The Understanding and Experience of Anxiety in Older Adults

Caring for Partners with Stroke

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ABSTRACT

Anxiety has been increasingly recognized as a serious health concern in older adults and is reported by many caregivers. However, still relatively little is known about the experience or presentation of anxiety in later life or about how that anxiety relates to caregiving. Much of the research into late-life anxiety has focused on anxiety disorders and has been carried out with reference to younger age groups, using diagnostic and psychometric measures developed, in the main, for younger people. There appear to be few studies in the literature that explore late-life anxiety as an independent phenomenon or that examine the effects of contextual factors on that anxiety. No studies could be found that investigate non-clinical experiences of anxiety in later life, starting from the perspectives of older adults themselves; neither could any studies be found that specifically investigate anxiety-related experiences of elderly people caring for partners with stroke.

The present study explores how older adults, caring for partners with stroke, understand and experience anxiety. Semi-structured interviews were conducted with nine older adults, aged from 65 to 80 years, who were living in the community and were caregivers for partners with stroke. Interpretative Phenomenological Analysis (IPA) was used to identify themes within their accounts. Three master themes were identified: the phenomenon of anxiety, views that influence anxiety, and the experience of anxiety. Emergent themes describe participants' shared, main sources of anxiety, the signs and symptoms by which they recognized anxiety and the strategies that they had developed to cope with anxiety. A range of views about self, caregiving and ageing was identified that appeared to shape the anxiety that participants experienced. Findings highlight the chronic nature of the anxiety experienced by older spousal caregivers and suggest ways in which older caregivers can successfully deal with that anxiety. They provide a useful foundation for further research that seeks to determine which older adults are likely to experience anxiety problems in caregiving and also for programmes that seek to support elderly people who are caring for partners with stroke.

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To my family and friends who have supported me in so many ways, and whose unwavering faith in my ability has kept me going through good times and bad: Thank you.

To my supervisor, Paul Merrick, whose care and enthusiasm for older people first led me to consider research in this area: Many thanks for your encouragement and your patient guidance over the course of this project.

And to the nine participants without whom this study could not have taken place: Thank you for sharing your time and your experiences. Your strength and generosity are truly inspiring.

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Anxiety weighs down the human heart,

but a good word cheers it up.

Proverbs 12:25

FORWARD

Elderly people have had an important place in my life for as long as I can remember. As a child, I grew up in an extended family with the support of grandparents and great aunts who lived well into their 80's and 90's. As an adult, and mother of young adults, I still have parents, uncles and aunts who are in their 70's and 80's and live independent, healthy and active lives. These family experiences have no doubt contributed to my positive view of older age as having the potential to be as enjoyable and varied as earlier stages of life, and to my view of older people as having unique and valuable perspectives and a continuing capacity to learn and adapt to changing times and circumstances.

The opportunity of growing up with older people, watching and talking to them about their lives, has played a large part in my current interest in older people and in the ageing process. My professional experience as a social worker and more recently as a volunteer for older adults with aphasia due to stroke has added to that interest. At the same time, it has given me an appreciation of the very real difficulties that many older people face and made me curious about why it is that some people appear to cope so positively with changes and challenges, while others experience considerable difficulty and distress. In my contact with the partners of the stroke patients I visit, I have become especially interested in how older people cope with the demands of caring for partners disabled by stroke, particularly in how they deal with the psychological demands of that role. The unexpected nature of stroke and the uncertainty it poses for future life and health led me to wonder what place anxiety, in particular, might have in the lives of older spousal caregivers.

Through voluntary work and postgraduate study, I have increasingly come to view older spousal caregivers as a somewhat marginalized population, both in terms of the health care system and in relation to psychological research and practice. It would appear that very few resources are available to those older people caring for partners with stroke; that healthcare services focus almost exclusively on the needs of stroke patients themselves and that little or no attention is given to assessing or addressing the psychological needs of their carers. In many instances it seems that older, spousal

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caregivers are somewhat "invisible", their availability and ability to care taken for-granted, perhaps because of their close relationship to patients but possibly too because, as older usually retired people, they are not perceived as having the same competing needs and responsibilities as younger caregivers.

My personal hope in carrying out this research is that it can give a voice to carers whose work and care often goes unrecognised; also that by attempting to understand their experiences of anxiety and presenting them in a meaningful way, this study can contribute something to a wider psychological understanding of anxiety that better reflects the experiences of older people and is more responsive to their needs.

Liz Cotton

CHAPTER ONE

Introduction

Anxiety

Anxiety has been a recognized part of human experience for thousands of years, a universal phenomenon that affects all people at some time during the course of their lives (Di Tomasso & Gosch, 2002; Sadock and Sadock, 2003). Hippocrates, writing over two thousand years ago, described cases of social anxiety and phobia and suggested herbal treatments for "nervous unrest". He also linked anxiety that to the functioning of the human brain, which he claimed, ''makes us mad or delirious, inspires us with dread and fear, brings sleeplessness... and aimless anxiety" (Stone, 1997, p10). Then, as now, anxiety was regarded as an unpleasant state, a feeling of nervousness or apprehension about things that are happening or that might happen in the future (Cambridge International Dictionary of English, 1995).

Anxiety as a psychological construct has a far more recent history, with interest and research into anxiety as a phenomenon having grown particularly in the past fifty years (Di Tomasso & Gosch, 2002). Psychological conceptions of anxiety can be seen to closely follow common or lay definitions. At the same time, they tend also to emphasize the symptomatic presentation of anxiety. Anxiety has been generally defined as "a future oriented, negative mood state characterized by bodily symptoms of physical tension, and apprehension about the future" (Barlow and Durand (2005, p. 121). A similar focus is evident in the following extract from Kaplan and Sadock's Synopsis of Psychiatry which describes anxiety as "a diffuse, unpleasant, vague sense of apprehension, often accompanied by autonomic symptoms such as headache, perspiration, palpitations, tightness in the chest, mild stomach discomfort, and restlessness, indicated by an inability to sit or stand still for long" (Sadock & Sadock, 2003, p. 591).

Overall, anxiety is viewed as having cognitive (worry, concentration difficulties), somatic (fatigue, muscle tension, sleep disturbance), and emotional components (restlessness, irritability), with the particular pattern of these symptoms tending to vary from person to person (Sadock & Sadock, 2003; Scogin, 1998). Feelings and symptoms

of anxiety are considered to be a natural and adaptive feature of everyday life, alerting us to impending danger so that we can take whatever action is necessary to deal with threats or lessen their consequences. Moderate levels of anxiety are known to improve performance and even severe levels are considered normal when they are "consistent with the demands of a situation" (Andrews, Crino, Hunt, Lampe & Page, 2003, p. 4). Anxiety then, is similar to fear which also signals danger and readies a person for action. However, while fear is seen as a response to definite, known and present danger, anxiety is usually considered to be a reaction to less pressing, less certain danger; a response to threat that is, for the most part, "unknown, internal, vague or conflictual" (Di Tomasso & Gosch, 2002; Sadock & Sadock, 2003).

Anxiety as a disorder

For a considerable number of people, however, the experience of anxiety appears to be neither a natural nor a functional response to circumstances. Rather than serving to motivate positive action, this anxiety is excessive and debilitating, causing considerable distress and interfering with a person's functioning in every day life. It is this maladaptive form of anxiety, anxiety as a disorder, that has been the main focus psychological investigations and which is the target of psychological assessment and treatment. From this perspective, anxiety is not, in itself, a problem. However it is considered to be a problem and a disorder when it exceeds what is "normal or expected" in a particular context and when it persists and interferes with a person's functioning in every day life (American Psychiatric Association, 1994; Rabins, 2005). This dysfunctional anxiety is also centred on apprehension about future negative events, but is marked by additional, core features of negative affect (distress), over-arousal, and a sense of uncontrollability (Di Tomasso & Gosch, 2002).

In keeping with the psychological definitions of anxiety presented above, psychological constructions of dysfunctional anxiety have tended to rest heavily on its various symptomatic presentations. Clinical anxiety and specific anxiety disorders have come to be defined largely according to threshold levels and numbers of specific target behaviours or symptoms (American Psychiatric Association, 1994; Rivas-Vazquez, Saffa-Biller, Ruiz, Blais & Rivas-Vazquez, 2004). Diagnostic criteria and interview formats developed for these specified anxiety disorders have allowed major advances in the identification, assessment and treatment of anxiety problems. They have also

provided a foundation for research into the prevalence of anxiety disorders, and for the evaluation of psychological treatments for anxiety. As a result, much is now known about the general experience, presentation and assessment of anxiety disorders: Epidemiological studies have consistently shown that anxiety disorders are more prevalent than any other mental health problem, and that they are particularly common in primary care settings. Studies have also shown that these disorders tend to be chronic, lasting for decades and even persisting over lifetimes if they go untreated, at considerable cost to individuals and to society as a whole (Barlow, 2002). In recent years, research has also led to the development of effective psychological treatments for anxiety, so that empirically validated treatments are now available for the majority of recognized anxiety disorders (Andrews et al., 2003: Chambless & Ollendick, 2001).

However, that anxiety as a psychological phenomenon has come to be defined largely in terms of symptoms, is also problematic. Many of the symptoms by which anxiety and anxiety disorders are recognized overlap significantly with those of other physical and psychological conditions (Westen, Heim, Morrison, Patterson & Campbell, 2002). This poses difficulties for both assessment and treatment, particularly in relation to depression which shares many of the symptoms of anxiety and which frequently occurs as a co-morbid condition. The exact nature of the relationship between anxiety and depression remains unclear and the subject of continuing debate, at the centre of which are uncertainties about current phenomenological definitions. (For more detailed discussion see Krueger, Barlow & Watson, 2005). A further difficulty associated with reliance on symptom-based definitions of anxiety as a phenomenon, is that in addition to the considerable variance in symptoms evident across individuals, research has also shown significant and systematic variations in the ways in which different groups of people understand and experience anxiety. Studies suggest that, although negative affect may be a universal experience, the perception and expression of anxiety can vary considerably across ethnic and cultural groups and across age groups (Barlow, 2002; Hilliard & Iwamasa, 2001; Sallis & Lichstein, 1982).

Anxiety in older adults

As yet, relatively little research has been directed at exploring age-related differences in the presentation and experience of anxiety (Flint, 1994, 2005; Fuentes & Cox, 2000; Kogan, Edelstein & McKee, 2000; Wetherell, Maser & Van Balkom, 2005).

Instead, psychological investigation of anxiety has focused primarily on anxiety in general populations or in younger people. Much of the research that has been carried out in relation to elderly people has centred on the disorders of depression and dementia, conditions that are more commonly associated with ageing and later-life. Consequently, despite the fact that research in clinical gerontology has flourished in recent decades, and in contrast to the progress made in the understanding of anxiety and anxiety disorders in general, still relatively little is known about the way in which older adults experience anxiety (Flint 2005; Kogan et al., 2000; Segal, 2000).

The reasons for this apparent lack of interest in late-life anxiety are not clear, although it does seem that much of the existing literature on anxiety is based in an implicit assumption that anxiety is experienced similarly by people of all ages. Flint (2005) suggests that the comparative lack of research into anxiety in the elderly may also be due to a general perception that anxiety presents less of a problem for older adults than it does for younger people: Epidemiological studies have consistently shown that anxiety disorders become less prevalent across the life span (Regier et al, 1988). However, for a number of reasons, these figures may not provide a reliable indication of the anxiety-related problems faced by older people: Anxiety disorders that are experienced by elderly people and dealt with in the mental health system are often chronic having developed earlier in life, and, as noted above, are frequently co-morbid with depression which becomes the focus of attention. Also, where disorders do have a late-onset, it would appear that they often go unrecognized, in part because older community-dwelling adults are less likely to come to the attention of specialists or mental health services, preferring instead to consult their GPs (Flint, 2005; Fuertes & Cox, 1997). Late-life anxiety problems may also go unrecognized because much of the anxiety that older adults do experience does not reach the diagnostic criteria for specific disorders. Ageist thinking may compound this situation; anxiety-related difficulties of elderly people may be overlooked or dismissed by others who see them as "appropriate" responses to life events and situations, or simply as a natural consequence of ageing (Flint, 2005; Knight, 2004).

The relative lack of existing information about anxiety as it is experienced by older adults is of particular concern given the apparent prevalence and influence of anxiety in later life. While, as noted above, prevalence rates for anxiety disorders for older adults

are generally believed to be slightly lower that those for younger adults (5.5.% vs. 7.3%) (Fuentes & Cox, 2000; Regier et al., 1988) epidemiological studies indicate that anxiety disorders are nevertheless among the more prevalent of psychiatric disorders in later-life (1 month and 6 month prevalence rates of 4.6% and 6.8% respectively (Regier et al., 1988)) and that they are typically more common than depressive disorders (Beekman et al., 2000; Depp, Woodruff-Borden, Meeks, Gretarsdottir & DeKryger, 2005; Knight, 2004; Wetherell et al., 2005). Furthermore, although anxiety in older adults is often co-morbid with depression, some studies suggest that the incidence of late-life mixed anxiety and depression is actually considerably lower than the incidence of anxiety disorders alone (Beekman et al., 2000; Wetherell et al., 2005).

Generalized Anxiety Disorder (GAD) and phobias are known to be the most common anxiety disorders in the elderly (Hopko et al., 2000; Stanley and Novy, 2000) with prevalences estimated to range from 0.7% to 7.1% (Flint, 1994) and 4.8% to 10% respectively (Kramer, German & Anthony, 1985 cited in Iliffe & Manthrope, 2002; Regier el al., 1988; Stanley and Beck, 2000), making them at least as prevalent as Major Depressive Disorder. Recent studies also suggest that the incidence of late-onset of anxiety disorders may be much higher than was previously thought. For example, although most older adults with GAD do report onset in childhood or adolescence, Le Roux et al. (2005) found that approximately 25% of subjects reported onset of GAD after age 60, while in a study by Lenze et al. (2005) that figure was nearly 50%, in both instances far higher than previous estimates of 7% (Lenze et al., 2005 and Ritchie, 1994 cited in Flint, 2005). Recent studies suggest too that late-onset panic disorder and post traumatic stress disorder may also be more common than was previously believed to be the case (Depp et al., 2000; Wetherell et al., 2005).

In addition to these findings related to specific anxiety disorders, studies also indicate that other forms of anxiety can have a strong, negative influence in the lives of elderly people. As has already been noted, most older adults with anxiety problems do not meet the criteria for identified anxiety disorders. However, sub-threshold anxiety disorders and anxiety symptoms have been shown to occur frequently in older adults living in the community (Fuentes & Cox, 1997; Heun, Papassotiropoulos & Ptok, 2000) and are frequently associated with significant distress, disability, and impaired quality of life (Kogan et al., 2000; Wetherell, Le Roux & Gatz, 2003; Wetherell et al., 2005);

For example, it is estimated that phobic anxieties are the underlying cause of around 20% of cases in which older individuals become housebound. Non-clinical panic has also been shown to be extremely disabling in later life and to be far more frequent in older adults than previous epidemiological studies would suggest (Depp et al., 2005). Studies of GAD have yielded similar findings; a community study by Himmelfarb and Murrell (1984) found anxiety symptoms severe enough to warrant treatment in 17% of the men and 21% of the women who participated in the study (cited in Wetherell et al., 2003).

Limitations of current measures and understandings of anxiety

These findings notwithstanding, existing information concerning the prevalence of anxiety disorders and anxiety-related problems in older adults must be treated with caution while the phenomenology of anxiety in later life is still largely unknown. As noted above, researchers have frequently assumed an homogeneity of experience and presentation across the life span, including the many years that separate the young-old (65 to 80 years) and the oldest-old (over 90 years). In the absence of specific understanding of anxiety in older populations, much of the information that is available on late-life anxiety relies on extrapolation of data from studies of anxiety in younger adults. Diagnostic criteria and assessment measures employed in research and clinical practice with older adults, have been developed, in the main, for use with younger adults (Laidlaw, Thompson, Dick-Siskin & Gallagher-Thompson, 2003) and may therefore be age-biased (Flint, 2005; Jorm, 2000). As Gretarsdottir. Woodruff-Borden, Meek & Depp (2004) point out in discussion of social anxiety in later life, the practice of generalizing symptoms of psychological distress developed with one group to another is at best questionable. Knowledge developed with younger adults cannot simply be transferred to older adults. Until such time as the construct and content validity of existing anxiety measures is determined for populations of older adults, the use of those measures with older adults should be viewed as problematic and research findings based upon them as of doubtful value (Fuentes & Cox, 1997). Development of relevant norms for use with older adults has been suggested as a means of overcoming these difficulties (Owens, Hadjistavropoulos & Asmundson, 2000). However, although appropriate normative data is needed, a focus on norms alone fails to address the possibility that older adults may understand and experience anxiety in fundamentally different ways from their younger counterparts (Laidlaw et al., 2003). Neither is it

likely to lead to the identification of aspects of anxiety that may be unique to later life. It is possible that current psychological conceptualizations, diagnostic criteria and assessment measures may fail to capture the quality of anxiety in older adults (Averill and Beck, 2000; Segal, 2000). Flint (2005) suggests that this may be the reason that most older people with anxiety problems do not meet the criteria for specific anxiety disorders. Certainly it would appear that the emphasis of current disorder criteria is not suited to older adults, recognizing as they do some conditions that rarely affect older adults, whilst excluding sub-clinical patterns of anxiety that appear to be more prevalent in the elderly.

Unique characteristics of anxiety in later life

There is evidence to suggest that anxiety may indeed be experienced and expressed differently in later life (Kogan et al., 2000). Older adults have been found to report less of virtually every negative affective factor (e.g. depression, anxiety, guilt, hostility) and to be more likely to experience anxiety directly (fearful, scared, afraid) than do younger adults for whom anxiety is linked more to guilt (Kogan et al., 2000). They have also been found to differ from younger adults in the structure and style of their emotional experiences, older adults showing greater leveling of positive and negative affect and less surgency of emotion than younger people (Kogan et al., 2000; Lawton, Kleban, Rajagopal & Dean, 1992). The object or situations of fear and content of worry have been observed to differ in older adults, with younger people reporting most concern about family and finances and older adults worrying most about health (Kogan et al., 2000). Studies further suggest that the process and presentation of anxiety may be somewhat different in older adults than in younger counterparts (Mohlman, 2004). It would seem that anxiety in older adults can be recognized less through specific content of worry, than through the presence of somatic, behavioural or cognitive symptoms (Iliffe & Manthrope, 2002) and that, as noted earlier, the patterns and inter-relations of these anxiety-related symptoms may vary across the life-span (Depp et al., 2005). A number of studies indicate that late-life anxiety is more likely to manifest itself in somatic symptoms (Fuentes & Cox, 1997): Age-related differential patterns have been reported for Obsessive Compulsive Disorder (Stanley, Beck & Zebb, 1996), and GAD (Mohlman, 2004), social anxiety (Gretarsdottir et al., 2004) and panic (Depp et al., 2005) have also been found to be present differently in older adults.

However, as with other findings of anxiety-related differences between young and old, the differences reported above are equivocal. While many studies show strong age-group differences in the occurrence of anxiety disorders and anxiety symptoms, patterns of differences identified are not consistent (Jorm, 2000). How the anxiety-related differences that have been observed across age groups should be interpreted then, is presently far from clear. It seems plausible that older adults should experience anxiety differently from younger counterparts. Reasons for these differences could be found in age-related physical and cognitive changes, generational differences in recognition and reporting of affective states, and natural shifts in concerns across life-stages (Beck & Stanley, 2001). It is possible too that the anxiety that older adults experience is influenced by previous learning, resulting in better cognitive control of negative effect, more effective emotional control and also desensitization to stress (Jorm, 2000). Age-related physiological changes in the nervous system (e.g. changes in levels of specific neurotransmitters) could also be expected to influence the experience and presentation of anxiety in older adults (Kogan et al., 2000).

Understanding and assessment of anxiety in elderly adults is further complicated by its relationship with a range of other age-related factors, some of which are also poorly understood. Issues noted earlier in relation to differentiation of anxiety and depression are particularly relevant to older adults in that there appears to be considerable and increased concurrence of anxiety and depression in later life (Antony, 2001; Segal, 2000). In addition, there is marked overlap and interaction between anxiety and medical conditions and cognitive decline in older adults (Gretarsdottir et al., 2004; Kogan et al., 2000). Psychological illness can increase vulnerability to physical disease. At the same time physical disease can cause psychological symptoms. Many of the illnesses that are common in later life produce symptoms that are difficult to distinguish from anxiety. For example, symptoms of anxiety in elderly are associated with neuro-cognitive changes that accompany dementia. Somatization may be due to actual medical problems and physical illness and prescribed medications may produce side effects that mimic symptoms of anxiety (Fuentes and Cox, 2000; Haley, 1996; Kogan et al., 2000). These factors can be seen to act and interact, adding to the marked heterogeneity that already exists among older adults and presenting a considerable challenge to researchers and clinicians alike.

There is a pressing need for research that clarifies the role that these factors play in late life anxiety and that affords a better understanding of the experience and expression of anxiety within and across diverse groups of older adults. Such direction is all the more important given that research continues to show that anxiety presents a serious problem for significant numbers of elderly people.

Anxiety in context: natural or excessive reaction to real-life situations?

Fundamental to an understanding of problematic anxiety in late-life, is an understanding of the normal course of aging and the experience and presentation of functional anxiety in older adults (Adams, Luscher & Bernet, 2001; Flint, 2004). The social contexts and circumstances in which anxiety occurs are of particular importance to these understandings and introduce additional, perhaps pivotal, ways in which older adults anxiety-related experiences may differ from those of younger people (Knight, 2004). In Western societies in particular, older adults often live in specialized environments (e.g. nursing homes, hospitals, retirement villages) that are unfamiliar to younger adults, they adopt roles that are distinct from those of younger people and that have their own unique characteristics and demands. Furthermore older adults frequently face problems (e.g. chronic illness, disability, losses due to the deaths of partners or friends, prolonged care-giving for family members with serious cognitive or physical impairment etc.) that, although they can beset people at any stage of their life, are more likely to be encountered later in life. These contextual factors are likely to have an important and unique role in the experience of anxiety in later-life.

How signs and symptoms of anxiety are interpreted by older adults and by those around them, is inextricably linked to the context in which they occur. Anxiety that older people experience in response to challenges, changes and losses of later life may be viewed as appropriate and normal reactions to real-life demands, or may, as noted earlier, be simply dismissed as a natural consequence of aging (Flint, 2005; Knight, 2004). Determining when the anxiety that an older person experiences is a 'normal', appropriate response, and when it is disproportionate or excessive can be difficult, particularly if little is known about the way older adults usually react and adjust to such circumstances. Rabins (2005) expresses the difficulties this raises for family members and for clinicians of elderly people asking, "Just how tense *should* a man be who has lost his wife? How nervous should a parent be who is facing chemotherapy or has

diminished mobility because of a stroke?" (p.18). In the context of this study one could ask, how anxious should an elderly husband or wife be when faced with the demands of caring for their partner who is incapacitated by stroke? Is anxiety a natural and useful response to the demands and difficulties of caregiving and when should it be viewed as excessive, over-protective, or debilitating?

Prevalence rates and normative data for anxiety in general populations, even in general populations of older adults, cannot provide the information needed to answer questions such as these. As was noted at the outset of this chapter, a more detailed understanding of anxiety in later life is needed if anxiety-related problems in elderly people are to accurately assessed and treated. This understanding must not only include knowledge of how anxiety is generally perceived and expressed in later life, but also an understanding of how contextual factors influence older adults' everyday lives and experiences of anxiety. In the absence of sound information to guide decisions, clinicians and researchers run the risk of pathologising healthy responses and failing to recognize difficulties that do warrant clinical intervention (Iliffe & Manthrope, 2002).

Caregiving and stroke as a context for anxiety in older adults

The need for more information and better understanding of late-life anxiety is a growing one as, across all developed countries, the number and proportion of older adults in the population is higher than ever before and is expected to rise exponentially in years to come. At the same time, and as a consequence of this and other societal changes, an increasing number of older adults are taking on the role of caregiver for husbands or wives who are chronically ill or disabled. It is the anxiety experienced by older adults in this context, specifically in caring for partners with stroke, that is the focus of the current study,

Aging populations and caregiving

In New Zealand, as in other developed countries, recent decades have seen dramatic shifts in the number and proportion of elderly people in the population, changes that are expected to become even more pronounced in years to come. Since 1970, the number of people in the population aged over 65 has doubled (this in comparison with a 44% over all population increase in the same period). By 2051, it is estimated that there will be over 1.33 million New Zealanders over the age of 65, and

that growth in this age group will account for some 87.0% of population growth. Not only is it expected that the population of elderly people in New Zealand will grow, but this population too is expected to age significantly. Whereas at present the oldest 10% of the population is aged over 68 years, by 2051, the oldest 10% of the population will be 81 years old or older (Statistics New Zealand, 2006). These changes are not unique to New Zealand but are part of a world-wide phenomenon brought about largely by lower fertility and mortality rates, and influenced by numerous other factors including medical advances and changes in living conditions that have led to significant changes in the major causes of death. As more people live longer, at less risk from acute illnesses, so the incidence and prevalence of chronic illness and disabilities has also increased. This in turn has led to greater numbers of older people in need of long-term care, and to a corresponding rise in the demand for caregivers, changes that are also expected to continue in coming decades (Blieszner &Bedford, 1996; Lyonette & Yardley, 2003; Statistics NZ, 2006).

In future, as at present, it is anticipated that the majority of community based-care for elderly, disabled adults will be provided by informal caregivers and, in particular, by spouses or family members of those in need (Dwyer, 1996; Secker & Brown, 2005). European and North American studies have shown that informal family caregivers currently provide between 75 and 80% of the home healthcare required by elderly adults (Hubley, Hemingway & Michalos, 2003; Shannon, 2001) with the average age of caregivers influenced by the age of the care recipients (the older the recipient, the older the carer) (Shannon, 2001). Spouses are the main providers of care for elderly people who need help (Pruchno & Resch, 1989): Not only are they most likely to be older themselves (most aged over 65 years and a third aged over 77 years, but they are also more likely than other caregivers to be sole-carers with responsibility for assisting in activities of daily living (Bumagin & Hirn, 2001; Dwyer, 1996). They are also more likely than any other group of informal carers to provide intensive, constant and comprehensive care, typically to the most severely disabled older people (Bumagin & Hirn, 2001; Prushno & Resch, 1989; Shannon, 2001). At the same time, other more recent, social changes (e.g. in family structure and size, increased geographical mobility, changing gender roles and greater participation of women in the workforce) that have led to fewer family members being available to provide spousal carers with

emotional and social support and to an increasing number of men caring for partners (Low, Payne & Roderick, 1999; Pierce & Steiner, 2004).

