Caregiver Burden in Different Stages of Alzheimer's Disease

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ABSTRACT

With an increasing number of patients being diagnosed with Alzheimer's disease (AD) daily, it has become one of the major problems in public health. The increase in the number of dementia patients in low- and middle-income countries is expected to be much more than that in developed countries. As a result, the economic burden of dementia, both worldwide and in Turkey, is growing. Moreover, AD leads to emotional burdens and psychological distress in family member(s) and caregiver(s) alongside the patient. Each stage of AD imposes different responsibilities on caregivers, increasing their burden. The suffering and emotional burdens of caregivers from these responsibilities lead to a decreased quality of life and disturbed body physiology. Incapacity, despair, weariness, and loneliness are the hidden emotions of this iceberg. This review aims to gather the results of studies on caregiver burden in different stages of AD, attract attention to those results that may have been ignored in Turkey, and shed light on the solutions required to overcome the problems in caregiving of AD patients.

Keywords: Alzheimer’s disease, burden, caregiver, dementia

As the elderly population grows, dementia becomes a widespread condition. Since Alzheimer's disease (AD) is responsible for 60–70% of dementia cases, it becomes one of the major problems in public health and neurology. The World Health Organization (WHO) recommended that every country should have a health strategy for improving the knowledge of health professionals and caregivers on dementia and a strategy that focuses on early diagnosis in its 2011 report. The WHO report titled “Dementia: A Public Health Priority” (published in 2012) aimed to raise awareness on dementia (1).

Since there is no treatment option to heal AD or stop its progress, presently, the goal should be to improve and support the quality of life in patients, their families, and their caregivers as much as possible. Considering how difficult it is for AD patients to adapt to environmental changes, it will be easier to understand the important role of caregiver(s) in providing care to patients. This burden on the shoulders of caregiver(s) can be reduced by educating them on proper care and taking necessary measures toward protecting the caregiver’s social life and psychological health.

Many people who provide care to their patients are overwhelmed with these responsibilities and emotional burdens, and their quality of life and even body physiologies become impaired. The incapacity, despair, weariness, and loneliness experienced by caregivers to AD patients are the invisible parts of the iceberg. By looking from the perspective of caregivers to AD patients in this review, we aimed to gather the results of studies on caregiver burden in different stages of AD, attract attention to those results that may have been ignored in Turkey, and shed light on the structure required to overcome the problems in this area.

There are 44.4 million dementia patients worldwide, with 7.7 million patients being diagnosed each year. This number is expected to rise to 75.6 million in 2030 and 135.5 million in 2050 (2). Unfortunately, 62% of these patients live in developing countries. The increase in the number of dementia patients is expected to be much steeper in low- and middle-income countries than in developed countries (3).

Considering hospitalizations, medical treatments, homecare expenses, and the loss of contribution to the economy on the part of the patient, the annual worldwide economic burden of dementia is calculated to be approximately 604 billion American Dollars. If dementia care expenses were treated like a country’s economy, it would have been the 18th largest economy in the world. Considering that this place falls right below the line where Turkey can be found, it is better understood how a large hump dementia is on the world economy (2).

With its symptoms and findings, AD is a chronic disease that impairs a patient’s quality of life. There are three variables in determining a patient’s quality of life: patients, caregivers, and health professionals (4). The process of providing care to an AD patient is toilsome in many ways, and it shapes not only the life of the patient but also the lives of their families and caregivers (5,6,7,8,9,10,11,12). Major factors affecting the stress of caregivers can be listed as loneliness, depressive mood, being exposed to behaviors not expected from the patient, and insufficient knowledge about the disease (13). This
process lowers the quality of life for the caregiver while also increasing the caregiver's burden (14).

As far as we know, the first study in the English literature about the quality of life in dementia was conducted in 1985, and the first randomized and controlled study covering ethnic groups was conducted in 2006 (15, 16). These types of studies that also cover caregivers, which developed countries have focused on for 30 years, are also available in Turkey, although not as many studies have been performed (17, 18, 19, 20). The expectations of some patients and their families in our country that the medical treatment of AD would regress and even reverse the symptoms and findings of the disease constitute an important obstacle to overcome in order for them to acknowledge the diagnosis and make their plans accordingly. While some patients/patients' families insist on not accepting the diagnosis, there are others who can succeed at combining the dementia diagnosis with the symptomatic period (a time that passes in distress before the diagnosis) and still others who experience a process consisting of various acceptance and denial stages for the dementia diagnosis (21). In a controlled, randomized study conducted with 206 caregivers in the UK, it was observed that when these caregivers were provided with places/people where they can get support, behavior management, spending quality time on education, psychological support, and the negative effect of patient symptoms on the caregiver decreased and the quality of life of the caregiver improved (22). Social support also seems to be vitally important during the progression of this stressful disease (21).

