

Effect of the Burden of Alzheimer Disease on Caregivers: A Review

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ABSTRACT

The purpose of this research is to investigate the ways in which the effect of Alzheimer in elderly persons can be cared for, with focus on the role of caregivers. Having carried out an online search, the research articles included both quantitative and qualitative studies. Furthermore, a detailed thematic analysis brought up three main themes from the literatures which include: the effect of Alzheimer on the elderly, caring for Alzheimer patients, and caregivers burden and adaptation. Consequently, the central message deduced from the work is that, Alzheimer disease affects the elderly in a number of ways. Physiologically, the disease causes decreased appetite and difficulty in eating. It also creates the tendency for over dependency on relations, hence the importance of caregivers. However, there is need to provide support to caregivers to decrease care-giving stress and enhance feelings of competence, so as to improve not just the caregiver's well-being, but also the experience of the person with Alzheimer receiving care.

Keywords: Alzheimer disease, caregivers and patients.

INTRODUCTION

Alzheimer's disease (AD) is an age-related neurodegenerative disorder characterized by progressive structural and functional lesions in the brain, which include neuronal atrophy and synaptic loss accompanied by neuronal death, brain network damage, and aberrant network oscillations [1]. These brain lesions are correlated with the accumulation and aggregation of amyloid β ($A\beta$) peptide and Tau protein [2], resulting in extracellular $A\beta$ plaques and intracellular neurofibrillary tangles of hyper-phosphorylated Tau protein in the AD brain [3]. This disorder is clinically characterized by evolving memory impairments followed by broad cognitive decline and brain degeneration that ultimately leads to death [1]. Alzheimer's disease appears to be a devastating disorder affecting approximately 40 million people worldwide, with that figure expected to triple by 2050 [4]. Despite massive efforts over the years to find a pharmacological treatment for the disease, there is no effective therapy that can stop or reverse brain pathology as well as cognitive and other behavioral deficits of AD [5],

highlighting the critical need for care-giving.

Informal caregivers are the most valuable resource available to people suffering from dementia. Caregivers are important because they provide consistent care in a familiar and comfortable environment, both of which are necessary when caring for individuals with Alzheimer's disease [6]. Alzheimer's dementia caregivers, for example, are responsible for completing daily activities for their loved ones as well as themselves while providing care. Alzheimer's caregivers frequently provide regular supervision [7], readdress difficult behaviour, and assist with bathing, dressing, and toileting. Aside from caring for a loved one with Alzheimer's disease's physical and emotional needs, caregivers are frequently in charge of their financial needs. The economic value of informal dementia care-giving is estimated to be around \$257 billion. Without informal caregivers, the cost of long-term care would skyrocket even further [6]. The global prevalence of dementia in people over 60 was estimated to be as high as 24 million in 2001, and it is expected to double every 20 years, affecting more

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than 80 million people globally by 2040 [8]. The expected rise in Alzheimer's cases is clearly due to an increase in the number of elderly people, primarily in low and middle-income countries. As a result, the number of people with dementia is expected to rise by 80-190 percent in Europe, North America, and the developed Western Pacific region between 2001 and 2040, while it is expected to rise

by more than 300 percent in Latin America, India, China, North Africa, and the Middle Eastern Crescent. Incidence rates have been reported ranging from approximately 0.4 percent in people aged 65-69 to nearly 10 percent in people aged over 90, with a prevalence ranging from approximately 2 percent in people aged 65-69 to more than 25 percent in the group aged over 90 [9].

METHODOLOGY

Scoping review is the methodology used to carry out this work. Accordingly, [10] notes that scoping review remains a veritable tool to establish the coverage of a body of literature on a given topic, and to give clear information on the volume of literature and studies available including an overview of its focus; thus [11] presented a framework that gives a methodical structure of how to conduct a scoping review, consisting of five main steps; Identifying the research question, identifying relevant literature, study selection, charting the data and collating, summarizing and charting results. This research work has been structured accordingly.

The effects of Alzheimer On the elderly

Every disease condition presents different symptoms which cause departure from basic behavioural standards or physiological dysfunctions. These behaviour demarcations or physiological dysfunction is conceived as the effects of the disease on the patient. Here, the researcher drew from the well of primary studies to identify how Alzheimer affects the elderly patients [12]. Consequently, [13] analysed family caregivers' and professionals' experiences of supporting people living with dementia's nutrition and hydration needs towards the end of life. The authors employed a semi-structured interview guide in data collection. A total of 41 respondents were interviewed verbally and recorded. The interviewees included 21 informal caregivers and 20 formal caregivers. After the interview, the recorded responses were transcribed verbatim. The collected data was thematically analyzed, and four major themes emerged: caregivers' access

to and seeking of help; perceived priorities of care; professionals' supportiveness and educational role; and strategies. Caregivers typically struggle because they are ignorant of the difficulties associated with food and drink in dementia patients. As a person approaches the end of life, families may emphasize comfort over ensuring a particular amount of nutrition. Professionals and caregivers must collaborate to enhance the care of people with dementia. Cognitive limitations typically cause initial eating and drinking difficulties in dementia, with physical issues taking control in later stages. Flexibility and inventiveness are required to adapt to changing circumstances. Based on their findings, they concluded that there is a need for increased awareness of the nutritional and feeding difficulties associated with dementia development. Professionals may assist carers in making the change from focusing on nutrition to focusing on comfort and enjoyment of eating and drinking at the end of life. This is especially true for people who are responsible for a live relative. Professional advice must be tailored with caregiver involvement.