Caregiving and stroke

Stroke is one of the medical conditions that are expected to affect increasing numbers of New Zealanders as our population ages (Gommans, 2004; Gommans, Barber & McNaughton, 2003; Low et al., 1999; Tobias, Cheung & McNaughton, 2002). It is predominantly a disease of the elderly, with risk increasing dramatically with increasing age (from 1 in 100,000 in younger adults, to 1 in 100 in those around 65 years of age, to 3 in 100 among the oldest old (Biegel, Sales & Schultz, 1991; Bonita, 1996)). In New Zealand, stroke is a leading cause of death and the most common cause of impairment and dependence (Bonita, 1996; Health Research Council, 2005). Of the approximately 7000 New Zealanders who experience stroke each year, 75 % will be aged 65 or more, and 50% will be 75 years or older (Bonita, 1996). Less than half will survive and be living independently a year later (Gommans, 2004) and, of those who do survive, some 50% are expected to be living at home with some impairment due to their stroke for which they require some form of ongoing support (Bonita, 1996). Overseas studies suggest that, a year after stroke, at least a third of the stroke survivors who live in the community continue to rely on informal caregivers without whose help they would require rest home or nursing home care (Low et al., 1999; Kerr & Smith, 2001).

Although the number of people who suffer strokes has continued to rise, stroke death rates in many developed countries, including New Zealand, have actually declined in recent years. Advances in stroke prevention, acute care and rehabilitation have kept the prevalence rates of stroke constant, increased rates of survival and reduced the risk of severe disability (Biegel et al., 1991; Kalra et al., 2005). At the same time however, rates of stroke-related disability remain high and trends to early discharge and greater community care mean that stroke patients are more likely than ever to return home and to do so earlier than they might have done in the past (Clark, Rubenach & Winsor, 2003; Hale, 2004). Across these changes then, the need for informal care for elderly people with stroke is expected continue and to increase, with care most often provided by close family members. In keeping with the general trends in caregiving outlined above, the family members most likely to take on the role of caregiver for older adults

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with stroke are husbands and wives who are often also elderly (Robinson et al., 2005; White, Mayo, Hanley & Wood-Dauphinee, 2003).

Responsibilities of caregiving

As was also noted earlier, the population of older adults, already far from homogeneous, is becoming increasingly diverse. Changes in social patterns (e.g. fertility, marriage and divorce, employment and income, financial and family support) add to individual differences and contribute to existing diversity within and between cohorts. These differences are equally evident among older spousal caregivers who are as varied as any other cross-section of the population (Shultz & Shultz, 1998). Caregiving responsibilities add to their heterogeneity, varying considerably depending on individual circumstances and also according to the type of illness and impairment suffered by partners. Almost invariably, however, those caring for partners will have adopted their roles due to force of circumstance, often with little notice and with little knowledge about how much and for how long their partners will depend upon them (Cavanaugh, 1998). Caregiving responsibilities may include assisting partners in activities of daily living (mobility, transport, dressing, feeding, toileting, etc.), managing medical regimes, coordinating and communicating with health professionals, and managing financial resources. In addition to providing practical support for physical problems, spousal caregivers are frequently called upon to provide additional emotional support and supervision for cognitive, emotional, and behavioural symptoms of illness or injury. Such symptoms frequently mean that, in addition to taking on the role of caregiver in day-to-day tasks, spousal carers must also take over tasks and roles that were formerly the preserve of their partners. At the same time, they must also often deal with personal losses when partners can no longer provide the support, companionship and intimacy that they once did. Together, these demands of caring (time, physical and emotional) can lead to restriction or withdrawal from other activities in carers' lives (work, social, leisure) and so to reductions in the quality of life they experience (Cavanaugh, 1998; Secker & Brown, 2005).

Adverse psychological effects of caregiving

It is perhaps not surprising then that a wealth of studies have shown that unpaid caregiving is associated with increased rates of emotional distress, and that informal caregivers experience higher rates of psychological and physical illness than do non-

caregivers (Draper, Poulos, Poulos & Ehrlich, 1995; Hirst, 2005; Hubley et al., 2003; Low et al., 1999; Mahoney, Regan, Katona & Livingstone, 2005). Caregivers who live with and have a closer familial relationship with elderly care recipients have been shown to experience greater levels of stress than other caregivers (Lyonette & Yardley, 2003). Spouses, in particular, appear to be among the more vulnerable of caregivers, more likely to experience mental and physical health problems (Pruchno & Resch, 1989) more limited in their social activities and more likely to experience lower life-satisfaction than other non-spousal caregivers (Hubley et al., 2003; Shannon, 2001). In line with these findings, research into caregiving and stroke indicates that caring for someone disabled by stroke can adversely affect the physical and psychological health of caregivers and that this, in turn, can negatively affect the person being cared for (Robinson et al. 2005). Risk factors for psychological distress in caregivers of people with stroke appear to follow a similar pattern to those for other groups of caregivers. Psychological difficulties are likely to be greater for women, for those caring for partners and for people with higher levels of behavioural and mood impairment and physical disability, for caregivers who have little social support and for those whose pre-stroke relationship with care recipients was dysfunctional (Biegel et al., 1991; Draper et al., 1995).

Caregiving and anxiety

While the great majority of studies investigating the adverse psychological effects of caregiving have focused on general emotional distress or depression, findings have also shown that caregiving is associated with increased levels of anxiety (Hirst, 2005). It has been suggested that the vast majority of those caring for partners or family members experience anxiety at some point in their caregiving careers (Cavanaugh, 1998). Surveys indicate that, along with depressive symptoms, anxiety is one of the most commonly reported symptoms and concerns of caregiving (Cavanaugh, 1998; Shannon, 2001). Anxiety and depression may be especially prevalent in those caring for people with stroke, affecting as many as 20% to 55% of carers (Anderson, Linto & Stewart-Wynee, 1995; White et al., 2003), with anxiety a more likely outcome than depression among those caregivers who live with care recipients (Mahoney et al., 2005). While some studies have found that anxiety is more prevalent in the early weeks following stroke, others suggest that anxiety persists over time. One such study, carried out by Macnamara, Gummow, Goka & Gregg (1990), showed that of a number of

variables measured, anxiety was the only one to increase concomitantly with time since stroke.

It seems probable that feelings of anxiety experienced by caregivers would contribute significantly to the burden that they experience. Although it has often been assumed that greater objective burden would lead to caregivers experiencing more subjective burden, this has not always proved to be the case. Studies do indicate that carers' emotional status plays a major part in determining perceived levels of burden in caregiving (Scholte op Reimer, de Haan, Rjinders, Limburg, van den Bos, 1998). Psychological morbidity amongst carers has also been strongly associated with low levels of participation in life activities, although whether withdrawal from social activities is due to psychological symptoms or to the demands of care giving is not clear (Draper et al., 1995). A study by Anderson et al. (1995) suggests that for a great many carers, curtailment of leisure activities is a direct consequence of care giving: One of the main reasons participants gave for withdrawal from activities was anxiety about leaving care recipients alone.

On the whole however, current literature concerning anxiety in caregiving is sparse. What information does exist is often drawn from studies that did not set out to investigate anxiety per se, or that have assessed anxiety as an adjunct to depression or as a component of more global measures of emotional distress. It would appear that few studies have been conducted that focus specifically on anxiety associated with caregiving, and few, if any, have been designed to investigate anxiety as it is experienced by elderly caregivers, or caregivers of people with stroke.

Benefits of caregiving

A further aspect of caregiver experience that has received little attention in research and that is still poorly understood is that of gain in caregiving. To date, the majority of care giving research has focused on investigating the negative, detrimental effects of care giving such as those discussed above. While such studies show that many caregivers do experience difficulties, they also show that care giving stress is not universal. Most caregivers do not perceive caring for partners as stressful, nor to they regard it as leading to mental or physical problems (Shannon, 2001). On the contrary, it would seem that a substantial number of spousal caregivers experience gain through

their caring roles - feelings of pride, satisfaction and closeness to their partners (Scholte op Reimer et al., 1998). Research suggests that viewing oneself as an excellent caregiver can boost self esteem; caring may provide a sense of accomplishment which helps to prevent feelings of distress (Hagedoorn, Sanderman, Buunk & Wobbes, 2002). Furthermore, studies suggest that it is caregivers' appraisals of the care they provide, rather than the nature or level of demands placed upon them, that most influences their physical and emotional wellbeing (Shannon, 2001).

While it is important that that those who work with caregivers understand the potential negative effects of caregiving, it is equally important that they recognize and understand positive aspects of care giving and adaptation in caregiving (Kramer, 1997; Toseland & McCallion, 1997). Such awareness could enable clinicians to work more effectively with caregivers by suggesting ways of enhancing and strengthening the experience of caregiving, at the same time perhaps reducing the stress and distress that often accompanies it (Hagendoorn et al., 2001; Kramer, 1997; Toseland & McCallion, 1997).

Caring for carers

Although a substantial literature concerning caregiving has been amassed over recent years, still understandings of caregivers' experiences and needs are far from complete. Methodological differences and shortcomings within and across studies mean that, as yet, it is difficult to know the full extent of and nature of the problems that caregivers face, difficult too to clearly determine what factors are predictive of poor caregiver outcome, what factors act to protect caregivers, and what forms of support or intervention would best meet caregivers' needs (Anderson et al., 1995; Kerr & Smith, 2001; Visser-Meilly, van Heughten, Post, Schepers & Lindeman, 2005).

One of the major hurdles encountered in researching caregiving (and in interpreting findings of existing research) lies in the variability of past studies and in the heterogeneity of caregivers and care recipients themselves. Although research has begun to identify some of the factors that affect caregiving experience and outcome, there is a continued need for studies that attempt to "disentangle" the effects of variables such as gender, race, relationship, type of illness and level of incapacity of those who receive care (Kramer, 1997; Visser-Meily et al., 2005) and that also distinguish between

sub-groups of carers, taking into account such features as the level, type and duration of care (Hirst, 2005). At the same time, it is important that studies explore the wider experience of caregiving so as to gain a better understanding of how individuals react, adapt and cope in their roles as caregivers, and that research is not restricted to negative aspects of caregiving but also takes account of positive experiences and outcomes.

In recent years an increasing number of studies have focused on caregiving for specific illnesses or disease, making distinctions too between informal care and paid care giving, and between family and spousal caregivers. Along with that, an increasing number of studies too have investigated the experiences of those caring for people with stroke, by far the majority of these using quantitative techniques to assess negative effects of caregiving (e.g. burden, quality of life, general psychological distress and depression). However, as yet very few studies have been carried out that focus on the experiences of elderly people caring for partners with stroke and few, if any, of those have dealt specifically with caregivers' experiences of anxiety. Study in these areas would seem to be much needed given the apparent prevalence of anxiety problems in the elderly population as a whole, and in caregivers in particular, and the growing number of elderly people who are called on to care for husbands or wives with stroke.

However, as previously outlined, investigation of anxiety in elderly spousal caregivers is complicated, and likely compromised, while late-life anxiety as a phenomenon remains relatively little understood. Given these limitations - somewhat of a 'Catch 22' situation - qualitative research is suggested as providing an appropriate and productive means of moving forward, furthering understanding of both anxiety and caregiving in later life. Qualitative, inductive methods allow the study of the phenomenon of anxiety in older spousal caregivers, at the same time providing a means of exploring the relationship between that anxiety and caregiving. Furthermore, such methods allow the researcher a wider view of caregivers' experiences of anxiety, one that takes in not only the anxiety-related problems that they face, but also the positive and adaptive ways in which they deal with anxiety in their daily lives.

Summary

Anxiety has been increasingly recognized as a serious health concern in older adults and is reported by many caregivers. However, despite this recognition and although the literature related to late-life anxiety has grown over recent years, still relatively little is known about how that anxiety is experienced and presents in older adults, and how best it can be assessed and treated (Flint, 2005; Kogan et al., 2000). Of particular importance in furthering knowledge in this field is an understanding of the phenomenology of anxiety in older adults. Current psychological conceptualizations of anxiety are based largely on research into anxiety in younger adults, current diagnosis and assessment then relies on a tacit assumption that the experience and presentation of anxiety in older adults is largely the same as that in younger adults. And yet, as has already been noted, there is much to suggest that this may not be the case. It seems probable that diagnostic criteria and assessment measures frequently fail to capture the quality of anxiety in elderly people (Flint, 2005). While comparative studies of responses of younger and older adults on existing psychometric measures are necessary and valuable, without a clearer definition of the concept of anxiety in older adults, the construct and content validity of those measures will remain questionable, normative data will be of limited use and diagnosis and assessment of anxiety in older adults may be compromised (Flint, 2005).

It is also important that understandings of late-life anxiety encompass the experiences of elderly people from all walks of life, in diverse situations and circumstances, among them that of elderly people caring for partners with stroke. This last circumstance is not uncommon as stroke is one of the major causes of disability and dependence among elderly people, husbands or wives being the people most likely to provide informal community-based care for elderly stroke survivors. Anxiety has been reported as a common symptom and concern among caregivers and studies indicate that it is especially prevalent among carers of people with stroke, and in particular among those carers who live with care recipients. However, still relatively little is known about the relationship between anxiety and caregiving, much less about anxiety as it relates to spousal caregiving for stroke. There is a need then for research that increases understandings of anxiety experienced in these contexts and also in later life. This knowledge is essential if clinicians are to provide appropriate and effective support for elderly spousal caregivers, and is equally important to the wellbeing of stroke survivors,

many of whom, if not for spousal care and support could not live in the community and outside of institutional care (Clark et al., 2003; Kerr & Smith, 2001; Low et al., 1999; Shannon, 2001).

Aims and objectives of this study

To date it appears that much of the research into late-life anxiety has been carried out with reference to younger age groups, or to existing diagnostic and psychometric measures developed for the most part with younger people. There appear to be few studies available in the literature that attempt to set aside existing psychological conceptualizations of anxiety, to allow wider and more independent exploration of late-life anxiety as a phenomenon. There are few studies too, that have as their apriori focus, anxiety as it is conceptualized and expressed by older adults in specific contexts and that have, as their starting point, accounts of older adults themselves.

This study attempts to address some of the apparent gaps in the literature and to further understanding of late-life anxiety and caregiving by exploring, from a phenomenological perspective, how older spousal caregivers understand and experience anxiety in their everyday lives. Interpretative Phenomenological Analysis (IPA) was employed as a method to address the study's objectives. Focusing on the in-depth accounts of anxiety given by a small number of older adults currently caring for partners with stroke, the study aimed (i) to investigate how participants understood and experienced anxiety in their daily lives and (ii) to identify any patterns or themes that might be apparent across those perceptions and experiences.

This study is exploratory in nature. The methodology selected for use was intended as means of gaining insight into participants' conceptualizations and experience of anxiety. It attempts to set aside, as far as is possible, existing suppositions and understandings about caregiving and anxiety in order to investigate anxiety from participants' points of view. As such there were no expectations or hypotheses held for the findings of the study, for participants' understandings and experiences of anxiety expressed in interviews or for the relationship between those and participants' roles as caregivers.

CHAPTER TWO
Theoretical models of anxiety

Any research into anxiety in later life is necessarily linked to prevailing psychological theories of emotion and anxiety. Whether implicitly or explicitly, these theories shape our investigations, determining what lines of enquiry are considered worthwhile and interesting, how results are interpreted, and what implications they are seen to have for ongoing research and practice. Current theoretical models of anxiety, cognitive behavioural models in particular, are a major feature of clinical courses in psychology and so have provided a base for much of the researcher's post-graduate training in psychology. They will undoubtedly have influenced her own understandings of anxiety and interpretations made in the course of this study. Consideration of these theories is important then, both in providing a context for this study and in relation to issues of reflexivity.

This chapter presents a brief overview of current psychological perspectives of anxiety and anxiety disorders. It focuses on two general models that are widely accepted and promoted in current clinical research, training and practice (Andrews et al. 2003: Chambless et al., 1998; Crits-Christoph, Franck, Chambless & Brody, 1995; Patchett-Anderson, 1997); the Stress Diathesis model of anxiety and the Cognitive model of anxiety developed by A. T. Beck and his associates (Beck & Emery, 1985). Beck's approach, and those allied to it, have provided a foundation for much of the research that has been carried out into anxiety in recent decades and provide a theoretical base for many of the recognised treatments now available for anxiety problems (Freeman & Di Tomasso, 2002; Starcevic, 2005; Wells, 1997).

Over the past century, the study of anxiety has dominated investigations of emotion, perhaps because anxiety is a common defining characteristic of many psychological disorders but possibly too because, unlike most other psychopathologies, anxiety is also recognized as a universal and useful experience (Antony, 2001; Barlow, 2002; Barlow & Durand, 2005). Across studies, anxiety, both 'normal' and 'pathological', has been viewed as multi-dimensional, comprised of "subjective experiences of affect, expressive behaviours, neurobiological responses and cognitive

perceptions and appraisals" (Barlow, 2002). On the whole though, investigators have tended to concentrate their attention on one or other of these components, or have conceived of anxiety primarily as either a biological or a psychological phenomenon (Starcevic, 2005). Both biological and psychological views of anxiety have progressed but most often independently. Etiological models especially have tended to be either biological or psychological: Biological models have generally emphasized brain function and genetic makeup that would predispose people to develop anxiety problems. Psychological models have focused on the cognitive and behavioural bases of anxiety and on predispositions arising from early childhood experience (Starcevic, 2005).

However, few scientists or clinicians would now accept either anxiety or anxiety disorders can be sufficiently explained or understood through linear or one-dimensional models (Barlow & Durand, 2005). Most believe that a number of different components are involved in the experience of anxiety and that each of these inevitably affects the others. There is increasingly recognition of the need of a more systemic integrated perspective of anxiety that takes account of biological, psychological, social and developmental influences (Barlow & Durand, 2005; Starcevic, 2005). However, as yet it seems that there is no one theoretical model that gives equal consideration to all these influences or that explains how and to what degree they are interrelated.

Both the Stress-Diathesis and Cognitive models, outlined below, recognize that there are multiple factors involved in the development and maintenance of anxiety and its disorders. Still, each can be seen to explain anxiety primarily in terms of either biology or psychology. Stress-Diathesis models focus on the interaction of genetic inheritance and environmental events in the development of pathological anxiety. Cognitive models, on the other hand, explain adaptive and maladaptive anxiety largely in terms of cognitive appraisals and beliefs (Starcevic, 2005). In common with other theoretical approaches to emotion and anxiety, neither Stress-Diathesis models nor the Cognitive model posits age as an influence in anxiety. As was the case with research and assessment measures discussed previously, current theories of anxiety appear to assume homogeneity of process and experience of anxiety across the life span.

Stress-Diathesis (S-D) models of anxiety

Stress diathesis models of anxiety are primarily concerned to explain, with reference to genetic or biological factors, why it is that, in adverse circumstances, some people develop anxiety problems while others do not. According to S-D models, individuals inherit biological tendencies to certain traits or behaviours that may be activated under conditions of stress (Barlow & Durand, 2005). It is these inherited tendencies (diatheses) that make some individuals more or less susceptible to developing certain psychological disorders. Anxiety problems and disorders are seen to arise then as a result of interaction between negative life events and individuals' pre-existing and inherited vulnerabilities (Barlow, 2002; Kendler, Myers & Prescott, 2002). Diatheses alone are not viewed as sufficient to bring about anxiety disorders. Rather, they are necessary antecedent conditions for the development of those disorders, and remain dormant until they are activated by adverse life events (Starcevic, 2005; Zuckerman, 1999). In the absence of those events, it is possible that an individual could go through life without experiencing serious anxiety problems, even though he or she may have inherited a vulnerability to them.

Diatheses

S-D models do not generally distinguish between the genetic and biological foundations of disorders, nor do they specify exactly what it is (neurological structures, aspects of physiology, or biological traits) that is inherited that predisposes a person to disorders (Zuckerman, 1999). The vulnerabilities that individuals are believed to inherit are regarded, for the most part, as 'polygenic', i.e. present to varying degrees in different individuals. (This is in contrast to dichotomous diatheses which are either present or absent due to the presence or absence of a specific gene (Zuckerman, 1999).) S-D theories hold that the greater an individual's inherited tendency to anxiety, the less life stress is required to trigger anxiety problems. Conversely, the less a person's inherited predisposition to anxiety, the more environmental stress is required to precipitate anxiety-related disorders (Barlow & Durand, 2005) and the greater the likelihood that they do not develop at all.

Stress

Within this model, the term stress is most often used to refer to objective situations that affect individuals. However, it can also be used to refer to internal reactions

(physiological, emotional, or behavioural) of individuals to those situations (Zuckerman, 1999). While no particular stresses are presumed to be pre-potent for anxiety disorders, the types of stressors or life-events most often believed to play a role in the development of anxiety problems are those associated with danger and threatened loss (Zuckerman, 1999). Stressors believed to be associated with depression, on the other hand, are those related to more immediate experiences of loss.

Relationships between stress and diatheses

Stress diathesis models of anxiety vary according to the assumptions that they make about the relationship between diathesis and stress. For example, in mediational models the effects of life events or stress are posited to activate psychological vulnerabilities reflecting diminished self control or negative attributional styles that in turn contribute to the development of anxiety (i.e. stress influences attributional style which then brings on anxiety (Barlow, 2002). By contrast, moderational models propose a more direct relationship between stressors and development of anxiety in which the experience of stressors is strengthened or enhanced by a more general psychological vulnerability (i.e. the vulnerability works to 'amplify' the event or stress) (Barlow, 2002). Personality traits are frequently linked to vulnerabilities. Broad character traits and narrower cognitive ones are often regarded as moderators of stress and are seen to predispose some individuals to anxiety. However, whether such traits should be regarded as diatheses is a matter for debate since that personality itself can be seen as arising from its own set of genotypes and life experiences (Zuckerman, 1999).

Stress-Diathesis perspectives of anxiety have become increasingly complex as research findings have shown that multiple vulnerabilities are involved in the development of anxiety disorders and that these vulnerabilities interact with each other and the environment to determine the anxiety that individuals experience. While it seems likely that some aspects of anxiety are indeed heritable in the form of vulnerabilities, almost all investigators (including geneticists) now believe that these vulnerabilities act in conjunction with a variety of psychological and social factors to produce anxiety disorders (Barlow, 2002).

Cognitive theory of anxiety

While, stress-diathesis theories of anxiety have given precedence to genetic inheritance and biological processes in explanations of anxiety, cognitive theories explain the experience of anxiety and the development of anxiety disorders largely in terms of cognitive structures. In common with S-D models of anxiety, the cognitive model views anxiety as arising from interaction between pre-existing vulnerabilities and negative life events. Beck and Emery (1985) identify five major areas of vulnerability that can predispose individuals to anxiety and to anxiety problems; genetic heritability, physical disease states, psychological trauma, and absence of coping mechanisms, or strategies. However, although they acknowledge this range of influences, the cognitive model directly theorises only cognitive predispositions to anxiety. It does not expressly include genetic and biological variables (Starcevic, 2005).

The role of cognitions in emotion

A fundamental tenet of Beck's cognitive model is that individuals' emotions and behaviours are largely determined by the beliefs that they hold about themselves and the world, and by the way in which they interpret and appraise events (Beck & Emery, 1985; Rachman, 1997); That is to say, it is the meaning that events hold for individuals that triggers emotions and behaviours and not the events themselves (Salkovskis, 1996). Consequently, no one event will be experienced by people in the same way as individuals can be expected to appraise events in different way depending on their own beliefs and circumstances. The same event, then, can be expected to evoke different emotions in different people and similar events may even provoke to different reactions in the same person on different occasions (Starcevic, 2005).

Cognitions and anxiety

The process, by which anxiety is believed to come about then, is essentially one of meaning making; Anxiety is said to arise when situations are appraised as being physically, mentally or socially threatening. Perceptions of threat or danger prompt other cognitive reactions that encourage caution (self doubt, negative predictions and evaluations) and a range of somatic symptoms (unsteadiness, weakness etc.) and behaviours (avoidance and escape) that are intended to discourage risk-taking and encourage self-protection (Freeman & Di Tomasso, 2002; Wells, 1997). The presence of anxiety is not necessarily viewed as problematic, rather anxiety is recognised as a

'normal' experience and the processes by which it is generated and maintained as also fundamentally normal. Beck and Emery (1985) describe anxiety as functioning in a similar way to pain, as an "attention getter" that diverts attention away from other concerns or preoccupations into what is an essentially unpleasant and subjective sensation - sufficiently unpleasant that we want to reduce it by protecting or removing ourselves from danger. They suggest that this 'survival mechanism' may even include an inherent tendency to favour false positives over false negatives, since one false negative could lead to us being "eliminated from the gene pool" (Beck & Emery, 1985, p. 4).

Appraisals of threat and coping

According to Cognitive theory, whether or not individuals experience anxiety in any given situation depends not only on how dangerous they perceive the situation to be, but also on what resources they believe they have available to them to deal with the danger. This is the case regardless of the objective reality of the threat. The level of anxiety experienced then is determined by a balance between appraisal of the risk and cost (potential damage) involved and appraisal of available resources.

$$\text{Anxiety} = \frac{\text{(perceived probability of threat)} \times \text{(perceived cost)} \times \text{(awfulness of danger)}}{\text{(perceived ability to cope with danger)} \times \text{(perceived rescue factors)}}$$

Figure 1. Cognitive components of threat and coping that influence the degree of anxiety experienced. (Salkovskis, 1996, p. 51)

This balance is summarised in the equation in Figure 1 above. If resources are perceived to outweigh risk or potential damage, then a person will experience little or no anxiety. However, if a person views the risk in a situation as exceeding his coping resources, he will become anxious (Beck & Emery, 1985; Freeman & Di Tomasso, 2002). This calculation is not seen to be applied in a deliberate, logical or even conscious way. Rather it is one that is reached very rapidly and to a large degree automatically (Beck & Emery, 1985). Under normal circumstances it ensures that people can judge danger realistically and quickly and react to ensure their safety.

The appraisals of threat and danger that individuals make in relation to situations are apparent in negative automatic thoughts. These thoughts are associated with feelings of anxiety and are tied to specific situations and are fleeting, often outside awareness, and generally accepted without question (Freeman & Di Tomasso, 2002). They demonstrate a belief that something bad is going to happen (Greenberger & Padesky, 1995). From a Cognitive perspective, these thoughts are believed to arise from anxiety-related core beliefs or schema that individuals hold about themselves, the world and the future. Automatic thoughts are created, as Teasdale (1996) puts it, as a "down line" product of related specific meanings" (p 35), and are seen to mediate feelings and influence behaviour.

Anxiety problems are said to arise, when people exaggerate threat or perceive danger where there is none. Individuals with anxiety disorders are believed to show systematic errors in the way that they process information about situations, that lead them to consistently overestimate the danger involved in situations and, at the same time, underestimate their ability to cope (Freeman & Di Tomasso, 2002; Beck, Emery &Greenberg, 1985). Rather than assessing events separately and flexibly according to their 'objective' context and demands, as would normally be the case, people with anxiety problems are seen to interpret situations more globally on the basis of dominant, maladaptive schema (Clark, Beck &Alford, 1999). These schema cause them to consistently see themselves as vulnerable, the world as dangerous, and the future as unpredictable (Wells, 1997). While these views may have been useful and appropriate at an earlier time in their lives, they become problematic when applied rigidly to new situations that call for different interpretation (Beck, Stanley &Zebb, 1996).

