

The experiences of family members who provide care for their relatives with alzhe...

[Health & Medicine](#), [Disease](#)



Taking care of an elderly relative can be quite challenging. When this relative is diagnosed with a terminal condition, with no known opportunity for recovery additional challenges are added. Alzheimer's disease is a debilitating condition which paralyzes the patient's ability to function normally and thus require personal care from either a nursing professional or an at-home care provider in the form of a family member.

Since the survival rate with the disease could reach to as much as 15 to 20 years (Coen et al. , 1999), caring for an AD patient is a long-term commitment. The experiences encountered by these caregivers must be quite unique and would of course vary among families. It is useful therefore to discover some of the commonly challenges faced by caregivers in order to obtain a better understanding of the issue and to develop appropriate strategies to address the issues.

2. 0 Literature Review Alzheimer's disease (AD) is the most common form of dementia among older people (Coen, O'Boyle, Swanwick & Coakley, 1999).

Dementia is a slow-onset neurodegenerative disorder marked by a severe decline of cognitive abilities (Ward, 2007) with obvious effects on daily life, mostly memory, which seriously affects a person's ability to carry out daily activities. AD begins slowly. It first involves the parts of the brain that control thought, memory and language. People with AD may have trouble remembering things that happened recently or names of people they know.

According to Carradice, Beail & Shankland (2003) this disease is more common among those persons older than eighty years. Given that there is a noted increase in life expectancy where more and more persons are living

longer it is quite understandable that the incidents of dementia are also increasing (Zarit & Edwards, 1996). The prognosis for elderly patients with AD is quite dismal. While there are treatment options available that may improve some of the behavioural and cognitive ill effectives of the disease.

No treatment current exists that will halt the progression of the disease of lead to full recovery (Mittelman, 2002). In order to ensure that the condition is controlled as far as possible and that AD patients are well cared for long-term care options have to be sought. While there are countless long-term care institutions, many with qualified nursing and other medical personnel to cater to the needs of the AD patient, most AD patients are given this long-term care within the domestic situation, primarily by family members (Coen et al.

, 1999). Research indicates that family members are the ones who are more often than not responsible for providing care for their relatives with Alzheimer's disease (Mittelman, 2002; Tettelman & Watts, 2004 and Caregiving & Alzheimer's Disease, 2004). In fact health professions usually feel it best that the elderly continue living at home for as long as possible (Teeri, Leino-Kilpi & Valimaki, 2006), and the elderly themselves also desire to be home (Aggarwal, 2003).

Additionally researchers have often criticized institutions on the basis that often many elderly are registered in these institutions against their wishes and are also often unhappy in these non-private situations (Teeri et al. , 2006). However for those relatives who opt to provide care for AD patients there are considerable day to day strains and difficulties that they face. The

financial burden is one of the most apparent. Grahm (2001) highlights that the costs of taking care of an elderly relative are very overwhelming, particularly one who has suffered a stroke or who has AD.

Statistics suggest that the usual cost of taking care of an elderly relative ranges between \$148 and \$158 billion dollars (Caregiving & Alzheimer's, 2004). Most research has, however, discovered that the greatest challenges for at home caregivers to elderly AD patients is not so much the financial burden, but the psychosocial and emotional difficulties faced by these caregivers. Thus considerable attention has been paid not only to the dismal prognosis of those suffering from the disease but also those who have to provide at-home care for Alzheimer's patients.

Various researchers have attempted to isolate the various challenges faced by caregivers of AD patients. Grahm (2001) contends that the pressures faced by caregivers are of both an emotional and physical nature. Gwyther (as cited in Caregiving & Alzheimer's Disease, 2004) mentions chronic stress and decrease health as one of the ill effects of caring for the elderly. Tettleman and Watts (2004) also allude to stress in addition to mental strain as issues of concern faced by these caregivers.

Anxiety (Caregiving & Alzheimer's Disease, 2004), fatigue and depression (Mittelman, 2002) and psychological distress (Carradice et al., 2003) are other issues commonly noted in the literature. The preoccupation of researchers examining this disease is, therefore, not only on the debilitating effects that it has on the patient but also the demands that are placed on caregivers who are required to take care of these patients.

Evidently caring for a loved one with Alzheimer's disease at home is not without its challenges as significant strains are put on the caregivers.

Each individual situation where a family member is responsible for taking care of a relative with Alzheimer's disease comes with its own challenges and it is very difficult to generalize specifically about the experiences of these caregivers. This study will seek to identify and categorize some of the more common experiences shared by them. This research will be of considerable importance to medical practitioners who have to interact with patients and their families as well as to the individual family members/caregivers.

The findings from this research will be useful to current caregivers in helping them realize that other persons face the same challenges as they do and therefore a network of caregivers facing similar problems could be formed where they formulate strategies to deal with problems together. Medical professional would also have this information and could share this with new caregivers that enter their offices in order to prepare them for the challenges ahead.

3. 0 Research design and justification

Considerable research has been conducted on the problems associated with Alzheimer's and challenges that have been associated with caring for a patient with Alzheimer's disease. Previous research has highlighted the challenges faced by caregivers of ill relative but not much research has focused specifically on the condition of Alzheimer's disease (Teeri et al. , 2006). Where research was specific to Alzheimer's disease, the focus on caregivers was not specific to family members providing this kind of care,

but generalized on the various categories of caregivers including compensated professionals (Ellor, 2005; Teeri et al.

, 2006). Further, research has failed to classify the problems faced by these family caregivers and place them into meaningful categories (Mittelman, 2002; Caregiving & Alzheimer's Disease, 2004). This will be a qualitative study explaining the common experiences of family members who are caring for elderly relatives at home. Where other researchers were not specific to Alzheimer's disease this research will be exclusive to this category of caregivers. The experiences of a cross-section of such caregivers will be compared and analyzed for common themes.

Unlike previous researchers this study will conduct a comprehensive categorization of the most common experiences based on the information garnered from the caregivers. The information gathering instrument will be primarily interviews. The use of interviews to gather information has long been lauded by researchers. Interviews may either be structured where the researcher directs the line of the conversation with specific questions requiring direct responses. Unstructured interviews allow the researcher to approach the interviewee with a general objective and allowing the conversation to flow in whatever direction it will.

Both of these interview tactics have their benefits. The first forces the respondent to focus specifically on the information that is required for the purposes of the research. The second type allows the research to gather a vast amount of information, even information that was unanticipated when the research was being prepared. For the purposes of this research the

unstructured interview would be quite useful as the research does not wish to restrict the extent of the responses given by the interviewees.

This research will therefore add to the wealth of knowledge about the nature of Alzheimer's disease and the direct and indirect effects it has on patient and family. This research will also help to improve understanding of the role that caregivers fulfil and the challenges they face in dealing with ill and elderly relatives, specifically those who have Alzheimer's disease. Respondents will not be restricted in the type of responses they produce thereby allowing the researcher to get a comprehensive and true picture of the real lived situation of caring for an AD patient.