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Alzheimer's and Patient Caregiver Burnout

Madeline J. Hekeler

Photo credit: "Old woman is drinking tea in her country style kitchen" by Halfpoint Images, via Storyblocks

Abstract

The term "silent epidemic" is fitting for Alzheimer's disease (AD), as its negative impact is widely felt but rarely discussed. Burnout among AD caregivers has become an epidemic of its own as caregivers experience an increase in health risks, stress, and financial burden. This literature review focuses on caregiver burnout and how imperative it is that caregivers are better supported in their role. Researchers have developed instruments to assess and intervene in caregiver burnout that have shown effectiveness among caregivers and their families. Nevertheless, further longitudinal research is warranted regarding more effective interventions, including stress management and social support mechanisms.

Alzheimer's disease (AD) is "a progressive neurologic disorder that causes brain cells to shrink (atrophy) and brain cells to die" (Mayo Foundation, 2021, para.1). AD has high prevalence and incidence rates. In 2019, it was the sixth leading cause of death in the US and the most common cause of dementia across the world (Mayo Foundation, 2021, para. 2). The term *dementia* serves as an umbrella term for when impaired cognitive skills affect "a person's ability to function independently" (Mayo Foundation, 2021, para.1). Patients develop cognitive problems, meaning they functioned at a higher level prior to developing dementia. A patient suspected of having AD cannot be officially diagnosed until an autopsy of the brain has been performed (Elison, 2019, p. 3).

AD not only has a tragic impact on those who have been diagnosed with the disease but also on their loved ones who face the pressures of providing physical care, offering emotional support, and dealing with the financial burdens associated with chronic illness. Caregivers are responsible for developing the skills necessary to deal with the interpersonal demands of the individual as their cognition declines. The caregiving experience can be very overwhelming, particularly because most caregivers are related to the individual suffering from the disease and have no professional training. Watching a loved one diminish before their eyes takes a toll on their physical and mental health (Sörensen & Conwell, 2011, p. 1).

There is no certification necessary for a relative to take on the role of caregiver for an AD patient. It can be satisfied by a spouse, child, sibling, or professional caregiver. A caregiver can be live-in, part-time, paid, or unpaid. In 2002, Brodaty and Green found that

Most persons with dementia live at home and are cared for by family and friends, of whom approximately 77% are women, 73% are over 50 years of age, 33% are the sole providers of care, 45% are children of the patient, and 49% are spouses. (p. 891)

A caregiver's integration into the patient's life varies depending on family comfort and financial status. Therefore, it is important for families to be aware of the symptoms associated with burnout, so they can obtain the help they need before their health takes a detrimental turn. Healthy caregivers are imperative for fostering healthy patients.

Overview of Caregiver Burnout

Caregiver burnout is "a state of physical, emotional and mental exhaustion" (Cleveland Clinic, 2019, para.1). Symptoms of caregiver burnout include fatigue, stress, anxiety, depression, withdrawal from everyday activities, changes in weight and appetite, and changes in sleep patterns (*Recognizing Caregiver Burnout*, 2020). Confusion, unrealistic expectations, lack of control, unreasonable demands, and the inability to recognize burnout symptoms are five factors that result in caregiver burnout ("Recognizing Caregiver Burnout," 2020). Caregivers are an integral part of AD research as active members and advocates in treatment plans for patients. They witness adverse effects, monitor progress, and report back to doctors for AD patients. It is imperative that caregivers are supported to ensure the best possible outcome for both patients and caregivers.

Multiple factors contribute to caregiver burnout, including psychological, physical, social, and financial burdens. Psychological morbidity refers to the stress, depression, and anxiety that a caregiver may experience and, according to Jorge et al. (2019), is the number one predictor in determining quality of life among caregivers. In a 2011 meta-analysis, Sörensen and Conwell reported that "compared to non-caregivers, dementia caregivers report higher levels of stress, more depression and anxiety symptoms, and lower levels of subjective well-being, self-efficacy, and anxiety" (p. 1). The reason AD caregivers experience higher psychological issues is associated with the variety of symptoms and unpredictable behavioral patterns patients can display. Shua-Haim et al. (2001) identified three risk factors for depression in caregivers of AD

