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Challenges experienced by home-based palliative caregivers of the elderly with Alzheimer's disease (AD): a review

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Abstract

As the world's population ages due to increasing longevity, many elderly people are affected by many diseases, and Alzheimer's disease (AD) is another disease susceptible more to the ageing population. AD is a kind of degeneration in the brain, and the elderly with AD suffer a progressive functional and cognitive decline. It is the most common cause of dementia, which causes challenges to the elderly patient as well as family caregivers. Home-based palliative care for AD provides care and support, especially to terminally ill patients, surrounded by their family caregivers. This article aims to describe: 1. introduction to Alzheimer's disease; 2. importance of home-based palliative care for the elderly; and 3. Challenges experienced by home-based palliative caregivers of the elderly with Alzheimer's disease. The study used a rapid reviewing method to collect relevant data, information, and contents related to the objectives from various electronic source search engines, searched by typing keywords such as Alzheimer's disease, goals, and challenges of palliative care of the elderly at home by family caregivers, and the relevant contents were analyzed. The result found major challenges experienced by family caregivers, including stress, fatigue, anxiety, sleep deprivation, expenditure burden, and less time for self-care and social responsibility. The findings of this article provide a better understanding of Alzheimer's disease, the importance of palliative care at home for elderly people with AD, and the challenges encountered in providing care, which can be useful to academicians, family caregivers, AD patients, policymakers, and medical professionals to improve the quality of life of both patients and caregivers through integration of applicable intervention measures in health care planning and policy making.

Keywords: Alzheimer's disease, home-based palliative care, challenges of family caregivers, elderly with AD

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1. Background

The world's ageing population, 60 years and older in the world, is an increasing trend, which is estimated to increase from 14 percent in 2022 to 26 percent by 2050 [1] due to changes in life expectancy. As the population ages, many elderlies are affected by many diseases, and Alzheimer's disease (AD) is another disease susceptible more to the ageing population. According to the World Alzheimer´s Report worldwide, approximately 47.0 million people in the global population suffer from the disease [2], and this proportion may triple by 2050, which will be a burden to healthcare

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providers [3] as the elderly with AD suffer a progressive functional and cognitive decline and gradually lose decision-making and value-expression abilities [4]. Alzheimer's disease is a kind of degeneration in the brain that starts slowly years before the symptoms appear and destroys memory and thinking skills, leading to changes in behavior and personality and affecting the skills to perform daily life activities. It takes years to notice the symptoms of brain disorders due to AD, such as memory loss, personality change, and language problems. Symptoms start showing when neurons or nerve cells of the brain, having functions for cognition, memory, thinking, learning, reasoning, walking, and swallowing, are affected, which gradually spread to other parts of the brain as the disease progresses. Over time, the person who is affected by AD has become disorganized with increased anxiety, lost abilities to perform daily normal tasks, manage money, move, communicate, or walk, and thus remains in bed, which requires all day and night care from a caregiver [5]. An elderly AD patient is said to be affected by dementia if the patient shows symptoms of failing to recognize the environment and familiar faces of people, lost memory, unsteadiness in getting up, and changes in behavior and communication. AD is the most common cause of dementia among elderly people [6]. Most ageing people usually suffer from chronic multi-morbidities, weakness, and cognitive decline, so AD is another disease that causes challenges to elderly patients as well as family caregivers. Age is the contributing factor of AD, but people less than 60 years old can also develop the disease. There is a growing challenge for the elderly with AD because, as the disease advances, it needs the utmost care and support from family or others, and no medicine has been discovered by medical science to cure it to date. Consequently, it causes lots of stress and challenges to the affected elderly, healthcare professionals, and family members, and this causes the need to adopt a palliative care approach [7].