Those who intend to provide care have great expectations of being informed about the disease prognosis, treatment options, and the things they can do to maintain the quality of life of the patient (23). Adults are knowledgeable about AD in general terms, but they do not know much about specific care and AD treatment; thus, they find themselves “insufficient” in regards to AD awareness (24). Support meetings, educational programs, and practical information on maintaining quality of life seem sufficient for meeting these expectations (23). As they are the people who can cause vital changes in the lives of patients, caregivers should not only be provided with information on the disease, but should also be educated to change their point of view and attitude toward the disease (25). Adequate allocations should be made for public health education to ensure that the question about AD are eliminated in the patient's/patients' families' minds and that they relax psychologically to receive the ideal support. Succeeding in this can only be possible if the health authority, media, healthcare institutions, and non-governmental organizations all work in collaboration (26). To do this, it is of great importance that people who will provide care are willing and all parties cooperate in this education process (27).

Many AD patients are being looked after by their family members at home (28). If the patient is married, he/she usually receives care from his/her spouse. Those caregivers who say that their marriage has a firm past encounter fewer difficulties (29). According to studies, patient spouses who have no care giving experience are more vulnerable to negative results (30). Additionally, those who have no cooking experience (mostly male caregivers) experience the greatest worry about not being able to provide sufficient and correct nutrition to the patient (31).

The influence of a caregiver is also great in the frequency and type of medication the patient will take and in efficacy assessment of the treatment (14). A questionnaire (Alzheimer's Disease Caregiver Preference Questionnaire) was prepared in a study conducted in the UK to measure the satisfaction and medical treatment preferences of caregivers. That study focused particularly on those caregivers who were dissatisfied with the efficacy of the medical treatment received, frequency of medication administration, non-compliance with the treatment, and side effects. It was concluded that the questionnaire was useful in determining the most appropriate medical treatment for the patient and caregiver (30). The illness process can be divided into three stages as early, middle and late.

**Early stage:** This is the most important stage for early diagnosis because this period is overlooked in many dementia patients. Since this stage is vital for the patient to receive more effective support, care, and treatment, the WHO defined early diagnosis awareness as the first goal in its 2011 report (31). There is now the possibility to make the treatment more effective by intervening with the preparations used in the symptomatic treatment of AD before most of the neuronal circuits are harmed (32). Because of early diagnosis, it is possible to improve cognitive functions, to prepare the patient and their family for the progress of the disease, to enable their participation in the treatment, to prolong the time before hospitalization, and to maintain a higher quality of life longer (32, 33, 34, 35, 36, 37). The European Primary Care Consortium for early and timely INTERventions in DEMENTia, INTERDEM) also emphasizes the necessity of early diagnosis and timely intervention because these enable the identification and treatment of reversible types of dementia (31, 38).

Since the first people who encounter memory disorders and problems are doctors, the doctors working at primary care institutions should be aware of cognitive disorders and depression problems as well as the steps that need to be taken (38). Despite this awareness, doctors still remain desperate in drawing the lines between the stages of dementia and in identifying the point where the patient has irreversibly lost his/her individuality and character. Despite these uncertainties, treatments to prevent advancement should be started rather than the “wait and treat” approach (39). By linking the early symptoms of dementia to the patient's character and aging, patients’ families can cause the diagnosis process to be delayed by up to 4 years, even though the symptoms have worsened. In such cases, it becomes necessary to convince the patient and their family to accept dementia and seek medical support (40). However, many doctors are uncomfortable when giving the diagnosis of dementia. The reasons for this difficulty may include doubt that the patient, and his/her family, would understand the disease, fear of prejudice in accepting the disease, personal uncertainties about the diagnosis, and the hesitation to raise hopelessness in the patient (41). Although patients in Western societies usually prefer to know about their diagnoses, doctors and patients' families choose to not give information to their patients about the diagnosis. In fact, studies have shown that only about a half of the patients are aware of their diagnoses (41).

Even if the patients want to be informed about their diagnoses, they often reject a brain scan when they consider the consequences of it (42). The patient's age and the burden of outcomes play a major role in the decision to undergo this test (43). The elderly in Germany wish to have their brains imaged for regular screening purposes, even if there is no suspicion of dementia (44).