patients: depression in the AD patient, an Activities of Daily Living (ADL) score of 12 or greater, and the presence of hallucinations. Shua-Haim et al. used an 18-point version of the Katz ADL scale to assess the functionality of the AD patient and their ability to perform everyday tasks. A higher ADL score indicates that the dementia patient requires a higher level of functional assistance from the caregiver, adding to the caregiver's responsibility and stress. Patients tend to wander, have emotional outbursts, and act in inappropriate ways (Sörensen & Conwell, 2011). While their behavior is unintentional, it can be mentally draining for caregivers. In 2005, Mahoney et al. analyzed anxiety and depression among family caregivers of AD patients. The study, based on 153 caregiver interviews, found that "nearly a quarter of caregivers of people with AD screened positive for anxiety and 10% for depression," which suggests the need for clinicians to be more aware of the warning signs of those conditions. The researchers also found a positive correlation between perceived physical health and tendency to experience anxiety and depression (Mahoney et al., 2005). Family caregivers may be at even higher risk of anxiety and depression, as they can experience grief twice, first watching their loved ones lose their unique personalities and later watching their loved ones die.

Poor physical health is commonly seen in caregivers experiencing burnout. Elevated levels of stress hormones can cause "hyperglycemia (elevated levels of blood sugar), hyperinsulinemia (elevated levels of blood insulin), higher blood pressure (BP), and poorer immune functioning" (Vitaliano et al., 2004, p. 14). If unmanaged, hyperglycemia and hyperinsulinemia can lead to diabetes, obesity, or heart disease (Davidson & Parkin, 2009, S331). A meta-analysis conducted by Vitaliano et al. (2003) reported on studies focused on physiological responses associated with caregiver burnout, including antibody response to vaccines and viruses, cellular immunity, cardiovascular levels, metabolic measures, and stress hormone levels. Their survey showed that caregivers reported poorer global health

and took more medications for physical problems than non-caregivers. Furthermore, caregivers had 23% higher levels of stress hormones and 15% lower levels of antibody responses (Vitaliano et al., 2003).

Social isolation in caregivers of AD patients is rather common because the disease demands more time, effort, and energy from caregivers as it progresses. Caregivers' ability to take time for themselves diminishes and eventually social and leisure activities become limited. According to Brodaty and Pavlovic (1990), some caregivers reported not seeing anyone besides their patient for more than a week. Eters et al. (2008) found that women "tended to report more emotion-focused coping" mechanisms, while "problem-focused or mixed coping strategies" were the most effective (p. 424). They also found that many male caregivers experienced "a lack of positive outlook and a need for social support, while females reported increased caregiver burden in their relationships with other family members as well as an increase in their own health problems" (p. 424). Eters et al. found that male caregivers did not have as many reported health issues or psychological morbidities as female caregivers (p. 424).

The level of responsibility associated with AD is a significant stressor for a family caregiver. The caregiver is often responsible for managing the patient's finances, including bills for doctors' appointments and other expenses, which leads to a workday that has been likened to 36 hours (Brodaty & Green, 2002). This constitutes many hours of unpaid work and a notable disruption in ability to manage paid employment. Researchers have estimated that in 2017, roughly 41 million caregivers in the United States provided "34 billion hours of care to an adult with limitations in daily activities," amounting to nearly \$470 billion in unpaid labor (Reinhard et al., 2019, p. 1).

There is a significant financial burden if a family chooses a professional caregiver instead of taking on the role themselves. The national average cost of assisted living facilities or a live-in

caregiver for AD patients was \$4,000 a month as of 2019 (*Paying for Alzheimer's Care*, 2020, para. 5). A high percentage of patients are placed in a nursing home facility due to their informal caregiver experiencing burnout. Even after patient relocation to an assisted living facility, caregivers may continue to experience burnout for at least a year because they question whether they made the right decision (Elmstahl & Andren, 1998).

Assessing Caregiver Burnout

A psychological examination is an instrumental part in diagnosing caregiver burnout. Symptoms of caregiver burnout include emotional and physical exhaustion; changes in sleep patterns, appetite, and weight; withdrawal from family and friends; loss of interest in activities and suicidal tendencies (*Recognizing Caregiver Burnout*, 2020). Professionals have established screening and monitoring tools due to the prevalence of caregiver burnout in relation to AD. There are several effective assessment tools that give excellent opportunities both for physicians to use in present-day cases and for researchers to use in expanding our understanding of caregiver burnout.