Barrado-Martn's [13] study though was on the analysis of the Alzheimer patients caregivers experience; it was able to identify some of the effects of Alzheimer disease on the patients which include changes in feeding pattern, cognitive ability reduction, indifferent behaviour such as aggressiveness and anxiety. This result was aptly supported with a further stretch by the National Health Survey - UK (2019) report. According to the report, having difficulties making decisions or

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establishing plans, Speech and language impairments, as well as inability to move around freely or perform self-care activities, Changes in personality such as being more aggressive, demanding, or distrustful of others, constituted some of the effects of the disease. Similarly, [14] found that Alzheimer alters the feeding and nutritional pattern of elderly people. According to them, an elderly mother or father diagnosed with Alzheimer's was discovered to be battling with eating. That is, they find it hard to eat. Hochwald *et al* [15] also observed eating difficulty among Alzheimer patients.

Caring for Alzheimer patients

Care giver education is highlighted in the study by [16] who describe family caregiving skill as the "ability to engage effectively and smoothly" in nine care processes consisting of psychomotor, cognitive, and psychological skills. Skill in this regard, is defined as "goal-directed, well-organized behavior that is acquired through practice and performed with an economy of effort." Farran, *et al* [17] further defined a caregiver skill as "something that care-givers do" using "goal-directed behaviors based on knowledge, experience, or personality style." The requisite caregiver skills described by Given *et al.*, cut across monitoring, interpreting, making decisions, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the ill person, and negotiating the health care system. Thus, [18], has reported that practitioners complained of lacking the training and confidence to support caregivers in making decisions about eating and drinking towards the end of life. Also, they were seen to have different levels of understanding of the eating and drinking difficulties commonly experienced towards the end of life in dementia. Care can change over time, with families prioritizing a person's comfort near the end of life by ensuring a specific level of nutrition. Subsequently, [19] observed that the lack of training focused on care of Persons with Dementia (PwD) or cognitive impairment can cause

professionals to feel incompetent and frustrated and lead to high levels of stress. This can result in heightened clinical practice risk [20]. Additionally, the unpredictable nature of dementia means that PwD can show lucidity one day, or inability to follow instructions the next day, which can worsen the situation [21]. In the same vein, [22] study's goal was to find out what stakeholders thought about adapting the WHO Support for use by informal carers of dementia patients in Australia. The researchers utilized an interpretative description study design. For starters, informal caregivers saw Support as a chance to create an online one-stop shop for their education and care management needs. Allen *et al* [23] study focused on three objectives: ascertain where people with dementia and their caregivers get dementia-related information now; establish how obtainable, credible, and understandable available sources of information are to people with dementia and their caregivers; and discern how people with dementia and their caregivers would like to receive information. An online or postal survey was completed by 171 female and 41 male participants who had a close relative or friend with dementia. The most significant influence on how consumers accessed information sources was accessibility, not quality. Participants preferred relational sources like healthcare professionals since they could give customized information, however these were difficult to reach and lacked dementia knowledge. As a result, people turned to non-relational sources like the internet. On the other hand, increased internet use was linked to feelings of information overload. Participants' impressions of information gathering were influenced by the effort used to obtain the information rather than the ultimate outcome of the information search. Future research should concentrate on how to create and provide knowledge sources that resemble relational touch.

Another critical aspect of Alzheimer's care is ethical behaviour. In this regard, [15] investigated and explained the

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differences in professional staff members' (PSMs') and family caregivers' perspectives of caring for people with end-stage dementia in two separate contexts. They discovered a predominant trend in palliative care issues, such as defining the condition as terminal, choosing "comfort" versus "life-prolonging," expressing patients' intentions, and deciding whether to use mechanical feeding. PSMs and family caregivers both face ethical challenges and have reached different, but equally valid, conclusions. The importance of hospice care for people with end-stage dementia was influenced by participants' understanding of dementia as a fatal illness. Disparities in caregiving between PSMs and care partners were discovered in both home hospice and home care settings, highlighting the possibility of disagreements over end-of-life care decisions. Communication is essential for discussing and bridging the gap between PSMs and family caregivers when it comes to the unique challenges of caring for people with end-stage dementia. The supply of an appropriate solution for best possible care in the best interests of persons with dementia might be hampered by a lack of interaction and resources.

Caregivers burden and Adaptation

Ghezalje *et al.* [24] did a comprehensive review to identify the evolutionary

CONCLUSION/IMPLICATION FOR PRACTICE

This paper has highlighted the impact of Alzheimer's disease on the elderly, as well as the fact that caregivers face a great deal of stress as a result of the disease, including financial, physical, emotional, time-related, work-related, and demographic stress. Thus, the findings highlight the importance of providing caregivers with support in order to reduce

notions linked with Alzheimer's patient caregiver burden. The Conceptual analysis revealed that the caregiver burden concept in patients with Alzheimer's disease had two key features which were familial and personal. Within the context of Familial, the authors observed that women were the most important caregivers and increased economic costs was somewhat the gravest burden. Looking at the persona, shortage of time, increased responsibility, and the workload of the caregivers emerged as critical dimensions.

Furthermore, [24] discovered that the antecedents - that is, the problems associated with caring for Alzheimer patients - were linked to three dimensions: 1) patients' characteristics, such as the patient's symptoms and comorbidity; 2) caregivers' characteristics, such as their level of knowledge of Alzheimer diseases, level of awareness, and caregivers' experiences over time); and 3) support resources available for the care of patients. Physical ailments, psychological problems, decreased social function, and the development of a sense of joy and hope were all included in the outcomes [25,26,27,28,29]. The authors concluded that caregiver burden is multifaceted and complicated, including a wide variety of behaviours and traits. In addition, it is dynamic and evolves through time.

care-giving stress and increase feelings of competence, thereby improving not only caregiver well-being but also the experience of the person with dementia receiving care. As a result, effective caregiver support is critical, given findings that poorer caregiver mental health is a unique predictor of mortality in people with neurodegenerative disease.

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