

## Exploring Burnout in Dementia Caregivers: Its Dimensions, Factors, and Why It Matters

Najwa Awwaliyyah<sup>1</sup>, Andini Dyah Sitawati<sup>2,3\*</sup>  
Novira Widajanti<sup>4,5</sup>, Damba Bestari<sup>2,3</sup>

<sup>1</sup>Medical Study Program, Faculty of Medicine, Universitas Airlangga, Surabaya, Indonesia

<sup>2</sup>Department of Psychiatry, Faculty of Medicine, Universitas Airlangga, Surabaya, Indonesia

<sup>3</sup>Department of Psychiatry, Dr. Soetomo General Academic Hospital, Surabaya, Indonesia

<sup>4</sup>Department of Internal Medicine, Faculty of Medicine, Universitas Airlangga, Surabaya, Indonesia

<sup>5</sup>Department of Internal Medicine, Dr. Soetomo General Academic Hospital, Surabaya, Indonesia

E-mail: najwa.awwaliyyah-2021@fk.unair.ac.id; andinidyah.s@fk.unair.ac.id;  
novira.widajanti@fk.unair.ac.id; damba.bestari@fk.unair.ac.id

\*Corresponding author details: Andini Dyah Sitawati; andinidyah.s@fk.unair.ac.id

### ABSTRACT

**Background:** Dementia is a progressive and persistent disease that usually affects the elderly population and causes neurocognitive impairment. This cognitive impairment makes people with dementia (PwD) can't do daily activities independently. Therefore, people with dementia require assistance from a caregiver. Dementia patient caregivers are very prone to burnout because of the high burden and time-consuming caregiving activities. **Objective:** To explore the burnout phenomenon in dementia patient caregivers, how it affects the caregivers, care recipients, and the intervention based on previous research. **Method:** Collecting the data and information from Google Scholar, PubMed, and ScienceDirect with a total of 35 works of literature using keywords like "caregivers", "burnout", and "dementia". **Result:** Burnout is a psychological syndrome that can have a negative effect on both caregivers and their care recipient. There are many factors contributing to burnout in dementia caregivers, whether it's an external or internal factor. It's crucial to put an intervention to reduce burnout, as it can enhance the well-being of caregivers.

**Keywords:** burnout; caregivers; dementia.

### INTRODUCTION

Dementia is a progressive and very persistent disease that usually impacts elderly people and causes a neurocognitive impairment [1]. Number of people with dementia (PwD) differs from one country to another. According to the latest studies, nearly 9.9 million people worldwide are suffering from dementia each year [2]. The increasing number in the elderly population is closely related to the number of people with dementia (PwD). In Indonesia alone, the estimated number of elderly people is close to twenty and a half million, or 8.03% of the total population. It makes the number of people with dementia hit one million people in 2015 and the number keeps increasing. It's predicted to reach around two million in 2030 [3][4]. Dementia symptoms also varied in each individual. The cognitive impairment is prompting changes in function and behavior of people with dementia (PwD). Dementia manifestations include a deficit in communication and language skills, incapability in recognizing objects, ineptitude to perform a recently learned task, and last but not least the most popular symptom namely memory loss [5].

These manifestations certainly can interfere with the performance of their daily activities. This is why caregiver assistance is necessary. A caregiver definition is an individual who gives his or her hand to assist another person who is incapable of doing their daily activities on their own because of an ailment or other conditions. Caregivers are divided into two categories, which are formal and informal caregivers. A formal caregiver is someone who's already qualified in the field, like an occupational therapist or nurse. Meanwhile, the informal caregivers are delivered by family members or close relatives [6]. Caregiving activities consist of activities like assisting in bathing, feeding, mobilization, and health-care-related tasks such as overseeing the treatment and medications, accompanying patients to doctor appointments, and also advocating for the patient to express their symptoms when the doctor conducts anamnesis [7]. It's important to know that current treatment for dementia patients can't cure the disease but only helps to manage the symptoms and behavioral problems. The effect itself lasts for only a short period of time [8]. Dementia patient treatment also involves a high financial cost to the family members [9].

