

## Review Article

## An Important Problem for Caregivers of Dementia Patients: The Burden of Care

Tuba DOĞRU<sup>1</sup>, Havva SERT.<sup>2</sup><sup>1</sup>Sakarya University Institute of Health Sciences, Sakarya, Turkey<sup>2</sup>Sakarya University Faculty of Health Sciences/ Institute of Health Sciences/Department of Internal Medicine Nursing, Sakarya, Turkey.

\*Corresponding Author

Havva SERT

**Abstract:** Dementia is a chronic disease that causes care dependency in daily life activities of individuals as a result of impaired cognitive functions and loss of existing cognitive abilities such as memory, speech, and attention. The progression of the disease and the dependence on the support enhance the care needs of patients supplied by caregivers. Caregivers of patients with dementia are suffering from psychological, physical, financial problems and social isolation. This increases the care burden and makes caregiver a secondary unseen patient. In the literature, it can be observed that many factors, especially the severity of disease, dependency level, gender of caregiver, age, education status, affect the care burden. Making initiatives for the factors that cause the burden on caregivers of dementia patients has an important role in reducing the burden of care. For this reason, caregivers should be supported in physical, psychological, financial and social areas, and the poor physical and psychological conditions which they experience due to care should be corrected and the care costs of the individuals should be reduced to the lowest levels. In this review, we aimed to examine the care burden experienced by relatives of patients with dementia.

**Keywords:** Dementia, Dementia Patients, Burden, Caregivers, Patients, Nursing.

### INTRODUCTION

Dementia is a latent and progressive disease that prevents people from continuing their daily life activities as a result of the deterioration of mental functions, such as loss of memory, speech, attention, and existing cognitive abilities (Akyar İ 2011; WHO 2017; WHO 2018). Dementia disease develops in 9.9 million people every year in the World (WHO 2017; WHO 2018). According to the prevalence number of dementia disease, it is seen as 24.3 million for 60 years old and above in 2001, 46.8 million in 2015, and nowadays 50 million people have dementia disease (WHO 2017; WHO 2018; Chan M *et al.*, 2012; Prince M *et al.*, 2016). The number of people with dementia is expected to be doubled in every 20 years, it is expected to be 82 and 152 million in 2030 and 2050, respectively. 60% of patients with dementia are living in low and middle-income countries and it is estimated that 71% of dementia cases will be seen in these countries in the future (WHO 2017). The economic cost of dementia worldwide is calculated as 818 billion USD, and this is a major obstacle to social and economic development (WHO 2017; WHO 2018a).

The most common form of dementia is Alzheimer's disease and it constitutes 60 to 70% of dementia cases (WHO 2017; WHO 2018a; Atkan F *et al.*, 2017). Other forms of dementia are vascular dementia, Lewy-body dementia, frontotemporal dementia, and vascular cognitive impairment (WHO 2017; Atkan F *et al.*, 2017; Yener G *et al.*, 2012). The most important dementia risk factors include hypertension, diabetes, long-term use of tobacco and tobacco products, age and low level of education (Akyar İ 2011; WHO 2017; WHO 2018a; Yavlal F *et al.*, 2016). Other risk factors are physical inactivity, obesity, irregular nutrition, female gender, long-term depression, social isolation, mental inactivity, and other genetic factors (WHO 2017; WHO 2018a; Yavlal F 2016). Ertekin *et al.*, conducted a study in the eastern region of Turkey, the incidence of dementia was found statistically increased by 4.1 times in patients with diabetes, 3.6 times in patients with heart disease, and 17 times in the old age, and also found to be more in females than males (Ertekin A *et al.*, 2015). Dementia is a major cause of disability for individuals over the age

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of 70, so it ranks second among the causes of disability and seventh among the causes of death. The symptoms of the disease, disability or progression of dementia cause increased dependence and needs for care (Atkan F *et al.*, 2017; Cheng ST 2017). Therefore, dementia affects not only patients but also their families, caregivers, and the society they live in (WHO 2018a; WHO 2018b). Giving care to the dementia patient causes especially the psychological, physical, and financial problems and social isolation of the caregivers in family, which allows increased care burden and makes the caregiver a secondary unseen patient (Brodaty H *et al.*, 2009).