Maintenance of anxiety and anxiety problems
Once people experience anxiety, they are motivated to reduce anxiety symptoms by acting to ensure their safety. In Cognitive terms, they may do this by reducing their perception of threat or increasing their confidence to deal with it (Greenberger & Padesky, 1995). In normal circumstances, people make use of external cues to reappraise situations, adjusting or correcting their perceptions of danger: They are able to recognise when danger has passed or when their initial interpretations of danger were incorrect (Beck, 1996). By contrast, in pathological anxiety, once danger is appraised and feelings of anxiety are aroused, these normal corrective processes do not take place.

Instead, a number of vicious cycles are set up that can maintain individuals' preoccupation with danger, prevent disconfirmations of dysfunctional assumptions and perpetuate anxiety symptoms (Wells, 1977).

Avoidance

The behaviour that is seen to characterize problematic anxiety is that of avoidance. Avoidance is considered to be an adaptive feature of normal anxiety, ensuring that danger is reduced and safety protected. However, when danger is misperceived, avoidant behaviour becomes counterproductive and is seen as working to maintain anxieties. Although it is intended to ensure safety and may relieve immediate feelings of anxiety, when threat is overestimated or non-existent, avoidance has the unfortunate effect of preventing people from discovering that their fears are groundless (Wells, 1997). In disorders of anxiety, when a person acts to avoid a perceived threat, that the feared outcome does not eventuate is taken as confirmation that the action was necessary and effective. Rather than interpreting the situation as one in which anxiety was misplaced, it is interpreted as a "near miss". Safety-seeking behaviour is viewed as 'successful' and so reinforced (Salkovskis, 1996; Wells, 1997). From a cognitive perspective then, disconfirmation or reassurance cannot be depended upon to resolve anxiety problems, especially when the situations that people fear are ones that they expect to arise at some time in the future. Instead, reduction of anxiety, whether it is grounded in misperceptions or realistic assessments of threat or harm, is dependant on individuals developing alternative, less threatening interpretations of the situations that they fear.

Summary

Both the Stress-Diathesis and Cognitive models of anxiety have been employed primarily in explanation of anxiety problems and disorders that, in both models, are seen to arise as a result of interaction between pre-existing vulnerabilities and negative life events. However, while Stress Diathesis models have tended to focus on biological or genetic predispositions, the Cognitive model explains vulnerability to anxiety problems in terms of cognitive structures, primarily in terms of deep-seated and enduring beliefs related to threat and danger. These beliefs are seen to give rise to distinctive patterns of appraisal and behaviour that generate and perpetuate feelings of anxiety. Within the model however, anxiety itself is viewed as a normal phenomenon

and the processes by which it is generated and maintained are also viewed as being essentially normal. As such the model is seen as particularly relevant to the present study which explores the every day, non-clinical experiences of anxiety of elderly caregivers.

CHAPTER THREE

Method

This chapter outlines the methodology and method adopted in the present study. It explains the rationale behind those choices, and describes key elements of the research process, including a discussion of ethical requirements and safeguards, participants, interview processes used in data collection, and procedures followed in data analysis.

Methodological rationale

A growing body of literature suggests that anxiety presents and is experienced differently in older adults than in younger people, and an increasing number of studies have been carried out to examine these differences. However, it appears that few studies have attempted to explore late-life anxiety as an independent phenomenon or have, as their a priori focus, anxiety as it is conceptualized and expressed by older adults in specific contexts. No studies could be found in the literature that consider late-life anxiety in context and have as their starting point, the accounts of older adults themselves.

While a number of research designs were considered for this project, a qualitative methodology seemed most appropriate to the study's aims and to filling the apparent gap in the existing literature. Given that this study's research questions centered on describing participants' subjective experiences and perceptions, quantitative approaches were not considered for the project. Qualitative methodologies, on the other hand, seemed ideally suited to the study's purpose: In focusing on meanings that participants themselves attribute to events and phenomenon, inductive approaches provide the researcher with an opportunity to step outside the constraints imposed by the use of preconceived variables to develop new or more comprehensive understandings of phenomena (Clark, 2004; Willig, 2001). These approaches are particularly appropriate in studies such as this where the phenomenon of interest is complex, little understood or investigated, and when research is essentially exploratory in nature (Creswell, 1998). Qualitative methodologies also provide a way of exploring phenomenon and experiences whilst taking into account the historical, cultural and social contexts in

which they occur. Again, this was regarded as particularly relevant and important to the investigation of anxiety in older adults.

Qualitative approaches then were seen as providing a way of gathering detailed views of anxiety in later life that would not be available through quantitative study, but that would nevertheless be helpful in generating theory or suggesting worthwhile directions for further research. It was hoped that this study would add to the existing quantitative research by exploration of issues that are difficult to access using more structured, statistically based techniques.

Interpretative Phenomenological analysis

The study was designed to explore participants' perceptions and experiences of anxiety through qualitative analysis of their accounts gathered in in-depth interviews. Of the qualitative methods currently in use in psychology, Interpretative Phenomenological Analysis (IPA) was considered to be particularly suited to the study's topic and main objectives. IPA is a relatively recent qualitative approach, developed in the UK through the work of psychologist Jonathon Smith who has explained the approach as "an attempt to unravel the meanings contained in…accounts through a process of interpretative engagement with the texts and transcripts" (Smith, 1997. p. 189 cited in Willing, 2001). From its initial application in Health Psychology, the use of IPA has spread to other areas of psychology. It is now widely used, particularly in the UK, not only in Health Psychology but increasingly in Clinical research (for examples see Crouch & Wright (2004), Mitchell, Clegg & Furniss (2006), Jarman, Smith & Walsh (1998) or visit www.psyc.bbk.ac.uk/ipa/references1.html.).

As an approach, IPA is idiographic and inductive, data rather than theory driven. It has its theoretical roots in phenomenology and symbolic interactionism and is concerned with investigating phenomena from new perspectives by learning from those who experience them, not with attempts to support or refute existing theory. It aims to explore, in detail, individual participant's views of topics under investigation and to understand how participants themselves make sense of their experiences (Smith, 2004; Smith & Osborn, 2003; Willig, 2001). In IPA then, it is participants' accounts and descriptions of experience that constitute the phenomena under investigation (Willig, 2001, p 53).

Although it aims to explore personal perspectives and experiences, IPA recognizes that it is not possible to access these directly. In that it does not make any claims about the external world, IPA subscribes to a relativist ontology. It focuses on individual, subjective experiences and is not concerned with whether or not participants' accounts correspond to an external reality, assuming that people can experience the same objective conditions (e.g. a social event or a disease process) in very different ways depending on their individual thoughts, beliefs and expectations. Thoughts and feelings then are seen as mediators of external 'objective' conditions; people attribute meaning to events which then shapes their experience of those events (Willig, 2001). At the same time, IPA recognizes that the meanings people ascribe to events are not completely idiosyncratic but are bound up in social processes and interactions. In this, the approach draws on ideas of symbolic interactionism in which meanings are seen as the product of social processes, created and understood only through interaction between people and modified in the process of interpretation (Smith & Osborn, 2003; Willig, 2001).

IPA also recognizes that knowledge produced through analysis is inevitably reflective of researchers' own thinking, assumptions and conceptions and that it is not possible to suspend all presuppositions and judgments when studying phenomena. However, the approach requires that a researcher keep an 'open mind', setting aside, as far as is possible, conventional knowledge and specific pre-existing theory around the subject in order to gain a better understanding of the experiences of others (Smith, 2004). While IPA does not theorize reflexivity, it nevertheless views the research process as a dynamic one in which the researcher plays an active role (Smith & Osborn, 2003). The process by which the researcher comes to understand accounts of participants is seen, of necessity, to involve interpretation. In this respect, IPA can be seen to be linked to hermeneutic versions of phenomenology (Willig, 2001, p. 66), interpretation in IPA involving what Smith has termed a 'double hermeneutic': "participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2003, p. 51).

In theory and in practice, IPA can be seen as adopting a different position from discursive or constructionist approaches, one that is apparent both in the way it views

cognitions and in the status it ascribes to text. Approaches such as discourse analysis are generally concerned with discovering how constructions are produced and so shape experience, and are skeptical about mapping verbal reports onto underlying cognitions (Smith & Osborn, 2003). IPA, however, is concerned more directly with what participants think or believe. It presumes that the accounts that people give are indicative of their private thoughts, attitudes, beliefs and feelings and that these in turn are linked to and reflected in their behaviour and their experience" (Willig, 2001, p 66). While it acknowledges the interactionist nature and constructive function of language, IPA does not systematically explore these aspects of text. Rather than focusing on text as a being one of many possible discourses, in practice IPA tends towards a more positivist position that presumes a relatively direct connection between verbal expression and mental process. Language is viewed primarily as a means to an end, 'a way of describing what is going on' (Smith 1996). Given this stance and its aim to produce knowledge about what and how people think about phenomena under investigation, IPA can be viewed as having a realist or critical realist approach to knowledge (Willig, 2001). However, as noted above, knowledge produced is seen as reflexive in so far as it is inevitably dependent on the researcher's own standpoint.

In its objectives and its procedure, IPA can be seen as more closely allied to subjectivist versions of Grounded Theory than to Social Constructionism. Both methods explore text systematically to identify themes and categories which are then progressively integrated until higher order categories are established that clearly and concisely express the phenomenon under study. Both start with individual cases which are integrated in order to obtain a fundamental understanding of the 'cognitive maps' that represent individual's or group's views of phenomena. However, Grounded Theory was developed as a means of identifying and explaining social processes that account for phenomena. It aims to move beyond description of phenomena to develop abstract theory that accounts for processes (Chamberlain, 1999; Willig 2001). IPA, by contrast, has been developed specifically as a psychological research method through which the researcher can gain insight into participants' psychological worlds. It is concerned with providing an understanding of the "quality and texture of individuals' experiences" and with exploring the nature of psychological phenomena (Willig, 2001, p. 53). Further, IPA was not developed as a 'stand alone' approach but rather as one that would produce findings that could be used to challenge or to complement existing quantitatively-based

psychological literature, with which it claims to share concepts and constructs (Smith, 2004).

Given its theoretical position, its aims and its process then, IPA was considered to be particularly fitted to the aims of the current research. It appeared to provide the most suitable and flexible means of examining a small number of in-depth accounts of anxiety in order to produce findings that could be considered alongside existing theories and models. As a method it was seen as having the potential to uncover information and constructs related to late-life anxiety that were not anticipated by the researcher and which had not been considered or developed in previous research. In addition, IPA allowed consideration of how contextual factors related to caregiving might influence perceptions and the experiences of anxiety in later life (Shaw, 2001).

Finally, IPA's epistemological and ontological stance (post-positivist and critical realist) was seen as in keeping with the researcher's personal views and the study's foundation in Clinical Psychology: Whilst acknowledging the influence of individual and social processes in the creation of meaning, clinical research and practice does assume that there is an 'objective reality' that can be approached through research, and that there are patterns of human experience and behaviour that can be understood, predicted and controlled (Highlen & Finley, 1996 p 182). This reality includes psychological phenomena such as anxiety which, through their research and clinical practice, psychologists seek to define, evaluate, and change (Hall & Marzillier, 1992). In IPA and in clinical practice and research, individuals' accounts of their experiences are afforded similar status, viewed for the most part as relatively direct expressions of mental processes and behaviour. Clients and participants are regarded as 'experts' of their own experience.

Method

Ethics

Approval for this study was granted by Massey University Human Ethics Committee in May 2005 (MUHEC 05/023).

Those people referred to the study were contacted by the researcher, firstly by telephone, to explain the nature of study and to ensure that they met the selection criterion (see below) for participants. Following this initial conversation, those who did meet the criteria and were interested in taking part were supplied with an information sheet (see Appendix A) detailing the purpose and process of the study and inviting their participation. After having time to consider the information and their involvement in the study participants were contacted again, and all but one person agreed to take part.

In conjunction with the interviews conducted for this study, a second series of interviews was held with the same participants in which additional information was gathered. This information was not an integral part of the present study and will be used in future research that includes development of a new psychometric measure of anxiety specifically suited to older adults.

Participants

To be included in the study, participants were required to be at least 65 years old and providing informal care, in their own homes, for partners with stroke. The nature of partner's incapacity, and duration of caring were not stipulated as criteria. However, participants were accepted for the study only if their partners were unable to live independently and were no longer receiving out-patient care or ongoing therapy for stroke. Sampling was purposive then, and participants could be considered a relatively homogeneous group for whom the research questions would be significant (this in keeping with the guidelines for IPA (Smith &Osborn, 2003)). However, given that participants varied in age, gender, care giving careers and social backgrounds, it was anticipated that their perspectives and experiences would also vary and that this diversity would provide a rich source of data. The choice of sample size for the study was also guided by recommendations for IPA student studies (Reid, Flowers & Larkin, 2005; Smith and Osborn, 2003). It was considered that between 5 to 10 participants would provide sufficient cases to allow investigation of similarities and differences between participants but not so many as to make data analysis unmanageable by virtue of its volume and also the time required.

Because the study relied on verbal data and self -report it was clearly important that participants be free of cognitive deficits that might limit their ability to recall or

express their experiences and also of any organic conditions known to induce anxiety-like symptoms. To this end, the use of a screening questionnaire, the mini-Mental Status examination (SSMSE) (Folstein, Folstein, & McHugh, 1975) was considered in selection of participants. The SSME provides a brief standardized screen for organic cognitive impairment covering domains of orientation, registration, attention, concentration, recall, language, and visual construction (American Psychiatric Association, 2000). However, it was decided that using such a screen would be of limited benefit in the study as participants would be living independently and would likely be known to the researcher or someone close to her, also because it was anticipated that functioning in the cognitive domains accessed by the SSME would likely be apparent in the preliminary arrangements and discussion with participants and through the interviews themselves. A brief background questionnaire (Appendix C) was completed at the beginning of interviews with each participant to identify other factors that might have a bearing on participants' accounts, particularly medical conditions or prescribed medications known to induce anxiety-like symptoms.

Participants were recruited by word of mouth, via acquaintances and colleagues, and through advertisements in local newspapers. Nine participants were selected for the study, eight women and one man aged from 65 to 80 years. None of the participants were known to the researcher prior to the study. All were of European descent, had English as their first language, and were living and caring for their partners in their own homes. All of the participants elected to be interviewed at home, most choosing times when their partners were asleep or involved in supervised community activities. Meeting in this way ensured privacy and provided an opportunity for relaxed and open conversation in settings that were familiar to participants, and where they would be available should their partners need them. It also led to the researcher being introduced to all but one of the participants' partners, something that though not planned, proved to be very helpful in establishing rapport and conversation with participants and in helping the researcher gain a better understanding of individual participants' circumstances.

Development of semi-structured interview schedules
Once the aims and methodology of the study had been decided, a schedule of questions and prompts was developed for use in semi-structured interviews with participants. These were based on general recommendations by Kaufman (1994) and on

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Smith's (1995) guidelines for IPA and were designed to facilitate discussion, ensuring that it remained focused on the research topic. At the same time they were intended to encourage dialogue that also followed participants' own interests and concerns and that allowed participants to express their personal views and experiences with minimal influence from the researcher. Questions were developed in discussion with other researchers engaged in similar research projects, to determine which were most likely to elicit the type of information required for study and to ensure that, as far as possible, they were open-ended and non-directive. They were ordered in a way that was expected to follow the natural progression of conversation, beginning with more factual or general questions and moving on to ones that invited more personal (and possibly more private) information and reflections. However, while the interview schedule was intended to ensure that areas of questioning were common across all interviews, it was expected, and considered important, that the sequence of questions and discussion around them would vary according to natural course of each conversation and in line with participants' individual concerns. The researcher was mindful too of the need to guide discussion and use language that reflected and followed participant's perspectives of anxiety and also of the need to avoid wording questions or comments in ways that might restrict or shape that expression.

Data collection

As outlined above, data was collected for the study through semi-structured interviews conducted over a six-month period from June to November 2005. Each of the interviews with participants lasted approximately 60 minutes. It was anticipated that participants might be unaccustomed to or uncomfortable about talking to a stranger about their personal lives and their emotions. At the outset of each interview then, time was taken in general conversation, to build rapport (usually over a cup of tea). Interviews were begun when the participants seemed sufficiently ready and relaxed. Interviews focused on participants' views and experiences of anxiety and were guided by the interview schedule in Appendix D. It was explained that although the researcher had questions to ask, participants own opinions and experiences were most valuable, and they should feel free to raise any issues that they thought were relevant (of which the researcher may have been unaware), and to decline any questions that they preferred not to answer. Prompts (e.g. Can you tell me more? Can you explain...? etc.) were used, along with occasional self-disclosures from the researcher, to facilitate discussion

and to encourage participants to share their thoughts and experiences. It was intended that the information gathered in these interviews be analysed through Interpretative phenomenological analysis (IPA) in order to address the study's research questions.

All interviews and discussions were digitally recorded and then transcribed verbatim by the researcher, as soon as was practically possible after the interview, with the aid of voice recognition software. The transcription process involved the researcher listening to and repeating speech from audio recordings through the software to convert them to written text. Each transcript was then reviewed several times, against the audio recording, to check for accuracy and to allow for the addition of notes and comments. Final transcriptions then included both the words of the researcher and participants, and also pauses, indications of emotion (laughter, tears) and notes of any movements or gestures that appeared to add meaning to the text. By conducting and transcribing all of the interviews with participants, the researcher became thoroughly familiar with the texts prior to beginning the process of formal analysis. Overall, nine individual transcriptions were produced, on average 15 and 20 pages long. Unfortunately, technical problems meant that one interview (Participant 1) could not be fully transcribed and that some information related to the topic was lost and could not be included in the IPA analysis.

Data analysis

Interpretative Phenomenological analysis of first interviews

IPA provides a structured yet flexible tool for the analysis of data gathered in semi-structured interviews. Through it, researchers can explore the experiences of individuals, to discover the idiosyncrasies of those experiences and also the elements that are shared (Shaw, 2001). Analysis is an idiographic process that begins with detailed examination of an individual case, moving one by one through analysis of other cases and then, only when these separate analyses are complete, shifting to cross-case analysis that establishes commonalities and differences across accounts (Smith, Jarman & Osborn, 1999). The process of IPA is also iterative: Analysis follows a series of steps to identify, position and then integrate themes that emerge from accounts, all the time checking this sense-making against the actual text and its context in transcripts. The four main stages of analysis are outlined below. Each stage is inevitably the

personal and interpretive work of the researcher herself (Smith & Osborn, 2003; Willig, 2001).

Initial notes

In the initial step, the transcripts of each participant's interview were read closely a number of times and the researcher's observations and comments about what the participant had said recorded in the left-hand margins. These notes were free flowing and wide-ranging, a record of the issues that arose for the researcher on first encounter with the text. They included summaries, paraphrasing, associations and early interpretations, comments on the use of language, links to what was said to other parts of the transcript, and notes about the sense of person conveyed by the text.

Identifying themes

Once the initial annotation was complete, the transcript was reread and the right hand margin used to record emerging themes in the text. These themes were more conceptual or descriptive, comprising key words and phrases that captured the essential quality of what was found in the text and also reflected the researcher's initial impressions. Emergent themes from each transcript were individually coded with the participant's number and the page and line numbers of the transcript to which they were linked, then copied and saved on computer in Word documents.

Connecting and structuring themes

This step introduced structure to the analysis, organizing, ordering and condensing data from transcripts into master-themes, themes and sub-themes. Initially, the lists of themes from individual transcripts were analyzed separately, the researcher looking for connections between the themes apparent in each account, identifying themes that clustered together, and themes that might be regarded as super-ordinate or explanatory of others. As themes were grouped and ordered under new or existing super-ordinate themes, each was checked against the transcript to ensure that the connection worked for the original data (i.e. that connections drawn in analysis were evident in what the participant had actually said). This process was carried out using the 'cut and paste' function on the computer. Initial lists of themes were reorganized and a 'master list' of themes was compiled for each transcript. This list identified the main themes that had emerged and the subordinate themes associated with them.

The structured lists of themes were then considered in relation to each other. (Again, lists of themes were integrated, organized and reorganized with the aid of the word-processor's cut and paste function.) Examination of the lists from all transcripts

led to identification of a number of main themes that were common to all and that subsumed a large part of the material in participants' accounts. The main themes that emerged across all transcripts were then considered one by one and all subordinate themes from all participants' accounts were examined for fit with each. Where material was found not to map onto a super-ordinate theme, it was usually found a better fit with other super-ordinate themes as the analysis progressed. Themes that had not fitted or had appeared isolated within the structure of individual transcripts were often found to be related to the super-ordinate themes that had emerged from other transcripts.

Throughout this process of analysis, connections between themes in individual accounts and themes drawn from different accounts were constantly checked against transcripts to ensure that any links made were evident in primary source material. These checks often highlighted interesting and subtle differences in material that had been clustered together because it had initially appeared to relate to a common theme. Sometimes the differences revealed led to disparate material being removed, and considered for fit with other themes or super-ordinate themes. Other times, reference to primary data suggested the need for new groupings or for changes in the labeling of themes and super-ordinate themes that were more faithful to meanings and links the primary data. At the end of the analysis, most of the themes identified in individual transcripts had been incorporated into the overall structure of themes. Those that remained were studied again for fit, and if none was found, were omitted from the final summary of themes. Throughout the analysis process, themes were not selected solely on the basis of their prevalence in the data. Analysis was intended as a means of understanding not only shared features of anxiety, but also of identifying differences in participants' perceptions and experiences of anxiety. Consequently, material that helped to shed light on the phenomenon or on other aspects of accounts was retained even if it was referred to by only one of two participants. At the same time, themes that were commonly expressed across accounts were dropped from the summary if they were marginally related to anxiety and did not fit well with the overall structure of themes or with the objectives of the study.

Production of a Master List of themes

This final stage in analysis involved the production of a structured master-list of super-ordinate themes, themes and sub-themes that had emerged, that individually and together could be seen to capture something of the quality of participants'

understandings and experiences of anxiety. In previous IPA studies, master lists have usually included key words and specific transcript references that link themes back to primary data. However, the number of participants in this study and the length of transcripts meant that numerous notations mapped to each theme and such a summary would have become unwieldy. For ease of reading then, references and key words were not included in the final table and were detailed instead alongside quotations in the expanded narrative in Chapter Five.

Reflexivity issues

Clearly the process and outcome of this study are influenced by the values, actions and interpretations of the researcher and are dependent on the researcher's credibility, sensitivity, and competence. The researcher's credibility with participants was crucial to the research in facilitating open conversation and disclosure around a topic that was personal and possibly sensitive. The researcher's willingness to meet with participants at the time and place of their choice helped to establish that credibility, as did time spent in general conversation before interviews. This talk frequently included discussion of participants' interests, daily activities and routines, and the researcher's own interests and motivation for the study. That the researcher had some experience of stroke and its effect on families and that she was keen to learn more about their experiences also helped to build rapport and establish credibility. Sensitivity was important in establishing a positive relationship with participants and in facilitating and interpreting their accounts. The researcher's personal interest and experience in relation to the research topic, life involvement with older adults, and experience in in-depth interviewing enhanced this sensitivity. Competence in the application of the qualitative method and analysis used in the study was maintained through regular supervision sessions in which procedures were clarified and feedback was sought and received. It was also aided by advice provided by other academic staff were experienced in qualitative analysis and familiar with the objectives of the study.

In accordance with the guidelines for phenomenological research and for IPA, literature on the research topic was not systematically gathered or read until after interviews, transcriptions and analysis for the study was complete. This course of action is generally recommended as a way of reducing the bias in research, helping the researcher to 'bracket' existing theory and presumptions in order to develop

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understandings based on the perspectives of participants themselves. However, it is acknowledged that existing views of phenomena can never be wholly set aside. Researchers inevitably bring their own perspectives to their work and these are implicated in both its process and its outcomes (Elliot, Fischer & Rennie, 1999). Given the central role of interpretation in the analysis of data in IPA and impossibility of the researcher remaining totally naïve or removed from the subject matter of her study, reflexivity was a vital part of the research process. It was important that the researcher be aware of the way in which her own interests, values and beliefs may have shaped the study and its findings, and that she stay close to the data whilst taking account of these 'biases' in order to develop a credible and useful account. In relation to this, an outline of the researcher's personal, professional and academic experiences prior to the study is presented in a Forward (see page 1) to this study since they undoubtedly will have played a part in the development and the execution of this study. Information related to psychological models of anxiety, presented in Chapter Two, is also directly related to issues of reflexivity as it has been an integral part of the researcher's training in psychology and will also have shaped this study and interpretations of the data gathered in it.

Throughout the study, in addition to the procedures already described for conducting interviews and analyzing data, some additional steps were taken to ensure that, as far as possible, findings stayed true to the actual accounts of participants. Phrases or comments that were not clear to the researcher at the time of transcription were clarified in conversation with participants themselves. The themes that emerged from analysis were assessed, in part, by another researcher engaged in similar research. While it was not possible to have another person conduct a full parallel analysis of data, this second researcher was able to provide an alternative check on the researcher's own interpretation of themes, by moving from the summary table of themes to identify whether and where those themes were apparent in a selection of transcripts.

CHAPTER FOUR

Participant Profiles

While the nine participants in this study can be seen to have much in common with each other by virtue of their ages and their roles as caregivers, each individual brought his or her own unique history, circumstances and perspectives to the study. The following brief profiles are presented to help reference the opinions and experiences expressed in participants' accounts and also to provide background information that may be of interest.

Participant 1

K. was aged 65 and in good health. When interviewed, she had been providing full time care for her husband for two months. K.'s husband had had a stroke ten years earlier that left him confined to bed or a wheel chair, unable to move about, feed or toilet himself without help. After the stroke, K. had continued in full time employment while her husband was cared for, at home, by a paid caregiver.

Having only recently given up her paid job, K found being at home each day rather like being on holiday. She was pleased to be free of the daily routine of her previous job and also of the responsibility of arranging for outside care. At the same time, there were many aspects of caregiving that were new to her, and she explained she was very glad of the ongoing support and advice her husband's previous carer was able to give.

Participant 2

L. was the only participant recruited through an advertisement in a local newspaper. She was particularly enthusiastic about taking part in the study as she viewed stroke and anxiety as having had a major influence on her life. At the time of the interviews, L. was aged 73. She had retired from full-time work three years earlier and had been under the care of a doctor for a number of years for high blood pressure, anxiety and depression. L. had also had heart problems that led to the insertion of a stent some years earlier. She explained that anxiety had always been a problem for her, particularly since her husband's stroke. In the past she had had panic attacks which

were successfully treated with psychotherapy. However, L. continued to depend on medication to control more general feelings of anxiety and depression.

L.'s husband had suffered a stoke ten years earlier which affected him both cognitively and physically. He could move about only with the help of a wheelchair and had aphasia. Although he could understand much of what was said to him, he could say very little. Since the stroke, his condition had apparently changed very little. However, L. believed that over the years her husband had become less motivated, increasingly demanding and more reliant on her to meet his day to day needs.