All the things above make caregiving for dementia patients a stressful experience. Dementia patients' caregivers are exposed to a prolonged high level of stress, which makes them very susceptible to burnout syndrome [10]. Burnout is still considered one of the mental health problems and thus considered taboo, so it's not commonly discussed. The negative stigma from social settings is also one of the reasons why caregivers rarely tell another person about burnout symptoms that they are experiencing [11]. Burnout symptoms usually cause people to undergo terrible mood changes and make them more irritable to their care recipient [12]. This review aims to explore the burnout phenomenon in dementia patients' caregivers, the dimensions, and also contributing factors of burnout. This review is also attempting to discover how burnout can affect both the caregivers and their care recipient.

## METHODS

To review burnout in dementia patient's caregivers, the researcher used several valid databases from Google Scholar, PubMed, and ScienceDirect to retrieve information from articles, journals, and books. We set the criteria of studies mainly including research published within the last ten years but also included several important journals published maximum within fifteen years. Keywords used were "burnout", "caregivers", and "dementia". While the thematic search consists of "burnout in dementia patient's caregivers", "dimensions and key factors of burnout in caregivers", "burnout and the quality of life of their care recipient", "physical and mental health correlation with burnout" and "caregivers' awareness of burnout phenomenon".

## RESULTS AND DISCUSSION

Burnout is defined as a psychological syndrome that arises as a result of prolonged stress exposure associated with an individual's job demands [13]. The occurrence of burnout syndrome has considerably increased in recent years. The frequency of people experiencing burnout within the general working population has been observed to fall within the range of 13% to 27% [14]. Burnout became increasingly popular among healthcare workers during the COVID-19 pandemic. A cross-sectional study conducted in Lebanon stated that 90.7% of healthcare workers experienced a significant level of burnout, with nearly 70% attributing the burnout to patient-related causes [15]. Even though burnout and depression share similar symptoms, such as sadness and fatigue, they are two distinct conditions [16] [17]. Burnout typically develops in occupations involving interacting with other individuals [21].

## DIMENSIONS AND FACTORS OF BURNOUT

In 2019, the World Health Organization (WHO) added burnout syndrome to the International Classification of Diseases (ICD-11) and categorized it as an occupational phenomenon resulting from work stress [18]. Burnout itself can be distributed into three dimensions that will help to elaborate the symptoms. These dimensions consist of emotional exhaustion, depersonalization, and decreased sense

of personal accomplishment [19]. The dimension that usually appears first is emotional exhaustion, followed closely by cynicism or depersonalization and detachment [21]. Emotional exhaustion can be described as a feeling of being emotionally drained by the psychological efforts made at work [20]. This dimension also consists of feelings of fatigue, weariness, and weakening [10]. The second one is depersonalization. It can be described as a negative response and detached personality [20]. Depersonalization is a feeling of indifference that eventually leads to inappropriate behavior toward the care recipient, irritability, and interpersonal avoidance [10]. The last dimension is the reduced personal accomplishment in an individual. It is when a person starts to feel lacking in their competency at work [20]. Burnout person is beginning to negatively evaluate their performance and come to poor conclusions. A recently conducted research stated that reduced personal accomplishment is affecting their coping mechanism [10].

Several factors are often cited as a trigger to burnout, such as workload, autonomy, recognition, social support, fairness, and values [13] [20]. In the case of dementia caregivers, heavy workload stands out as a particularly relevant factor. Caregiving experiences in dementia patients are deemed more stressful than caregiving in other disability cases. This statement is associated with the changes in behavior and the dependency of dementia patients that require a very long time duration of care, and physical fitness from the caregivers [22]. Dementia caregivers need to assist with simple daily activities like feeding, grooming, and dressing while also dealing with behavioral change. Patient with worsening cognitive function were heavily dependent on their caregivers. Research about dementia caregivers in Seoul, South Korea states that nearly 26% of dementia patients need assistance for the majority of their daily activities [23]. As mentioned in the previous section caregivers are divided into formal and informal caregivers. In 2021, more than 11 million informal dementia caregivers are dedicating over 16 billion hours to provide their care to the patient. It poses a physical, mental, and financial burden to the informal caregivers as a family member [24]. Aside from the considerably heavy workload, another notable factor is recognition. Recognition itself refers to the acknowledgment and appreciation of someone else's work or achievement. In this case, it will refer to the gratitude from dementia patient for their caregivers. A study states that dementia caregivers who have a high level of gratitude from care recipients and others, tend to experience lower levels of burden and higher resilience. It also states that gratitude is one of the factors for caregivers' sense of the meaning in life [25]. Several other factors can contribute to the occurrence of burnout in dementia caregivers. These factors can stem from the caregiver's characteristics or the care recipient's side (dementia patient). The levels of burnout experienced by the caregivers can be influenced by the dementia patient's behavior problems, functional disabilities, and whether the care recipient is also experiencing other comorbidities [27].

