance. Acceptance coping was then entered and this slightly decreased the ability for the model to explain PTG (i.e. the amount of variance explained reduced from 43% to 42%). Level of functioning was also entered and explained an additional 3% of variance. The final model (model 4) accounted for 45% of the variance in PTG scores ($F_{4,65} = 15.10, p < 0.001$).

Standardized beta values (β) for the final model (Model 4) indicate that:

- as Rumination scores increased by one standard deviation, PTG score increased by 0.62 standard deviations
- as Social Support scores increased by one standard deviation, PTG score increased by 0.26 standard deviations
- as Level of Functioning scores increased by one standard deviation, PTG score *decreased* by 0.20 standard deviations.

3.5.3. Regression 2: Factors identified by Shaefer and Moos (1998) model

Table 2.8 Multiple Regression: Predictors of PTG (Shaefer and Moos model)

	Adjusted R ²	B	Std. Error B	β
Model 1	.10			
Constant		13.77	13.53	
Social Support		0.60	0.21	.38**
Model 2	.11			
Constant		2.50	16.10	
Social Support		0.58	0.21	.32**
Active Coping		1.1	0.84	.14
Model 3	.11			
Constant		10.0	17.72	
Social Support		0.60	0.21	.34**
Active Coping		1.1	0.84	.15
Level of functioning		-0.63	0.60	-0.12
Model 4	.10			
Constant		23.00	24.00	
Social Support		0.62	0.21	.35**
Active Coping		1.1	0.84	.15
Level of functioning		-0.68	0.61	-0.13
Age		-0.20	0.25	-.10

*** p<0.001, ** p<0.01, *p<0.05; Std Error B = standard error of B; β = standardized beta.

Note: R² = .114 for Model 1 (p<0.01); R² change = .06 for Model 2 (p=N.S.); R² change = .003 for Model 3 (p=N.S.); R² change = .04 for Model 4 (p=N.S)

3.5.3.1 Method of regression

Factors identified by the Shaefer and Moos (1998) model (i.e. social support, active coping, level of functioning and age) were entered into the model in blocks using the Enter method and according to their simple correlation with PTG (Table 2.6).

3.5.3.2 Results

Only Social support significantly added to the model. Social support was entered first and explained 10% of the variance in total PTG scores. Active coping was entered second and explained an additional 1% of variance but did not significantly increase the ability of the model to predict PTG (R-squared change, not significant). Level of functioning was then entered but did not add any additional variance. Age was also entered but this reduced the variance explained by the model (from 11% to 10 %). The final model (model 4) accounted for 10% of the variance in PTG scores ($F_{4,65} = 2.98, p < 0.05$).

Standardized beta values (β) for the final model (Model 4) indicate that:

- as Social Support scores increased by one standard deviation, PTG score increased by 0.35 standard deviations

However, no other standardized beta values were found to be significant at the $p < 0.05$ level.

3.5.4. Regression 3: All factors

3.5.4.1 Method of regression

Stepwise regression was used ('stepwise function', SPSS ver. 18). Here, the computer selects the predictor with the highest simple correlation with the outcome first; followed by the predictor with the largest semi-partial correlation. As each new predictor is added all predictors are reassessed and predictors are retained if the R-square change remains significant (F_{df} , $p < 0.05$), but excluded if the R-square change becomes non-significant (F_{df} , $p > 0.10$). In this way redundant predictors can be removed (Field, 2009).

This method was used to assess the impact of all variables when using objective, mathematical criteria (i.e. predictors were not entered in terms of a specific model). A stepwise approach also allowed for the impact of avoidance coping on PTG to be assessed, a factor not included in any model of PTG, and so its relative importance is unknown.

3.5.4.2 Results

Table 2.9 Stepwise Multiple Regression: Predictors of PTG

	Adjusted R ²	B	Std. Error B	β
Model 1	.37			
Constant		2.05	8.23	
Rumination		1.46	0.23	.62***
Model 2	.43			
Constant		-23.98	12.39	
Rumination		1.40	0.22	.58***
Social Support		0.45	0.17	.25**
Model 3	.46			
Constant		-12.81	13.00	
Rumination		1.44	0.22	.61***
Social Support		0.47	0.16	.27**
Level of functioning		-1.07	0.48	-.20*

*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$; Std Error B = standard error of B; β = standardized beta.

Note: R² = .38 for Model 1 ($p < 0.001$); R² change = .062 for Model 2 ($p < 0.01$); R² change = .041 for Model 3 ($p < 0.05$)

Rumination had the highest simple correlation with PTG (see Table 2.9) and when entered into the model explained 37% of the variance in total PTG scores ($F_{1,67} = 41.05, p < 0.01$). Social support was entered second (this having the largest semi-partial correlation with the outcome) and explained an additional 6% of variance ($F_{2,66} = 41.05, p < 0.01$). Level of functioning was also entered and explained an additional 3% of variance ($F_{3,65} = 41.05, p < 0.01$). No other variables met the inclusion and elimination criteria for the regression.

3.5.5. Summary of Regression Analyses in terms of Hypothesis 11

H11: Variance in PTG will be explained by two significant regression models - one based on factors identified in Tedeschi and Calhoun (2004a) model (e.g. rumination; social support, acceptance coping) and the other based on factors identified in Schaefer and Moos (1998) model (e.g. active coping, level of functioning, social support, age).

Both regression 1 and 2 (based on factors identified by Tedeschi and Calhoun, 2004a; Schaefer and Moos, 1998, respectively) predicted variance in PTG. However, the factors identified by Tedeschi and Calhoun appear to account for more variance (48%) than those identified by Schaefer and Moos (10%)¹¹.

This finding, coupled with the fact that rumination initially explained 38% of variance in PTG, provides strong support that the Tedeschi and Calhoun (2004a) is a suitable model to explain variance in PTG in stroke carers. However, it should be noted that acceptance coping, itself, did not predict PTG as Tedeschi and Calhoun (2004a) would suggest.

¹¹ N.B. It was not possible to test whether the adjusted r squared value for regression 1 was significantly greater than that of regression 2, as such a test assumes separate sets of IVs (see Tabachnik & Fidell, p 152)

DISCUSSION

4.1 Discussion

4.1.1 Overview

A stroke is a highly stressful experience for carers (Carek *et al.*, 2010; Greenwood *et al.* 2009a). Carers may suffer acute effects due to the sudden, unexpected and life threatening nature of the stroke (Carek *et al.*, 2010). Over the longer term, carers may also face changes to roles, disruptions to future plans and altered relationships due to changes in the survivor's personality (Greenwood *et al.*, 2009a).

Most of the literature on stroke carers has focused on negative outcomes, such as decreased quality of life (Visser-Meily *et al.*, 2005). However, several qualitative studies (e.g. Buschenfeld *et al.*, 2009; Greenwood, 2008b) have found that carers also report positive outcomes, or 'posttraumatic growth' (PTG) arising from their experiences.

Studying PTG in stroke carers is important in order to add to models of stress and coping which have traditionally only focused on negative or pathological outcomes (Lincoln *et al.*, 2012). PTG has also been associated with improved well-being and adjustment in carers (see Table 1.3). Therefore fostering PTG may improve outcomes for this population.

In terms of quantitative studies, there is evidence that stroke carers report PTG (see Table 1.2). However, such studies have failed to use standardized measures or assess the variables associated with PTG. This study therefore aimed to: (a) examine PTG in a sample of stroke carers when using a standardized measure, i.e. the Post Traumatic Growth Inventory (Tedeschi & Calhoun, 1996) and (b) assess which variables (including coping style, social support, level of functioning) were associated with PTG in this sample.

It was also hoped that the findings would help determine which model of PTG best predicted PTG in stroke carers (see H11, below).

4.1.2 Summary of main findings

The main findings suggested that PTG was reported by stroke carers and that PTG was best predicted by ruminative coping. Social support and the level of functioning the survivor also predicted growth.

The findings add to our understanding of growth in stroke carers but also to our understanding of general models of PTG (see H11, below). Several implications for clinical psychologists working with stroke carers also arise out of this work (see section 4.4 below).