Participant 3

G. was aged 79 (one month away from her 80th birthday) and was referred to the study by her friend, Participant 2, whom she had known for many years, before either of their husbands had had strokes and they had become caregivers. Both women shared an interest in prose and drama and were members of the same community education group for older adults (U3A). They had also attended the same stroke support group. G. was fit and active with no health problems other than colitis which she said she had had for a long time and was controlled by medication.

G.'s husband had suffered a stroke five years earlier which, although it seemed not to have affected him at all physically, had resulted in significant cognitive impairment, including aphasia, problems in comprehension and reasoning, and short and long term memory loss. He enjoyed walking and working around the home but, because of his limited understanding and memory difficulties especially, required constant care and close supervision.

Participant 4

O. was aged 68 and referred by an acquaintance of the researcher. She had retired from work some ten years earlier and was an active church member and a volunteer teacher in a community music programme for children. After initial telephone contact with the researcher, but before being interviewed, O. had had surgery to remove a large melanoma from her neck. Test results had been clear but because this was not the first melanoma she had had removed, she was scheduled to have regular, ongoing checks. O. described herself as being in good health, save for mild angina that did not require any medication. O. appeared to be less comfortable than other participants talking

about herself and her feelings and explained that, while she had no trouble discussing factual matters, she found it more difficult to answer questions that called for self-evaluation.

O.'s husband was extremely deaf and had suffered a series of minor strokes over the previous year. These had exacerbated existing problems caused by chronic lung disease that had restricted his activities for a number of years. Since the strokes, he could walk only with difficulty over very short distances. At the time of the interviews, he could no longer drive himself and was dependent on O. for all his activities and contact with people outside of home. O. expected that her husband's health would continue to deteriorate in part because of worsening of his lung condition but also because he continued to experience regular small strokes.

Participant 5

F. was aged 65, retired and providing full-time care for her husband who had suffered a severe stroke fourteen months earlier. The stroke had left him confined to bed or his wheelchair, with very limited movement and little, if any, speech. However, his cognitive abilities appeared to be unaltered. Over the course of the previous year, he had regained some movement and was now able to communicate through facial expressions.

Both F. and her husband had experienced severe and unexpected health problems in the four years after they retired and before his stroke. F.'s husband had developed Chronic Fatigue Syndrome that went undiagnosed for several years. F. was diagnosed with breast cancer that required surgery. She had continued with six-monthly cancer checks (all clear for the two years since surgery) and long-term anti-cancer medication (Tamoxifen). In spite of this and her husband's severe disabilities, F. seemed generally optimistic about her current situation. She said that her husband's health and mobility had actually improved since the stroke. She hoped that this progress would continue and that he might even be able to stand or walk again. F. also explained that, despite their difficulties, she believed that both she and her husband were actually in far better health now than they had been for many years.

Participant 6

N. was aged 77 and had retired from fulltime work eight years earlier. She had also been referred to the study by Participant 2 and was a member of the same U3A group and active in other community and voluntary activities. N. had cared for her husband for three years since a stroke that left him with cognitive difficulties (including memory loss and aphasia) and that had also restricted his movement. He no longer had the understanding needed to continue with his previous activities or to carry out tasks around the home. Although he could walk by himself, he could only move slowly and unsteadily and often needed help.

Since her husband' stroke, N. had had surgery for cancer. The treatment had been apparently been successful and she was receiving regular follow-up checks. At the time of the interviews, N. was taking medication for high blood pressure and for thyroid problems and seemed very mindful of the possibility that the cancer might recur and that she might require chemotherapy.

Participant 7

S. was aged 69, had been retired for nearly ten years and was in good health and on no medication. S. had been providing full time care for her husband for a year following a stroke that left him paralyzed from the waist down, with only limited use of one arm, and consequently dependent on S. for all his daily needs. Although his understanding of written and spoken language appeared to be intact, his only speech (save for one word), was involuntary.

S. and her husband had moved to live in Auckland several years before his stroke, leaving behind extended family and long-time friends. She was very open about her feelings of isolation in a new city and more recently, in a new home and in a new neighbourhood. S. missed the companionship of her old friends and felt that her adult children were generally unsupportive and "didn't want to know" about the difficulties she faced in caregiving. She also expressed frustration at what she saw as inadequate care and help available through the hospital system and also over the lack of respite care available for people, like her husband, with very high needs.

Participant 8

P. was aged 68 and the only male participant in the study. He had given up work to care for his wife who had suffered several strokes nearly ten years earlier and could not stay at home by herself throughout the day. Although her cognitive abilities had not been affected by these strokes, P.'s wife had lost mobility. At the time of the interview, she was confined either to bed or to a wheelchair, unable to move from either without his help. Since the last stroke, her kidneys had failed so that she was also dependent on her husband for daily injections and twice-daily dialysis (on a machine at home).

P. had taken medication for heart problems and high cholesterol for nearly thirty years, but was otherwise very fit and healthy. He had keen interest in the martial arts and had been an instructor and active member of his local club for many years. P. was still involved in teaching and exercised at the club for a short time most evenings. He practiced a form of meditation, that was part of the martial art, which he said helped him greatly in coping with the demands of caregiving.

Participant 9

H. was aged 65 and had resigned from full-time work to care for her husband when he had a stroke three years ago. She had considered retiring from work prior to that however because of long-standing anxiety problems (including severe wide-ranging worry and panic attacks) and depression. These had been treated with medication for nearly ten years. At the time of the interview, H. continued under the care of her GP and had been prescribed Arapax and Amitriptyline. Although her medication had been considerably reduced before her husband's stroke, H. explained that doses had since been increased, especially in the months immediately following the stroke, when she had been become extremely distressed.

H's husband had been affected by stroke both physically and cognitively. H. explained that cognitive changes presented the greatest difficulty for her as she had previously relied on her husband for support with her emotional problems. The stroke had severely limited her husbands' comprehension and reasoning abilities so that he no longer recognized the danger in situations and needed constant supervision. However, because he was largely unaware of his limitations, he was often insistent on 'doing things his way' and frequently resisted any attempts to restrict or control his behaviour.

CHAPTER FIVE

Results

This chapter presents the results of the analysis of interviews with the study's nine participants. Transcribed interviews were analysed one by one to identify super-ordinate themes related to individual participants' perceptions and experiences of anxiety. When viewed collectively, these themes led to the identification of three master themes. These, along with related sub-themes, were common to the accounts of all participants and appeared to incorporate the majority of material gathered in the interviews. The three master-themes were labelled respectively: 'The phenomenon', 'Views that influence anxiety' and 'The experience of anxiety'. Not surprisingly, themes identified often followed questions from the interview schedule that formed the basis of discussions. However, all three super-ordinate themes, in particular 'Views that influence anxiety', subsume themes that emerged in analysis but were not anticipated in scheduled interview questions. These include themes related to the nature and management of anxiety (in particular issues of control and acceptance) and to factors that influence the experience of anxiety (e.g. self-identity and views of the world and care-giving). Taken together, identified themes show the value of IPA in providing an analysis that, while retaining its focus on issues of interest to the researcher, is sufficiently flexible as to allow unanticipated topics and links to emerge that reflect participants' concerns, so providing a richer understanding of their perceptions and experiences.

A summary of the themes that emerged in analysis of interviews is presented below. Although IPA studies have conventionally summarized results by listing such themes along with identifiers that indicate where and in which transcript the themes arose, for ease of reading, themes are here presented alone following the format adopted by Cooper (2003). Identifiers are provided in brackets alongside quotes in the expanded narrative that follows. All identifiers are made up of three numbers; the first refers to the participants, the second and third numbers respectively to the pages and lines of transcripts where quotes are situated.

Summary of Analysis

The phenomenon

Participants' definitions of anxiety
What it is and what it is not

Participants' understandings about anxiety
Types of anxiety
  Main anxieties / everyday anxieties
  Legitimate anxiety / unjustified anxiety
  "Conscious" anxiety / Anxiety in response to
  Emergencies
  Anxiety / Panic attacks
Nature of anxiety
  Anxiety as a trait characteristic
  Anxiety as transient and controllable

Views that influence anxiety

Self identity
  Nature and outlook
  View of own coping skills
  View of self as care-giver

View of care-giving
  An ongoing responsibility
  Like caring for a child

View of the future
  Uncontrollable

Aging
  Nature of aging
  Influence of age on:
    Sources of anxiety
    Levels of anxiety
    Perspectives, priorities, needs,
    confidence and experience

Summary of Analysis (cont.)

The experience of anxiety

Main sources of anxiety
Own health / death
Partner's health
Temporary separations from partner
Money
Family and children
Conflicting needs/ lack of personal freedom

Influence of main anxieties
Place in everyday life
Triggers for anxiety
Relationship with other anxieties

Signs and symptoms of anxiety
Anxious thoughts
Physical signs
Changes in behaviour

Management of anxiety
Active management
Self talk / Counter thought
Distraction
Time
Practical action - reducing risks
Support from others
Medication and counselling
Acceptance of current situation
Comparison - "Things could be worse"

The phenomenon - conceptual understandings about anxiety

This master-theme emerged across all transcripts both directly, as participants described their understandings of anxiety in general, and embedded in participants' descriptions of their personal experiences of anxiety.

Definitions of anxiety - what it is and what it is not

For all participants, this theme followed the researcher's question, "What does anxiety mean to you?" Most participants needed time to consider before answering and did so with reference to their own experience:

> *It's a feeling of concern. Usually at this stage, it's mostly concern for X [husband] such as if he is late home, later than I am expecting him…And if he's late, then I'm pretty well stressed thinking, Is this going to be the next stage? What is the next stage? …It just gets me tight and I'm sort of trying to prepare myself for the worst, and I'm hoping for the best at the same time. (3.1.1)*

> *…It's really the little things that could go wrong and you wonder if you are going to be able to cope with what goes wrong. Umm, even if it is just worrying about the kids coming in through the door late, whether they've been involved in an accident, or little things like that… (5.1.6)*

> *Anxiety for me means being in a constant state of stress. You feel that something bad is going to happen. And you're not sure what it is, but it's impending, it's out there waiting to happen, and you live in a constant state of 'what if?'…always the negative side, never the positive side. I mean, you could imagine what if something wonderful happened but it's never that. It's always the negative. (2.1.4)*

> *Something that causes concern, or that you're worrying about, and a sort of … not permanent, but an ongoing problem…I mean, you can be anxious if your children are late home from school, but they turn up and that's gone. But if you've got something that's a slightly bigger problem… (6.1.6)*

Three participants said that they found it difficult to define anxiety: Two directly related that difficulty to the term 'anxiety' which they said they would not ordinarily use:

> *It's a word I don't use to be honest, anxiety. Stress, yes, or concern. (7.1.6)*

> *It [the word anxiety] just doesn't sit easily with me. Sometimes you get things that worry you a bit … (8.1.8.)*

Both suggested alternative, more familiar terms and then went on to describe anxiety using those:

> *Well, something that you really worry about, you know. When I've got to do something, like if I'm dealing with nurses, or something like that and I'm a bit worried about how it's going to go. (8.1.20)*

I would have thought, when you said anxiety, I would have put more on a <u>stress</u> side of things...What stresses do you have or do you perceive to have in the future? And, what are you worrying about? What is going to concern you and what will you worry about most? That's where I would put it. (7.1.6)

A third participant also struggled to define anxiety, explaining that it was something she seldom thought about, particularly in relation to herself.

From the definitions above, it can be seen that participants used other terms such as stress, concern, and, more particularly worry, to define anxiety. At the same time, it was apparent that these terms were not necessarily seen as synonymous. Without prompting, most participants went on to qualify their initial descriptions and to distinguish between these terms. However, the terms did seem to be closely linked and participants, although seemingly sure that the phenomena were distinct from one another, often found it difficult to put those differences into words:

It [anxiety] perhaps becomes an obsession, originally from the worry sort of umm perhaps, you start to think about it too much and gets out of hand and you can't shake it off and you get yourself in a mental sort of state with it. (9.1.21)

But <u>worry</u> is something, you know, is more trivial perhaps. No not trivial that's not the right word... (4.2.10)

Well I guess, in the true sense of the word, anxiety is worrying about anything, whether it be physical or emotional. ... No... an emot... More... You know, you worry about children, you worry about your husband, you worry about your grandchildren umm... But that's not <u>anxiety</u>. No, that's just natural. No...Oh that's a hard one. (4.1.19)

The word worry was used by all participants to define anxiety, and the words worry and anxiety were often used interchangeably throughout interviews as participants described their experiences of anxiety. However, participants' definitions suggest that they did regard anxiety as distinct from worry, more intense, more disturbing and enduring. Most participants referred to anxiety as a feeling or a state, characterised by worrying thoughts. Only two mentioned physical sensations in their initial descriptions of anxiety, one briefly noting the 'tight' feeling that accompanied her anxious thoughts, the other explaining that anxiety for her was not only extremely frightening but also physically debilitating:

Umm...Well, as far as affecting me, I get scared of whatever is happening here feeling totally out of my depth, afraid, needing someone there to support me through whatever it is here. Just generally being very uptight and to a state where you're feeling quite unwell with it. (9.1.4)

This participant was the only one who mentioned fear in relation to anxiety and also the only one to consistently link anxiety to panic attacks. While all other participants appeared to view anxiety as primarily a cognitive phenomenon, this participant clearly regarded anxiety as having both physical and cognitive properties. Common to all participants' accounts, was a perception of anxiety as future oriented and negative, focused on unpleasant or undesirable outcomes which were, for the most part, uncontrollable, either by virtue of their nature or because they were beyond what participants felt they could handle.

Understandings about anxiety

The following themes were apparent across discussions with most participants, encompassing a range of individual viewpoints. The first theme (Types of anxiety) gathers together accounts of a number of different 'types' of anxiety identified by participants. These various forms of anxiety were often introduced by participants, in contrast to their own expressed anxieties, by way of clarification or further description and possibly, for some, as a way of distancing themselves from anxiety that was seen as abnormal or unjustified. The second theme (Nature of anxiety) emerged embedded in participants' explanations of the place or influence that anxiety had in their lives. Although these references were almost all made in the context of participants' views about their personal traits and ability to control anxiety, they can also be seen as reflecting participants' understandings about anxiety itself.

Types of anxiety

This theme was not common to all accounts. However, it is included here because it appears to be pivotal to an understanding of the accounts in which it did occur and also because it points to at least some participants having been selective in the anxieties they raised for discussion. The subject of different types of anxiety often arose when participants were asked if they had any anxieties in addition to those they had first identified. In response, a number of participants described other anxieties that they had not previously mentioned, at the same time explaining that these were different from the ones they had already mentioned.

Main anxieties vs. everyday anxieties

Two participants talked about "normal" anxieties that "everyone" faces in their everyday lives, making a distinction between those and the main anxieties they had already identified as affecting their lives:

> *After that, again there's little day to day things, but they're not important and half the time you wouldn't even know you were worrying about them because, Oh I can fix that , you know [...] But you know, little things like that but they're not a ... they're normal. (5.16.47)*

> *No, not really* [no anxieties aside from those around her own and her husband's health] *Just general run-of-the-mill things that everyone has I think [...] what are we going to have for dinner, you know, and the children are coming this weekend, and umm just general things...No, nothing really. (4.3.6)*

These comments suggest that, at least for the purposes of the interviews, participants may have confined their definitions and discussion of anxiety to concerns that they saw as relatively strong, enduring, and unusual (perhaps unique to care-giving). It is possible that they saw other lesser or more common concerns, ones that might also be labelled anxieties, as somehow less noteworthy or appropriate to the study.

Legitimate anxiety vs. unjustified anxiety

One participant clearly distinguished between worries and anxieties that she believed were justified by circumstance and those that were not. She considered that many people's worries were "self inflicted" and talked about *"people who moan and groan about things that aren't really important"*:

> *I can think of a particular person who really, when I look at her from my point of view, they have absolutely no worries. Financially, umm lovely home, can do anything they wish and no worries in that regard whatsoever. But they are so unhappy, and so miserable. You know. And there's a lot of people like that out there. (4.13.13)*

"Conscious" anxiety vs. anxiety in response to an emergency

In explaining the various situations and issues that led to them feeling anxious, a number of participants made a distinction between anxiety that focused on future possibilities, and anxiety in response to unexpected events or emergencies. One participant labelled these different types of anxiety 'conscious' and 'unconscious' anxiety in recognition of what she saw as the different processes involved in each:

> *But, that* [worrying thoughts going through her head at night] *is a kind of conscious anxiety, whereas I think other things can just flare up and there's no 'what ifs'. It's something's gone wrong and you panic, you know what I mean. So you've got to start sorting yourself out so you can cope with it. But I think a 'what if' is a more conscious thing. (5.8.12)*

Another participant appeared to make a similar distinction after describing her main anxieties and how she had usually dealt with them:

> *Mind you, I haven't been in a situation where I have to do something instantly, umm like, you know, if he fell down the stairs. That would be a terrible anxiety and I hope I could think enough to ring 111 or something before I try and do too much myself. (6.11.46)*

Several other participants also associated this second type of anxiety with feelings of panic, and with their initial reactions to their husband's strokes. These participants described feelings that were intense, short-lived, centred on having to think quickly about how best to deal with an immediate, presenting problem, and relieved by practical action:

> *And while I was doing all the things and organising things, I got him into the hospital and he was put in to a ward where they were going to see what was wrong with him and whether they were going to admit him or not...And then there was no more to be done. And then, I turned to jelly. (3.1.8)*

> *But when X. had the stroke I didn't have them [usual feelings of anxiety], because I was so busy. Thinking of what I should do, getting him up on the chair and getting him organised to go down to the hospital. Yeah So I didn't. That's a different situation because you don't have time to think about it. (7.16.46)*

From their accounts, it was clear that the 'type of anxiety' that participants had referred to in their definitions and in discussion of their main anxieties was the 'conscious' form of anxiety; future-focused and negative, characterised by worrying thoughts and apprehension.

Anxiety vs. panic attack

It was also apparent that the feelings of panic that participants described in relation to emergencies were distinct from the panic associated with panic attacks that two participants had experienced and described. Feelings of panic in these attacks were not linked directly to any external events, nor did they prompt participants to action. Rather, they were described as focused on internal, physical sensations, and feelings of helplessness:

> *I have had panic attacks for years, yeah, I have... umm. Yeah, over jobs and all sorts of things you know, stress at work and things just get me of into a ... You start to feel that you're dragging, you feel unwell, you might get heart palpitations, not really bad ones, but enough that you...and your head is really banging.... It's very scary. (9.1.45)*

> *It's dreadful because it comes out of the blue and, you know, you are just going about your normal business and this... It started off with a feeling of warmth, just in your tummy, and you feel it rising up slowly into your chest, and gradually up until*

it suffuses you.... And I thought, I'm going to die! For the uninitiated it's the most
frightening thing you can experience because you feel you have no control over
what's happening. (2.12.20)

Both of the participants above noted that the anxiety that they felt in relation to panic

attacks was different from anxiety related to specific situations and eventualities:

Panic attack is something completely different because that's not triggered by
anything. That's a build up inside you that you're not aware of, that manifests itself
in that attack. But feelings of panic of, How will I manage? It's a different thing.
That's a panic about umm a flat tyre, a discovery that you haven't got as much
money in the bank as you thought you had, or yeah that sort of thing. (2.22.13)

[Where there is a clear source of anxiety] *Well, it's usually night, of course, when*
that happens. You can't sleep. You're walking up and down to the door. You're
looking at the clock. Shall I ring somebody? No I won't. It is stupid, and that sort of
thing. Yeah. Not that same physical feeling. (9.11.6)

Clearly participants recognised that they used the term anxiety in a variety of

contexts to refer to a range of feelings. While these differences do suggest potential for

misunderstanding, in the context of these interviews they can actually be seen as

strengthening understanding as participants often drew on these distinctions to better

explain themselves. That participants were aware of other possible understandings of

anxiety is an indication that at least some participants gave precedence to certain 'types'

of anxiety in their descriptions and discussion. However, their explanations also point to

a shared, core understanding of anxiety on which their accounts in interviews were

based; one in which cognitive symptoms predominate, that is distinct from panic or

panic attacks, and linked to difficulties that are greater or different from those that might

be encountered by most people in their everyday lives.

Nature of anxiety

This theme emerged as participants talked about the way they viewed themselves

in relation to anxiety. In many instances they explained their experiences in terms of

the type of people they believed themselves to be and the degree to which they felt able

to control feelings of anxiety. By inference, their descriptions can also be seen as

comment on the nature of anxiety itself.

Anxiety as a trait characteristic

As participants described themselves, it was apparent that many viewed anxiety, at

least in part, as a trait, linked to individuals' personality characteristics as much as to

situations or events:

They say there's two kinds of people. There's the ones that see half a glass of water, and the other ones that say, "Well, it's nearly full," type of thing and I think that depends a lot. I've always been very positive. (5.20.45)

Well, I have a neighbour here who's a very unhappy person and, you know, lots of little things seem to worry her. So I think that depends entirely on a person's physical and emotional makeup and life values. (4.12.31)

No, let's face it, some people are anxious the whole time about all sorts of things, not necessarily because their husband's just had a stroke. They live on the knife edge, more or less so anything that happens seriously must affect them much more dramatically than somebody who is a more even-keeled person. (6.4.14)

Participants frequently talked about the 'type' of people that they were; their 'type' offered in explanation of past and present experiences of anxiety. For example, most participants explained their usually low levels of anxiety in terms of their being *"not an overanxious person," "not a nervy person,"* or *"not one of those people who gets anxious."* Conversely two participants who had experienced long-standing anxiety problems referred to themselves as *"prone to anxiety", "a worrier"*, and *"a worry-wort"*.

Anxiety as transient and controllable

In addition to talking about how their personal characteristics influenced their experiences of anxiety, participants also spoke about the extent to which they felt able to control anxiety. Again, comments about their ability to control anxiety were offered in explanation of the degree to which anxiety affected their lives. At the same time, they also reflect participants' views of anxiety as a state or feeling that is inherently transient and controllable. For some, that anxieties could be controlled seemed to go without saying:

No, I don't let them [anxieties] *bother me so much. (8.12.32)*

Oh, well they [anxieties] *don't take over your life, because you couldn't let them could you. (7.17.47)*

It is...I've always been a very positive sort of person. So, it's [anxiety] not something that would come in and take over my life. (5.1.46)

Several participants talked about the anxiety that other people experienced, implying that anxiety was not inevitable and could be changed or avoided:

I think people who worry are perhaps too much within themselves. They're not giving out. Not necessarily physically giving out. (4.13.30)

I think that's why some people can't cope, because they've got no sort of structure to their life, no routine, that they just did this or that when they felt like it. (7.13.10)

At the same time as participants linked anxiety to personal traits or tendencies then, they also saw it as able to be controlled by changes in behaviour. Even the two participants for whom anxiety presented ongoing problems, who doubted their own ability to cope with anxiety, still spoke of anxiety as controllable, albeit only with the help of others or with medication:

> *It's manageable. And I can laugh at it. And I can recognise it for what it is… I'm sure the pills help too! (2.9.11)*

Views that influence anxiety

This master theme emerged across all accounts as participants not only tried to describe their anxiety but also to explain why it featured in their lives as it did. Initially a wider range of material was gathered here, related to participants' accounts of both intrinsic and extrinsic factors that appeared to influence their experience of anxiety. However the sub-themes that emerged at that stage were particularly difficult to order and were seemingly disjointed. As further checks were made against transcripts, and links between themes and sub-themes were reworked across all the master-themes, it became apparent that much of the material (for example 'Triggers for anxiety' and 'Acceptance') had stronger links to the themes subsumed under other master-themes. With that material repositioned and transcripts revisited, themes emerged that linked the originally disparate material.

The material now subsumed by this master theme focuses on beliefs and attitudes voiced by participants that appeared to shape their experiences of anxiety. Together they can be seen as representing participants' attempts to make sense of their experiences of anxiety. These views and beliefs, although expressed as separate sub-themes, are clearly interlinked, influencing each other as well as anxiety. Themes of 'Self-identity' and 'Ageing' were, for the most part, directly identified by participants as moderators of anxiety, while those of 'Caregiving' and 'Uncontrollable future' were implicit in broader accounts of experiences of anxiety. With the exception of 'Ageing' which directly follows Question 11 in the interview schedule (see Appendix D) the themes presented here were completely new.

Self Identity

Nature and outlook

Most participants explained that, while they did have anxieties, they were seldom aware of feeling anxious. In talking about whether, when and how they did feel anxious, participants often couched their explanations in terms of the type of people they considered themselves to be. Most described their 'nature' as relatively fixed, something that was and always had been a part of them, and that served to limit their anxiety:

> *Well, I would say, generally I'm not an over-anxious person. I cope fairly well, and I can just accept things, fairly well. (3.7.21)*

> *But I can't say I'm one of those people that gets anxious about any little thing that happens. It is not my nature... I'm just, Oh well, excuse the expression, shit happens. Let's get on with it. [Laughing] (5.4.15)*

> *I'm normally a placid sort of person. (6.15.24)*

> *You see I'm not a kind of nervy person I'm pretty calm, actually. I think I'm a strong, tough bird. (7.12.1)*

A number of participants talked about being outward looking rather than focused on themselves, saying they believed this was a factor in limiting feelings of anxiety. Several spoke of their general outlook on life as being something akin to a trait (rather than something learned or cultivated):

> *I'm just lucky. I am a very outward-looking person, rather than an inward one. (5.2.12)*

By contrast, two participants explained that anxiety had always been a prominent feature of their lives. Again, as noted above, they linked their experience to traits and to the type of people they considered themselves to be:

> *I have always been prone to it. (2.8.14)*

> *I've always been sort of a worrier. I felt I inherited it from my father. He saw a danger in everything you know. As a child we weren't allowed in boats, we weren't allowed to have pushbikes... umm. Yeah, he saw danger in everything you and I was always afraid. (9.16.42)*

View of own coping skills

Participants also explained their experience of anxiety in terms of their coping skills. Again in contrast to other participants, the last two participants quoted above saw themselves as lacking the qualities and skills needed to manage anxiety. When

they spoke of coping with anxiety, it was usually with reference to the need for external help:

> *My GP had suggested antidepressants, and I was very reluctant. But she said I needed them and so I started taking them and when I saw X [therapist], he said... because I said I really want to come off them, I should be able to cope with this on my own...He said, No, in fact, I think you should increase your dose. [...] I felt more secure. I didn't feel as though I was using something as a crutch, and so I have continued to take them. And as my doctor said, some people need more than others, and if it's there use it. So I do. So my 'happy pills' are swallowed very happily every morning. (2.2.43)*

> *I really always need someone to back me up. Well, not back me up but be there as support, to know you're not alone. (9.11.25)*

The majority of participants, however, talked confidently about being able to deal with anxiety that arose in their lives and were able to describe specific skills that they possessed that allowed them to do this. Often they did this with reference to their past and childhood experiences, describing abilities that had become almost 'second nature' to them:

> *I am an organised person, an organised mind, and I get on with things and I've got a lot of common sense. When I was the oldest of nine children, I was brought up to have a lot of common sense. (7.2.40)*

> *When I was a kiddie, because my father he couldn't go away to war, because he had a weak heart so he was an ARP warden (and don't think of 'Dad's Army'!) [laughing] and so if there was an air raid so it sort of started like this, it was my mum and I that took my brothers and sisters down to the shelter. It was me that looked after my brothers and sisters, took them off to play took them to the park, did all this sort of things. Because my Mum wasn't very well. So I've always been in a situation where I've had to make decisions... I've had practice if you like. (5.10.31)*

On other occasions they talked about having skills and abilities acquired over the course of their lives (See 'Ageing'), and since they became care-givers:

> *But I did [learn] and I'm fairly determined. I am strong-willed. Yes, so I learnt. I had to learn because I was on my own, more often than not. (7.10.10)*

View of self as caregiver

Embedded in accounts of both their care-giving and their experiences of anxiety were participants' views about themselves as care-givers. These were seen as distinct from, though strongly linked to, views about the nature of care-giving itself, which emerged as a separate theme. Participants' views of themselves as caregivers often emerged in the context of comparisons or comments made about alternative care. Most expressed the belief that they were the people best able to meet their partners' needs, that

institutions or extended family could not provide the same quality of care and attention that they, as spouses, could give:

> *Well, you do learn very quickly. Yes, you become more adept than any of them, to be honest. You have to. [...] I evolved my own system and did it, quite honestly, the opposite of everything I was told, the opposite. (7.10.26)*

> *If she wants to go to the toilet she presses her bell, I'm there within 10 seconds. In the hospitals and that she has to wait half an hour. (8.2.42)*

> *They [son and daughter-in-law] would of course look after J but not in the way that um...Well, they couldn't possibly do... They couldn't possibly live with him and look after him in that way could they? [...] Fifty-five years of marriage, it's a long time and you know... (3.14.46)*

Only one participant expressed doubts about the care that she was providing her husband:

> *Sometimes, the anxiety that you feel is that you are not doing enough for him, that I've stopped caring to such a degree that I'm not out there looking for...In the beginning somebody...because I'd read Roald Dahl's book about Patricia Neal, and I thought, Oh my God, that man! What he did for her. And I should have been organizing 24 hour care. But where would I start? And I used to feel guilty about that. And now I've got to the stage where I'm almost letting that go. And I've stopped putting so much energy into finding new ways to stimulate, new ways... Yeah...*[Pause and sense of sadness] *(2.13.22)*

While positive views of one's capability and worth as a caregiver appeared to ameliorate feelings of frustration or anxiety (in particular on those related to conflicting needs), negative views were identified as a direct source of anxiety and guilt.