The caregiver's characteristics that relate to burnout levels are the caregiver's gender, financial income, educational status, cohabitation residence, duration, and amount of care provided to the patient [28].

### IMPACT OF BURNOUT IN DEMENTIA CAREGIVERS

As mentioned in the previous chapter, dementia is a very persistent disease. The symptoms of dementia worsen progressively each year. As the dementia symptoms keep worsening, their caregivers can undergo increasing stress levels, physical health issues, or financial problems [26]. There are several distinctive symptoms in dementia patients, like where they go wandering and have a disorientation of time and location. In this case, it is related to one of the burnout dimensions namely emotional exhaustion. Emotional exhaustion comes with a fatigue feeling which will be increasingly felt when the caregivers do extensive standing, walking, or do another course [30]. The prolonged state of burnout state can impact the daily life of the caregivers. There will be a decrease in contentment of the caregivers which may lead to depressive symptoms [29]. Other studies also reported that dementia caregivers are often found with anxiety and depression problems [23]. It's important to note that there's a strong correlation between burnout syndrome and someone's tendencies to commit suicide. Burnout syndrome also prompts a social worker to quit or stop doing their job [31] [35]. A recent study states that the consequences of burnout can be divided into two main categories. The first one is mental consequences and the second one is behavioral consequences. The impact on the caregiver's mental health includes low self-esteem, fatigue, frustration and anxiety, difficulty focusing, as well as various physical manifestations like headaches, insomnia, and gastrointestinal issues. Meanwhile, the impact on behavior is regular caffeine consumption, tranquilizers, and in some cases narcotics consumption. Long drawn-out stress conditions (burnout) can also increase the risk of dealing with high blood pressure (hypertension) [33]. Burnout in dementia caregivers also can compromise the care received by the dementia patient. For example, the depersonalization dimension in burnout can lead to an individual acting negligence or apathy towards the care recipient. This may result in worsening behavioral disruption in the dementia patient [30]. The same can be found in research about parental burnout and how it's affecting their children. Parents who experience burnout may find themselves to be neglectful and also be more violent to their children [32]. It is feared that violent tendencies will also be happening to caregivers with high levels of burnout [29].

This discovery, of course, leads to the main question about the best strategies to overcome burnout in caregivers. Some studies suggest that reducing burnout in workers is by following a counseling activity or a social group gathering in the hope to refresh their mental and physical state [34]. There's also another research that suggests a mindfulness-based therapy for burnout intervention. This kind of therapy will allow caregivers to acknowledge and

adapt their emotional and behavioral responses instead of avoiding them [35]. As has been mentioned repeatedly Behavioral and Psychological Symptoms of Dementia (BPSD) are highly related to caregiver burnout. This statement implies the necessity of interventions, such as instructing dementia caregivers on coping strategies and stress management. However, there's one study that already conducted a systematic review on the best way to mitigate burnout in caregivers, but the results show that there are various levels of someone's self-efficacy and it makes the intervention have to be an individualized treatment approach [32].

### CONCLUSIONS

Burnout is a psychological syndrome that has become increasingly popular in occupations that involve interaction with other individuals, one of them being dementia caregivers. Burnout is highly encountered in dementia caregivers because of the extensive hours of caregiving, behavior changes of the care recipient, and financial demands. The heavy workload and lack of recognition from the care recipient significantly increase the burnout level. Burnout in dementia caregivers can affect both of the caregivers and also compromise the care recipient. Given the persistent nature of dementia caregiving, reducing burnout can be done by social support, counseling, or individualized strategies to improve the well-being of the caregivers.

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