4.1.3 Structure of discussion

The discussion is structured in four parts: Part 4.2 considers each of the hypotheses in light of the findings; Part 4.3 describes the strengths and weaknesses of the project; Part 4.4 considers the clinical implications and Part 4.5 considers areas of future research.

4.2: Discussion of hypotheses

H1: PTG will occur in a sample of stroke carers, with scores significantly greater than zero on the Post Traumatic Growth Inventory

Scores on the PTGI ranged from 6-104 indicating that all respondents that completed the PTGI (n=70) reported growth in at least one area of their experience. Mean scores on the PTGI (mean = 52.6, SD 24.7) were also found to be significantly different from zero ($t(69) = 17.86, p < .001$).

These results confirmed hypothesis one and add to the limited body of evidence suggesting that stroke carers report growth in response to their experiences (see Table 1.2). These results also represent the first attempt to assess PTG in a sample of UK stroke carers.

H2: PTGI scores in this sample will not differ significantly from that of carers of other health conditions

The total mean score (mean PTGI score = 52.6, SD, 24.7) in this sample of stroke carers was significantly lower than that reported in a sample of cancer carers in India (mean PTGI score = 74.13, SD 18.73, Thombre *et al.*, 2010). This finding disconfirmed hypothesis two and was unexpected. However, it may be explained, in part, by carers in India scoring particularly high on the religious growth items of the PTGI compared to stroke carers in the UK. Indeed, Carboon *et al.* (2005) note that scores in this domain may be particularly sensitive to cultural differences; whereby people from more religious cultures are more likely to find spiritual meaning in traumatic experiences.

Post-hoc tests revealed that spiritual subscale scores for this UK stroke carer sample were toward the lower end of the 10 point subscale (mean = 2.5, SD 3.2). Thombre *et al.* (2010) did not report on individual subscale scores, thus a comparison was not possible. However,

Thombre *et al.* (2010) did find that most carers positively endorsed religious coping strategies, which suggests that Indian carers may have been more open to spiritual growth.

It was not possible to compare scores between this sample and other studies of carers due to the use of differing measures of PTG (see Table 1.1; Table 1.2). However, PTGI scores reported in this study are comparable to those of survivors, including studies of stroke survivors ($M = 50.93$, SD , 19.92; Gangstad *et al.*, 2009) and cancer survivors ($M = 55.1$, SD , 24.7; Carboon *et al.*, 2005).

Further research is needed to confirm whether levels of PTG differ between stroke carers and carers of people with other health conditions, particularly when factoring in cultural differences. Future research should also aim to standardize the measure of PTG so direct comparisons between studies can be made.

H3: PTG in stroke carers will be positively associated with higher levels of rumination

Rumination refers to 'several varieties of recurrent [event related] thinking, including making sense, problem solving, reminiscence, and anticipation' (Martin & Tesser, 1996, p. 192). It is a key component in the model proposed by Tedeschi & Calhoun (2004a) as it helps the person to reflect on their situation and discover positives in their experience.

In this study, rumination was positively related to PTG and this confirmed hypothesis three. Rumination also significantly added to regression models and explained more variance in PTGI scores than any other variable (i.e. 38% of variance in Regression 1 and 3). Moreover, when rumination was not entered (see Regression 2), the predictive power of the model was reduced. These findings suggest a strong link between PTG and rumination, whereby carers who scored highly on the PTGI also scored highly on the Rumination Scale. The results also corroborate the few studies (of college students reporting a variety of life crises) that have included a measure of rumination and have found that rumination predicts PTG (see Taku *et al.*, 2009; Calhoun *et al.*, 2000).

However, it should be noted that rumination can take different forms (i.e. deliberate rumination recently and soon after event; intrusive rumination recently and soon after event; see section 1.3.6.2.). Previous research has suggested that recent, deliberate rumination best predicts growth in people suffering a variety of life events (Taku *et al.*, 2009). However, in order to retain statistical power in this study a 'total rumination score' was used rather than

scores for each subscale. Future research should therefore examine exactly which type of rumination predicts growth in stroke carers.

It should also be noted that the exact mechanism by which rumination predicts growth is neither well defined nor understood (Maercker & Zoellner, 2004). For example, is it the *process* or the *outcome* of rumination that best predicts growth?

Hayes *et al.* (2005) studied the effects of a novel psychotherapy for depression and found that the *process* of ruminative coping was associated with growth. However, the results of Thombre *et al.* (2009) suggest that the *outcome* of ruminative process is also important. For example, Thombre *et al.* (2009) found that carers who made positive religious meanings from their experience (e.g. 'saw my situation as part of God's plan') showed higher growth compared to those that made negative meanings (e.g. 'decided that God was punishing me for my sins'). The findings of Thombre *et al.* (2009) are important as they suggest that *outcome* (or the 'meaning-made', Park *et al.*, 2010) is crucial in predicting growth. They also run contrary to Tedeschi & Calhoun (2004a) who suggest that the *process* of meaning making, *per se*, allows for PTG to develop.

H4: PTG in stroke carers will be positively associated with active coping

Active coping refers to proactive efforts to respond to the stressful situation (e.g. 'I take direct action to get around the problem', COPE; Carver *et al.*, 1989) and Schaefer and Moos (1998) suggest that people who use such coping strategies (and show a 'fighting spirit') are more likely to positively reappraise stressors and experience growth.

However, active coping was not significantly related to PTG in this study. This finding disconfirmed hypotheses four and failed to replicate previous findings (see Morris *et al.*, 2007).

This finding, although unexpected, may be reconciled if proactive efforts to cope are construed as a form of denial – i.e. the person focuses on day-to-day problems in order to avoid thinking about their experience. Here, any such avoidance may actually limit the possibility for rumination, a key process assumed to lead to growth (see Tedeschi & Calhoun, 2004a; H3 above).

H5: PTG in stroke carers will be positively associated with acceptance coping

Acceptance coping was assumed to be associated with PTG as it may allow a person to disengage from unobtainable goals and undertake a process of rumination which aids growth (see Tedeschi and Calhoun, 2004a; Figure 2). It has been associated with PTG in a sample of college students reporting a range of traumas (Park *et al.*, 1996).

In this study, PTG was found to be unrelated to acceptance coping. This disconfirmed hypothesis four and was unexpected. However, it should be noted that, in a post-hoc test, acceptance coping was found to be related to rumination coping ($r=.25$, $p<0.05$). This gives some support to the idea that acceptance coping may aid the ruminative process (see Tedeschi and Calhoun, 2004a).

H6: PTG in stroke carers will be negatively associated with avoidance coping

Avoidance coping was assumed to be negatively correlated with PTG, given that people who avoid thinking about their experience should be less likely to engage in ruminative processes and therefore less likely to experience growth (see section 1.3.6.2; Figure 2).

However, avoidance coping was positively associated with PTG in this study. This finding disconfirmed hypothesis six (as a negative correlation was expected) and is difficult to discount given its replication in other research. For example, avoidance and PTG have been found to be positively correlated in cancer patients (Widows *et al.*, 2005) and in parents of children treated for leukaemia (Best *et al.*, 2001). Pakenham (2005a) also found a positive relationship between avoidance and PTG in Multiple Sclerosis carers.

One way to reconcile the use of avoidant coping strategies is through the 'dual process model' (Stroebe and Schut, 1999); a model that was primarily devised to understand the grief process following bereavement, but which can equally be applied to the aftermath of trauma. In this model it is suggested that to successfully cope with a loss, an individual 'oscillates' between confronting and avoiding thoughts about the loss; with avoidant coping seen as particularly important in order to take respite from the associated stress. The model is relevant to these findings as it raises the possibility that an individual may employ ruminative processes on some occasions and more avoidant coping on others; and that the use of both may be most helpful in coming to terms with a trauma (and therefore in experiencing growth).

In summary, the 'dual process model' gives a rationale for why avoidance coping may be associated with growth when acting in tandem with other variable (e.g. rumination). However, further research is needed to explain the exact mechanisms by which avoidance coping may aid growth and how it can integrate into existing models of PTG (see Tedeschi & Calhoun, 2004a; Schaefer and Moos, 1998).

