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# 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 latelife 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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## 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

caregivers are somewhat "invisible", their availability and ability to care taken forgranted, 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