### THE CARE BURDEN AND ITS MAJOR FACTORS

The concept of care is a form of behavior that includes managerial, emotional and cognitive abilities to meet the needs of patient by the caregiver (Altıok HÖ *et al.*, 2011). Caregiving is usually performed with the essence of volunteering by family members due to the sense of duty, spiritual satisfaction, love, feeling guilty if they does not care for the patient, it is mostly performed by women and is fulfilled by the patients' spouse and young adults (Brodaty H *et al.*, 2009; Eters L *et al.*, 2008; Oğlak S *et al.*, 2017). Sörensen *et al.*, reported that the majority of the caregivers (average 69%) were women, 50% were spouse and 40% were young adult (Sörensen S *et al.*, 2002). The burden of care is expressed as all the physical, psychological, financial and social problems that the caregivers are often caught unprepared (Yalçın E *et al.*, 2005). Also, the burden of care is expressed as a response to stress that the caregiver are experiencing during the care process (Villapando MV 2015). The impairment of cognitive and functional processes of individuals, regular application to the healthcare institutions, care and treatment costs brought to the family, increased domestic duties and responsibilities, and change in relationships due to dementia affect the quality of life of caregiver and increases the burden of care (Atkan F *et al.*, 2017; Özer S 2010; Koca E *et al.*, 2017). In a study on the caregivers of Alzheimer's patients, 64% of the caregivers was found to experiencedomestic difficulties due to the care responsibility, there was a significant difference between the economic burden of diseases and the domestic difficulty situation ( $P < 0.05$ ) (Akyar İ 2009).

Factors affecting the burden of care can be examined in two ways as "properties belonging to dementia patients" and "properties belonging to caregiver persons". It is known that some conditions affect the care burden of caregivers significantly, including especially socioeconomic characteristics such as age and education level; dementia severity, type of disease, duration, extended dependence due to poor functional status, the patient's pain, constipation, incontinence, insomnia experience, and high levels of neuro-psychiatric symptoms (apathy, unrest,

aggression, negative behavior to request help, shouting, being unable to nominate objects, inconsistent conversations, unwittingly wandering around at night, depression, etc.) (Atkan F *et al.*, 2017; Eters L *et al.*, 2008; Villapando MV 2015; Ornstein K *et al.*, 2012; Chiao CY *et al.*, 2015). Researchers determined that high levels of agitation (such as meaningless words and questions, aggression, general unrest) were statistically significantly affecting the care burden ( $P < 0.001$ ) (Kızıl ET *et al.*, 2014). Valente *et al.*, reported that caregivers of patients with moderate dementia had more care burden than caregivers of patients with early dementia. Akyar and Akdemir state that caregivers of severe dementia are experiencing problems in care process and that the patient's wandering aimlessly and the presence of incontinence negatively impact the care burden (Akyar İ *et al.*, 2009; Valente LE *et al.*, 2011). Studies have shown that the age of dementia patient, the diagnosis, stage, duration of the disease and the time spent on care for the patient have significantly impacted the burden of care of caregivers (Kim H *et al.*, 2012; Çetinkaya F *et al.*, 2012; Eğilli CS *et al.*, 2017). Gallagher *et al.*, determined that higher neuro-psychiatric symptoms and the lack of cognitive functions increased the care burden, and 33% of them exhibited significant depressive symptoms (Gallagher D *et al.*, 2011). In addition, studies have revealed that the patients given care are limited in daily life activities and are dependent on caregivers, causing the burden of care (Gallagher D *et al.*, 2011; Razani J *et al.*, 2014; Abdollahpour I *et al.*, 2012 ). In a study conducted based on type of disease, the caregivers of patients with Lewy body dementia were determined to have higher burden of care than those with Alzheimer and dementia, and their stress and exhaustion were found to be more progressed (Naharcı MI *et al.*, 2016). Some characteristics belonging to the caregivers were reported to affect the burden of care, for example; socio-demographic characteristics such as age, gender, monthly income, level of education, ethnicity, relationship with the patient (spouse, bride, caregiver, son or daughter, etc.); life perspective and spirituality level, aggressive attitudes, authoritative, inadequate self-sufficiency for symptom management, high levels of anxiety, depression and hostility, social isolation, financial problems, chronic illnesses or health problems, family relationships, getting help for care or not, extreme fatigue and exhaustion, having children, duration of care, the level of responsibility and cultural differences in perception of care (Brodaty H at al 2009; Eters L *et al.*, 2008; Villapando MV 2015; Chiao CY *et al.*, 2015; Beinart N *et al.*, 2012). The studies revealed that the burden of the young adult caregivers was higher than the others, that the living with the patient and the low-income level increased the care burden, that the young adults were followed by spouse for the burden of care, and that the care burden was higher especially in women (Ankri J *et al.*, 2005; Andren S *et al.*, 2007; Conde-Sala JL *et al.*, 2010). A similar study found that women caregivers spend more time for their patients