H7: PTG in stroke carers will be positively associated with higher levels of social support

PTGI scores were associated with social support ($r = 0.34, p < 0.01$). This confirms hypothesis seven and suggests that those carers who reported a high level of social support also reported growth. The findings corroborate an association between social support and PTG in studies of carers of people with HIV (McCausland & Pakenham, 2003) and cancer (Kim *et al.*, 2007).

Social support also predicted PTG in each of the regression analyses, adding an additional 6-10% of explained variance (see Regression 1, 2 and 3). This suggests that social support increased levels of PTG when other factors were held constant. However, Tedeschi & Calhoun (2004a) also suggest that social support provides an indirect effect on PTG; specifically, that people who feel comforted by others may be more able to engage in a process of rumination (and therefore report growth). Future research – using moderator analysis - should therefore assess the indirect impact of social support on PTG through additional processes, such as rumination (see section 4.5).

It may also be useful to examine the exact role of social support in predicting growth in carers compared to survivors. For example, no association was found between PTG and social support in patients with heart disease (Sheikh, 2004) or with chronic illnesses (Abraido–Lanza, 1998). This difference between carers and non-carers is unexpected. However, it may be explained by social support being particularly important for carers in reducing the burden of caring and allowing time for rumination and meaning making.

H8: PTG will be associated with the level of functioning of the stroke survivor

Level of functioning refers to the degree to which the stroke survivor is able to perform day-to-day activities (such as washing and feeding) independently and Schaefer and Moos (1998) suggest that loss of these functions is a key factor that negatively impacts on growth, at least

in survivors. However, within the literature there is little evidence to suggest that the level of physical functioning of the survivor impacts on growth in *carers* (see Table 1.3).

In this study, level of functioning was unrelated to PTG when using a simple correlation and this appeared to disconfirm hypothesis eight. However, level of functioning was found to negatively predict PTG when entered into the regression analysis (see Regression 1 and 3). This suggests that, when controlling for other factors (namely the effect of rumination and social support; see Regression 1 and 3), carers were less likely to show growth if they cared for survivors with higher functioning and greater independence.

If we take level of functioning as a measure of the severity of the event, then the results also appear to provide additional support for the work of Tedeschi & Calhoun (2004a) who suggest that more traumatising experiences offer more opportunity for growth. However, level of functioning may not be the best measure of acute trauma and severity of the event. Future research should therefore aim to use a more specific measure of the severity of the event in the acute stages of trauma (an issue described in more detail in section 4.3.2, below).

H9: PTG will be negatively associated with age

Previous research with stroke carers (Thompson, 1991) found that younger carers were more likely to experience PTG. Tedeschi & Calhoun (2004a, p4) also propose that older people are more likely to have 'learned life's lessons' and be less open to growth (Tedeschi & Calhoun, 2004a, p4.). It was therefore assumed that age would be negatively associated with PTG.

This study, however, found no correlation between age and PTG. This disconfirmed hypothesis nine and runs contrary to the studies cited above, but may be reconciled with the suggestions of Bauer & Park, (2010, p1) who suggest that 'growth is not just for the young', but forms a fundamental part of an older person's identity.

Further research is needed to assess how the caring role may impact on the process of growth in younger carers. Such research should also attempt to sample from a wide range of ages, given that the current sample was skewed around a mean of 66.5 years old (SD, 11.4).

H10: PTG in stroke carers will be positively associated with quality of life in carers

PTG was positively associated with quality of life ($r = 0.20$, $p < 0.05$); a finding which confirmed hypothesis ten and corroborates studies of carers of other health conditions. For example, PTG was found to be positively associated with carer's life satisfaction in cancer carers (Kim *et al.*, 2007).

This finding is important as it suggests that people who report PTG also report a higher quality of life. It also adds to the body of evidence that suggests PTG is associated with measures of adjustment when PTG is assessed over the longer term (see Zoellner & Maerker, 2006).

H11: Variance in PTG will be explained by two significant regression models - one based on factors identified in Tedeschi and Calhoun (2004a) model and the other based on factors identified in Schaefer and Moos (1998) model.

Both regression 1 and 2 (based on factors identified by Tedeschi and Calhoun, 2004a; Schaefer and Moos, 1998, respectively) produced models that were significant and predicted variance in PTG. However, the factors identified by Tedeschi and Calhoun (i.e. rumination; social support, acceptance coping, level of functioning) accounted for more variance (48%) than those identified by Schaefer and Moos (i.e. active coping, level of functioning, social support; 10%).

This finding, coupled with the fact that rumination initially explained 38% of variance in PTG, provides strong support that the Tedeschi and Calhoun (2004a) model explains PTG in stroke carers. The finding is also replicate in a study by Senol-Durak and Ayvasik (2010) who assessed PTG in spouses of people with heart disease and found that coping style (including rumination and emotional coping) explained the majority of variance in scores (16 %).

4.3: Strengths and Limitations

4.3.1 Strengths

The current study is the first quantitative study to examine PTG in a sample of stroke carers within the UK. Other studies of stroke carers have been conducted in the United States (see Haley *et al.*, 2009; Thompson, 1991). However, PTG may be sensitive to cultural differences (see discussion of H2 above) and it was therefore important to assess PTG in this UK sample. In comparison to the work by Thompson (1991) the current study also benefits from setting PTG as the outcome variable in regression analysis. In this way, it was possible to assess the amount that different factors predicted growth.

The study represents one of the few studies to assess PTG and its correlates based on an explicit model of PTG (see Senol-Durak, 2010 for review) and, to the author's knowledge, is the only study to explicitly compare the model of Tedeschi and Calhoun (2004a) to that of Schaefer and Moos (1998). This is surprising given these represent the two main models of PTG as an outcome (see Zoellner & Maerker, 2006).

Carers were recruited a minimum of 18 months since their spouse had suffered a stroke. This is a strength of the study as it increased the probability of genuine growth and valid associations between PTG and its correlates (see section 1.3.4; Zoellner & Maerker, 2006). Indeed, other studies of carers (e.g. McCausland & Pakenham, 2003) and stroke carers (e.g. Thompson, 1991) have recruited carers only 1 month into the caring role; this is problematic as it increases the likelihood of illusory growth and may confound associations between variables such as PTG and adjustment (Zoellner & Maerker, 2006).

This study also benefits from a systematic search of studies of PTG in both carers and carers of people with physical health problems. Indeed, although other studies have reviewed the literature on PTG (see Zoellner & Maerker, 2006; Helgeson *et al.*, 2006; Linley & Joseph, 2004) these do not have an explicit focus on carers. The current review suggests that both stroke carers and carers of people with physical health problems report growth.

4.3.2. Limitations

Design - a cross sectional design meant that the study was limited in drawing conclusions of causality. For example, social support was found to be positively associated with PTG. However, the design meant it was impossible to determine whether social support allowed PTG to develop or whether PTG simply increased appreciation for the social support

available. As moderator analysis was not used, it was also not possible to determine the route by which social support exerted any influence on PTG (either by direct or indirect means).

Response – Carer populations often provide low return rates (Chesson *et al.*, 1998) with some studies of carers reporting return rates as low as 20 % (see Simon *et al.*, 2003). The current study therefore had a relatively good response rate (73 %). However, 27% of people still failed to return their questionnaire. This increased the risk that only carers who had positive experiences chose to participate (Kazdin, 1980) and increased the risk of over-inflating reported levels of PTG. Indeed, these are difficult issues to resolve, since asking people why they are choosing not to participate would be unethical.

Prior experience - Carers were not asked about their previous caring experiences. This was an important omission as prior experience of life crises can boost people's confidence and enhance coping strategies (Shaefer & Moos, 1998). For example, people in Kentucky who had experienced previous floods were found to be better adjusted following a flood compared to those who had no prior experience (Phifer and Norris, 1989). Future research should examine the role of prior experience of a trauma on PTG. Indeed, people with prior experience (e.g. of the caring role) may actually be less prone to growth because they cope better in acute stages of trauma and their core assumptions are less likely to be affected (see Tedeschi and Calhoun, 2004a).