According to the World Health Organization [8], palliative care aims to improve the quality of life of patients suffering from chronic life-threatening illnesses like AD. Home-based palliative care brings benefits to the patient and family as its main objective is to lessen the pain and suffering of the patient through communication with health care staff and provides psychosocial support to the patient and family caregivers to ease the burden, symptoms, fear, and worries and to be prepared for the pending outcome. Home-based palliative care is provided by family caregivers in consultation and advice of trained medical staff and professionals and has many positive contributions. Firstly, it saves the increasing financial cost of long-term inpatient hospitalization fees for illnesses such as AD. Many families find it hard to pay for long-term care in hospitals in the absence of financial protection to meet the cost of treatment and care. So family caregivers have an important role in providing palliative care at home. Thirdly, palliative care reduces the workload of congested hospitals or hospitals with inadequate healthcare staff in rural areas. However, efficient home-based palliative caregivers need training and advice from medical personnel or staff to learn the basics of palliative care [9].

The study used a rapid reviewing method to collect relevant data, information, and contents during 2000–2023, related to the objectives from various electronic source search engines, searched by typing keywords such as Alzheimer's disease, goals, strategies, and challenges of palliative care of the elderly at home by family caregivers, and the relevant contents were analyzed. The article is organized into sections: Background; Introduction to Alzheimer's disease; Importance of home-based palliative care for elderly with Alzheimer's disease; Challenges experienced by home-based palliative family caregivers of elderly with Alzheimer's disease; and lastly, Discussion, Conclusion, and Recommendations.

This article aims to describe the following:

1. Introduction to Alzheimer’s disease
2. Importance of home-based palliative care for the elderly
3. Challenges experienced by home-based palliative caregivers of the elderly with Alzheimer’s disease.

2. Introduction to Alzheimer’s disease

Alzheimer's disease (AD), derived from the name of the German scientist 'Alois Alzheimer', is a slowly progressive neurodegenerative brain disorder associated with loss of memory, reasoning, thinking skills, and disability [10]. AD is the most common cause of dementia among elderly people and one of the greatest challenges in health care of the twenty-first century. It has been estimated that about 47 million people in the world are affected by dementia, and the yearly increase is about 10.00 million [11]. Medical researchers found "tau-proteins built up" as the main cause of brain damage in the ageing brain leading to dementia [6]. Common symptoms of dementia include a decline in thinking, remembering, reasoning, judgment, and behavior. AD is characterized by damage in the brain causing plaques that result in the loss of nerve cells or neurons and their connections [12]. Ageing elderly people 65 years and above are more at risk of dementia due to AD, commonly characterized by symptoms such as an inability to recognize familiar surroundings and people, selection of the right word for daily communication, or performing a normal daily life activity. It is estimated that one-third of the ageing elderly, 85 years and above, may be affected by AD [13] since age is the main factor for dementia among the elderly [7]. Also, several factors cause functional changes or degeneration in the ageing brain, such as chronic inflammation, damage in the human anatomy, blood vessels, high blood pressure, exposure to pollutants, diabetes, heart disease, stroke, genetic factors, head injuries, and environmental factors that affect neurons and other brain cells [14].

AD is challenging as there is no cure for the disease and the patient loses abilities in reasoning, communication, thinking, and performing daily activities such as taking a bath, eating, going to the toilet on their own, and getting up from bed. The affected patient has to be monitored and provided supportive care by family caregivers all day and night if not hospitalized. The cost of staying in the hospital for a prolonged period is very expensive and unaffordable in the absence of health care insurance, which only a few have the privilege to possess, especially in developing rural communities. So, home-based palliative care provided by family caregivers will help to solve double issues. One, it reduces the workload of a congested hospital or hospital with inadequate health care staff in rural areas, and two, it provides support and end-of-life care for elderly AD, as the main treatment for AD is to provide affection, care, and support to have a better quality of life to AD patients in a congenial home environment surrounded by closed family members. In home-based palliative care of elderlies with AD, family caregivers have to take on the role of nurses in hospitals all around the clock. For effective care and management of symptoms, they have to be aware of the progressive nature of the disease and collaborate with medical staff in the hospital or clinic to have proper guidance for imparting palliative care to their loved ones and to increase the well-being of AD patients [15]. In this regard, caregivers need to be aware that AD patients with advanced dementia need to provide support and care with various restrictions, including mobility, pain, difficulty eating, anxiety, and sleeping disorders. Along with these include symptom management such as disorganized behavior, agitation, loss of appetite, excessive weight loss due to refusal to eat food, problems in swallowing and drinking, etc. [16]. As the disease progresses to an advanced stage, the patient shows problems in body functions, including incontinence, difficulties in walking or performing daily activities, symptoms of indifference, changes in behaviors, asking the same question repetitively, asking meaningless questions and answers, confusion, depression, and nervousness, ultimately leading the patient to be fully dependent on the family caregivers.