than men, and their physical and social burdens were higher than men (Akpınar B *et al.*, 2011). A study conducted with the participation of 1164 people revealed that the relationship with patient, age, and gender of caregivers were significantly associated with the burden of care (Kang H *et al.*, 2014). Two different studies reported that some factors belonging to caregivers such as age group, education level, financial status, marital status, gender, relationship status with patients, duration of care and having children were associated with the burden of care (Çetinkaya F *et al.*, 2012; Eğilli CS *et al.*, 2017). Another similar study reported that women caregivers had more care burden than men caregivers, primary school graduated caregiver's life satisfaction is lower than other educational level of caregivers, and low-income level reduced in much more care burden (Isık K 2013). Another study suggested that caring for patients with dementia reduced informal support in caregivers, depending on this, caregivers had more depressive symptoms and the care burden increased (Clyburn LD *et al.*, 2000). A meta-analysis study covering 176 research revealed that the poor physical health of caregivers caused severe depressive symptoms and increased care burden. In the same study, the age of caregiver, low-income level, low education level were associated with depression and care burden significantly (Pinquart M *et al.*, 2007). Skarupski revealed that black caregivers showed fewer depressive symptoms than white caregiver persons, and care burden increased on white caregivers over time (Skarupski KA *et al.*, 2009). A review of 18 studies revealed that American caregivers had more activity limitations, financial problems, stress, depression and care burden than African-based caregivers. The mentioned study also stated that the Latin-based caregivers experienced more stress and depression than the American caregivers, and the cause of this situation was due to the relationship between the patient and caregiver as well as the ethnic origin (Janevic MR *et al.*, 2001). As a result, when the studies are evaluated, it is observed that many factors such as the severity of illness, dependence level, gender, age, and education status of caregivers affect the care burden. Knowing these factors will facilitate the planning of the initiatives that need to be done to reduce the burden of care.

#### **INITIATIVES TO REDUCE THE CARE BURDEN**

Making an attempts for factors that cause the burden in caregivers of dementia patients have an important role in reducing the burden of care (Etters L *et al.*, 2008; Çapan BE 2016). The following factors significantly reduce the care burden for caregiver people, for example; the reduction of neuropsychiatric symptoms caused by dementia; giving caregivers the trainings to help them cope with these symptoms; helping them to develop care management and care roles; supporting their physical and emotional health; regulation of training programs about stress management and how to cope with stress; providing a

break to the caregivers sometimes by nursing homes or a health institution; ensuring that the caregiver share their concerns and thoughts, and preventing social isolation by creating support groups; taking support or counseling for the patient at any time in need; depression occurring in caregivers; treatment of impairments such as depression, anxiety or insomnia in caregiver individuals by pharmacological or non-pharmacological methods; giving psychosocial support (speech therapies, social fields creation, professional support, etc.); providing supportive trainings via computer or web-based applications, and providing versatile initiatives (psychoeducation, family therapy, skill development, domestic arrangements for patient safety, pharmacological treatment, etc.) and ensuring the continuity of these supporting activities (Atkan F *et al.*, 2017; Etters L *et al.*, 2008; Özer S 2010; Strivens E *et al.*, 2014). In a study conducted for 16 weeks, the patients with Alzheimer's disease treated with donepezil (5-10 mg/day) and caregivers were investigated. In the study, researchers observed that time-space orientation and speech and swallowing functions were improved in patients with Alzheimer's disease, while care burden of caregivers decreased significantly compared to the first week (Nakamura K *et al.*, 2014). In a meta-analysis study involving seven randomized controlled trials, an education was given for caregivers to cope with the psychological and behavioral symptoms of dementia patients. At the end of the training, researchers determined that the Zaritcare burden scale scores of the caregivers decreased (Marim CM *et al.*, 2013). In another study on caregivers, to help patients with dementia to cope with behavioral problems, a support was provided via the computer for 12 months, so the depression and anxiety levels decreased in caregivers without adequate experience, and also significantly positive effect on spouse caregivers was observed (Mahoney DM *et al.*, 2003). In a randomized controlled study, web-based remedial interventions were performed to treat dementia patients and to support caregivers. Then, the measurements were taken on 6., 12., and 18. months, so the researchers found that the web-based remedial intervention reduced the patient's behavioral and psychological symptoms and also reduced the level of depression during the care process (Callahan CM *et al.*, 2006).

#### **CONCLUSION**

As a result, care service is mostly carried out by relatives of patients with dementia, causing physical, psychological, financial and social problems in caregivers and bringing care burden for caregivers. The increase in the care burden affects not only the care providers but also the patients with dementia. The support of the caregiver in maintaining the daily life activities of the dementia patients, in keeping the mental and behavioral functions, in treatment and follow-up process is of a great importance. For this reason, caregivers should be supported in physical, psychological, financial and social areas, and the poor

physical and psychological conditions due to the care should be corrected, and the care burden of the individuals should be reduced to the lowest levels.

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