Subjective experience - Carers were not asked whether they perceived the stroke to be traumatic and this meant that the impact of the severity of the event on PTG could not be assessed. One way to solve this problem would have been to ask carers to provide retrospective accounts of their experience. However, retrospective accounts may be biased by how well a person has adjusted to an experience (Roemer *et al.*, 1998). Future research should therefore employ prospective designs to enable carers to report on trauma in the initial stages (in order to reduce recall bias) and then report PTG in later stages (when there is less risk of illusory reports of growth; see Zoellner & Maerker, 2006).

It should also be noted that, rather than the actual event, it is the subjective experience (e.g. lack control, helplessness) which best predicts trauma (Briere & Elliot, 2000). Indeed, for some carers it may be their partner's discharge from hospital and the sudden shock of taking on a caring role that may be viewed as most traumatic (Brereton & Nolan, 2000). Future research should therefore ask participants to report on which aspect of their experience they deem as being most traumatic.

Generalizing findings – carers were primarily identified through stroke clubs, either because they attended themselves, or because their partner attended the club (see Appendix 2.2 for the number of carers recruited by source). This is an important issue in terms of the generalisability of the results.

For example, Anderson (1988) reported that the demographics of stroke survivors and carers are an important determinant as to whether they choose to attend a stroke club or not. Anderson (1988) recruited informal stroke carers (n= 147) and survivors (n=172) aged 60 years and over through their GP, within a London borough. Anderson found that stroke patients were more inclined to use a stroke club if they were younger (aged 60-75) and less severely disabled. Carers were less influenced by the patient's disability but more likely to attend if they had positive attitudes towards the patient's recovery.

The findings above are important as they may suggest that the sample may be atypical in some ways. For example, they suggest that stroke survivors that attend stroke clubs may be less severely disabled. This, in turn, may either inflate or deflate PTG scores depending on how level of functioning influences carers' scores (for example, in the current study an increased level of functioning in survivors negatively predicted PTG in carers –see H8, section 4.2). The results from Anderson (1988) also suggest that carers who were recruited through stroke clubs may show more positive attitudes towards the patient's recovery. This finding may inflate PTG scores in the current study as people who are more optimistic in their outlook may be more likely to experience PTG (Tedeschi & Calhoun, 1995).

Further research is therefore needed utilising samples drawn from wider populations. Tracking carers from hospital and GP databases for several years post stroke could be particularly useful in assessing whether carers attending stroke clubs report differential patterns of growth to those who do not.

It should also be noted that the study only recruited spouses, generally aged between 55 and 75 years old (see section 3.3.2). The results may therefore not generalize to younger carers and other family or friend carers.

4.4: Clinical Implications

Given the current findings, it is important that clinicians acknowledge that carers can report growth in response to their experiences. Indeed, an acknowledgement of growth may be particularly important in stroke services which may focus on issues of pathology rather than positive experiences and growth.

Fostering growth - In terms of fostering growth it should be noted that a pressure to think positively is not helpful (Held, 2002; Brennan, person communication). Rather, people should be helped to ruminate and make meaning out of their experience (Calhoun & Tedeschi, 2010; Taku, 2009); a suggestion that is supported by the strong association between rumination and PTG in the current study.

Narrative Approach - Neimeyer (2006) has suggested that a narrative approach may be particularly helpful in making meaning and fostering growth. For example, therapeutic journals can help people find meaning and the act of writing about painful aspects of one's life have been shown to lead to mental health benefits in several controlled trials (see Pennebaker, 1997). Neimeyer (2006) also considers the use of techniques where a person is asked to describe themselves through oral and written means as if they were the principle character in a movie or play. This can help a person step outside current distress and observe their self narrative from a broader perspective.

Support from others - Social support was also strongly associated with growth and Calhoun and Tedeschi (2010) highlight the role of an 'expert companion' –i.e. a person who is willing to explore beliefs and doubts with the person affected, in addition to providing comfort and reassurance. Indeed, such a companion may be particularly important for carers who, through a combination of personal or societal pressures, may not feel they should seek help from others (Bruce *et al.*, 2002).

Role of clinical psychology - In terms of the role of clinical psychology, there could be a direct role in helping a person talk through and make meaning of their experiences. Alternatively, clinical psychologists could help train stroke-service staff (and friends and family) in providing support to carers. Indeed, through the support provided to carers, carers may also be able to support and engender growth within the survivor (see Weiss, 2004).

Any direct or indirect intervention provided by psychologists should also take account of the time since the stroke occurred. Premature attempts to find positives in an experience may result in denial, illusory growth and maladjustment (Zoellner & Maercker, 2006). Calhoun & Tedeschi (2010) have also suggested that people are often simply trying to cope (and 'get through') in the acute stages of trauma. People may therefore need help with emotional distress in these early stages but that a focus on growth should only occur when deemed 'clinically appropriate' (Calhoun & Tedeschi, 2010, p 13). Here, Calhoun and Tedeschi (2010) draw on the work of Zeldow (2009) in suggesting that the decision to intervene should be based on the judgment of clinicians with appropriate experience.

Calhoun and Tedeschi (2010) also suggest that if, in the later stages, a person is still suffering intrusive rumination then it is useful to encourage more deliberate rumination. Additionally, clinicians should take care to attribute any growth to the struggle with the experience rather than the experience itself. Indeed, suggestions that growth has occurred because of the negative event may be misplaced and met with resistance by people suffering life crises (Calhoun and Tedeschi, 2010).

4.5 Future research

Based on the discussion above there are a number of areas for further research:

1. Longitudinal, prospective designs- these are required to provide evidence for the predicted causal relationships between variables. For example, if rumination coping is a key factor in predicting subsequent growth then it could be expected that levels of rumination at a given time (T1) would predict PTG scores at a later time (T2). Additionally, a prospective design would enable researchers to assess the degree and the type of trauma in the acute stages and avoid difficulties with retrospective reports (see section 4.3.2).¹²
2. Avoidance coping – avoidance coping was associated with PTG in this study. This was unexpected but several other studies have replicated this finding (see Table 1.3). Further research is needed to determine whether avoidant coping oscillates with more active, meaning making processes (as described by ‘dual process model’, Stroebe and Schut, 1999). It may also be beneficial to reconsider current models of PTG in order to incorporate the role of avoidant coping.
3. Social Support - social support predicted PTG in each regression model (see section 3.5). However, it may also be useful to use moderator analysis to assess the indirect effect of social support on PTG through other processes (such as rumination; see Tedeschi & Calhoun, 2004a). Future research should also examine whether social support is particularly important in predicting PTG in carers, versus non-carers (see discussion on H7).

¹² N.B. some studies of carers of health conditions other than stroke have used a longitudinal design (see Table 1.1). For example, Pakenham (2005b) found that practical assistance coping (e.g. ‘I talk to others about the problem’) predicted PTG 3 months later in Multiple Sclerosis carers who had been caring for a minimum of 3 months. However, no longitudinal studies have examined PTG in a large sample of carers or of the impact on rumination on PTG.

4. Negative meaning making – preliminary research (Thombre *et al.*, 2010) suggests that carers that make negative meanings out of their experience may not experience growth. This runs contrary to Tedeschi & Calhoun (2004a) who suggest that rumination and meaning making, per se, allows PTG to develop. Future research should therefore focus on the impact of negative meaning making on PTG.
5. Nature of the trauma – further research with stroke carers is required to assess the nature of the trauma that occurs after stroke. For example, rather than the stroke itself, some carers may find their partner's discharge from hospital and the consequent increasing demands most traumatic (Brereton & Nolan, 2000). Future research should therefore aim to assess the nature of the trauma and determine its impact on PTG.
6. Quality of care giving - Hilgeman *et al.* (2007, cited in Halyley *et al.*, 2009) studied dementia carers over a 12 month period and found that carers who found benefits in their experience responded better to care-giving interventions. Although outside the remit of the current research, future studies could assess the impact of PTG on the quality of care-giving – i.e. do stroke carers who show higher levels of PTG also provide better care?
7. *Models of trauma* – it should be noted that this study has focused on PTG, a positive outcome following a traumatic experience. Future research should therefore aim to study both the positive and negative sequelae of trauma in order to develop integrated models of the stress and coping response (see also Park, 2010; Park and Folkman, 1997; Brennan, 2001).