View of Care-giving

This theme emerged in conjunction with the sub-theme above, gathering material related to participants' views about the role of care-giving and their opinions about the different forms of care available. Participants' views of their own ability to care for their partners were often directly related to their assessments of the quality and suitability of alternative forms of care. Doubts or negative views about alternative care were, in turn, related to anxieties about health problems that might limit or prevent their continued care-giving. They were also directly linked to anxieties that arose when partners' needs conflicted with their own. This conflict of needs appeared to be an ongoing issue for most participants and emerged as a separate theme.

<u>An ongoing responsibility</u>

All participants talked of care-giving as a serious responsibility and seemed to be acutely aware that their partners depended on them to meet not only their everyday needs, but also their needs for safety and, in some cases, for the medicine and procedures that kept them alive:

> *Well yes, that's right, because the fear and the concern is with you so much. It is a huge concern when you're responsible for someone else or you feel responsible. It's not a role I'd been in... (3.4.44)*

> *I think I've always been concerned about other people and their reactions and so on, and I guess I'm much more conscious now that I have to be alert for X when he's doing things or going out, or just living.... (6.3.14)*

> *Yeah, and this is where the injection* [Partner needs daily injections in the abdomen] *comes in. It's got to be right. And the machine has got to be right, because if it's not right, and it packs up, then I'm going to worry about it because it's someone's life you're dealing with. (8.1.36)*

Even for the participant quoted earlier, who felt that, after ten years of care-giving, she was beginning to let go, it was clear that the role of care-giver was not one that she could easily set aside. This sense of responsibility was clearly linked to views of alternative care available. While three participants spoke very positively of the respite care they used and continued to use, the majority of participants expressed doubts about the suitability of the alternative care, both in the long and short-term:

> *I've looked at rest homes – and I don't like rest homes – and he looks well. He looks like there is nothing wrong with him. And he is a young ....he's younger than me, a young looking man, and so his life in a rest home would be hell and he would not like it. That's one of my biggest concerns. (7.6.47)*

> *And another funny thing I find, I put him in respite care - not as often as we were doing it because he's not happy there - and I suffer. But even although he is there and I know he is well looked after, I just get uptight that they're not doing everything properly. Stupid, because they are trained staff. But... And you can't go well, they say ... So you're still anxious even if... say, I went away, sometimes I go down to my brother for a break at R., I'm ringing every night, you know. I can't let go, I suppose. (9.5.15)*

> *I've talked to other women when we used to go to the Stroke Group and their husbands went away for a week each month. But I couldn't do that to X. because the time leading up to him going away is miserable for both of us. He's bitterly resenting going, and I'm feeling guilty for making him. So it's...I end up going to visit him every day and that doesn't achieve anything. But I feel so sorry for him, stuck there with a lot of <u>old</u> people. (2.4.19)*

> *So when I'm looking after myself, if she's in hospital, I don't... I worry about, Are they actually looking after her when she is in hospital? Because sometimes it is not always the best. (8.2.25)*

Like caring for a child

A number of participants likened the responsibility of caring for their partner to that of caring for a young or dependent child who needs constant adult attention to meet everyday needs and for protection from dangers that might arise. This was particularly the case for those whose partners' cognitive abilities had been limited by stroke:

> *Well, it's like having a newborn baby, I mean, you know, you need to sleep. You're dog-tired, You go... but the moment that the baby cries, you're awake because you're responsible for it. That's how I feel about X, you know. If he gets up in the night and collapses somewhere, I need to be there. (6.6.37)*

> *And you know when you're at home, or in bed at night, I mean and I'm down here and he's upstairs, But it's just like when you have a child, you've got one ear cocked, you know, and if I hear sounds up there, I'm up there like a shot. And you know, I do, I'm all the time thinking, Is he all right, What's he doing? ....Does he need any help? (3.5.17)*

> *As I say, just general worry about umm where my husband is, what's he doing outside. Well, he can get away pretty quick and they ring and tell you that is taken off, you know, he's only a little way up the road but is coming home...And all those sorts of things. It's like having a child who depends on me, you know. Yeah it is. Except that a child, you can pick up and put under your arm and take them home. But a grown man you can't ... (9. 13.21)*

One participant pointed out that, for him, the stress in caregiving lay, not in the everyday tasks he carried out, but in the fact that the care was needed indefinitely:

> *It's almost the same situation. It's like having a young baby, but the young baby is not going to get better [...] And this is what it's like looking after an invalid. It is almost the same...For the rest of your life you've got this. (8.9.20)*

Anticipation of needs and protection from danger

Perceptions of their partners' needs and of their responsibilities as caregivers were clearly linked to the anxiety that some participants felt when they were apart from their partners and also to the anxieties that arose when their partners' needs conflicted with their own. However, few participants related their general care-giving duties to anxiety and few linked their watchfulness and anticipation of danger or mishap to feelings of anxiety. Instead, most participants appeared to view their attentiveness as simply a necessary and proper part of caregiving, and their constant evaluation of risks as a practicality of everyday life. One participant specifically noted that her constant attention and anticipation of mishaps could be, and indeed was, sometimes construed by others as anxious behaviour, although she herself did not see it that way:

> *I don't feel anxious. As I say, I might go and check on his room actually, because I haven't heard anything and I might just, you know, go and check that he is all right.*

But I don't know that I'm really <u>anxious</u>. That perhaps is too strong a word. I just <u>check</u> that he's okay, like you would a child. If you suddenly think, Gee, I haven't heard...Tommy, What's he up to? You go and find, you know, that he is into the paint or your make up or something...Umm, but I wouldn't put <u>too</u> strong a stress on that because it's just part of <u>caring</u> for somebody else. (4.5.16)

It seemed, however, that this participants' family or friends did not share her view and often saw her attention as disproportional to the circumstances and her worries as unfounded:

I know people say I <u>worry</u> too much and I fuss too much. So I don't know. It's just me. (4.9.33)

Although this distinction was only made explicit in one transcript, it does highlight an area of possible confusion that could arise in evaluation of anxiety in care-givers. It is possible that the line between heightened vigilance and caution associated with proper caregiving and the excessive vigilance and avoidance associated with dysfunctional anxiety may sometimes become blurred.

View of the future

This theme was embedded in participants' accounts of the specific anxieties they experienced and how they dealt with them. It represents the view, frequently expressed by participants, that while there was much in their lives that they could control through their own actions, there were many aspects of their present and future situations that they could neither change nor predict, regardless of their personal skills. This sense of limited control appeared fundamental to the experience of anxiety itself:

You know, you have to think about, What if the worst happens? And once you confront that, you realise of course that you can't protect your children...Adult children for God's sake! They are grown!... from crises because <u>you</u> have crises in your life, they are bound to have crises in theirs. Everybody has crises in their lives at some stage and so some things are just out of your control. You do your best to put your finger in the dyke and hope that the flood waters won't come over the wall, but you can't stop everything from happening. That is irrational. (2.2.17)

But that would perhaps be my most...The biggest anxiety is, what would happen to X if anything happened to me? That would be the biggest one... But you can't do anything about it so... (5.2.42)

If we just go back to health with X., we know he's had those strokes. I can't do anything more about it. We do everything we can to keep him as he is. If he has another one, well, it's not his fault, it's not my fault. It's God, or whatever I don't know. (6.22.40)

> *I've thought about it* [husband having another stroke]. *It's no good worrying about it because it is going to happen somewhere. Something's going to happen, you know it is. It's no good worrying yourself to death about it, no. (7.5.49)*

However, recognition of limited control over events, present or future, did not of itself appear to be a source of anxiety for most participants. Rather, for some, it seemed that determining what they could and could not control was instrumental in helping them deal with negative situations and prospects, directing them either towards practical action (where they could effect change) or to acceptance of situations when they could not:

> [In answer to a query about how she would normally deal with anxieties] *That depends on what it is. If it's something to do with X., I'll sort it out. I'll think about it. Now what can I do to alleviate this problem? If it's just an ordinary problem for me and outside, if I can't solve, I sleep on it and forget about it [laugh]. (7.11.38)*

Participants' ability to consciously put anxieties aside, also appeared to be directly related to how confident they felt to deal with anticipated situations if or when they actually came to pass. This theme is interlinked then with the themes 'Views of self' and 'Coping' discussed earlier. As was noted in discussion of those themes, most participants seemed to be relatively confident that they would be able to deal with eventualities, however unwelcome or difficult they might be. Two participants however, seemed far less certain of their ability to meet new or different situations and were considerably more anxious about the future. For them, realization or reinforcement of their lack of control seemed only to increase feelings of anxiety and helplessness:

> *I remember years ago, reading a Somerset Maugham story and one of the characters observed that it isn't the things you think might happen that kick you in the gut. It's the unexpected that really knocks the blocks from underneath your life completely and make you realise how fragile your hold on things is...um...and so yeah that's that. And then your total reliance on others... (2.8.14)*

Ageing

This theme was a focus of the study, and of particular interest to the researcher. It directly follows the Interview schedule (Question 11; Appendix D), which invited participants to say whether and how their experiences of anxiety had changed as they grew older. Most of the material subsumed by this theme was gathered in response to that question.

<u>Nature of ageing</u>

As they talked about themselves and concerns, participants expressed a variety of opinions about the aging process and about older adults themselves. Several participants associated increasing age with increasing vulnerability. In particular they pointed to older adults as having less control than younger people over certain aspects of their lives, especially their health and their finances:

> *But you are more vulnerable, there's more things that can go wrong with you, both physically and mental-wise, umm and so you're aware that that these things can go wrong. So you tend to be a bit more, if you like, anxious about how things will go. (5.10.37)*

> *But when you're older you're at the mercy of other influences. That's what it is. And there's nothing you can... You can't go out to work anymore. You're reliant on what you've got to get you through. (7.17.8)*

Another participant, talking about the possible recurrence of a cancer, voiced her concern that older adults might not receive the same standard of care or treatment as younger counterparts:

> *I think they look at the older population and umm think, What do we do for this? Is surgery warranted or will we just leave it? You know, I know they weigh that all up, because there's all those dollar signs there and if somebody younger needs treatment then, we get put on the scrapheap a bit... (6.4.26)*

<u>Influence on anxiety</u>

All participants said very definitely that their experiences of anxiety had changed as they grew older, albeit in a variety of ways.

On sources of anxiety

The change in anxiety that participants most commonly associated with growing older was a change in the sources of their anxiety, i.e. what 'made them anxious'. This change was noted by all participants, each of whom referred to different stages of life as giving rise to particular difficulties and anxieties:

> *Of course when you're thirty, your anxieties are totally different to what they are when you're in your sixties... (4.11.41)*

> *You have different problems depending on what stage you're at in life. (6.22.18) They've changed. Yeah. The older you get, they change, yes. You have different concerns. (7.18.28)*

> *...The things that you worry about shift and change, you know, as your children grow up. You sort of think, oh you know will they be all right when they go to kindy? Will they be alright when they go to school? Will they get bullied? Will they get hurt? As they grow up, are they going to have any problems? You know, all those little things that they might have. So your worry is essentially outside yourself*

- they're concerned with the people that depend on you. And then they start to grow up and go through the teenage years, and you used to think well there's drugs and all that sort of thing - Fortunately nothing like that happened, but you've got to be very aware of it, What would you do? How would you cope? type of thing. And then after that they grow up they leave home. (5.11.26)

Well, thinking back, well often there were challenges you didn't really want to cope with and you did ... They would cause quite a bit of anxiety and work would cause anxiety and umm URGG, <u>Kids</u> would cause a great deal of anxiety [...] 3.12.36 ....And none of that now is there any more, you know and I can let go of those things, in one sense. (3.12.44)

A number of participants talked about feeling less stressed or anxious once they had given up full time employment. At the same time, they noted that going out to work had also provided them with opportunities for dealing with anxieties:

Well, yes. It is different when you're in the workforce. You push through it to go to work even if you're feeling really bad, and often, the company and being out, you forget about it. Umm, so you do really push yourself more to do things, whereas now that happens you just don't go anywhere. (9.16.49)

I don't miss having to go there. I don't miss the getting up and having to rush through everything to get out the door and all the rest of it. But the initial opening of the garage door and getting into the car and thinking, Oh, I'm on my own, and I've only got myself to think about! (3.8.44)

While anxieties associated with earlier ages and stages had subsided, participants noted that other anxieties had arisen that were distinct to their later stage of life. Not surprisingly, these included a number of the major, current anxieties that participants had identified:

Yeah...So you do worry about different things [...] What if <u>you</u> are disabled? Or what if? You know the whole thing changes because your time isn't there anymore. Your time is running out.[...] They [issues and worries] loom up which you would never have thought about 20 years ago, or even 10 years ago. (7.17.42)

Well I suppose, health is one issue that when you're in your 20s you hear somebody's got cancer, and yes, they eventually died. Okay, it might have been your mother and you might have been terribly upset but you get over it. But when you get older, and you see it happening to a lot more people, and to yourself, of course it's a greater concern, mm. (6.20.49)

And I mean, you don't think of it when you're younger, but it's much easier to hurt yourself when you're older, even though you don't think it should be. It's still much easier to hurt yourself. It's easier for health things to go wrong. They can go badly wrong much more quickly. So that's a thought there but it's something you just have to live with. (5.11.8)

And a friend of ours died on Sunday night and when I think of M. and J., and I think of how <u>their</u> lives were changed, I think health plays the biggest part of most people

growing older. The fact that a debilitating illness for instance, that's what they most would worry about, and because you become a burden. (2.14.2)

On levels of anxiety

Overall, however, most participants explained that they were now less anxious than they had been in earlier years, and said that nowadays they seldom felt very anxious. None of the participants associated ageing with increased anxiety:

> *Do you know, I think I'm less anxious. I mean, my anxieties are centred around X [her husband] really [...] So all my anxieties now are one, centred round one thing. (3.12.9)*

> *I'm probably less anxious, but I have more anxieties, on a wider scope. I think when you are growing up, your focus is on your family. And you live through that, the ups and downs... and my job, I guess I coped there. And now I have a different sort of anxiety...well, there's a lot more of them, little ones. But not so much focus on the child, say, who got into drugs for a while. We got it sorted and he's fine but while it was going on, I was probably much more anxious then than I am now. Does that make sense? (6.22.25)*

On perspectives, priorities and needs, confidence and experience

Although many of the changes in anxiety they mentioned were attributed to changes in their situations and responsibilities, participants also noted other factors that they believed had led them to feel less anxious. Among these were changes in perspectives, priorities, needs and abilities that they saw as having come with older age:

Perspectives and priorities

> *Yes. Well yes. Over the years I suppose all people get to that stage where they just think, Well really, that's not my worry. It's not my problem. [...] I think its just part of aging. (3.13.8)*

> *I think, you learn to handle them better umm. When you are young, they're big things. You know, like if you haven't got a dollar in your pocket you're, you know, What am I going to do? I can't go here and I can't go there! And when you get to our age, we keep the deepfreeze stocked up with food, so if I haven't got a dollar, I've got food in the deep-freeze. I don't have to worry about it [...]. So the worries are not as bad. You don't make big pantomimes out of them, if you like to call it that. (8.12.14)*

Needs

> *We don't need much, really. Buy the odd clothing, and as long as we have got enough to eat and to be able to go out sometimes. Life's pretty simple when you get to our age. (6.15.3)*

Confidence and experience

> *I feel I can cope better with all sorts of things, because I am a lot more confident now than I was as a younger person as well as having had that experience. I guess one blends into the other doesn't it? (6.22.8)*

Maybe its maturity too, maybe you've lived life's experiences and you've had friends who have gone through experience. Whereas in your 20s, 30's, you know, you think you know everything. But you don't. So yes, I think it does change as you get older and have had wider experiences of course and therefore different sorts of anxiety come into that. (6.20.37)

I would say that's changed. I am more accepting that if something has happened, you'll hear about it, yeah. (9.17.8)

I think we get more cynical and we don't put up with any rubbish. You're inclined to... You learn to speak your mind a bit more. (8.8.30)

One participant attributed the greatest change in her experience of anxiety to having had cancer three years earlier. She described this experience, rather than ageing, as having determined her present her approach to life and difficulties:

...That changed my whole outlook on life. And I start now thinking, we're not going to worry too much about the future. We'll take each day and we'll go for each day, and as each day passes, we'll take those experiences and plan something for the next day, type of thing. So, it has changed my whole outlook, that there is worse things that can happen than 'C', type of thing. (5.13.45)

For the two participants who had longstanding anxiety problems, ageing did not seem to have brought about the changes in anxiety that others described, although their anxiety did appear to have become less debilitating in recent years. One of these participants wryly suggested that with maturity she should be better able to deal with anxiety:

You would think now, that at my age, you would have learned quicker or better, but [laughing] some things don't sink in! (2 7 18)

From discussion, it seemed that the reduction in anxiety that these two participants had experienced in recent years was primarily due to medication.

Experiencing anxiety

Five themes emerged under the master-theme of 'Experiencing Anxiety'. These focused on the anxieties that participants currently experienced in their everyday lives and on how they recognised and dealt with their anxieties. Together these themes subsumed a large portion of the material gathered in the interviews. While the first can be directly related to specific questions posed by the researcher in interviews (Questions 5 and 6 Appendix D), a great deal of the material presented here was not anticipated in questions, in particular information related to 'Acceptance' and the 'Influence of Anxiety'.

Main sources of anxiety

This theme was present across all transcripts and details participants' anxieties: the issues and situations that participants identified as 'making them anxious'. None of the participants appeared to have any difficulty naming or describing their main anxieties which were surprisingly few in number and consistent across participants. Each of the sub-themes that emerged was acknowledged by at least seven of the nine participants as a main source of anxiety. In each case, and consistent with their definitions of anxiety, anxieties were related to specific, negative situations that participants expected they would have to deal with at some time in the future. Only two participants (Participants 2 & 9) spoke of having significant anxieties in addition to those discussed here. In the main, these appeared to be varied and general in nature (as opposed to being tied to particular situations and issues). For one of these participants, panic attacks were a continuing source of major anxiety.

Own Health

All participants identified health (their own and their partner's) as being a major source of anxiety. As noted earlier, some linked the likelihood of ill-health directly to older age.

> *You're not dwelling on it all the time but you know its there. You know that umm anything could turn up and go wrong because you've passed your 'use by' date. [laugh] (5.10.46)*

> *But you can't* [continue as a caregiver] *if it goes on for years. You become less active as you get older, umm you lose your strength, a bit. You need quite a lot of strength. And that is one of my biggest concerns… (7.7.9)*

However for many participants, it seemed that concern about future health problems was linked more to specific medical conditions or health issues. Only one participant talked about concern for her own health without linking it to an existing or recent health problem. Three participants had received treatment for cancer in recent years, and underwent regular cancer checks:

> *To a degree, I worry about myself. You've just bought it to my mind. I have to have regular skin checks, because I was exposed to the sun and I'm having melanomas removed, quite frequently. I've just had a bad one cut from my neck. Um and while that was going on, although I didn't <u>really</u> worry too much, I thought, Oh well, if it's happened, it's happened…But underlying, you do worry…until you've got results back and everything. (4.3.42)*

> *Well, just going back to <u>my</u> health status, I mean, I am fine but if these wretched cancer cells take root, I'm obviously going to have to have chemotherapy or*

something, And that's not pleasant because X's <u>been</u> through that and I know the results. But what is going to happen to him? I suppose he would go to respite care for as long as needed. But that's a bit of a worry. (6.3.28)

Okay, every time I go for a mammogram, for about a week beforehand, ooh, I mean you know, six months and then six months later, I have a scan. So I know that nothing much is going to happen, <u>But</u> you've always got that little - Is it or isn't it? (5.13.2)

Another three participants explained how they had become anxious about their health as a result of experiencing sudden, serious health problems.

[In response to tests that showed angina and heart problem] I was then plagued with doubts about my <u>own</u> state of health, because it <u>all</u> revolves on X. Because if anything happens to me, who's going to look after <u>him?</u> (2.1.4)

[In relation to unexpected complications that occurred in routine surgery on a vein] I always had said, That's one thing I hope does happen, that I outlive him and he wasn't put in full time care. Mm. But no, I hadn't been too concerned about that. ... But now I realise how quickly and how easily I could end up having a stroke, and end up being in the same position he is in. (9.6.39)

I was really upset, really, really upset. I got terrible migraines, I couldn't sleep and a few days after that I came out in some wild kind of a rash. Now, when it all happened, I thought to myself, Oh, dear God, I hadn't thought about that but I could go first and I haven't got the wheels in motion properly for this. (7.7.35)

For the majority of participants, as suggested by the quotes above, anxieties about their own health were directly related to their roles as caregivers. Almost all explained that they felt anxious about their continued good health, because without it they would be unable to care for their partners. For many participants, concern about their partner's care seemed to outweigh health concerns on their own account:

I'm not too concerned about that [cancer treatment] because with the regular checks... If it hits, hopefully, it would be early stages, and they can do something...Yes, and as long as M. is well cared for... (6.4.14)

If anything happens to me, then she is in a home, because there is no one to look after her. So I <u>do</u> worry a bit about my health [...] So, you just think, don't have a heart attack or stroke, because she's got a problem if you do. (8.7.13)

...I suppose the main one with X that I worry about and that would cause me the most anxiety would be if <u>I</u> were sick. That would <u>really</u> concern me about <u>him</u>. (3.14.23)

Several participants also linked anxieties about not being able to continue to care for their partners to concern that, in their absence, the burden of caregiving would fall on their children:

Because if anything happens to me, who's going to look after <u>him</u>? And I didn't want the...I don't want my kids lives changed or altered. I want them to be able to... which is irrational...but I don't want them to have the responsibility of looking after their invalid Dad, because they have enough going on in their own lives. And so that seemed to treble my burden and my anxiety, because not only do I not want to be ill myself, but I don't want my state of health imploding on their lives. (2.1.47)

As with concerns about their health, participants' concerns about their own deaths were linked to anxiety about not being able to continue as caregivers. Death, in and of itself, did not seem to be a source of anxiety for most participants:

Fear of dying? I think, not really, at my age. I've been on a cholesterol diet since I was 39 so I feel I've had another 30 years, so I've got no fear. I don't have any... I mean like all people, you want to live longer and see what happens. I mean, I'd like to see this motorway system finished...[laugh] (8.4.6)

Only one participant described death as being a major current source of anxiety, and then only over the past few months since she had been unexpectedly admitted to hospital:

Well, naturally, I'm anxious about my health. Death frightens the daylights out of me so I am quite uptight worrying about that...Yeah. (9.5.34)

This participant also expressed concern about the effect her death would have on her husband and on her adult children.