The Zarit Burden Interview (ZBI) is the most common instrument used for assessing burnout among AD caregivers. The ZBI is a "22-item questionnaire measuring subjective burden, which has demonstrated high consistency and validity, and a higher score indicates greater burden" (Etters et al., 2008). A version of the ZBI was used successfully in Bangkok, Thailand, to compare quality of life and subjective burden among AD patient caregivers at the Psychiatric Outpatient Unit of Siriraj Hospital (Sittironnarit et al., 2020). Along with the ZBI, the Pictorial Thai Quality of Life scale was used, and questionnaires were distributed among 155 dementia caregivers (Sittironnarit et al., 2020). The results indicated that 40% of caregivers who answered the questionnaire experienced some type of burden from their job. Individuals with higher education, income, and a cultural propensity for caregiving were less likely to experi-

ence burden. Individuals who experienced more characteristics of burnout and a lower quality of life were mostly women with financial problems, illnesses, low income, low education, and responsibility for taking care of multiple family members. Pinguart and Sörensen (2005) noted that Western caregivers tend to follow a more individualistic routine while Eastern caregivers emphasize family. Different cultural expectations will lead to a different level of responsibility in caring for an elderly family member with AD. In a broad sense, caregiver burnout highly correlates with caregivers' overall quality of life, socioeconomic status, and cultural background (Sittironnarit et al., 2020).

The Caregiver Strain Index is another easily accessible tool that consists of 13 questions related to employment, finances, physical health, social health, and time. A positive score of seven or higher warrants further follow-up with a doctor to receive more in-depth assessment and treatment (Sullivan, 2002).

Guilt can be a negative byproduct of caregiving for Alzheimer's patients. Losada et al (2010) sought to survey guilt among caregivers, especially caregivers of dementia patients, by developing the Caregiver Guilt Questionnaire. Losada et al. developed the questionnaire through face-to-face interviews with 288 dementia caregivers. Five main factors were consistent throughout the interviews: "guilt about doing wrong by the care recipient, guilt about not rising to the occasion as a caregiver, guilt about self-care, guilt about neglecting other relatives, and guilt about having negative feelings towards other people" (p. 650). Higher scores on the Caregiver Guilt Questionnaire correlated with prevalence of depression, anxiety, and behavioral issues. Respondents who scored higher on this scale tended to be women caring for an ailing parent. Losada et al. noted that the scale could be used to acknowledge and validate caregivers' feelings and to let them know that they are not alone in their feelings of guilt. The scale also could be helpful in determining psychological interventions to reduce caregiver burnout.

The Screen for Caregiver Burden (SCB) was initially designed as a 25-item questionnaire to determine caregiver burnout among AD caregivers. The test measured the quantity of negative experiences and the caregiver's response to them, resulting in a measurement of overall burden (Vitaliano et al., 1991). Hirschman et al. (2004) responded to demand for a rapid screening test for caregivers by developing a faster and shorter version of the SCB. The team used a combination of measurements from the SCB, the Center for Epidemiologic Studies Depression scale, the Medical Outcomes Short Form, the Mini-Mental Examination, and characteristics of depression, anxiety, and fatigue amongst the AD patient-caregiver dyads, which refers to the relationship of the patient and caregiver and how they impact one another's wellbeing. Results showed seven factors with a high association and correlation, and these factors were then used to create the shorter scale for the rapid test. The rapid test was used in multiple clinical diagnoses after its development. Hirschman et al. (2004) reported that physicians responded positively to the rapid test because it allowed them to diagnose and treat specific causes of burden in a timelier manner.

Another instrument, the Perceived Change Index (PCI), is a 13-item scale that allows caregivers to gauge various facets of their personal wellbeing (Gitlin et al., 2006). The National Institute of Aging-Funded Resources for Enhancing Alzheimer's Caregiver Health Initiative administered the test to 255 caregivers and determined three underlying factors: somatic well-being, ability to manage, and affect. Individuals with higher scores on the PCI tended to be less depressed because of their acknowledgment of the importance of self-care and social interaction with others. Gitlin et al. (2006) concluded that this index was valid to use in future studies, as it helped determine caregiver acknowledgment of well-being and how the lack of acknowledgment contributes to burnout.

A physical health examination is another instrumental part in the diagnosis of caregiver burn-

out. The Swedish National Study on Aging and Care conducted a longitudinal general population study called "Good Aging in Skåne" to compare the health of informal caregivers versus non-caregivers. Ekström et al. (2020) used several measurement tools in surveying 5,457 individuals regarding their socioeconomic status, health, life circumstances, cultural background, and caregiver status. The questionnaire asked questions related to 23 somatic symptoms and 10 psychological symptoms. Ekström et al. (2020) determined that caregivers had higher rates of depression, tension, gastrourinary symptoms, and fatigue compared to non-caregivers. Knight et al. (2000) suggested that differences in health and coping mechanisms relative to poor health are related to background variables, severity of illness among different groups, social support, and cultural values. Human samples in research vary based on their backgrounds but still tend to result in similar trends no matter the caregiver burden assessment tool used (Williams & Wilson, 2001).