4.6 Conclusion

PTG has been reported in previous studies of carers of physical health problems (see Table 1.2) and of stroke carers (see Table 1.3). However, this study is the first to assess PTG in a sample of UK stroke carers and investigate factors associated with PTG within this population.

Studying PTG is important as it has been associated with improved wellbeing and adjustment for carers (see Table 1.3); a population that often suffer depression and PTSD, due to the challenging nature of their role (Han & Haley, 1999, Carek *et al.*, 2010). PTG is also an important concept as it represents a general shift in the literature from a disease-focused approach towards an approach highlighting resilience and growth (Lincoln *et al.*, 2012). Moreover, carers' positive well-being has numerous benefits for those they care for; including improved physical and psychological outcomes (Tsouna-Hadjis *et al.*, 2000; Palmer and Glass, 2003), and a reduced risk of survivors being institutionalised (Bishop & Evans, 1995).

All carers reported growth in at least one area of their experience. Ruminative coping and social support best predicted growth and these findings provide strong evidence for the Tedeschi and Calhoun (2004a) model in explaining PTG in stroke carers. Higher levels of functioning of the survivor also predicted lower PTG in carers; a finding that can be seen to provide additional support for the work of Tedeschi and Calhoun (2004a) if higher level of functioning is taken as a measure of a decrease in the severity of the event.

The results suggest a role for psychology in teaching stroke service staff about the possibility of growth in carers. Staff could also be made aware that ruminative coping can aid growth. However, it should be noted that a pressure to think positively is not helpful (Held, 2002) and that growth rarely develops in the acute stages of the experience (Tedeschi and Calhoun, 2004a).

Areas for further research include: the use of prospective longitudinal designs to assess causality between PTG and associated factors, measurement of the acute impact of the stroke on the carer and the role of negative meaning making on PTG. Finally, although a study of PTG is an important shift from a disease-focused approach towards an approach highlighting resilience and growth, future research should aim to develop integrated models that account for both the positive and negative reactions to traumatic experiences.

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APPENDICES

Appendix 2.1. Description of Research Sites

Voluntary stroke clubs

Voluntary stroke clubs provide a peer-support service for people who have suffered a stroke and their carers. Many are independent and choose to affiliate to a larger body (e.g. the Stroke Association) for marketing, legal and training reasons. The following description is provided on the Stroke Association website:

“Stroke Clubs are local groups for those affected by stroke, including stroke survivors and carers. They aim to provide a regular meeting place for people to come together and share their experiences as well as opportunities to take part in a programme of activities” (Stroke Association, 2012)

Internet sites

Internet sites are accessed by stroke survivors and their carers nationwide. They provide: information resources (e.g. information on the causes of stroke), links to services and access to on-line communities.

For this study, an advert was placed on:

- ‘Talk Forum’ - an on-line community running on the Stroke Association website for people affected by stroke (<http://www.stroke.org.uk/applications/discussion>)
- ‘Different Strokes’, a web site dedicated to the needs of younger stroke survivors and their carers (<http://www.differentstrokes.co.uk>)
- Different Strokes Facebook group (<http://www.facebook.com/groups/2364892925/>)

Communication Groups

Communication Groups are groups that are run by trained volunteers that help teach communication skills to those people who have a stroke and who suffer from communication problems. The group is often facilitated by a paid member of staff from the Stroke Association. Carers either attend the group or are known to facilitators through their work with the person who has had a stroke (Stroke Association, 2012).

Appendix 2.2: Participants by source

Source	Number of participants
Stroke Clubs in Wales (affiliated to the Stroke Association)	54
Stroke Clubs in West of England (affiliated to the Stroke Association)	1
Stroke Clubs in West of England (affiliated the Bristol Area Stroke Foundation)	1
Communication Groups	14
Internet Adverts	5
Total	75 (of which 71 met inclusion criteria)

Appendix 2.3: Ethics Approval

School of Psychology

Head of School Professor Dylan M Jones OBE BSc (Tech) PhD DSc FBPsS AcSS CPsychol

Ysgol Seicoleg

Pennaeth yr Ysgol Yr Athro Dylan M Jones OBE BSc (Tech) PhD DSc FBPsS AcSS CPsychol



Cardiff University
Tower Building
Park Place
Cardiff CF10 3AT
Wales UK

Tel Ffôn +44(0)29 2087 4007
Fax Ffacs +44(0)29 2087 4679
www.cardiff.ac.uk/psych

Prifysgol Caerdydd
Adellad y Tŵr
Plas y Parc
Caerdydd CF10 3AT
Cymru Y Deyrnas Unedig

Ref: EC.11.09.06.2859R

9th March 2011

To Whom It May Concern,

This letter is to confirm that the work on the study by William Hallam entitled 'Coping, Post Traumatic Growth and Quality of Life in Stroke Carers' has received ethical approval from the Cardiff University School of Psychology Research Ethics Committee.

If you have any questions relating to this, please do not hesitate to contact me.

Regards,

A handwritten signature in black ink that reads 'DMortlock'.

Dominique Mortlock

Secretary to the School of Psychology Research Ethics Committee

psychethics@cf.ac.uk

02920 870360

Appendix 2.4: R&D Approval



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

02 November 2011

Mr William Hallam
Trainee Clinical Psychologist
South Wales Doctoral Programme in Clinical Psychology
Archway House
77 Ty Glas Avenue
Cardiff

Dear Mr Hallam

Cardiff and Vale UHB Project Ref : 11-MEH-5233
NISCHR PCU Ref: 84382
Title: Coping, Posttraumatic Growth And Quality Of Life In Stroke Caregivers

The above project was forwarded to Cardiff and Vale University Health Board R&D Office by the NISCHR Permissions Coordinating Unit. A Governance Review has now been completed on the project.

Documents approved for use in this study are:

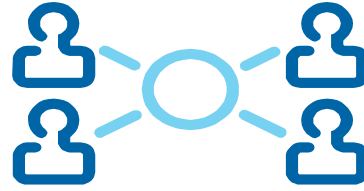
Document	Version	Date
NHS R&D Form	3.1	Received 25 August 2011
SSI Form	3.1	Received 25 August 2011
Protocol	2.0	8 September 2011
Participant Information Sheet	2.0	8 September 2011
Spouse Carer's Survey	2.0	8 September 2011
Participant Consent Form	-	-

I am pleased to inform you that the UHB has no objection to your proposal.

Appendix 2.5. On-line Advert



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL



Carers needed for research into the care-giving experience

Can I take part?

Yes – if you care for a spouse/ partner who has had a stroke, and the stroke occurred at least 18 months ago.

What is the study about?

This research looks at the care giving experience. We aim to understand how carers cope and how is it that some carers come to benefit from their experiences.

What will I be asked to do?

If you decide to partake in the research I will post you a questionnaire. This should take no longer than 30 minutes to complete.

How can I take part?

For more information and to be sent a questionnaire please email, me, Will Hallam (Trainee Clinical Psychologist) at hallamw@cardiff.ac.uk or telephone 02920 206464.



1st Floor, Archway House 77 Ty Glas Avenue Llanishen Cardiff C
Ty Archway, 77 Ty Glas Avenue, Llanishen, Caerdydd CF14 5DX



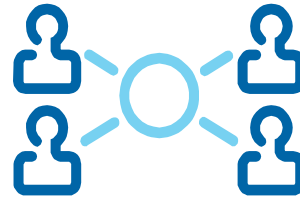
Tel/Ffon 029 2020 6464 Fax/Ffacs 029 2019 0106

Email/Ebost deborah.robinson2@wales.nhs.uk

Appendix 2.6. Participant Information Sheet



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL



Dear Stroke Carer,

Let me Introduce Myself

My name is Will Hallam, I'm a Trainee Clinical Psychologist working for the NHS and I'm hoping to do some research with stroke carers.



Brief Description of Project

This research looks at the experiences people have after they discover that their spouse/partner has had a stroke. It looks into their coping strategies, their overall experience as a carer and how people may 'grow' from their experiences.

What will I be asked to do?

If you decide to partake in the research we will ask you to fill in a questionnaire. This should take no longer than 30 minutes to complete.

If you agree to partake in the research I may meet you at the stroke club to give you a questionnaire. Please bring your glasses if you wear them.