3. Importance of home-based palliative care for the elderly with Alzheimer's disease (AD)

The global ageing population of 60 years and older is increasing rapidly and is expected to increase by double digits in 50 years, from 11.00 percent in 2000 to 22.00 percent in 2050 [17] due to the impact of medical science, which increases longevity. However, this increase in life expectancy is associated with various kinds of comorbidities, disabilities, and diseases, and Alzheimer's disease (AD) has gained prominence recently and is the main cause of dementia among the ageing population. The proportion of AD in the world has increased by 117.0 percent in 26 years (1990-2016), and this proportion of AD is estimated to increase in large numbers due to the population ageing by 95.4 million from 2019 (57.4 million) to 2050 (152.8 million) [18]. According to the report, cases of AD increased in large numbers—20.2 million in 1990 and 40.8 million in 2016 [19]. Consequently, these changes in the ageing population due to changes in life expectancy and increases in cases of AD among ageing elderlies lead to increasing demand for palliative care. In recent decades, there has been an increasing number of elderly people suffering from various deadly diseases such as cancer, heart disease, chronic multi-morbidities, and Alzheimer's disease, leading to the increasing need for end-of-life palliative care. This is quite in contrast to the past decades, as most elderly people suffered mainly from acute infections. The term 'palliative care' refers to the alleviation of the patient's symptoms, intending to improve the well-being of patients and their families while facing various kinds of deadly diseases [20, 21]. Providing palliative care at home to terminally sick elderly is important, as elderly people deserve dignity, comfort, and affection together with the family during the final stage of life [22]. Palliative care (PC) aims to improve the quality of life of both patient and family by adopting appropriate measures, such as detecting and preventing the disease at an early stage, assessing the stage of the disease, managing the treatment plan, and relieving pain and suffering. In other words, the adoption of home-based palliative care will help to increase the quality of life of AD patients, taking into consideration five dimensions (physical, social, spiritual, and economic) [23]. This has been confirmed from reports of previous studies, which stated that patients who received home-based palliative care at home surrounded and observed by their family caregivers and loved ones had a lower burden from symptoms and health care costs, achieved better care, and died a dignified and peaceful death [24, 25]. Most family caregivers prefer to provide home-based palliative care to terminally ill elderly people, as most patients do not get adequate healthcare coverage and support. However, the quality of home-based PCs depends on the family caregivers.

For home-based palliative care, family caregivers need to learn how to impart and manage palliative care at home effectively by having consultation and guidance from a palliative care-trained team of doctors, nurses, or health care specialists to assist the patient in controlling sleeping disorders, anxiety, and other common symptoms of AD. The family caregivers should organize the daily routine of care to be given to the patient from morning till bedtime. The bedroom environment of the patient should be quiet, calm, and not very bright so that the patient can rest without getting disturbed since the main goal of palliative care is to relieve suffering and pain [7]. Family caregivers can soothe pain and other symptoms by taking advice from the palliative care team in the hospital or clinic, through medication, spiritual, and social support, as palliative care aims to provide comfort care for terminally ill patients, unlike medical care that aims to cure the disease. Through palliative care, the lifespan can be extended and should be given simultaneously with other medical treatments, care, and options [26]. This implies that the approach of palliative care is interdisciplinary, integrates physical science, psychosocial, and practical dimensions, focusing on symptoms treatment instead of the disease, relieving suffering and pain, and increasing comfort to terminally ill patients before leaving their near and dear ones forever [27, 28].