In the process of establishing a dementia diagnosis, doctors seem to demonstrate unwillingness in their behaviors and attitudes (45). Doctors should act in a disciplined manner at the stage of diagnosis because the patient, and patient's family, has the right to know the diagnosis, the requirement of starting treatments as soon as possible, the relaxation caused by learning the reason, the elimination of stress associated with memory problems, and many other reasons (45).
Forgetfulness and losing the concept of time begin in the early stages of AD. The patient may lose the same question repeatedly and re-tell the same events as if she/he had never told them before. They may forget their shopping list or keys at home, or leave the stove on after cooking so as to invite home accidents. AD patients experience problems in learning new information, but there is no distinct change in behavioral problems and social life at this stage, making it possible for the patients to lead their lives without help. However, if the patient is aware of his/her symptoms, this may lower the quality of life of the patient, caregiver, and the patient’s family; increase the burden and expenses of care; or bring the time of hospitalization to an earlier date. Behavioral and psychological symptoms associated with dementia (BPSD) may develop. Such symptoms may include anxiety, hallucinations, delusions and depressive moods (psychological), aggression, skepticism, wandering, and actions incompatible with the patient’s cultural background (behavioral). The major factor impairing the quality of life of a patient is depression. Patients should be monitored strictly for neuropsychiatric diseases (4). Less attention had been paid to these symptoms in the past than the cognitive symptoms of dementia; but the number of studies on this issue has been increasing recently (46,47,48,49,50). A study consisting of 119 people diagnosed with AD and their caregivers has shown that BPSD are more destructive in caregiver depression than the cognitive disorder itself (51). It has also been found that the perspective and attitude of the caregiver, with respect to the disease, are more determinant in rating disease burden than the patient’s character or illness (52).

Although it is not surprising that dementia affects the caregiver negatively in many respects, another point explored in recent years is the positive outcomes of dementia on the caregiver (53). One of the Positive Aspects of Caregiving is that the caregiver feels helpful, satisfied, and rewarded by looking after the patient (54). Such feelings diminish the negativities arising from the routine requirements of care, and those who look after a patient feel better psychologically and render more quality care (55,56,57). Study results demonstrate that the caregiver’s character is more effective for the occurrence of these positive aspects than the patient’s character for the negative aspects (55). These positive aspects are seen more in young caregivers who look after antisocial patients and spend more time with them (55).

Middle stage: The symptoms of the disease become more prominent and restrictive at this stage. Patients are not able to walk alone outside their homes. They may show awkwardness when eating, They struggle during dressing, undressing, and going to the bathroom if they do not receive help. Their time orientation becomes impaired, and they wish to go to sleep as soon as it becomes dark. Their social relationships deteriorate. Aggression and paranoid delusions may begin. Their BPSD may aggravate, and this may increase the burden on their caregivers. These symptoms have been found to increase the depression symptoms two-fold in caregivers, and female caregivers become more depressed than male caregivers (58,59). Patients found most annoying by their caregivers are reported to be those who still had social responsibilities but who exhibited abnormal behaviors in the presence of others (55).

One of the most important decisions patients’ families have to make in AD is whether to outsource professional support for the patient or to hospitalize them. In closed communities in particular, patients continue with their normal life in the subclinical period, and support from professional entities is sought only at advanced stages (60). The socioeconomic statuses, traditions, or beliefs of a community can influence the determination of their perspectives with respect to medical treatment and doctor reliability, mental diseases, and distress and hardship. Compared to communities with no religious beliefs, those living in a believing community need less medical support for their health problems (61). Furthermore, although majority of studies show that there is a direct association between hospitalization and BPSD, studies showing the contrary also exist (62,63,64,65,66,67,68). The most important indicator in determining the willingness of patients’ families to reduce the caregiving burden is the time they allocate to looking after their patients. This time span is comparable in importance to the expenses to be made for a caregiver (69).

As time passes after the diagnosis, the awareness, decision-making abilities, and knowledge of patients’ families, which are the components of Preparation for Future Care, increase and neglect behaviors decrease. With the contribution of education, planning for the future becomes more realistic and sophisticated (70).

Advanced stage: The patient is unable to perform self-care at this stage and needs a caregiver. Eating, bathing, and dressing can only be performed with complete dependence on others. Patients do not recognize their children and even themselves when looking in a mirror. Sphincter dysfunctions become prominent. In a neurological examination, pathological findings such as myoclonia and hyperactive reflexes may be detected. The most frequent causes of death in AD patients are bedsore infections, lung embolisms/infections, and nutritional deficiencies (71).

Since symptoms become more distinct from stage to stage, each new stage onset is a separate trauma for the patient’s family. However, the advanced stage is the most important stage in terms of the responsibility of caregivers as the patient is unable to perform self-care during this stage.

Since patient dependence increases as the disease progresses, mortality and morbidity increases in caregivers (72). In a two-year longitudinal study conducted in 2005, cortisol levels in the morning saliva of 57 caregivers were found to be significantly higher than those of the control group and this was linked to chronic stress (73). Those who had caregiving responsibilities were found to present to a doctor more often due to the suppression of their immune systems and use of more medications and remained more susceptible to memory disorders (74,75).

Providing care to a chronically ill patient is a long-term, wearing, and serious process depending on the clinical stages. AD alters the quality of life not only in patients but also in patients’ families and more intensely in caregivers. AD impairs the psychological health of caregivers and even involves organic pathologies. All these results constitute the invisible part of the AD iceberg. Although it is not possible to prevent all these problems, as AD is a progressive disease, the burden can be minimized with the collaborative work of health policy makers, the media, social institutions, doctors, and the patient’s caregivers.

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