<u>Partner's health</u>

In addition to worries about their own health, all but one participant identified their partners' future health as being a major source of anxiety. These concerns were clearly associated with possible worsening of their partners' conditions rather than with the continuation of any present difficulties. Naturally, most participants were anxious about the possibility of their partner having another stroke:

I suppose, my main concern is... or knowing that once you've had a series of strokes there's going to be more, that sort of, When? and If? and How bad is it going to be? That's sort of at the back of your mind because you live with it everyday, with the results of the previous ones, anyway. ... And we know there's not going to be any improvement; it's only going to get worse. (6.1.25)

I would worry about if X. gets sick or something like that. Then I'm going to worry because a lot of people have had two strokes and three strokes and she's had one. So when she gets sick, you think is this going to be another one, you know, so how are we going to survive? (8.1.45)

One shouldn't... but you do wonder and worry, is he going to be all right today? That's that anxiety, which is a daily thing now, because these little strokes are happening so frequently. (4.2.29)

Two participants talked specifically about possible deterioration in their partners' health, again linking this to concern that they may be unable to cope or to continue as caregivers:

> *I feel I can cope with now, but if tomorrow changes, then you know, it's an adjustment again and would I be able to cope? (3.3. 26)*

> *If she gets any worse, if she has another stroke and she can't walk, in this house it would be impossible to move around the house, because you'd have to literally lift her everywhere... (8.10.1)*

Participants' anxieties about their own and their partners' health were frequently linked to their views of alternative forms of care and their own abilities as caregivers and for some, were exacerbated by fears that they could not afford to pay for fulltime care. While participants all identified partners' health as being major sources of anxiety, none mentioned their partner's deaths as being a source of anxiety. The four participants who did discuss the possibility of their partners dying said that they did not mind the prospect of living alone:

> *I'm fortunate that I'm very happy with my own company and the thought of being on my own doesn't frighten me at all. (4.12.22)*

> *Yes, I mean, I don't mind being on my own - that doesn't worry me. I like that. I quite like that. (7.6.17)*

> *If I lose R., you know, God forbid, I still have grandchildren I'd like to visit and I'm sure the grandchildren would like us to visit. They want us to go and live in Australia, the grand-kids, because I can play with them, and I can still do that. (8.4.17)*

For most of them it seemed that their partner's death, coming before their own, would be something of a relief:

> *I remember <u>my</u> doctor saying to me, the tragedy isn't that X <u>had</u> the stroke, it's that he <u>survived</u> it. And I've thought about that a lot. And I don't know how that would be ...If he had died as a result of the stroke, my life wouldn't be as it is today... (2.10.13)*
> *So you just keep your fingers crossed, and it may seem cynical, that she dies first. A lot of people think that we're nasty when we say, I hope she dies first. Because, if she does, then I'm going to be fine. If I die the next day, it don't matter. But if I die first, say I die at home here and she's in bed asleep, then she's going to have to get help. (8.7.4)*

> *Umm I've fixed it all up. It's fine if E. goes. But if I go it's going to be another sort of – not for me because I won't have to worry about it any more - But you're trying to get everything sorted out. (7.17.30)*

Temporary separation from partner

This theme emerged across most transcripts as participants described anxiety they experienced when they were apart from their partners. For one of the two participants who did not mention this as a difficulty, it seemed likely that this was because she spent very little time away from her husband: Her anxiety and view of alternative care seemed more influenced by a need for time-out from caregiving:

> *All the time you're <u>with</u> them, and of course normally in a life you're not with that person all the time. You're doing your own thing. You're in your clubs or your own interests. And you're thrown together all the time, which he wouldn't like either...[...] ...I've had to search all over the place* [for respite care]. *Found one, took him to try it out. It seems reasonably okay. He always falls out of bed there, but that's okay, never mind. (7.14.14)*

Other participants, however, described temporary separations from their partners as being a continuing source of anxiety, especially when they involved leaving their partners at home alone. Naturally these concerns appeared to be greater for those whose partners were more seriously incapacitated by stroke:

> *He has no fear. Never did. Anyway, he just doesn't comprehend. He thinks he can still do something on his own. (9.15.8)*

> *Well, I guess there's an underlying anxiety all the time in the situation at the moment, umm albeit sort of hidden and kept hidden umm ....about my husband. Is he all right down there? I can't hear him. That's there are all the time. (4.1.43)*

> *I don't feel good about leaving him on his own if he's awake. Because if anything went wrong, okay he's got his St Johns ambulance alarm, but he can not talk, So that would, if you like, be my biggest worry. (5.3.43)*

> *It's there <u>all</u> the time. You never ever really get rid of it. Every time you go out you come back and you think, you know, Is she going to be sitting on her armchair when I get home? I used to rush home and run in the house and she'd say, No, I'm still in my armchair. Okay, that's fine. (8.4.45)*

> *I didn't get home until 4:00 and it was only round the corner, but he was getting <u>terribly</u> anxious, wondering what had happened to me and where I was. And <u>that</u> causes me, in turn to be anxious. (4.16.34)*

> *And some mornings, of course, I <u>have</u> to go out and then he stays home and then I get <u>really</u> anxious because I know when I come home, he will have done some job that I didn't want him to do and he will have done it all badly. And he will have done something terrible in the garden or in the house, and ...yes, that's very irritating, but he tries to help you see. (3.1.37)*

This theme was also linked to participants' views of their responsibility as care-givers and to the theme of conflicting needs. Participants described encouraging their

partners in activities that they knew were enjoyable or beneficial even though these involved risks that made them, as caregivers, feel anxious:

> *X will go out for a walk around the block, and I'm always pleased to see him home. I know he takes about 40 minutes to go around there and back and if he hasn't turned up in about 40 minutes, I begin to think, should I go and look for him? (6.4.39)*

A number of participants explained that the anxiety they experienced when they were separated from their partners, sometimes continued even when their partners were in alternative care (e.g. on supervised outings, in hospital or in respite). As with anxieties about health, these concerns were often linked to participant's views of themselves as carers and to their judgements about the suitability of alternative care.

Money

Money emerged as an anxiety-linked theme across most transcripts, but was reported as a current, main anxiety by only one participant. It is included here as a main source however, because the majority of participants noted that it had been a source of anxiety in their time as a caregiver or because they expected it to become a major concern in the future. Most participants commented that money did not pose a problem for them currently and explained that, although they might not be wealthy, they did have sufficient money to live comfortably:

> *And I don't worry, you know, about where the next dollar's coming from or that sort of thing. I mean, we are not wealthy by any means, but I am comfortable. (4.3.44)*

> *No, you see we're fortunate that we don't have to worry about anything financial. (5.4.29)*

> *Yeah, and financially you think, oh my God, how will I cope? So I had to go on the pension with my husband because he was already on Super and umm...But you get by, you just adjust. Yeah. (9.3.46)*

Several participants explained that they had been concerned about a lack of money when first they gave up full time work to care for their partners. For one, this had become a major problem that ended only when he qualified for a retirement benefit. For another, difficulties related to money and managing finances had continued and were still a major source of anxiety:

> *And then a big worry of course is money...managing. Because I look after the money now and I have moments of panic. But we have managed so far and I hope we continue to do so [...] So, providing nothing major happens, we're okay at the moment, but that's a major worry. (2.3.13)*

Other participants, who had commented that they could live comfortably at present, also doubted that they would have sufficient money in future:

> *I suppose there's always the old-age problem of money. I mean we live in a nice street, we own our house, umm But continual care, it all costs. Well, we're not down to the bread-line yet. I suppose when we get there that'll be another anxiety but at the moment, we're coping all right. But I imagine it must be quite a problem for a lot of people. I think it can be very much so. (6.14.7)*

These anxieties were linked to the knowledge that, because of their age and situation, participants had little option but to make do on the money they already had. As noted earlier, a number of participants were particularly concerned that they could not afford to pay for fulltime care for their partners, should that become necessary, and that they may be forced to sell their homes to meet costs:

> *...Something like X having a stroke affects all that because you could be up for paying for him to be cared for, you know. [...] ...Which brings you to the point, well, how long can you stay in your house if he's got to be cared for? Because, you know, it doesn't take much to be over the allowances which are pretty pathetic. (7.17.21)*

> *[Money] isn't a huge concern, but it could be if I had to pay for full-time care for X...If he was there fulltime, I don't know what would ... I think you have to use up your money don't you? And I don't know what the situation is if it became full-time...I would hate to think there was nothing in the bank. (6.14.23)*

Anxiety related to family and children

All participants had adult children with whom they kept in contact and all but two mentioned having experienced some anxiety associated with their children or grandchildren. This was most often described as related to difficulties in participants' relationships with adult children or to difficulties that their children faced in their own lives:

> *I suppose, when you're a mother, you're mother for ever, and you see your children making mistake, perhaps, or friends' children making mistakes...You can't do much about it, really... (6.21.8)*

> *Different events happen, like when my oldest daughter, she and her husband decided to buy their own business and you think, Oh, Are they going to make it, make a go of it? What is going to happen? (6.3.49)*

> *Oh well, two of our children weren't speaking. And that's been a source of anxiety but that breach has been healed at the moment... And, that's good. Our son's marriage broke up, that was dreadful and but, you know, what can you do? What can you do? You don't want your kids to be unhappy. It's all right for other people's kids to be unhappy but you don't want yours to be. (2.9.33)*

He never spoke to us for two weeks, never came near us. It was upsetting for us. He didn't come near us, didn't want to know us because we hadn't taken his advice... (8.8.47)

Also, you had a thing of the two kids saying it would be better for me to have my life and him to go into a home, go into care, and myself saying, We're not doing it. So there was that bit of tension there for a while and that is a hard one. (9.19.3)

For this last participant, the responsibility and day-to-day care of her granddaughter was a source of considerable anxiety:

I've had a grand daughter living with us these 12 month. She is 19, doing UNITEC and am back to worrying about why she is a home late at night and driving cars in the Auckland City...And those can get me really anxious. (9.5.35)

Another participant whose children had long since left home said that the anxieties she used to experience when they were younger and living with her, often returned when they came to stay:

If they're at home, even if they're an adult, I know if my daughter and her husband when they stayed with us for a short while before they shifted from one place to another, if they were late home, I would lie awake until they got in, just in case anything went wrong ... (5.11.26)

Conflicting needs / lack of personal freedom

This emerged as a strong theme in discussion with the majority of participants. Initially, a significant portion of the material presented here was incorporated under the heading 'Frustration'. Participants had frequently talked about feelings of frustration in direct response to questions about their anxieties, although why they linked them to anxiety in that way was not clear. Further examination of the transcripts showed that the frustrations reported by participants were invariably related to the constancy of caregiving, to perceptions of lack of freedom and to limited opportunities to tend to their personal needs. This suggested that the frustrations described by participants could be viewed as anxieties related to ongoing and seemingly unavoidable conflict between their own and their partners' needs. Most participants described uncomfortable feelings and emotions related to being unable to follow their own interests or to do things in their own time. For some, it seemed that acknowledging these feelings was difficult, perhaps because they were unsure of them, perhaps because they were seen in some way as unacceptable or inappropriate:

I sometimes wish I had more time to do the things I want to do. That's possibly being rather selfish. But I know it's important to have a bit of time-out, and that I

have to look after me so that I can look after him [...]umm ...I don't feel resentful, but I just sometimes wish that I had a bit more free time. (6.5.18)

The sense of freedom, the loss of freedom, that's an underlying factor [...] I don't want to give the impression that that worries me or annoys me... It does a bit, but not to the point that it's driving me, you know, up the wall. But it's one of the factors that isn't...isn't good. (4.17.9)

Well as far as physical things go, sometimes I would like ... I mean ... it gets frustrating because our original plans were, you know, when we retired, okay, we would get up and, no ties, we could go here there and everywhere. But of course you can't. (5.3.31)

I miss...I worry... Well not worry. I suppose...I fret about the fact that I don't have the freedom to do things spontaneously... I don't know whether it is a sense of loss or an anxiety. (2.11.30)

Several participants stated more clearly that they found their lack of independence distressing. They used words like 'freedom' and 'escape' to describe their need for time-out:

When I'm feeling mellow, I can accept. But other times I'd love to have a break, and it is no way of having one, really. X.'s gone into respite care a couple of times but he hates it. And when the doctor suggests it, X. looks at me and says... and I know he's angry. His attitude is, I'm the one that's had a stroke, why should she need break? There's nothing wrong with that. Because he doesn't realise the limitations of my life, that there isn't the freedom. That's it! There isn't the freedom. No freedom. And, yeah, that's probably it. (2.14.18)

My kids say, "Every time I come over you're complaining about something or moaning about something"... It's usually, I want to escape, I want to get away from here! (7.15.49)

Two participants clearly described anxiety related to conflict between their need to be with siblings overseas and their responsibilities to their partners at home:

My only sister lives in England and has no family, and unfortunately her husband was diagnosed with a brain tumour [...] I was unable to go to her... I probably might have gone. I kept saying, No I won't umm ...My son says I'm always negative... I said, if I go, something will happen and your father will pass away and I couldn't live with that. (9.6.46)

My brother's just lost 25% of the stomach with cancer, and it may be on his liver. Now, it is his 70th birthday in May next year...Now, I'd like to go next year, if my brother is still alive, to his 70th. So it's worrying me a bit at the moment, because I'd like to go, and we do have enough money that I can go out, but what do I do with X? Can I put her in a home? Are they going to look after her? Will she be all right? So I'm worrying about my brother, Can I get to see him before he dies? Is he going to last? (8.11.3)

Influence of main anxieties

This theme emerged across all interviews as participants explained how their anxieties affected their everyday lives.

Place of main anxieties

In apparent contradiction of their having identified main anxieties, all but two participants said that they were not generally anxious and that the anxieties they had described were not prominent in their everyday thoughts and lives.   At the same time however, most participants described those anxieties as being 'constantly there':

> *Well, I don't dwell on them, if that's what you mean, but you know it's always there and ...aah... I just ... Well, you can't really forget it... but it's not the predominant thing. I don't wake up and say, is he going to have a stroke today? (6.1.49)*

> *But you do worry all the time. You're living with it. Are they going to have another stroke? So this is where the stress comes into it. You are continually worrying and sometimes you'll go in and their breathing will be shallow and you think, Are they still alive?...Have they passed away? These thoughts go through your mind all the time. They are constantly there. You never... I don't think you ever really lose them. (8.2.7)*

> *But I don't consciously worry all the time, but subconsciously, of course I guess I do ... And I'm going to check on him, do you mind? (4.15.33)*

> *Oh, well they don't take over your life, because you couldn't let them could you. But it's there in the back of your mind, really. Of course it is. (7.17.47)*

> [re leaving his wife alone]
> *So it is still at the back of your mind, all the time, at the back of your mind. And she's also had one stroke and then she had a very minor one. So there's always this worry that she is going to have another one. (8.4.39)*

As can be seen in the quotes above, participants frequently used expressions like 'subconscious', 'underlying', 'at the back of your mind' and 'background' to describe the place of anxieties in their daily lives.

Triggers for anxiety

Participants also explained that the influence of their main anxieties was not static: They were more aware of their anxieties at some times than at others:

> *Sometimes they pop up from time to time. You know and umm, then they just slide out again and you don't worry about them for a couple of months. (8.6.48)*

> *They can be there all the time yeah...Yeah, I suppose it just goes through in the day, and other days, they become a major. (9.11.29)*

All participants explained that their main anxieties moved in and out of prominence in this way. While the majority of participants described themselves as able to control their anxieties, keeping them in the background, they also talked about external events that could trigger anxious thoughts, bringing their main anxieties to the fore:

As I say the only time I get anxious is thinking if I feel it's moved from where we are comfortable now. I feel I can cope with now but if tomorrow changes then, you know, it's an adjustment again and would I be able to cope with that? (3.3.23)

Even now when I've just been in the hospital seeing somebody else have a seizure it just brings on dreadful anxiety for me, where I start to shake and feel unwell. (9.1.32)

I would worry about umm if X. gets sick or something like that then I'm going to worry, because a lot of people have had two strokes and three strokes and she's had one. So when she gets sick, you think is this going to be another one, you know, so how are we going to survive? (8.1.45)

[Things that trigger anxiety about her own health] *Getting a phone call from one of my friends at Stroke Club, who's only in her late 40s early 50s. And she's got bowel cancer and she had an operation last week. And I thought, Oh, that's just awful. It could have been much worse than it was but it's bad. Umm She... Yeah, ...And things happen in other people's lives, I suppose, that. (2.15.43)*

[Trigger for anxiety about the future and further stroke] *Well after I spoke to you I suppose... perhaps if X. does something that's a bit silly, which he wouldn't have normally done You think, you know, of gosh, fancy him not being able to cope with that or fancy them doing that. And, you know, stupid little things. (6.2.15)*

Anxiety related to leaving partners alone was naturally prominent whenever participants were separated from their partners or when they made plans for outings or alternative care. Not surprisingly too, participants who had regular cancer checks felt more anxious about their health in the times leading up to checks and while waiting for results. Several participants also mentioned that they were more likely to feel anxious, and less able to set anxieties aside, under some circumstances than others:

And the mornings are always kinder than the nights, I've found. In the night, things seem terrible and I keep having to tell myself the morning will be nicer. It won't seem so bad in the morning. And it isn't is it? (3.8.12)

I was so upset, really. Perhaps I was tired that week or - because I do get very tired sometimes - and perhaps that came on it because I had been a bit tired, when I look back. And that came on top of it and that tipped me over a bit. (7.8.29)
And they [anxieties] can tend to take over, because it just perhaps hits you at a low spot. Usually a low spot when it hits. (5.1.11)

Probably if you're really tired or really hungry or not feeling 100% it's more likely. (1.21.2)

<u>Relationship to other anxieties</u>

As they explained what made them anxious, some participants also talked about what did <u>not</u> make them anxious and why. Their accounts suggest that consideration of their major anxieties influenced perceptions of other, potentially worrying situations. Several participants explained that their main anxieties were such that, by comparison, other lesser problems or worries were of little consequence. Few participants were able to identify anxieties other than the main ones they had described:

> *Those are the two crucial ones [anxiety re further strokes and own health]. Umm, the next one thing we would be going down to...It's very hard then because umm once you've got those two big ones out of the way. The others seem quite ... you know well they just seem such immaterial things...(5.16.29)*

> *I don't think anything else really worries me [Everything else that crops up day to day seems]... Well, it doesn't matter. (3.14.3)*

However, the anxieties described by the two participants who were receiving treatment for anxiety problems appeared to be fundamentally different from those experienced by other participants. These participants described their anxiety as more prominent, frequent, and for one in particular, broader-based. From their comments it seemed that the anxiety they experienced was more easily triggered and less predictable and not limited to the main anxieties they had identified:

> *Well, there's something most days that will appear to make me anxious. It's always things that <u>might</u> happen...Oh well, daily is probably putting it a bit much... There's always an undercurrent of anxiety. But, and doesn't take much to trigger it. (2.7.16)*

> *Yeah, I guess there are things throughout any week that you get anxious about...I think, it could be anything that could trigger it off, yeah. (9.14.1)*

Signs and symptoms of anxiety

This theme subsumes material related to how participants recognised anxiety in themselves and others. It was anticipated that participants would be aware of changes that accompanied anxiety and that these observations would form a large part of their accounts of anxiety-related experiences; Four of the questions in the interview schedule invited responses related to signs and symptoms of anxiety (see Questions 6, 8, 9 and 10). However, the material gathered was surprisingly limited. Furthermore, much of the material that did map onto this theme was embedded in participants' general definitions and accounts of anxiety. Very little was gathered in direct response to the

scheduled questions and by far the most part related to thoughts that accompanied anxiety.

Anxious thoughts

Anxious thoughts appeared to play an integral part in all participants' perceptions and experiences of anxiety. Whether discussing anxiety in general or their own in particular, all participants spontaneously mentioned thoughts that accompanied anxiety, and all save one, in talking about times they had felt anxious, described experiences in terms of their anxious thoughts:

> *All sorts of stupid things go through your mind. All these little things start playing through your mind and you think, Can this happen? Can that happen? (8.15.13)*

> *Yes, and if he's late then I'm pretty well stressed thinking, Is this is going to be the next stage? What is the next stage? Umm That's really what stresses the most or anxiety. (3.1.10)*

An overwhelming proportion of these thoughts were presented in the form of questions or exclamations. Consistent with participants' definitions of anxiety, these focused on negative situations that might arise in the future:

> *What would happen to X if anything happened to me? (5.2.44)*

> *So when she gets sick, you think, Is this going to be another one? You know, so how are we going to survive? (8.1.47)*

> *You know, of course he came home springtime and ... I used to sit outside at night and think, Dear God! What am I going to do here? You know, you'd be frantic thinking, How the heck am I going to do this? I'm never going to cope with all this! (7.11.23)*

> *God, What if I had a stroke too! (2.13.46)*

Physical symptoms

Only one participant spoke of physical feelings and fear as dominating her experience of anxiety, which typically had taken the form of panic attacks:

> *...You start to feel that you're dragging. You feel unwell. You might get heart palpitations, not really bad ones, but enough that you ....and your head is really banging. (9.2.2)*

When talking about these and other anxieties related to more specific issues and situations, however, this participant too described anxious thoughts:

> *Do I ring somebody? That's really what goes through my mind. Do I need the support of someone to say "Well, you're being silly" or "Do this" or "Wait till the morning." (9.11.25)*

Changes in behaviour

Some participants mentioned changes in behaviour that they associated with anxiety. However, these observations were comparatively few and were generally only offered in response to the question, 'How do you know when you are anxious? (Question 7, Appendix D)

Sleep: A number of participants associated interrupted sleep with anxiety:

> *It turns over in my head all night, for a whole night, might be for a whole night. I will sit there and think of all the pros, the cons, What could go wrong? Why it's going wrong? Will I be able to fix it? All that sort of thing, instead of sleeping for a night you're blimmin' well twisting this all around in your brain all the time. (5.7.18)*

> *And you know I have had nights when I just have not slept and I'm thinking, Why am I not sleeping?, What am I anxious about? I know I'm anxious, but I can not pinpoint what is. (3.8.29)*

> *Umm I have written here sleep, because each time M.'s had a stroke it's been during the night. ....And you know, old people have to get up and go to the toilet at night. Each time I hear him get up, I am sort of half awake, waiting to see, does he get to the toilet? Does he get back properly? (6.6.21)*

One participant explained that he usually lost his appetite when he felt very anxious:

> *I don't eat. ...I stop eating. I lose my appetite altogether. (8.15.34)*

Several participants said that they telephoned their children more often when they were anxious and that they were probably more short-tempered or grumpy than they would normally be:.

> *Perhaps I am a bit short tempered. I'm normally placid sort of person, umm or I might sort of ring... No, I don't ring them often but when I do ring it's probably what I say or how I say i. Possibly I would ring them more often than I would normally rather. (6.15.43)*

Another two participants spoke of being more restless than usual:

> *...I tend to not to be able to concentrate on anything very much. I'll start something and shoot off and do something else, and think, Oh, have I finished that yet? You know, that kind of pattern. (5.8.36)*

Aside from these examples, participants seemed unaware of any other changes in their behaviour that took place when they were anxious. Most believed that other family members would know if they were anxious, but were unsure of what signalled their anxiety:

> *Probably the face and sometimes the way you walk. (8.14.43)*

They can see, yeah, not necessarily my physical manner, you know. I don't mean, my physical demeanour, the way I walk in the way, I move. Not that, but facial. (4.9.4)

They'll say, "Mother I've seen it coming for the last couple of days." So obviously they've noticed something ...probably that I might be a bit short with them or ... don't know ... don't know, but they say, "I've seen this building for a couple of days." Mm (9.10.28)

Interestingly, in contrast to their apparent uncertainly about the outward signs of their anxiety, all participants were quick to say that they could identify anxiety in their partners and were able to describe changes in their partners' behaviour.

Management of anxiety

This theme emerged across all transcripts as participants explained how they usually dealt with anxiety. The information presented here often followed the scheduled question "What do you typically do when you are anxious? (See Appendix D). This outcome was actually not anticipated by the researcher, the question having been expected to invite comments about behavioural symptoms of anxiety. However, participants clearly interpreted the question as asking what they typically did in order to relieve anxiety. When talking about their anxieties, participants frequently distinguished between situations over which they believed they had at least some control and others that they believed were completely beyond their control. This distinction is reflected in the following sub-themes. The first, 'Active management,' emerged from participants' accounts of the specific actions that they took to assess and to deal with their anxieties. The second, 'Acceptance,' was usually embedded in participants general accounts of the difficulties they faced, and talk about their approach to negative situations (present and future) that could not be controlled or avoided.

Active management

This sub-theme gathers together material related to specific strategies that participants employed to deal with anxieties. In many cases, these strategies appeared to be steps in a process that allowed participants to take stock of their anxieties; to determine why they felt anxious, whether or not their anxiety was warranted (i.e. based on outcomes that were realistic and probable), and whether the situations that provoked it were able to be changed in any way. In contrast to the tentative way in which participants often responded to questions about symptoms of anxiety, most were quick to

describe clear strategies that they used to cope with or to reduce feelings of anxiety: They appeared to be confident that the approaches they had found useful in the past, would be similarly helpful in future.

Self- talk and Counter-thought

Just as thoughts had been a prominent feature of the anxieties reported by participants, so they were frequently described as means by which participants countered anxiety. All participants spoke about using self-talk or thought to combat anxious thoughts, particularly in situations where they saw their anxiety as unproductive or somehow irrational. The goal of this self-talk appeared to be to convince themselves that their worry was pointless or unwarranted:.

> [I] try *and reason that there's not a need to be anxious, and that does help. I haven't yet got to a situation where I haven't been able to reason... (6.11.26)*

> *All sorts of stupid things go through your mind. All these little things start playing through your mind and you think, Can this happen? Can that happen? And you think now you're being stupid! Don't worry about it. Forget it, forget it. (8.15.13)*

> [re her granddaughter being out at night] *Well, of course, you are wondering if she's safe and then you're telling yourself you can't do anything till morning. She's a big girl, it'll be all right. Just all those sorts of things, trying to convince yourself to go to sleep and stop worrying about it... (9.11.12)*

Distraction - Temporarily pushing anxiety aside

Some participants also described strategies that allowed them to put their anxiety aside temporarily. Sometimes, it seems, they did this in the knowledge that time passing would, of itself, lessen their anxiety, other times recognising that they would be able to deal with issues more effectively at a later stage:

> *I can balance things. And I can um do what he* [her therapist] *says. He always says, "When the thought strikes, just say to the thought, I'll think about that later when I've got time." And that sort of...I'll think about that later if I've got time. They're all coping mechanisms. (2.14.43)*

> *Sometimes you get yourself all worked up but you go to sleep and you give yourself 24 hours and you think, Oh well, I'm not worried about that anymore. (7.11.46)*

> *So you just wonder... just wonder sometimes ...where everything is going...But you can't do anything about it. So then you just keep going and take what one day at a time. And it really is, that's the best way to deal with it is to take one day at a time. And I'm sure you'll find that with a lot of people. (5.17.34)*

> *In the night, things seem terrible and I keep having to tell myself the morning will be nicer. It won't seem so bad in the morning. And it isn't is it? Night-time's... So*

*out come the books! ...Get to a book and eventually fall off to sleep at about six in
the morning and then don't want to get up then at about seven! (3.8.24)*

*A good book and the television will put it out of my mind all right... That's why I
think these detective books are really good, I mean, it's impossible to think of
something else if you get a really good author. (1.12.45)*

One participant explained that he used meditation and breathing exercises as a main
means of dealing with anxieties:

*Sometimes worries do stick around for awhile and umm, what you have um you have
a magic pot here [showing the place - centre of body] you see, and you put your
worries into it. And at the end of the day you look down and there's nothing there.
So you've got nothing to worry about. Because of the martial art that I do, this is the
way we think. Mind over body. (8.5.35)*

Time to problem solve

Participants also described making time to concentrate on their anxious feelings to
decide what was behind them and how best they could deal with them. The five
participants who spoke about this, all talked about thinking problems through on their
own, often while taking a walk, and of trying to determine what, if anything, they could
do to resolve the situations that were troubling them:

*Well, I might go for a walk or both of us go to the waterfront and walk along. And
usually by the end of the walk and that I've decided what to do about it. (3.7.37)*

[Thinking about the future when her husband first had a stroke] *But you know you sit
out there, have a cup of coffee or a glass of wine at night ... And you sort of think,
okay, tomorrow I'll try this. I mean, you've got to. You've got no option. You've got
to find a way around it. (7.11.22)*

*The way I work things most out is that if I've got something that's really bugging me
I'll go through it at night, but I'll go out for a walk. And during that walk, I'll look
at all the angles... This is in broad daylight after having had a sleepless night if you
like - Go out for a walk, look at all the angles and, completely on my own, and then
I'll sort something out and then I'll probably ring up one of the kids and discuss with
them and say, Which way do you think I should go? And they will say... and what
they say will probably be what I've already decided anyway...And that's it and then
it's sort of dealt with. You might still have to do the practical things but the actual
anxieties have gone. (5.15.30)*

Practical action - reducing risks

For most participants, it seemed that deciding on some practical action that they
could take, helped to relieve their anxiety. Finding elements of those situations that they
could control or modify appeared to be helpful, even when for the most part the
situations remained unchanged:

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It'll be the immediate things, sort of like when I first came home from hospital, I'll never cope! How on earth will I do it!" But you do, because you take over the practical side, and you get the control back. (5.2.1)

I think it's my mother again. She'd say, if you are really upset or worried about something, you've really got to get up and do something. (1.19.20)

Participants described taking what practical action they could to avoid the problems or unpleasant situations associated with some of their main anxieties. With regard to their anxieties about health, they recognised that there was nothing to guarantee their future health. However, several talked about doing what they could to prevent problems:

So you don't do anything stupid, and you watch what you eat. I don't eat any fats or anything like that. So you're aware of what you can do. If I get tired, I stop and sit down. I don't push it. (8.3.46)

And umm so you tend to make...I make sure that I keep myself as fit as possible so that it doesn't... the situation doesn't...It could arise. Obviously one day it going to arise, but at the moment we'll just try to keep clear of it. (5.2.40)

Many participants used mobile phones or monitored alarms systems to reduce risks associated with leaving their partners alone:

Even now that she can't get up and walk now, she sits in her armchair and I can leave her for an hour or two hours. No problem, but I take the mobile phone with me. (8.4.37)

I'll tootle out and do what I have to do. But I'm always conscious umm like if I am sitting in church, I'll have it [the mobile phone] *in my hip pocket, or somewhere where I can feel at vibrating so that....you know, if he needs to ring me... So no, it's always there at the back of ...you know, an underlying thing. (4.2.45)*

Although these plans appeared to reduce the anxiety participants felt, it was clear that some anxiety remained. However, knowing that there was nothing more they could do appeared to play a part in allowing them to set these anxieties aside.