4. Challenges experienced by home-based palliative family caregivers of the elderly with Alzheimer's disease

There have been many studies that reported experiences faced by healthcare staff and professionals in imparting home-based care services for terminally ill elderly people [29, 30], but on searching about challenges and obstacles met by family caregivers for taking care of terminally ill AD patients at home, there are only a few research reports relating to it in the available literature. The present article aims to fill the knowledge gap to increase the efficiency of home-based palliative care for elderly people with AD. Taking care of an elderly person with AD is more challenging than other ageing elderly people who are sick with other common diseases because AD causes disorganization in the behavior, personality, and reasoning skills of elderly people. Since the brain of an AD patient is damaged, there is a deterioration of the patient's cognitive function, resulting in judgment, orientation, and the ability to understand and communicate effectively. Managing these changes is a common challenge for family caregivers. As the disease progresses, the elderly suffer from many symptoms and need all day and night care from family caregivers who suffer from emotional stress, depression, health, and financial impact [31]. The following provides some challenges and interventions for the caregiving of AD patients obtained from the literature review.

Table 1. Challenges for caregiving of AD patients obtained from literature review

References	Challenges and interventions
Yazdanmanesh et al. [31]	Investigated the challenges faced by family caregivers of elderlies with AD with aims to lessen the problems of caregivers and to improve the knowledge and quality of caregiving with minimal impact on the well-being of caregivers as well as care recipients.
Brodaty & Donkin [32]	Family caregivers have to play many challenging roles in the palliative care of elderly patients with AD. The well-being of the care receiver depends on the quality of the care provided by the care provider. A family caregiver has to meet many burdens, including health, psychological (stress, depression, social isolation), and financial burdens in addition to family, occupation, and other social responsibilities.
Hosseini et al. [33]	This study explored the family caregivers' experiences of AD patients in Iran. The result showed five dimensions of challenges such as commitment, control, challenge, communication, and culture.
Supaporn et al. [34]	Investigated the challenges that Thai family caregivers experienced while imparting home-based palliative care to terminally ill elderly patients. Results found five categories of challenges, such as (1) caregivers' burden in bathing, turning positions, feeding, and managing waste; health, economic, and anxiety impact the caregivers; (2) problems how to manage symptoms; (3) diagnosis of the disease; (4) not prepared for death; and (5) taking decisions regarding place and procedure of treatment.
Ashrafizadeh et al. [35]	This study explained family caregivers' experiences in providing palliative care to elderlies with AD in Iran. The obtained result revealed various challenges related to the caregiving burden, strain, and the associated stage affecting the patient with the disease. Finally, the study suggested health planners identify and incorporate challenges, pain, and burden experienced by family caregivers in policy planning and adopt appropriate strategies for interventions of palliative care of elderly patients with AD.
Liao et al.[36]	It is commonly observed that most family caregivers experience fatigue and physical and mental stress due to the long-term care of patients with AD. So this study investigated family caregivers' health-related quality of life to explore those factors. The result revealed that the quality of life of family caregivers was highly affected, and the responsible factors include the nature of AD symptoms, long-term care, reduced cognitive function, and the stage of the disease. Suggested to relieve this family caregivers' burden in making health policy and planning for interventions.
Eisenmann et al.[37]	Studied challenges and distress as burdens in the management of symptoms, complications, and place of treatment. The result of the study revealed that family caregivers need support with the