Do I have to take part?

No - your participation is entirely voluntary; you do not have to take part if you do not want to.

Who can partake in the study?

You can take part in the study if:

1. Your spouse/partner has had a stroke
2. You are an informal carer for your spouse/ partner (by 'informal' we mean a person that takes on a caring role and are not paid or trained by any statutory body).
3. Your spouse/partner had their stroke **at least** 18 months ago.

What are the benefits of this research?

I am hoping that the research can help provide insights into how we can help people, not only to adjust to the caring role, but also to grow as people through their experiences.

What are the risks in taking part?

The project has been passed by Cardiff University Ethics Board and there do not seem to be any significant risks in conducting this project. It is unlikely that you will find the questionnaire distressing. However, I would urge you to contact your stroke club if this is the case.

How will the data be kept?

We will ask you to complete a questionnaire but not put your name on it. In this way all data and questionnaires can be kept anonymous.

We will also ask you to complete a consent form. This will be kept separately from your questionnaire in a locked cabinet at the course base (South Wales Doctoral Course in Psychology, Archway House, Cardiff).

What is this research for?

This research will be part of the trainee's PhD research project to be completed by September 2012. You are very welcome to have a summary of the findings by providing your address on the consent form (attached).

Should I tell my spouse/ partner about the research?

You may like to share this information on this sheet with your spouse/partner. However, this is your choice.

Further Information

For further information about the study, please contact Will Hallam (Trainee Clinical Psychologist) on 02920 206464 or at hallamw@cardiff.ac.uk

If you would like to make a complaint about this research at any point please contact: Dominique Mortlock, Ethics Secretary, School of Psychology, Cardiff University on 029 208 70360 or at psychethics@cardiff.ac.uk



1st Floor, Archway House 77 Ty Glas Avenue Llanishen Cardiff C
Ty Archway, 77 Ty Glas Avenue, Llanishen, Caerdydd CF14 5DX



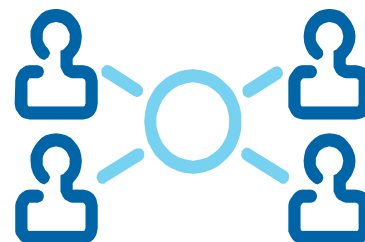
Tel/Ffon 029 2020 6464 Fax/Ffacs 029 2019 0106

Email/Ebost deborah.robinson2@wales.nhs.uk

Appendix 2.7. Consent Form



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL



Consent Sheet

Coping, Growth and Quality of Life in Stroke Caregivers

I consent to being a participant in this study. I am aware that my participation is entirely voluntary. I have read the information sheet and am aware that to be eligible for this research I must be:

- an informal carer **and** the spouse/ partner of a person who has had a stroke
- my spouse/ partner had their stroke **at least** 18 months ago

SignatureDate.....

Name (Please Print).....

Signature of Researcher.....Date.....

Name (Please Print).....

OPTIONAL:

I would like a summary of the findings of this study sent to my email **or** postal address below:

(If you do not want to receive a summary of the findings please leave this section blank)

Email address:	Or	Postal Address (including post code)
-------------------------	-----------	--

There are 2 copies of this form. Please return one form in the envelope attached and hand it back to the Stroke Club Facilitator or post it back to Mr Will Hallam (Principal Investigator) at the address below. Please keep the other copy for your own information.



1st Floor, Archway House 77 Ty Glas Avenue Llanishen Cardiff C

Ty Archway, 77 Ty Glas Avenue, Llanishen, Caerdydd CF14 5DX

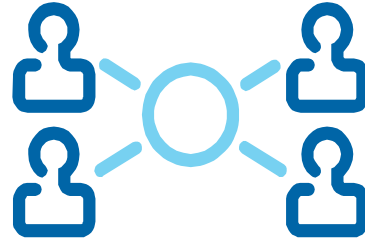
Tel/Ffon 029 2020 6464 Fax/Ffacs 029 2019 0106

Email/Ebost deborah.robinson2@wales.nhs.uk



Appendix 2.8. Questionnaire

SPOUSE CARERS' SURVEY



Instructions:

The questionnaire should take no longer than 30 minutes to complete.

Questionnaires will be **anonymous**. Therefore, please do not write your name on the questionnaire.

Please try to answer all the questions even if you are unsure about some of them. However, it is your right to omit any items or stop the questionnaire at any time if you wish to.

Please remember that you should only fill in this questionnaire if:

- You are an informal carer **and** the spouse/partner¹³ of person who has had a stroke
- Your spouse/partner had their stroke **at least** 18 months ago

¹³ We will use the term 'spouse' through the questionnaire for simplicity

Part 1: About You

1. Please give your age

2. Please give your gender:

1) Male

2) Female

3. Please indicate your ethnicity?

(Please tick whichever box applies to you)

1) British

9) Pakistani

2) Irish

10) Bangladeshi

3) Any other white background

11) Any other Asian background

4) White & black Caribbean

12) Caribbean

5) White & black African

13) African

6) White and Asian

14) Any other black background

7) Any other mixed background

15) Chinese

8) Indian

16) Any other ethnic group

4. When did your spouse have a stroke?
(Please try to indicate a month and year)

Month _____ Year _____

5. How long have you been a carer for?

..... years

6. How many hours a week do you spend caring for your spouse:

- | | | | |
|----------------|--------------------------|-----------------------|--------------------------|
| 1) 0-10 hours | <input type="checkbox"/> | 4) 31-40 hours | <input type="checkbox"/> |
| 2) 11-20 hours | <input type="checkbox"/> | 5) 41-50 hours | <input type="checkbox"/> |
| 3) 21-30 hours | <input type="checkbox"/> | 6) More than 50 hours | <input type="checkbox"/> |

7. I attend a stroke club or group

- | | | | |
|--------------------------|--------------------------|---------------------------|--------------------------|
| 1) More than once a week | <input type="checkbox"/> | 4) Once a month | <input type="checkbox"/> |
| 2) Once a week | <input type="checkbox"/> | 5) Less than once a month | <input type="checkbox"/> |
| 3) Once a fortnight | <input type="checkbox"/> | 6) Never | <input type="checkbox"/> |

Part 2: About Your Spouse

8. Has their communication been affected:

1) Not at all

2) Mildly

3) Severely

9. Do they have memory problems:

1) Not at all

2) Mildly

3) Severely

10. Does your spouse receive professional carer visits?

Yes No

11. If yes, how many visits per week?

_____per week

12. Does your spouse:

• Get upset, angry or 'difficult'?

Yes No

• Know that they have had a stroke?

Yes No

• Seem to have changed in personality since their stroke?

Yes No

- Suffer from depression or anxiety?

Never Sometimes Often

13. Is your spouse able to:

- Clearly communicate their needs and wishes to you?

Yes No

- Show you affection?

Yes No

Barthel ADL Index (Collins *et al.*, 1988)

The following questions ask about your spouse's level of independence **over the last 2 weeks**. Please *circle* the number that describes how independently your spouse is able to the following tasks:

FEEDING

0 = unable

1= needs help cutting, spreading butter, etc., or requires modified diet

2 = independent (when food is provided in reach)

BATHING/SHOWERING

0 = dependent

1= independent

GROOMING

0 = needs help with personal care

1= independent at cleaning face/hair/teeth and shaving (when implements provided)

DRESSING

0 = dependent

1= needs help but can do about half unaided

2 = independent (including doing up buttons, zips, laces, etc.)

BOWELS

0 = incontinent (or needs to be given enemas)

1 = occasional accident (about once a week)

2 = continent

BLADDER

0 = incontinent, or catheterized and unable to manage alone

1 = occasional accident (once a day)

2 = continent

TOILET USE

0 = dependent

1 = needs some help, but can do something alone

2 = independent (on and off, dressing, wiping)

TRANSFERS (BED TO CHAIR AND BACK)

0 = unable, no sitting balance

1 = major help (one or two people, physical), can sit

2 = minor help (verbal or physical)

3 = independent

MOBILITY (ON LEVEL SURFACES)

0 = immobile or unable to use a wheelchair more than 50 yards

1 = wheelchair independent, including corners, more than 50 yards

2 = walks with help of one person (verbal or physical) more than 50 yards

3 = independent (but may use any aid; for example, stick) more than 50 yards

STAIRS

0 = unable

1 = needs help (verbal, physical, carrying aid)

2 = independent (up and down)

COPE (Carver, 1989)

These items deal with ways you've been coping with the stress in your life since you found out that your spouse had a stroke.

Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with this stress. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says.

Please don't answer on the basis of whether it seems to be working or not, only whether or not you're doing it.

Please rate the following items on a scale of 1 to 4 by circling a number:

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

1. I concentrate my efforts on doing something about it. 1 2 3 4

2. I say to myself "this isn't real." 1 2 3 4

3. I get used to the idea that it happened. 1 2 3 4

4. I accept that this has happened and that it can't be changed. 1 2 3 4

5. I take additional action to try to get rid of the problem. 1 2 3 4

6. I refuse to believe that it has happened. 1 2 3 4

7. I pretend that it hasn't really happened. 1 2 3 4

8. I accept the reality of the fact that it happened. 1 2 3 4

9. I take direct action to get around the problem.	1	2	3	4
---	---	---	---	---

10. I learn to live with it.	1	2	3	4
-------------------------------------	---	---	---	---

11. I act as though it hasn't even happened.	1	2	3	4
---	---	---	---	---

12. I do what has to be done, one step at a time.	1	2	3	4
--	---	---	---	---

PTGI (Tedeschi & Calhoun, 1996)

Please indicate, for each of the statements below, the degree to which this change occurred in your life as a result of your spouse having a stroke.

Please answer all questions as honestly as you can.

The rating scale is as follows:

0	1	2	3	4	5
I did not experience this change as a result of my spouse having a stroke	I experienced this change to a very small degree as a result of my spouse having a stroke	I experienced this change to a small degree as a result of my spouse having a stroke	I experienced this change to a moderate degree as a result of my spouse having a stroke	I experienced this change to a great degree as a result of my spouse having a stroke	I experienced this change to a very great degree as a result of my spouse having a stroke

1. I changed my priorities about what is important in life. 0 1 2 3 4 5

2. I have a greater appreciation for the value of my own life. 0 1 2 3 4 5

3. I developed new interests. 0 1 2 3 4 5

4. I have a greater feeling of self-reliance. 0 1 2 3 4 5

5. I have a better understanding of spiritual matters. 0 1 2 3 4 5

6. I more clearly see that I can count on people in times of trouble. 0 1 2 3 4 5

7. I established a new path for my life. 0 1 2 3 4 5

8. I have a greater sense of closeness with others. 0 1 2 3 4 5

9. I am more willing to express my emotions. 0 1 2 3 4 5

10. I know better that I can handle difficulties. 0 1 2 3 4 5

11. I am able to do better things with my life. 0 1 2 3 4 5

12. I am better able to accept the way things work out. 0 1 2 3 4 5

13. I can better appreciate each day. 0 1 2 3 4 5

14. New opportunities are available which wouldn't have been otherwise 0 1 2 3 4 5

15. I have more compassion for others 0 1 2 3 4 5

16. I put more effort into my relationships 0 1 2 3 4 5

17. I am more likely to try to change things which need changing. 0 1 2 3 4 5

18. I have a stronger religious faith 0 1 2 3 4 5

19. I discovered that I'm stronger than I thought I was. 0 1 2 3 4 5

20. I learned a great deal about how wonderful people are 0 1 2 3 4 5

21. I better accept needing others 0 1 2 3 4 5

MSPSS (Zimet *et al.*, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

(The term 'special person' can refer to anyone e.g.: a spouse, friend or professional).

1	2	3	4	5	6	7
Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree

1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Rumination Inventory (Calhoun, Tedeschi, Cann & McMillan, 2000)

Discovering that your partner has had a stroke can be a stressful and traumatic experience/event.

We would like you to keep this in mind when answering the following questions (on a scale of 1 to 4).

1	2	3	4
Not at all	Rarely	Sometimes	Often

1. Soon after the event, I thought about the event when I didn't mean to. 1 2 3 4

2. Recently, I have thought about my experience when I didn't mean to. 1 2 3 4

3. Soon after the event, thoughts about the experience came into my mind and I
could not get rid of them. 1 2 3 4

4. Recently, thoughts about the event came to my mind and I could not get rid of
them. 1 2 3 4

5. Soon after the event, I decided to think about the experience to try and make
sense out of what happened. 1 2 3 4

6. Recently, I decided to think about the experience to try and make sense out of
what happened. 1 2 3 4

7. Soon after the event, I tried to make something good come out of my struggle. 1 2 3 4

8. Recently, I have tried to make something good come out of my struggle. 1 2 3 4

9. Soon after the event, I reminded myself of some of the benefits that came from adjusting to the experience. 1 2 3 4

10. Recently, I reminded myself of some of the benefits that came from adjusting to the experience. 1 2 3 4

11. As a result of what happened, soon after the event I found myself automatically thinking about the purpose of my life. 1 2 3 4

12. As a result of what happened, recently I find myself automatically thinking about the purpose of my life. 1 2 3 4

13. As a result of what happened, soon after the event I deliberately would think about and ask questions about whether or not life has a meaning or purpose. 1 2 3 4

14. As a result of what happened, recently I will deliberately think about and ask questions about whether or not life has a meaning or purpose. 1 2 3 4

AC-QoL (Elwick et al, 2010)

This questionnaire asks you about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer.

Never	Some of the time	A lot of the time	Always
1	2	3	4

1. I have a good level of emotional support 1 2 3 4

2. My needs as a carer are considered by professionals 1 2 3 4

3. I am happy with the professional support that is provided to me 1 2 3 4

4. I feel able to get the help and information I need 1 2 3 4

5. I have all the practical support I need 1 2 3 4

6. I feel that my life is on hold because of caring 1 2 3 4

7. My social life has suffered because of caring 1 2 3 4

8. I feel I have less choice about my future due to caring 1 2 3 4

9. I feel I have no control over my own life 1 2 3 4

10. Caring stops me doing what I want to do	1	2	3	4
--	---	---	---	---

11. I feel depressed due to caring	1	2	3	4
---	---	---	---	---

12. I feel worn out as a result of caring	1	2	3	4
--	---	---	---	---

13. I am mentally exhausted by caring	1	2	3	4
--	---	---	---	---

14. I am physically exhausted by caring	1	2	3	4
--	---	---	---	---

15. I feel stressed as a result of caring	1	2	3	4
--	---	---	---	---

16.	I am satisfied with my performance as a carer	1	2	3	4
------------	---	---	---	---	---

17.	I can take care of the needs of the person I am caring for	1	2	3	4
------------	--	---	---	---	---

18.	I feel I am able to make the life of the person I am looking after better	1	2	3	4
------------	---	---	---	---	---

19.	I can manage most situations with the person I care for	1	2	3	4
------------	---	---	---	---	---

20.	I am able to deal with a difficult situation	1	2	3	4
------------	--	---	---	---	---

21.	Caring is important to me	1	2	3	4
------------	---------------------------	---	---	---	---

22.	I resent having to be a carer	1	2	3	4
------------	-------------------------------	---	---	---	---

23.	I feel frustrated with the person I am caring for	1	2	3	4
------------	---	---	---	---	---

24.	I enjoy being a carer	1	2	3	4
------------	-----------------------	---	---	---	---

25.

I am satisfied with my life as a carer

1 2 3 4

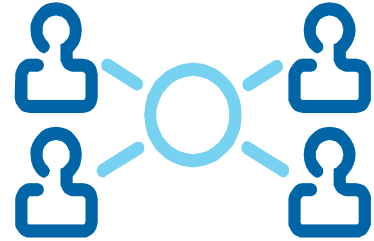
Thank you very much for completing this questionnaire.

If you have found any of the material in this questionnaire upsetting please contact your local stroke club facilitator.

Appendix 2.9 Debriefing Letter



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL



[Date]

Dear sir/madam,

Thank you for returning your questionnaire. The answers you have provided will now be entered onto a database to investigate whether growth (or benefit finding) occurs in a group of stroke carers.