Support - asking for and accepting help from others

All participants talked about the role of support in dealing with the anxieties they experienced. This support came from a variety of people and places, among them friends, family, social activities, and religious beliefs. Most participants described support that came from being able to share their thoughts and feelings with people who would listen and understand:

Now, I do rely, I must confess, on all the kids. If there's something I really want to think about, I can get on the phone, talk it through. It's a good way. Once, I've been for a walk and sorted it out, I can talk it through. (5.16.4)

What I tend to do is ring each child in turn when I need to go out so they all, sort of, have a turn of looking after him and can see for themselves that he's not the dad that he used to be. So in that way, I guess I'm getting rid of some anxiety. I'm sharing it with them. (6.10.9)

My dear friend, I will tell her and we have quite long talks and I will tell her and she really understands...So if she says, "How are things?" I can tell her truly how they are instead of my usual reply, Yes, fine, coping. (3.22.31)

Two participants explained that their religious beliefs provided an important source of support in dealing with problems and anxieties:

I've got quite a firm belief in God, so I tend to, sort of, fall back on him. Tell him, Look, come on, you know, I need a hand - Quite personal - There's none of this down on your knees sort of thing. [Laugh] It's, God, Do something! So I have found that that is quite a calming...That's very calming. So, um, to a certain extent, if you like it's shoving it off to somebody else. (5.7.39)

I tell you what, I am a Christian and whether a not that has...That probably has a lot to do with it, because I hand a lot of my worries over...Because some things I can't change and I just ask for help to cope. I've probably handed a lot over, and say, Well, I can't cope. You take over. (4.5.35)

Two participants talked about the support that they enjoyed in the past but that was no longer available:

Unfortunately, X. and I weren't Auckland people...We're not from Auckland we're from X. So you don't have... our friends are in X.... So you don't have those close friends that you can talk to. You don't have them. (7.11.43)

Well, they [her adult children] might just say, "You look a bit tired today." It is that it. Nothing else. No, they say, "You're doing a good job, Mum, keep going." (7.15.43)

One explained how she had always relied on her husband's support to deal with anxieties but that she had lost this support when he had his stroke:

He has lost the capacity to empathise. He was <u>always</u> my greatest support...He was always my... umm...He'd get things into perspective, you know. (2.12.4)

Medication and counselling

For two participants, as noted earlier, medication and counselling appeared to provide a main means of coping with current anxieties. Both had been taking antidepressants (Arapax), prescribed by their doctors, for a number of years. One had also received successful psychotherapy for panic attacks:

And a couple of hours with him [her therapist] certainly helped me enormously. And he gave me a lot of stuff to read which I keep in a file in there. And when I find

myself on that black path, I take it out and read it and get myself back on track again (2.1.2)

Yeah, well, of course he [her GP] put me on some medication, antidepressants, just to keep me on the straight and narrow. A couple of times I've tried to come off them, but I'm on just a mild dose now. Unfortunately, I was pretty well off them but after the stroke with X., I had to go back on. (9.2.19)

While other participants had talked about the value of support but seemed confident in their own abilities, these participants expressed doubts about being able to cope with current or future problems without the help of medication or the direct involvement of other people.

Acceptance

This sub-theme emerged as participants described their experience of coping with anxieties arising from situations that they believed they could not change. One participant talked specifically about having to approach these concerns in a different way:

For instance, you think, if something went wrong with you, what's going to happen in future. How are you going to cope? All the different little things that come together and can make you very anxious... Of themselves they may not be much at all, but they're things that can happen that are outside your control. So you have got to start thinking of a different way of dealing with them. (5.1.32)

Another participant, explaining how she usually dealt with anxieties, spoke directly about the need to accept what she could not change. For her, it seemed, acceptance was a conscious goal:

Is there anything I can do? Is it able to be changed? If it isn't, well then, what you do you do? You have to accept it. So, how do you accept it without it ... and you just work it through and think, Oh well, that'll have to be. And Oh blow it! But...And that's it. (3.7.39)

The participant quoted above was the only one who talked about working to achieve acceptance; most participants spoke of acceptance in a passive sense as something that had come about with time. However, recognition of the need to accept situations beyond their control was inherent in the view expressed by the majority of participants, that there was "no point" worrying about the things they could not change:

But I know, twenty years down the track... You're thinking, yeah well, you won't be able to do quite what you're doing now. But you may not need to twenty years down the track. So that's a kind of a... a kind of an anxiety you can push aside for the time being because there're not much point concerning it. (5.10.18)

I've thought about it [husband having another stroke]. *It's no good worrying about it because it is going to happen somewhere. Something's going to happen, you know it is. It's no good worrying yourself to death about it... (7.6.49)*

If you can't fix it and you can't help, then don't worry about it because there's nothing you can do about it. So just forget it. (8.4.32)

Acceptance of own limitations and abilities

A number of participants talked about having to accept their own limitations:

To start with, yes. [the change of responsibilities made her anxious] *But it's... Once you realise that you can only do what you can do and after that you get someone else to do it for you. So, umm... And you call on help and umm people have been really so good that if I've needed help, I've got it, on call. (5.6.34)*

So you look at it, and basically, it's evaluating yourself and your own capabilities, and you're the only person who can do it. No one can do it for you. So if am not sure of anything, I will ring up and ask advice. Doesn't matter what is... (8.5.13)

No time to sweep the kitchen floor or do things like that. That's how it goes - that doesn't matter. That's' just how it goes. (6.13.33)

Acceptance of current situation and partners' disabilities

Several participants also spoke about having come to accept their current situations and their roles as caregivers:

... I've come to accept that what will be, will be, that I can't change it. Um, You know, at first I was determined that I could do everything in my power to get him okay but, because of the damage, I know that I can't. (9.4.40)
I only think about it when maybe I sense X hasn't umm ...is not improving and that if I see an obvious state where he is getting worse, then I get anxious. But umm, other than that I don't, just accept. (3.3.32)

Acceptance of lack of control over future health

Other participants talked of having come to accept that that they had little control over the ageing process or future health problems:

Maybe I've come to accept that this is what happens. If we just go back to health with X., we know he's had those strokes, I can't do anything more about it. (6.22.39)

And I mean, you don't think of it when you're younger, but it's much easier to hurt yourself when you're older, even though you don't think it should be. It's still much easier to hurt yourself. It's easier for health things to go wrong. They can go badly wrong, much more quickly. So, that's a thought *there, but it's something you just live with. (5.11.8)*

Comparison - "Things could be worse"

Comparisons, in favour of existing circumstances, were embedded in descriptions of most participants' lives and experiences. Participants frequently talked about others

who were worse off and about their own situations as better than they used to be or than they might have been. The inclusion of 'Comparison' here, as a sub-theme of Acceptance, is tentative since the links between comparison, anxiety and acceptance were seldom made explicit in the transcripts. However, several participants did suggest that making favourable comparisons helped them come to terms with their current situations and so control their anxiety or distress:

> *So, it's* [anxiety] *is not something that would come in and take over my life. There'd be some way I would think, well, there's worse happening to somebody else, so what are you worrying about, type of thing. (5.1.46)*

> *And we know, there's not going to be any improvement it's only going to get worse... And then I try and counteract that by saying, well it could be a lot worse. He could be in a wheelchair. He could be in a hospital bed. He could be completely gaga. So we do have some quality of life left, even though it's not what we'd planned for our old age. (6.1.35)*

The comparisons that participants made were many and varied, but all touched upon situations and issues that had been identified as major sources of anxiety. In many cases participants compared their own situations with those of others whom they considered were worse off:

> *X's always been a very good, placid, good-humoured, loving person and he really hasn't changed, which is wonderful, because so many people with strokes become disgruntled and frustrated and angry. Well, I don't have to deal with that, so that's a great relief. (6.8.50)*

> *It must be awful for families where there is no contact and where there is no caring and nurturing going on. (2.17.1)*

> *I'm fortunate. I've been involved in that* [martial art] *for years and I can still continue it. But for some people who don't have that, they don't have that outlet, then it would be more stressful for them than it is for me, because I do have that hour, hour and a half each night where I go and do training. (8.12.35)*

> *There was a guy that lived next-door but one, and his wife has been an invalid for thirty years, and he hardly ever left the house. Now, I'd have gone stir-crazy in five minutes. And the fact is that, now, if I want to go out and do something and X's up, well, I put him in the car and we go off and do it. (5.19.12)*

> *Fortunately, I did have control of the money before, so I didn't need to learn to that, which can be a major problem for some people. I mean, at least I knew about paying bills and budgeting. So I didn't have that. (9.18 48)*

> *You know, I've known people who say, Now, look I'm lumbered with this when I really didn't have a good relationship. I think that must be awful. I think if you've had a reasonably good relationship in marriage, it's not so hard. (3.17.9)*

At other times, participants explained how their present situations were better than those they had had to deal with in the past or not as difficult as they had expected they might be:

> *We are on the old age pension now. So, we're $40 a week better off. (8.3.33)*

> *And that was bad.* [The time when husband had undiagnosed CFS] *If you'd hit me with it then, [laughing] I mean, But that's gone. And his physical health is absolutely terrific. He's just, really, he's never been as well as this for a long time and so ah... (5.4.37)*

> *I was terribly worried at first. I thought I'd go mad stuck at home with X. all day, but in actual fact, of course, I belong to* [community organisation] *and I do voluntary work for* [same] *so umm, most days there's something on. (2.3.34)*

> *So everything has ... as I say there's been so much support that it's been just ... It's made life so easy.. It's made life just so much easier and ...really the experience hasn't been nearly as bad as I thought it would be. (5.18.42)*

Although all participants talked about having accepted certain circumstances or possibilities, none explained how they had come to that point. Across all accounts, acceptance was described as a state, a way of thinking that had developed over time. Comparison appeared to provide participants with a way of coming to terms with their present circumstances. Acceptance appeared to provide a means by which participants could cope with difficult and unavoidable prospects on a daily basis. Finally, most participants also seemed to have accepted, and learned to live with, anxieties associated with care giving and with growing older. From discussions it seemed that participants were always mindful of their anxieties, but at the same time, were able to live their lives relatively unaffected by them.

Summary

Three super-ordinate themes emerged from the analysis: 'The phenomenon of anxiety', 'Views that influence anxiety', and 'The experience of anxiety'. 'The 'phenomenon of anxiety' refers to participants' conceptual understandings of anxiety expressed in their definitions of anxiety, and to the attitudes and beliefs they put forward about anxiety. Together these can be seen as playing a part in all other themes.

Each of the participants described anxiety as an unpleasant feeling, linked to stress or concern or worry, and characterised by worrying thoughts about things that were happening or might happen in future and that they believed they could not cope with or

control. At the same time, some accounts are suggestive of additional more complicated meanings or connotations, ones that by implication could be seen as reflecting badly on the individuals who experience anxiety. For several participants, it seemed that anxiety was seen not only as undesirable but also, in some circumstances, as unacceptable or abnormal and perhaps as an indication of weakness or lack of competence. Overall, the majority of participants indicated that they believed that the way in which people experienced and dealt with anxiety was in large part due to individual personalities or character traits, and to coping skills. It seems very likely that meanings such as these would shape participants views and disclosure of their own experiences of anxiety, and important that this be considered in interpretation of their accounts in interviews.

'Views that influence anxiety' captures participants' attempts to explain their current personal experiences of anxiety. Participants talked about how their personal characteristics and abilities influenced the anxiety they felt, and about how age and life-experience had changed their experiences of anxiety. Most saw the influence of anxiety in their lives as being directly related to the 'type' of people they were and to their ability to cope with new or difficult situations. Most also associated growing older with being less anxious. They noted that the things they were anxious about had changed considerably with different life stages. They explained too that their present perspectives and needs were such that many of the situations or issues that would once have worried them, were no longer cause for concern. The knowledge that they had coped successfully with past difficulties also appeared to give many participants confidence in their ability to cope in future and to limit their current anxiety. (Conversely, those who felt that they had not been able to cope by themselves in the past, did not expect to manage without help in the future and experienced the most anxiety.)

Participants' evaluations of their abilities and responsibilities as caregivers were also directly linked to the anxiety they experienced. In this, positive views of their own abilities, coupled with views of alternative care as inadequate or unsuitable, appeared to contribute to much of anxiety that participants expressed about their own deaths and about deterioration in their own or their partners' health. The sense of responsibility that they felt for their partners' safety and wellbeing was directly related to these

anxieties and to the anxiety that most of them experienced when they were apart from their partners. Awareness of their lack of control over situations and events seemed to be fundamental to participants' anxiety. However, in itself it did not appear to be sufficient cause for anxiety. Indeed recognition of what aspects of their current and future situations they could and could not control appeared to be instrumental in helping participants deal with feelings of anxiety; In making this distinction, it seemed that participants were able to take whatever practical action they could to lessen or avoid problems, and then, when they considered there was nothing further to be done, to somehow set their anxieties aside. Whether or not specific situations were associated with anxiety appeared to be tied more to the meaning that they held for the individual participants than to situations themselves, particularly to whether participants felt able to manage or cope with eventualities.

'Experiencing anxiety' refers to participants' descriptions of their own anxieties, and their accounts of how they recognised and responded to feelings of anxiety when they arose. The main anxieties identified by participants were surprisingly few and consistent across individuals. With the exception of anxieties related to adult children or grandchildren, all of the anxieties that participants outlined were in some way connected to their partners' strokes and to their roles as caregivers, and were concerned with realistic, probable outcomes. Given the identified focus of this study and that, as noted above, some participants seemed to view anxiety as reflecting somewhat negatively on individuals who experience it, it seems likely that at least some participants were selective in the anxieties that they chose to present or discuss. However, in the context of their wider comments, it was considered that participants were generally open and frank in their discussion. Most explained that they seldom felt anxious but that the anxieties they did have were always there 'in the background'. In general, they appeared to be less aware of their anxious feelings than they were of how they usually dealt with those. Most participants described 'tried and true' ways of dealing with feelings of anxiety but had more difficulty identifying signs or symptoms of their anxiety. The exceptions to this were the two participants with longstanding anxiety problems, who were able to describe their feelings in detail but appeared to have developed few strategies of their own to deal with them.

All participants referred to comparison and acceptance to explain the influence of anxiety in their lives. Comparison, it seemed, played a part in determining what worries or concerns constituted 'anxieties' in participants' minds - anxieties connected to their partners' strokes and to caregiving were described as 'overshadowing' lesser concerns or worries making them seem insignificant. At the same time, comparison also provided participants with a way of dealing with their anxieties - consideration that 'things could be worse' seemed to help participants cope with the current problems and with the prospect of future difficulties. Finally, acceptance was mentioned by all participants as a way of dealing with the anxieties and uncertainties that were a part of their every day lives. Participants variously described themselves as having come to accept their situations, their abilities, their partners' abilities, and their limited control over future circumstances. Most also explained that they had learned to live with the anxieties they had described and that, although they were always mindful of them, those anxieties did not have a significant influence on their everyday thoughts and lives.

CHAPTER SIX

Discussion

Anxiety has been recognized as a serious health concern in older adults: Epidemiological studies indicate that anxiety disorders are among the most prevalent psychiatric disorders in later life with 1 month and 6 month prevalence rates of 4.6% and 6.8% respectively (Regier et al., 1988), making them 4 to 7 times more prevalent than Major Depressive Disorder. At the same time, anxiety is reported by many caregivers (Cavanaugh, 1998; Shannon, 2001) and is thought to be especially prevalent among those who care for people with stroke, affecting as many as 20% to 55% of caregivers (Anderson et al., 1995; White et al., 2003). Still relatively little is known about the presentation and experience of anxiety in later life or about how that anxiety relates to caregiving.

The results of this study show how a group of elderly adults understand and experience anxiety in their daily lives caring for partners with stroke. Patterns apparent as themes across participants' accounts indicate common elements in participants' perceptions and experiences: They show that the anxiety that participants experienced centred on very similar issues and presented in similar ways; commonly held views and attitudes were identified that appeared to shape that anxiety. Findings suggest that participants' experiences of anxiety were significantly influenced by their age and by their roles as caregivers. Systematic differences were apparent, in relation to almost all themes, between the accounts of those participants who experienced anxiety problems and those who did not.

Understandings and experiences of anxiety

Main source sources of anxiety

The 'main sources of anxiety' detailed in participants' accounts appear to be issues that participants were most often anxious about. Other than anxieties associated with family matters, all of these sources (their own and their partner's health, separation from partners, money and conflicting needs) can be seen as reflecting ongoing or recurrent concerns that arose as a result of stroke or participants' roles as primary caregivers.

These concerns can be seen as grounded primarily in fears for their partners' day to day safety and wellbeing and doubts about their ability to provide care in the longer-term.

Although stroke and caregiving were the life-events that marked the starting point for most of the anxieties that participants described, the ongoing relationship between external events and experiences seemed to be less distinct or direct. Some anxieties appeared to be episodic, triggered by discrete events, particular times and situations, (e.g. waiting for the results of medical tests or being apart from partners while on outings or when they were in alternative care). These were usually resolved when those situations had run their natural course (e.g. test results were negative or participants were safely reunited with partners). Other anxieties, however, were less directly related to specific current events. These anxieties appeared to be more chronic, longer term concerns, ones that centred on events that had not yet happened, but that participants believed were likely to happen in the future (e.g. anxiety about further stroke, future health or financial problems and continued lack of personal freedom). It was these anxieties that participants often described as being 'always there in the background'. They were associated with anxious feelings from time to time, when situations arose (sometimes even seemingly irrelevant or insignificant ones) that prompted chains of thought that reminded participants of difficulties they may have to face in future.

Consistent with Stress-Diathesis (pp. 23-25) and Cognitive perspectives of anxiety (pp. 26-29), all of the sources of anxiety that participants identified, chronic and episodic, can be seen as associated with potential loss or danger: Each of these sources could be related to a wide range of situations that were perceived as involving similar risks. It seemed that participants' appraisals of events rather than the events themselves, determined the anxiety they felt. For example, the anxiety that participants expressed about further stroke appeared to be largely based on concern that this could lead to further incapacity that precluded home care, not on fears that another stoke might be fatal.

The main sources of anxiety for participants in this study appear to be common to many adults in later life and have been reported in a range of studies. These include anxiety about one's own health or that of a significant other (Gretarsdotir et al., 2004; Le Roux & Gatz, 2005; Wetherell et al., 2003), fear of death or injury (to oneself or a

loved one) (Gretarsdottir et al., 2004; Mohlman, 2004; Stanley & Beck, 2000) and anxiety about finances (Laidlaw, 2003). However, these sources appear to take on special significance in the context of caregiving. Participants attributed much of the anxiety they felt about their own ill-health or their deaths to concerns about who would then be available to look after their partners. Views of themselves, as the people most suited to caring for their partners, and of alternative care as being inferior appeared to add to those anxieties. Although they did not attribute these concerns to aging per se, participant comments nevertheless suggest that age may have contributed to those anxieties. Several talked of older people as being more vulnerable or more likely to develop health problems, one of being "past her use-by date". For some too, concerns about their health were linked to actual medical conditions and health problems. It seems likely that anxiety about one's own wellbeing would be more common among older caregivers than younger counterparts; that older adults, by virtue of their age or existing medical problems, may be less likely to take their continued strength or good health for granted.

Existing research, though sparse, suggests that some of the sources of anxiety identified in this study are shared by many caregivers, regardless of their age: Issues of safety of care recipients have been reported as among the major concerns of caregivers in weeks and months after stroke, along with difficulties related to loss of independence and to confinement (Grant et al., 2004). Over the first one to two years following stroke, many carers continue to report feeling tied down and having little time for themselves (Draper, Poulos & Ehrlich, 1995; White et al., 2003) and limit their own activities for fear of leaving care recipients alone (Anderson et al., 1995). Even those caring for people who have suffered mild strokes report continued distress related to fear of a second stroke and are afraid of what the future might hold for the person with stroke (White et al., 2003). It is interesting that although participants in this study had been caring for their partners for very different periods of time (ranging from one to ten years), their concerns were centered on very similar issues, many of which, as noted above, appear to be relatively common in the early weeks and months of caregiving. This finding is important as it suggests that a number of the anxieties that caregivers experience soon after stroke may persist and even be relatively common across the entire course of caregiving. For instance, participants in this study still struggled (some after many years of caregiving) with issues related to limited independence and lack of

time to attend to their own needs and interests. In addition, the safety and general wellbeing of their partners continued to be a prime concern for all participants, regardless of how long they had been caregivers. Most still experienced anxiety about leaving their partners alone, about the possibility of further stroke, and also about what the future held for their partners, particularly if they could no longer be cared for in their own homes.

Influence of main anxieties

Participants could readily identify the issues or circumstances that 'made them anxious'. However, despite this and contrary to what might be expected given the challenges of caregiving, most reported that they seldom felt anxious. They explained that this had been the case for much of their lives and had not changed appreciably since their partners' strokes or since they became caregivers. The main anxieties they did have were often described as being 'at the back of their minds' having little impact on their daily lives. None of the participants associated aging with increased anxiety. In fact, most believed that anxiety had actually come to influence them less over the years. These reports are consistent with previous studies that show that anxiety disorders are less prevalent in later-life (Fuentes &Cox, 2000; Regier et al., 1988) and that older adults generally experience greater mood stability (Lawton et al., 1992), less negative affect and lower levels of worry and anxiety (Beck, Stanley & Zebb, 1996; Mroczek, 2001) than younger people. Set against these findings are others that suggest that anxiety is a relatively common experience among caregivers for stroke (Anderson, Linto & Strewart-Wynee, 2005), one that may persist and even increase over the course of caregiving (McCullagh, Brigstocke, Donaldson & Kalra, 2005; MacNamara et al., 1990). However, in common with most other studies of caregiving, the studies above do not differentiate between caregivers on the basis of their age or their relationship to care recipients. There are no findings available at present then that indicate in what way and to what extent elderly people might be expected to experience anxiety in caring for partners with stroke.

Worsening of relationship between caregiver and patient, being a spouse, shorter period of time as a caregiver, and greater physical disability, behaviour or mood disturbance in the patient, have all been shown to be risk factors for burden among elderly people caring for stroke survivors (Draper et al., 1995). However, whether or
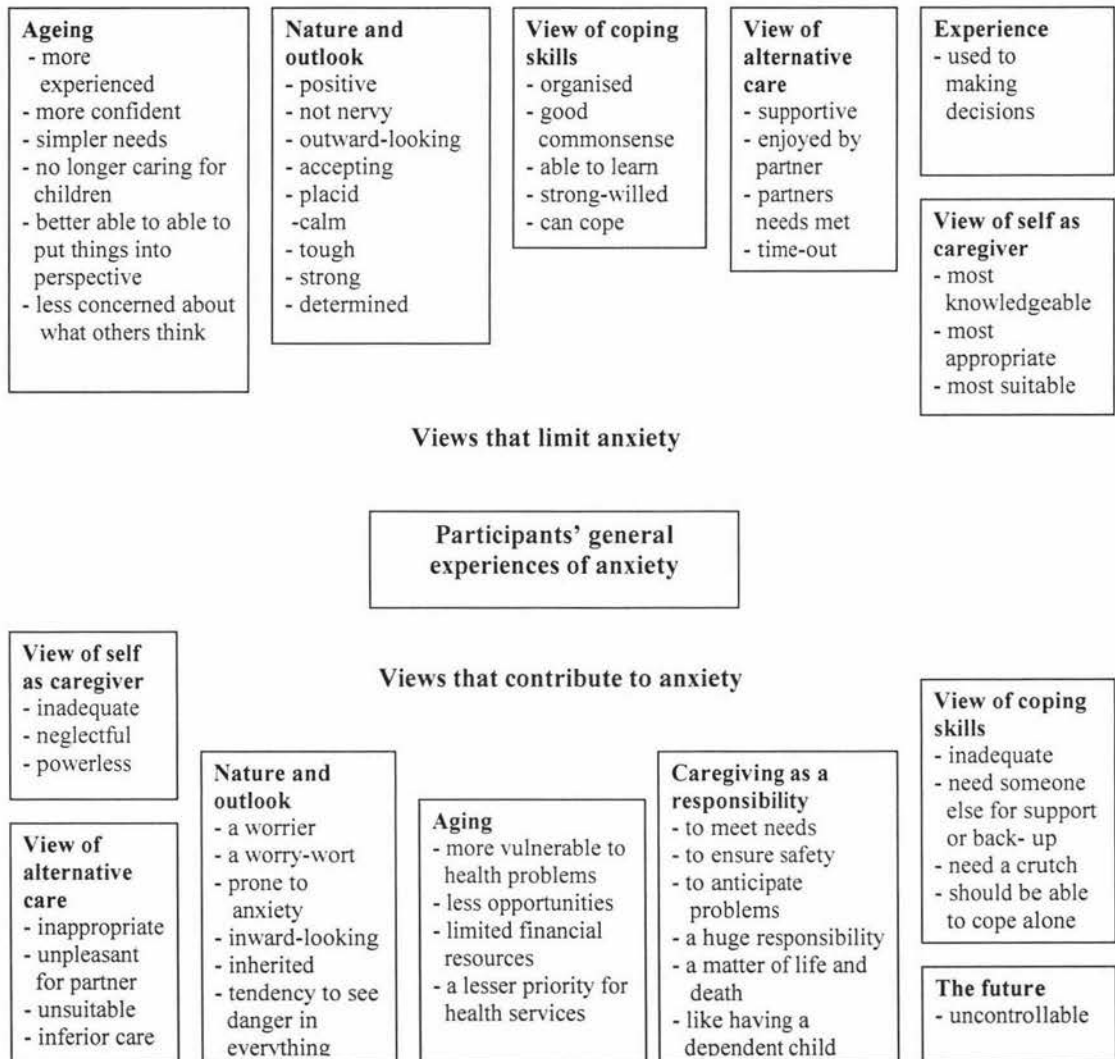
how these same factors might contribute to levels of anxiety or to anxiety problems in older caregivers is not known. It is possible that the low levels of anxiety reported in this study reflect participants' stage of caregiving: None of their spouses was in the acute stage of stroke or receiving ongoing treatment and most participants had been caregiving for at least a year, some for many years. Certainly, many drew on situations that had arisen at the time of their partners strokes or early on in caregiving to describe the way they felt when they were most anxious.