References	Challenges and interventions
	provision of proxy decision-making and collaboration with healthcare officials in every stage of the disease from the beginning to the end stage of home-based palliative care at home for better management and well-being of both AD's patient and family caregivers.
Lindeza et al.[38]	AD caregivers experienced negative feelings such as fear, sadness, social isolation, and concerns about the future impacting their emotional and social aspects. The result provides holistic insights into caregiving experiences with suggestions to solve the negativity through intervention for better care of AD patients without affecting the quality of life of home-based palliative caregivers.
Kawaharada et al. [39]	This study confirmed family caregivers' challenges in feeding patients with AD and the decision of food selection, as many AD patients have disorders in eating behaviors and appetite changes, and due to these changes in eating habits, difficulties in swallowing and consuming lots of time in preparing soft, wholesome food for AD's patients and feeding them. After taking lots of time to prepare the food, caregivers have emotional fatigue if the patient hardly eats or refuses to eat the meal.
Sandberg et al.[40]	This study revealed that more than 60% of elderly with dementia need a caregiver's help in bathing. Family caregivers have to help the patient in the bathroom or clean the body if very weak with wipers and sanitary requirements for maintaining proper hygiene of elderlies with AD, which causes lots of physical effort and stress to the family caregivers.
Grabher [41]	This study reported that family caregivers often have emotional feelings, including sadness, discouragement, loneliness, anger, fatigue, depression, and stress along with many challenges of job and family responsibilities. Family caregivers have stress as they have to balance caregiving with other demands, have to take double or multiple responsibilities such as adjustment of work schedule, going late to work, leaving early, or taking time off, and difficulty in full-time concentration to important office work, besides taking care of families as well as the ailing patient with AD.
Mars et al.[42]	This is a study about African-American caregivers' experiences of palliative care. The result indicated some challenges faced by informal family caregivers, such as inadequate support from healthcare staff and a lack of knowledge and guidance on palliative care. The study suggested that family caregivers should be provided information and training through knowledge sharing, collaboration, and support from a professional healthcare team.
Sinha et al. [43]	This study compared the caregiving burden of elderly patients with AD and other psychiatric elderly patients in India. The result revealed that taking care of dementia elderlies is more challenging than elderlies with other diseases and therefore suggested lessening the burden through the government. policies, training, guidance, and other innovative interventions.
Lethin et al. [44]	This study revealed that in the absence of family support, taking full-time care of an elderly person with AD has many impacts on the caregivers, as they have to perform multiple roles besides caregiving for their beloved elderly, such as job, family, and society. These caregivers were socially isolated, as they hardly had time to join social gatherings or activities. Finally, the study pointed out the importance of collaboration with formal agencies of formal care to impart better care according to the condition of the patient and the stage of the disease.
Meyer et al. [45]	This study aimed to improve dementia care and lessen the family caregiving burden in Vietnam through the adoption of intervention measures such as organization of training, awareness programs, publicity, education, and communication with formal professionals and staff. The study revealed that sociocultural values, beliefs, norms, and expectations influence the quality of care provided to the patients and the caregiving experiences of the family caregivers.

References	Challenges and interventions
Park et al.[46]	This research used community data to explore factors that increased the caregiving burden for family caregivers of AD patients. The result revealed factors such as the stage of dementia, the behavioral problem of the patient, the physical health status of the family caregivers, the number of family caregivers, and the length of caregiving (time).
Xiao et al.[47]	This article aimed to compare facilitators and obstacles associated with caregivers of dementia patients in Australia and China by analyzing the subjective as well as objective experiences of those caregivers. The target goal of the study was to improve the available dementia care strategies and management. The result of the study found challenges experienced by caregivers of the family such as less time for personal care, neglect of caregivers' other responsibilities, difficulties in performing multiple roles of caregiving, family responsibility, employment, parental responsibility, and social participation.
Richardson et al.[48]	This research reviewed recent literature on caregivers' experiences in taking care of a relative with AD and dementia. The result revealed problems associated with managing behavioral and other disorderly symptoms of dementia. The result concluded with the need to adopt psychosocial intervention measures to solve the problem of caregivers and, at the same time, improve the quality of care for the well-being of both patient and family caregivers.
Tasci et al. [49]	This study was conducted to investigate the family caregivers' experiences and challenges in taking care of patients with AD in Turkey. The result revealed challenges such as too much demand for the caregiver's role and time. Due to the need for intense care of a family member with AD at home, the caregiver faced difficulties in finding time for relaxation, professional, family, and social life.
Chan [50]	This research was conducted by reviewing the literature of published works during 1990–2010 on the issue of challenges of home-based caregiving for the elderly with AD. The result revealed various forms of challenges, including physical, emotional, work (employment), and family responsibilities. The result suggested the requirement of systematically planned intervention measures through training and education to lessen the caregiving burden to family caregivers.
Valera et al. [51]	This article described major challenges experienced by family caregivers in taking care of relatives with AD. Some notable challenges listed were: intense anxiety, stress, and sleep deprivation as most caregivers need to remain awake at night to monitor the advanced-stage patient.
Hudson et al. [52]	The study reported that since the main goal of palliative care is to provide all kinds of support to terminally ill patients all day and night, the family caregiver has to remain vigilant and look after the needs and welfare of the patient, and this causes many negative impacts to the caregivers, such as neglect of self-care, health deterioration, and less time to interact with friends, families, and social life.
Pahlavanzadeh et al.[53]	The study results revealed the benefits of the family education program to relieve, lessen, and solve problems of caregiving to family members of AD patients to decrease the burden. Recommended to develop and evaluate such programs in scientific research for policy implications.
Takai et al.[54]	The study examined challenges experienced by family caregivers of dementia patients. Examples of challenges were burnout, depression, emotional and physical stress, and retarded quality of life. The result of the study suggested more research and interventions in family care to solve the problem and improve the quality of life of both patients and caregivers.