We will also use your answers to see whether growth is related to a number of factors such as a person's coping style and their level of social support. These areas have never been studied within a large population of stroke carers.

Your answers will be stored anonymously. Your consent form will be kept separately from your answers in a locked cabinet in at South Wales Doctoral Course in Clinical Psychology, Archway House, Cardiff.

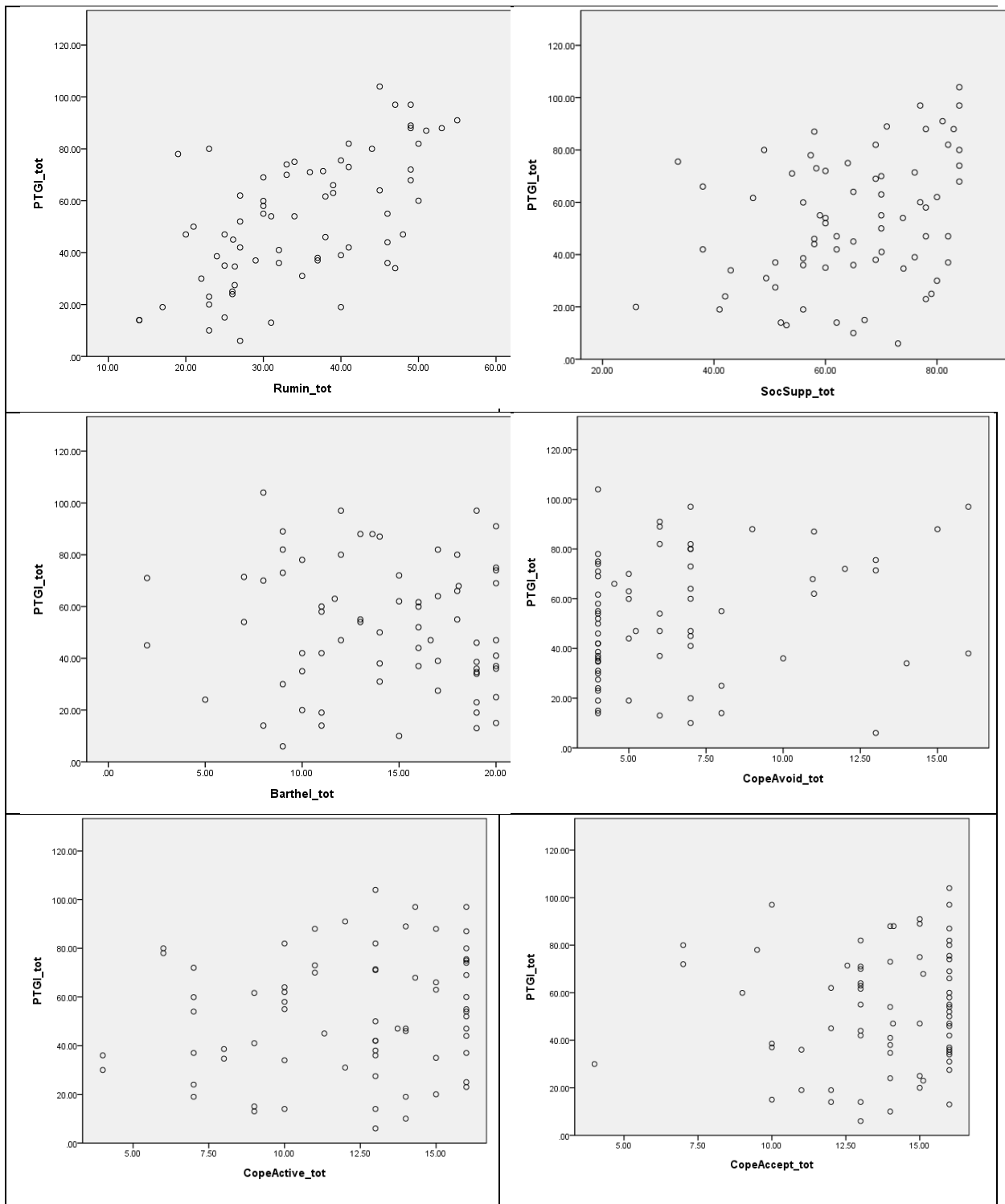
I will be very happy to send you a summary of my findings if you have indicated this on your consent sheet. Also, please do not hesitate to contact me with any questions or comments that you may have.

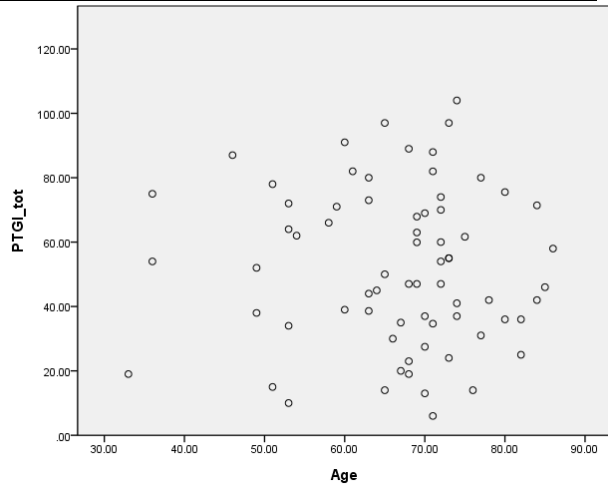
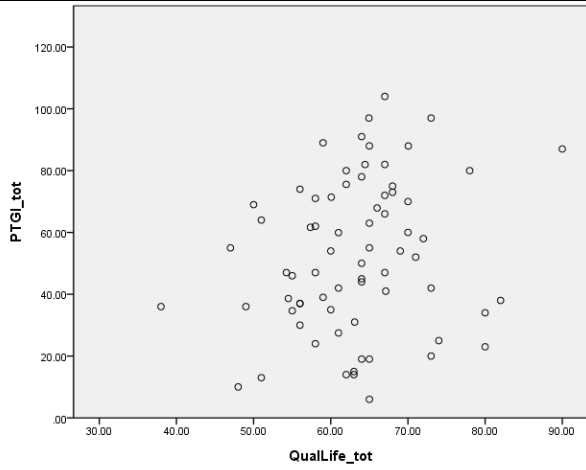
Yours truly,

Will Hallam
Trainee Clinical Psychologist
South Wales Doctoral Course in Clinical Psychology

hallamw@cardiff.ac.uk

Appendix 3.1: Scatter plots of PTGI scores against each independent variable





Appendix 3.2 Correlation between PTGI and each independent variable – including parametric and non-parametric correlations

		PTGI (Pearson's r)	PTGI (Kendall's Tau, τ)
Level of Dependence	τ / r value	-0.86	-.075
	Sig (2 tailed)	.480	.377
	N	69	69
Active Coping	r	0.17	.134
	Sig (1 tailed)	.077	0.60
	N	69	69
Acceptance Coping	r	0.07	.076
	Sig (1 tailed)	.273	.194
	N	69	69
Avoidance Coping	r	0.21*	.176*
	Sig (1 tailed)	.042	.024
	N	69	69
Social Support	r	0.34**	.236**
	Sig (1 tailed)	.002	.002
	N	70	70
Rumination	r	0.62***	.447***
	Sig (1 tailed)	.000	.000
	N	70	70
Quality of Life	r	0.20*	.159*
	Sig (1 tailed)	.045	.027
	N	70	70
Age	r	0.04	-.038
	Sig (1 tailed)	.383	.324
	N	70	70

*p<0.05; ** p <0.01; *** p<0.001

Appendix 3.3 Correlation Matrix

	PTGI	Level of Dependence	Active Coping	Avoidance Coping	Acceptance Coping	Social Support	Rumination	Quality of Life	Age
PTGI	1								
Level of Dependence	-.09	1							
Active Coping	.17	.03	1						
Avoidance Coping	.21	-.02	.10	1					
Acceptance Coping	.07	.08	.69	.02	1				
Social Support	.34	.09	.09	.16	-.07	1			
Rumination	.62	.16	.27	.43	.25	.15	1		
Quality of Life	.20	-.18	.31	.30	.21	-.00	.15	1	
Age	-.04	-.10	.01	-.05	.15	.12	-.07	-.21	1