The levels of anxiety reported by participants appear to be consistent with some caregiving research that suggests that, in contrast to risk factors for burden noted above, caregiver anxiety is generally unrelated to the degree of physical disability or dependence of care-recipients and more influenced by the emotional status of care-recipients (Dennis, O'Rourke, Lewis, Sharpe & Warlow, 1998). However, for the two participants who experienced anxiety problems, it seemed that that the nature of their husbands' disabilities did play a part in the anxiety they experienced after stroke. The partners of both these participants had suffered cognitive impairment that significantly limited their ability to interact or to empathize with others. Both of these participants talked of having relied on their husbands to help them deal with anxiety problems prior to stroke. For them, the loss of their husband's emotional support was a particularly salient consequence of stroke; in the case of one participant, a loss that she still felt keenly some ten years later. The experiences of these participants suggest that the emotional or cognitive status of care-recipients may uniquely impact on spousal caregivers, in particular on those caregivers with existing anxiety problems or who were dependent on their partners' emotional support prior to stroke. Whether the participants above were more reliant on their partners than others had been prior to stroke is not known. However, the lack of confidence that they expressed in their own abilities set them apart from other participants and appeared to have a major role in the anxiety they experienced.

Views that influence anxiety
Related to that, a range of beliefs and attitudes were identified across all accounts as shaping participants' general experiences of anxiety and influencing the levels of anxiety that they experienced from day to day. Some of these were offered by participants themselves in explanation of their experiences, others emerged in analysis.

These views are presented together in Figure 2 below. Participants general experiences of anxiety are shown to be influenced by views about themselves, caregiving and aging that either served to limit or contribute to the anxiety they experienced. Although they are presented separately, these views are clearly interrelated and could be expected to influence each other. Whether or not differences in participants' assessments of their abilities were based on actual differences in their knowledge or skills is not known.

| Ageing
- more experienced
- more confident
- simpler needs
- no longer caring for children
- better able to able to put things into perspective
- less concerned about what others think | Nature and outlook
- positive
- not nervy
- outward-looking
- accepting
- placid
-calm
- tough
- strong
- determined | View of coping skills
- organised
- good commonsense
- able to learn
- strong-willed
- can cope | View of alternative care
- supportive
- enjoyed by partner
- partners needs met
- time-out | Experience
- used to making decisions

View of self as caregiver
- most knowledgeable
- most appropriate
- most suitable |

Views that limit anxiety

Participants' general experiences of anxiety

Views that contribute to anxiety

| View of self as caregiver
- inadequate
- neglectful
- powerless

View of alternative care
- inappropriate
- unpleasant for partner
- unsuitable
- inferior care | Nature and outlook
- a worrier
- a worry-wort
- prone to anxiety
- inward-looking
- inherited
- tendency to see danger in everything | Aging
- more vulnerable to health problems
- less opportunities
- limited financial resources
- a lesser priority for health services | Caregiving as a responsibility
- to meet needs
- to ensure safety
- to anticipate problems
- a huge responsibility
- a matter of life and death
- like having a dependent child | View of coping skills
- inadequate
- need someone else for support or back- up
- need a crutch
- should be able to cope alone

The future
- uncontrollable |

Figure 2. Participants' views identified in analysis as influencing their experiences of anxiety

Interestingly, participants' explanations of why they experienced anxiety as they did were almost entirely couched in terms of their own attributes and abilities which they saw as working either to protect them from or prompt them to anxious feelings.

Most expressed clear opinions of their anxiety as determined largely by the 'type' of people they were and by their ability (innate and learned) to cope with difficult situations and with anxiety itself.

The pattern of characteristics and skills that participants saw as determining their own experiences of anxiety was markedly different for those who experienced anxiety problems and those who did not. Those participants who reported that they were seldom anxious expressed positive views of themselves and the care that they provided for their partners and were able to identify skills that they had acquired with age that had allowed them to cope with difficulties that arose in their lives. That they had coped successfully in the past appeared to give them greater confidence in their ability to cope in future. By contrast, participants with anxiety problems talked of anxiety as being part of their nature, something that had changed little with time or experience. They saw themselves as lacking the skills or the confidence to deal with anxiety or with adverse situations on their own. While the views outlined in Figure 2 could be expected to develop or change over the course of caregiving, it seems likely that, for participants in this study, differences in their views of self and coping skills, as outlined above, would have been apparent at the outset of caregiving. Whether or not participants experienced anxiety problems prior to stroke appeared to be the key factor in determining the anxiety they experienced after stroke and in caregiving.

Signs and Symptoms of anxiety

Frequent mention is made in the existing literature related to late-life anxiety of the tendency of older adults to express their anxiety primarily through somatic symptoms (Fuentes & Cox, 1998; Owens et al., 2000; Palmer, Jeste & Sheikh, 1997; Sallis & Lichstein, 1982; Stanley et al., 1996). It is notable then, that the anxiety symptoms reported by the majority of participants in this study were overwhelmingly cognitive: These cognitive symptoms were all anxious thoughts about negative situations that might arise in future. Consistent with cognitive perspectives of anxiety, they reflect participants' appraisals of situations as dangerous or threatening loss (e.g. "What if the worst happens?"; "How are we going to survive?") and of themselves as lacking the resources to cope ("How the heck am I going to do this!"; "I'm never going to cope"). These thoughts were evident across the accounts of all participants, most often recounted quite spontaneously as they recalled times when they been most anxious.

Beyond those thoughts, very few symptoms were reported and then each by only one or two people. Those that were reported were restlessness, interrupted sleep, loss of appetite, irritability, and muscle tension, all of which appeared to be relatively mild and short-lived. Again, in contrast to the rest of the group, the only participants who reported somatic symptoms as being prominent in their experiences of anxiety were those who had also reported current anxiety problems. Both related their physical symptoms primarily to panic attacks and both could readily identify a range of other sensations that they associated with general feelings of anxiety.

It is likely that those participants with anxiety problems had had more occasions to talk to others (e.g. family and GPs) about their anxiety. It is possible then that the limited range of symptoms reported by other participants was due, in part, to them being less accustomed to talking about themselves and describing their feelings. Several participants commented, at the outset of interviews, that such conversations were new to them and said that they were not used to reflecting on their feelings. Perhaps it was easier for these participants to convey thoughts in discussion than it was to express subjective or physical feelings.

Most participants, other than the two mentioned above, seemed to be largely unaware of changes that took place when they were anxious. This observation would seem to be consistent with Levy et al.'s finding (2004) that older adults are less likely to report anxiety symptoms than younger adults and also less likely to identify anxiety symptoms in other family members. Perhaps participants did experience somatic symptoms but attributed them to something other than anxiety, although there is nothing in participants' accounts to suggest that this was the case. It is possible too, that participants might have reported, or been more aware of, physical symptoms, at times when they were more anxious but that in retrospect cognitive aspects of anxiety were somehow more salient. However, from their accounts, it seemed that cognitive symptoms were still dominant in most participants' experiences of anxiety, even when participants were most anxious and distressed.

Existing research offers little guidance as to how the predominance of cognitive symptoms in this study should be interpreted. Most studies of late-life anxiety to date have focused on symptoms of anxiety disorders rather than on non-clinical or adaptive

experiences of anxiety in older adults and have produced inconsistent findings. Not all studies support the view that older adults are more likely to experience anxiety somatically (Brenes, 2006; Hilliard & Iwamasa, 2001). While the strong emphasis on cognitive symptoms reported in this study could be attributed to any of the factors outlined above, it is also possible that it is related to the nature of this participants group (older, well-educated and verbally able, high-functioning adults) and that it might even be a relatively common feature of non-clinical anxiety in later life. Interestingly, again in contrast to the participants who reported anxiety problems, participants quickly and confidently identified techniques that they used to limit and reduce anxious feelings when they arose: Many (if not all) of these also focused on cognitions and on changing their ways of thinking about issues or situations. Regardless of whether or not those participants actually experienced symptoms over and above the thoughts they reported in the study, it is conceivable that their focus on cognitive (as opposed to affective or somatic) symptoms and the relative emphasis they placed on strategies over symptoms is characteristic of adaptive experiences of anxiety in later -life.

Management of anxiety

The information gathered in this theme was seen as particularly interesting given that existing research related to the management of anxiety has focused almost exclusively on disorders of anxiety and on the outcome of therapist-led interventions. Although strategies that individuals naturally adopt to reduce anxiety symptoms in normal adaptive experiences of anxiety are a part of psychological theories of anxiety (including the Cognitive theory) they have seldom been explored in research.

Participants described the influence of anxiety in their daily lives as being determined by traits and skills such as those outlined in Figure 2, but also by strategies that they had developed to deal with anxiety when it arose. Once they were aware of being anxious, all participants described taking action to reduce the discomfort they felt. Although, as noted above, the two participants who experienced anxiety problems reported very few strategies for dealing with anxiety (aside from the use of medication and the support of other people), most other participants described a variety of means by which they had successfully managed anxiety in the past and which they seemed confident would work for them in the future.

Strategies that participants used to manage anxiety can be directly related to their main anxieties and are consistent with Cognitive perspectives of anxiety reduction as involving reappraisal of initial perceptions of threat and coping. Within the Cognitive model, individuals are seen to alleviate anxiety by acting either to reduce their perception of threat or by increasing their confidence to deal with it (Greenberger & Padesky, 1995). Strategies that allow individuals to "maintain composure and limit the debilitating effect of high anxiety" are seen as having a key role in this coping process (Andrews, 2003, p. 11). In line with these observations, some of the techniques that participants used to combat anxiety appeared to be aimed explicitly at relieving immediate feelings of anxiety until participants were more able to assess the situations that faced them and decide how best to deal with them. Most of these techniques can also be seen to involve reassessment of initial impressions of threat or danger. 'Self talk and counter talk' seemed aimed at reducing the perception of threat, at convincing oneself that the feared outcome was unlikely to happen and that initial feelings of anxiety were, in fact, an overreaction. 'Distraction' also appeared to provide participants with a means of controlling initial feelings of anxiety by putting them aside until they knew they would be better able to deal with them.

Other strategies, such as taking 'time out to problem-solve', 'practical action', and 'seeking support', can be directly related to the main anxieties that participants expressed, in particular to 'episodic' anxieties that were associated with specific situations. These techniques can also be seen as functioning either to reduce the risks involved in situations or to increase participants' ability to cope with them. 'Practical action' also seemed to play a part in helping participants deal with their chronic sources of anxiety: For example, some participants talked for making sure they kept fit and ate healthily to reduce the risk of injury or health problems. For most participants, recognizing that they had done all they could to prevent the situations they feared, and that there was nothing more that could be done, appeared to be an important step in helping them set those anxieties aside.

'Comparison' and 'Acceptance' also appeared to provide participants a means of coping with or controlling the 'chronic' sources of anxiety that were an ongoing part of their daily lives as caregivers (i.e. anxiety related to deterioration in their own health or their partner's health, their own death and conflict between their own needs and those of their

partners). Acceptance and comparison are less easily related to the Cognitive model as working to relieve anxiety though reducing perceptions of danger or increase perceptions of coping ability. Rather, they appear to provide a means by which participants could come to terms with situations and prospects that they did see as threatening but that they also realized were essentially uncontrollable and unavoidable. All participants talked of having to accept what they could not change and of having learned to live with or to tolerate uncertainties and negative prospects (akin to current conceptions contained in mindfulness theory; see Orsillo & Roemer (2005) for application of mindfulness and acceptance theory to anxiety). Downward comparisons (i.e. "things could be worse") appeared to have a role in helping them come to terms with those difficulties. From a psychological perspective, social comparisons have been viewed as mediating adverse life events and response shifts; response shifts being changes in perspectives of ones-self, one's abilities or life circumstances that allow individuals a means of adjusting to stressful situations over which they can have no real control (Gibbons, 1999). Such shifts can be considered an adaptive or even essential means of coping with chronic stressors where nothing else can be done. In the context of the present study, it seems that acceptance and comparison should be seen as adaptive and successful coping strategies. Participants' appraisals of their lack of control appeared to be realistic. Acceptance appeared to provide them with a means of dealing with difficult, intractable prospects on a daily basis.

Limitations of this study

The use of semi-structured interviews and IPA in this study allowed for flexible, in-depth exploration of participants' perspectives and experiences of anxiety leading to findings that could be considered alongside existing research and theory but which were not confined by them. In addition, the approach allowed investigation of relationships that might exist between the anxiety that participants experienced and their roles as caregivers for partners with stroke. As with any research, however, the study has limitations that must be considered along with its findings.

Research such as this necessarily focuses on the perceptions of a small number of participants. Findings for this group of elderly adults cannot be generalized then to the wider population of older adults or to all those older adults caring for partners with

stroke. Although the older caregivers who took part in the study did have much in common with one another, there is also much that sets them apart. This includes differing ages, stages of life, backgrounds, caregiving experiences, and the nature of their partners' disabilities. In other respects too, participants cannot be seen as a representative group; all were of similar socio-economic background, retired and living in their own homes and apparently financially secure. Furthermore, participants were all of European descent and fluent in English, which was their first language. .

As an approach, IPA has a number of limitations that impact on this study. Firstly, IPA's reliance on language as a means of capturing participants experience is not without problems. In common with all other language-based methodologies, IPA relies on the "representational validity of language" in the investigation of phenomena (Willig, 2001, page 63). How well findings reflect participants' actual experiences of anxiety then is dependent on the extent to which language can adequately convey those experiences. There were times in this study when participants had difficulty putting their thoughts and experiences into words (e.g. describing their general understandings of anxiety, finding terms they felt best represented how they felt, defining the discomfort they felt about not being free to meet their own needs). Some expressly linked this difficulty to their being unaccustomed to talking about themselves or their feelings. That their accounts were largely retrospective may have added to these difficulties and again limited their expression of anxiety-related experiences. It is difficult, however, to imagine a way in which subjective experiences of anxiety could be explored that does not depend on language. These same constraints can be seen to apply to clinical practice related to anxiety, which also relies heavily on client self-report.

IPA acknowledges that the same event or experience can be described in many different ways and that language has a constructive function. However, this aspect of accounts is not systematically explored in IPA generally or in the present study, both of which proceed on the assumption that the accounts that participants give are relatively direct expressions of their thoughts, feelings and behaviours. From a constructivist standpoint however, participants' accounts are chosen ways of talking about those experiences in a particular context, rather than simply indicative of the experiences themselves. Options for description and experiences too are seen as shaped by the

language that precedes them. While IPA was regarded as the most appropriate method to address the research questions posed in this study, exploration of the constitutive role of language in accounts of anxiety would nevertheless be valuable and a useful basis for future research. Constructionist approaches, such as discourse analysis, could provide insight into how and why older adults might chose to present their anxiety-related experiences in particular ways. This would be an aid to clinical assessment and practice and could suggest useful directions for further research. In the present study, emergent themes suggest that participants were selective in their accounts of anxiety, highlighting some types of anxiety over others and giving precedence to anxieties that they saw as particularly pertinent or tied to caregiving. Furthermore, as has already been discussed, it seems likely that participants' accounts of their own anxieties were influenced by wider views that they held about anxiety problems as reflecting somewhat negatively on those who experience them. These views could be expected to vary according to wider societal views and cohort and cultural values.

Finally, IPA cannot be viewed as providing a definitive reading of participants' accounts. As with any qualitative approach, "results reflect the researcher as much as the researched" (Salmon, 2003, p. 23) and are inevitably subjective. The themes that were extracted and developed in analysis in this study must be seen as a subset of a wider set of themes that could be identified and explored. Inevitably, those that were selected are reflective of the researcher's own viewpoints, interests and understandings. In particular, it is likely that familiarity with the Cognitive framework will have influenced what was attended to in discussion and which interpretations were made in analysis, perhaps limiting the extent to which the study has been able to take a critical approach to anxiety. In order to ensure the credibility of the final account of participants' anxiety, care has been taken to ensure that the themes and interpretations developed in the study were actually represented in transcripts and, wherever possible, they have been presented along with verbatim quotes from participants themselves.

Considerations for further research

Despite its limitations, this study makes a valuable contribution to current understandings of anxiety in older adults and in caregiving. It expands on a previously neglected area, highlights the limitations of existing research and knowledge and

suggests useful avenues for further research. The following aspects of findings are outlined as suggesting areas in which further research might be particularly fruitful.

Results of this study highlight the chronic nature of the anxiety that older people experience in caring for their partners with stroke. Despite considerable differences in the time for which they had cared for their partners, participants concerns were remarkably similar. They suggest that anxieties that have been observed in early caregiving may persist well beyond the first months or years of caring. To date, the great majority of studies that explore caregiving for stroke have focused on the acute stage of stroke or the very early stages of caregiving, with only a handful exploring caregiver well-being over the one to two years after stroke. Few studies have focused on anxiety as an outcome of caregiving. There is a for need studies that investigate longer-term experiences of those caring for partners with stroke and also for studies that chart the course of caregiving to determine which issues are likely to present the greatest concern for spousal caregivers of different ages and at different stages of caregiving. Information gained would provide a better understanding of their needs and a firmer base from which to offer support.

The prominence of cognitive symptoms across accounts in this study was an unexpected finding and one that is difficult to explain in relation to existing literature. It highlights again the limitations in current understandings of the presentation of anxiety in later life and the need for studies that establish what types of symptoms are characteristic of adaptive and pathological experiences of anxiety in older adults. For the participants of this study, it seemed that cognitive symptoms would still have dominated their experience even when they were most distressed. That being the case, it seems likely that current anxiety measures, based as they are on a very different range of symptoms, would fail to detect their anxiety.

Whether or not participants experienced anxiety problems prior to stroke and caregiving appeared to be the key factor that determined the anxiety they experienced as caregivers after stroke. It is possible then, that the differences apparent in views of self (both general and in relation to caregiving) expressed in this study by both those participants who experienced current anxiety problems and those who did not, are grounded in differences that existed prior to stroke and caregiving. As such, these

views may not of themselves then be indicators of which older adults are more likely to develop anxiety problems as caregivers. However, factors identified by participants as either predisposing them or protecting them from anxiety in caregiving may, nevertheless, provide a useful starting point for further research that seeks to identify which elderly spousal caregivers are most likely to experience anxiety problems. They may also serve as a guide to interventions that seek to support older spousal caregivers, suggesting which aspects of caregiver experience might usefully be strengthened or enhanced to guard against anxiety problems.

Related to that, the strong link that emerged in this study between participants' views of themselves and their abilities (in general and in caregiving) and the levels of anxiety they experienced, suggests the importance of support that empowers elderly caregivers, increasing their confidence and mastery in caregiving tasks and enhancing their perceptions of the worth of the care that they as partners can provide.
To date, interventions to support caregivers have met with variable success (Clark, Rubenach & Winsor, 2003; Kalra et al., 2004; McCullagh, Brigstocke, Donaldson & Kalra, 2005). Where they have been beneficial, the reasons for that success have not always been clear (Mant, Carter, Wade & Winner, 2000). It is possible that the variability of outcomes shown for support programs is due, at least in part, to differences in the degree to which programs address these issues. Practical and informational support may be not be effective in relieving the stress or anxiety that carers experience, unless it is offered in such as way as to enhance carers' views of their own worth and competence as caregivers.

Finally, the strategies identified in this study as helping participants cope with the anxiety that they experienced in caregiving are particularly valuable in furthering understanding of adaptive experiences of anxiety in later life. They show how older caregivers successfully deal with chronic anxieties that are grounded in real difficulties and probable negative outcomes. They also suggest a need for interventions for anxiety in caregiving that take account of the realistic and chronic nature of the anxieties that spousal caregivers face. Research is needed to determine which types of intervention are likely to provide the most appropriate and effective help to older caregivers who experience anxiety problems: While Cognitive therapy has been suggested as an appropriate means of helping people adjust and cope with adverse life circumstances

(Moorey, 1996), pragmatic approaches that focus on the manageability of anxiety may provide valuable alternatives. Approaches that encourage acceptance and that centre on building resilience could be expected to be particularly useful in helping older caregivers cope with ongoing and difficult prospects on a daily basis.

Conclusion

This study aimed to address an apparent gap in the current literature into late-life anxiety using Interpretative Phenomenological Analysis to explore the understandings and experiences of older adults in the context of caring for partners with stroke. Although findings cannot be generalized to wider groups of elderly people or caregivers, they can, nonetheless, be seen as making a valuable contribution in an area that has previously been neglected. They provide unique insights into how a group of older adults experience and cope with anxiety in their daily lives caring for partners with stroke. In addition, they suggest that anxiety-related experiences of older adults, caring for partners with stroke, are significantly influenced by their roles as caregivers; and, as such, can only be fully understood within that context. .

Findings highlight the need for further research that will lead to clearer understanding of the way in which normal and pathological anxiety presents in later-life. They also point to the need for research that specifically investigates anxiety in caregiving; research that identifies the concerns of caregivers and the factors that influence the anxiety they experience, not only in the period immediately after stroke but over the entire course of caregiving. This knowledge is essential if clinicians are to provide appropriate help and support for those elderly people who are caring for partners with stroke.

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The understanding and experience of anxiety in older adults caring for partners who have had a stroke

INFORMATION SHEET

You are invited to take part in a study of anxiety and what it means to older adults caring for partners who have had a stroke. The aim of the study is to learn about how older adults, caring for partners who have had a stroke, experience and deal with anxieties in their everyday lives. The study also aims to learn more about how older adults respond to some of the questionnaires that psychologists often use to assess anxiety, and whether or not these questionnaires are appropriate for use with older adults.

If you choose to participate in this study you will be interviewed on two occasions, each time for between 1½ - 2 hours, about what anxiety means to you and your experience of anxiety. You will also be asked to complete some questionnaires about anxiety. The interviews will be held, over a two week period, at your convenience and will be audio-taped. It is not anticipated that there will be any harmful effects resulting from the interviews. However, it is recognised that some of the issues involve participants being asked to provide quite sensitive and personal information. For this reason, any information provided for use in this study will be kept strictly confidential.

The results of this study will be used for a Masters Thesis, and may be published, but only in a form that ensures that you cannot be identified. All interviews will be conducted by me with individual participants and no names will appear on any questionnaires, interview notes or audio-tapes. Only my supervisor and I will have access to the information that is received.

Te Kunenga

Participant's rights

Please note that taking part in this study is completely voluntary. You are under no obligation to accept this invitation. If you decide to participate, you have the right to:
- withdraw from the study for any reason and at any time up until two weeks after the interviews are completed;
- decline to answer any particular question;
- ask any questions about the study at any time during participation;
- ask for the audio tape to be turned off at any time during the interview;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded.

If you would like any further information, or would like to take part in this study, please contact Liz Cotton (Researcher) or Associate Professor Paul Merrick (Supervisor) at the addresses or phone numbers listed below. Your participation would be much appreciated.

Researcher:

Liz Cotton
C/- Assoc Professor Paul Merrick
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Supervisor:

Associate Professor Paul Merrick
Telephone: (09) 414 0800 ext.9865
Email: P.L.Merrick@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee, ALB Application 05 / 023. If you have any concerns about the conduct of this research, please contact Associate Professor Kerry Chamberlain, Chair, Massey University Campus Human Ethics Committee, Albany, telephone 09 414800 x 9078, email: humanethicsalb@massey

The understanding and experience of anxiety in older adults caring for partners who have had a stroke

PARTICIPANT CONSENT FORM

This consent form will be held for a period of five (5) years

I have read and understand the Information Sheet for volunteers participating in this study. The nature and purpose of the study has been explained to me. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any time.

I **agree/do not agree** to take part in two interviews which will be audio taped. I have the right to ask for the audio tape to be turned off at any time during any interview.

I **wish/do not wish** to have the tapes returned to me.

I **wish/do not wish** to have data placed in an official archive

I understand that I have the right to decline to answer any particular question.

I understand that I have the right to withdraw from the study for any reason and at any time up until two weeks after interviews have been completed.

I agree to provide information to the researchers on the understanding that my name will not be used.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full name (printed): ....

I am available to answer any questions about this study: Liz Cotton, (09) 361 3977, 021 140 4001. If you have additional queries or concerns, you can also contact my supervisor, Associate Professor Paul Merrick, School of Psychology, Massey University, Albany Campus, Auckland, (09) 414 0800.

Appendix C

The understanding and experience of anxiety in older adults caring for partners who have had a stroke

BACKGROUND QUESTIONNAIRE

(Presented verbally and answers recorded by the interviewer before commencing interview proper.)

1. Participant **Information Letter** is read and understood   **Yes / No**

2. **Consent form** is read, understood and signed   **Yes / No**

3. **Questions:**

    a) What is your date of birth?

    b) Do you have any illnesses at the moment?
       (probe) What did your doctor call it?

    c) What medication has been prescribed for you in the last 3 months?

      Permission to ring later   **Yes / No**
      Medication sighted   **Yes / No**

    d) How old were you when you left school?

      (probe) What were your highest qualifications?

    e) In which country did you have the majority of your schooling?

    f) What was your last full-time paid job?

MUAHEC 05/023

Appendix D

Semi Structured Interview Schedule 1

Introduction
Everybody experiences anxiety at some time in their life - for example, anxiety about finances, health, the future and so on.

My aim in this study is to learn more about the nature of getting older and the anxieties that people face as they get older - particularly when they are caring for a husband or wife who has had a stroke. There are no right answers to any of the questions that I will ask - what is most helpful and valuable to me and to the project are your personal opinions and your own experiences.

Questions and prompts
1. What does anxiety mean to you? (What do you relate to the term anxiety?; How would you define anxiety?)

2. How does anxiety feature in your life? (In what ways (if any) does anxiety affect your life?)

3. What influence / effect does anxiety have in your life? (Where does anxiety appear in your life?)

4. How often do you feel anxious?

5. What makes you anxious?

6. Do the same types of situations bring on anxious feelings?

7. How do you know when you are anxious?

8. What do you typically do when you are anxious?

9. Do others know when you are anxious? How can they tell that you are anxious?

10. Do you think your partner experiences anxiety in the same way you do? How can you tell when he/she is anxious? (Pre stroke? Post stroke?)

11. Has your experience of anxiety changed over the years?

12. Has your understanding experience of anxiety changed since your partner's stroke? (Since you became a caregiver?)

13. What are your anxieties? (What do you get anxious about?) Top 10?

14. (For a typical situation - one that has arisen at some time in the past two weeks)
    Can you describe that experience?
    > What went through your mind when you were anxious?
    > How did you feel?
    > What did you do?
    > What physical sensations?