References	Challenges and interventions
Papastavrou et al. [55]	As taking care of an elderly person with AD has many challenges, including physical, emotional, financial, and social problems, this study investigated the burden of caring for a family member with dementia and the impact on the mental health of the caregivers. The study concluded with the essential strategies that should be used to solve stress and other problems of caregivers.
Serrano-Aguilar et al. [56]	This research aimed to assess informal family caregivers' experiences of taking care of family members with AD by analyzing the impact on the health-related quality of life of caregivers. The study was conducted in Spain and the result reported that a high proportion of family caregivers (83.3%) experienced a high level of burden.
Mahoney et al. [57]	This study analyzed a sample of AD family caregivers who suffer from anxiety, stress, and depression and then compared it with those who did not suffer from stress or anxiety. The result revealed that one-fourth of family caregivers of patients with AD have anxiety, while 10 percent have depression.
Schulz & Martire [58]	This study reported on the challenges and physical and psychological impact of palliative caregiving to elderly patients with AD at home and concluded with a suggestion to adopt intervention measures to lessen family caregivers' burden and, at the same time, improve the quality of life of patients and caregivers.
Choo et al. [59]	The study selected factors such as socio-demographic, social support, and coping to investigate whether these variables have any association with the caregiving burden experiences of families having a dementia patient at home. The result showed the need to improve social support and coping skills to lessen the burden on family caregivers of relatives with AD.
Farcnik & Persyko [60]	This study was conducted by reviewing available literature on the complexities of caregiver's burden, ways of measurement of the challenges, characteristics of the caregivers, symptoms shown by patients, and type of intervention measures to reduce those challenges. The study suggested the importance of intervention measures both pharmacologically and psychosocially.
Connell et al.[61]	This paper aimed to examine the impact of caregiving to a dementia relative at home from two dimensions, physical and psychological. It also examined the magnitude and intensity of these impacts and finally discussed many approaches for inventions to solve and minimize caregiving challenges.
Leong et al. [62]	This article reported on the challenges of home-based dementia palliative care at home. The study recommended interventions needed to improve the health and well-being of family caregivers. Some of these intervention needs include (1) finding a replacement caregiver when the caregiver is absent or busy with other work; (2) availability of a telephone number for consultation and assistance; (3) finding some free time for rest; (4) finding means and support to cope with extreme stress; and (5) finding means for solving impacts on health, emotion, social, and family.
Clyburn, et al.[63]	The study reported the importance of effective management of symptoms and disturbing behavior of highly impaired dementia elderly based at home by family caregivers through consultation with the health care team, social support, and improvement of coping skills.

Since most developing countries have insufficient AD care homes, the family takes the responsibility for caring for the elderly patients with AD. In traditional families, it is a familial responsibility to take care of each other, and young people are disciplined in the socialization process to be responsible for taking care of elderly or sick parents. So, in traditional society, it is customary for youngsters to take care of their elderly parents when they are helpless and bedridden, and due to this norm, most elderly patients with AD stay at home and are provided all necessary care by family caregivers. However, taking care of an elderly person with AD is more challenging than taking care of other elderly people who suffer from other diseases. This is because, in the advanced stage of AD with advanced dementia, the patient displays various types of complicated symptoms. So, family caregivers need to monitor the patient 24 hours per day, and this causes challenges that have an impact on the family caregiver, including physical, psychological, emotional, social, and financial problems. Palliative care aims to solve the various disorders and symptom management by an efficient family caregiver through systematic planning and consultation with health care providers so that the elderly patient with AD can have a relaxed environment surrounded by loved family members till the patient breathes his/her last. Understanding the caregivers' challenges is important as the finding will lead to an effective intervention for health care planners and family caregivers for elderly AD patients at home with due consideration that consideration of care issues and management is influenced by the available culture and society, which varies from one society to another. AD is a product of neurological and physiological changes in the brain that are not spontaneous but pass through long-term changes in brain function. Common symptoms include retardation in memory, thinking, and reasoning skills. The disease commonly affects mostly the elderly, and if affected in the advanced stage, it makes the elderly patients dependent, bedridden, and need to be monitored and cared for all around the clock by the patient's family and caregivers [64]. However, since a person with AD lost the ability to perform personal care and tasks, they are dependent on the family caregivers for everyday routine personal care such as getting up from bed, brushing teeth, sitting and getting up from a chair, eating breakfast, going to the bathroom, and getting dressed up. Having an AD patient at home increases the caregiving burden of the family to family caregivers, as caregivers have to assist the patient in getting up from the bed, bathing, feeding, getting to and fro from the toilet, etc. In the absence of a family caregiver, the elderly patient needs to be monitored and assisted by another caregiver, family member, or other. Traditionally, the family system is joint, and there is close bonding and interdependence among members, so palliative family caregiving was not so difficult. However, with the disintegration of the joint family into a nuclear one due to urbanization, modernization, population control, declining household income, and lifestyle changes, there are changes in supportive families, and many helpless parents live alone or without adequate support from family members. Also, those families who took care of their elderly parents with AD do not have the knowledge and training to manage the symptoms of AD at home. In addition, these caregivers have multiple roles besides caring for the elderly, so these caregivers have to adapt and need to be trained through education and collaboration with healthcare staff to improve their caregiving abilities and competence [65].

From the above review of literature, many studies have reported challenges experienced by family caregivers, including physical health, psychological state of mind, and expenditure burden. Having an AD patient at home causes changes in the lives of family caregivers in many ways, such as insufficient time, impact on emotional feelings, having limited time for social life or gatherings, along with continuous stress physically and mentally. These changes can be factors that have an impact on their physical health and mental state of mind. This has been supported by previous studies [49–52] that reported family caregivers to have suffered from stress, anxiety, and insomnia, which affected their health and quality of life.

5. Discussion, Conclusion, and Recommendations

As the ageing population is increasing worldwide, dementia due to Alzheimer's disease (AD) commonly affects the ageing elderly. This disease is a progressive neurodegenerative disease of the brain. Symptoms can be commonly felt by forgetfulness and behavioral changes due to deterioration of memory, learning, speaking, reasoning, and communication skills, finally leading AD elderly patients to be dependent on family caregivers. In most developing countries and traditional societies, it is customary obligatory for grown-up children to take care of their elderly parents, as parents have devoted themselves to bringing up and looking after their children. Due to this customary norm, elderly parents, when they become sick with any disease, including AD, adult children, and their families take care of the dependent elderly. There is so much stress and strain on the family members of AD, as family caregivers play a major role in caring for the elderly patient in every stage of the disease. For instance, most AD patients sleep excessively during the daytime while at night they remain awake, and this causes disruption in the sleeping hours of the family caregiver and affects their health, having fewer sleeping hours at night. So, providing caregiving to an elderly AD patient is not an easy task, as caregivers need to monitor the patient all around the clock, consequently affecting the normal life of the caregiver in terms of their health, emotions, and family life [47]. Home-based palliative care provides care and support, especially to terminally ill patients, surrounded by their family caregivers. The main aim of home-based palliative care is to provide the sick elderly with the maximum level of care, comfort, and love till death. However, palliative care in developing countries is still at a nascent stage with inadequate facilities for geriatric care of elderly people with AD. Currently, utilization of home-based palliative family caregiving is essential to provide support and care for elderly patients with AD. Due to this important role of caregiving to dependent home-based AD patients, it is considered necessary to study the challenges of caring for dementia patients caused by AD, with a target to improve the health and well-being of both the dependent elderly patient as well as the family caregiver. Public health policymakers need to adopt interventions that can reduce the challenges to family caregivers and improve the role of caregiving. This will help to improve the role of caregivers without affecting their health and thus will improve the well-being of both patients and caregivers [42, 44]. Even though home-based caregiving affects the health, family, job, and social life of caregivers, it has many positive contributions. Firstly, it increases the patients' happiness, reduces loneliness, and improves well-being surrounded by their loved ones and close family members. Secondly, it saves the cost of hospitalization. As the care of AD patients is for a prolonged period and 24-hour care is similar to caring for a patient in ICU, the financial cost of hospitalization fees is huge, which is quite difficult to manage in the absence of health care support and insurance, especially for poor and middle-income families. Thirdly, it reduces the burden on the health care system. Due to these positive aspects, the WHO has encouraged healthcare systems to promote home-based palliative care. However, it is important to have collaboration and support from healthcare medical professionals and family caregivers to provide better reliable decision-making and guidance in everyday care, symptom management, and other critical care situations. Many studies from the above literature review reported challenges experienced by family caregivers while taking care of the elderly with AD. Some of the notable challenges include the emotional state, financial expenditure, negative health impact due to mental stress, physical fatigue, inadequate sleeping hours and social life, work stress for not being able to concentrate on office work, duties, going to the office late and returning home early by skipping office working hours, etc., as found in previous studies [32, 51]. Many family caregivers suffer from social isolation, deprivation of social and financial support, inadequate time for leisure or family life, and disruption of family relationships. All these factors can be a pioneer in impacting caregivers' and patients' well-being [41, 52]. Below are listed some main challenges as obtained from the above literature review:

- Depression, anxiety, and impact on the health of health caregivers physically as well as mentally
- Reduced earnings and finances due to negligence on the job
- More expenditure for patients with AD
- Need support, proxy decision-making, and guidance from expert health care professionals in symptom management, pain, and other needs when demanded of the patient,
- Fatigue and deterioration in social and family relations due to stress and insufficient time.

The findings of this article provide a better understanding of Alzheimer's disease, the importance of palliative care at home for elderly people with AD, and the challenges encountered in providing care. Understanding the disease symptoms and challenges experienced by caregivers can pave the way for solutions to palliative care teams with comprehensive care for AD elderly patients, as well as improving the health and well-being of both patients and family caregivers. In the end, it can be concluded that the knowledge obtained from this article can be useful to academicians, family caregivers, AD patients, policymakers, and medical professionals to solve the challenges of palliative care at home and to provide better care, symptom management, and pain management with minimal negative effect on the caregivers of elderlies with AD through education, government support, and rehabilitation. Some recommendations for improvement are given below:

- Provide integrated palliative care in collaboration with healthcare providers to manage symptoms, have awareness of the signs of approaching death, and plan care [37].
- Make home-based palliative care fully functional needs development with the availability of all facilities for elderly care.
- Collaborate with public health organizations to improve the effectiveness of palliative care of the elderly at home through education, training programs, and research works [42, 44].
- Collaborate with family caregivers, medical staff, the community medicine palliative care team, and other health care professionals to manage the complex care needs of people with AD and solve any hurdles for family caregivers [42].
- Given the importance of reducing caregivers' burden and improving patients’ well-being with AD, various aspects should be studied, including challenges encountered and factors causing the problem, through research studies, and then integrate applicable intervention measures in health care planning and policymaking of palliative care.

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