Islam et al. (2017) conducted a study to analyze the characteristics of caregivers in care facilities (e.g., nursing homes) and residential facilities (e.g., retirement homes) and their associated stress levels. Questionnaires were given to 212 caregivers from 72 care facilities. Islam et al. determined that caregivers who worked in a nursing home experienced more burnout than caregivers who worked in a residential home. The responsibility for multiple patients in nursing homes increased pressure and correlated with reports that their mental health inhibited their ability to perform job-related tasks. The results emphasized how important it is for caregivers to be trained in dementia caregiving to prepare them more adequately for the emotional and physical demands of the job (Islam et al., 2017). It is important to note that, given the prevalence of caregiver burnout, additional research is warranted to develop assessment tools that fully gauge the depth and breadth of the AD caregiver experience.

Caregiver Burnout Interventions

Establishing a community of resources and interventions to aid in the alleviation and prevention of caregiver burnout is a priority for families around the world. Once caregiver burnout is clinically diagnosed, it is the role of healthcare professionals to provide resources and treatments to address burnout. It should also be the job of physicians to educate potential caregivers, especially family members, on interventions that can be started beforehand to reduce chances of developing burnout. In 2000, Kasuya et al. noted that interventions being studied included counseling, education, preplanning, self-care, and hiring professional caregivers. Counseling can benefit caregivers by giving them an outlet to vent their feelings and to have those feelings validated by a mental health professional (Kasuya et al., 2000). Educating caregivers on what to expect when taking care of an individual with AD can increase their confidence and enable them to perform better as caregivers (Kasuya et al., 2000). Educating caregivers on the signs and symptoms associated with burnout may encourage them to seek help from professional caregivers when they cannot manage the workload themselves (Kasuya et al., 2000). Hiring a professional caregiver allows the family caregiver to maintain an identity separate from their caregiving role. Mental and physical self-care is imperative for the caregiver's mental health, which is why more support groups should be developed to avoid the social isolation some caregivers may feel (Kasuya et al., 2000).

A study conducted by Spruytte et al. (2001) researched the dyadic relationship between patient and family caregiver and determined risk factors that led to the institutionalization of the AD patient. They found that installing assisted living devices, such as stair chair lifts, reduced the number of family caregivers institutionalizing their loved ones. Spruytte et al. (2001) suggested that practitioners should be aware of these home improvements and explain their benefits for both patients and caregivers.

Pinquart and Sörensen (2006) also determined

that psychoeducational interventions, such as active role playing, better equip caregivers to perform caregiver duties and reduce depression. Family intervention programs that address stress management and coping skills have been found to reduce depression in caregivers and improve the overall quality of life for patients and their caregivers (Marriott et al., 2000).

Some researchers have suggested that a clinical belief set, focusing on practical knowledge and skills rather than familial tendencies, should be taught to caregivers to reduce burnout. In a study conducted by Hepburn et al. (2001), caregivers were randomly assigned to an immediate training group or a waitlist control group. The training program focused on teaching caregivers stress management and coping mechanisms over seven weekly 2-hour sessions. The study concluded that the caregivers who went through the training program were more emotionally stable, less depressed, and had a better understanding of the knowledge and skills needed to take care of their loved ones.

The implementation of a collaborative care model among AD caregivers has also been a topic of study in the medical community. A collaborative care model can be defined as

a systematic approach to the treatment of depression and anxiety in primary care settings that involves the integration of care managers and consultant psychiatrists, with primary care physician oversight, to more proactively manage mental disorders as chronic diseases, rather than treating acute symptoms. (Eghaneyan et al., 2014, p. 503)

Callahan et al. (2006) studied the effects of burnout when a collaborative model was implemented with the aid of geriatric nurse practitioners. Caregivers were randomly assigned to groups, with one group receiving collaborative care management and the other group receiving traditional care management. Patients in the collaborative care management group integrat-

ed a geriatric nurse into their everyday lifestyle for one year. Ultimately, “collaborative care for the treatment of Alzheimer disease resulted in significant improvement in the quality of care and in behavioral and psychological symptoms of dementia among primary care patients and their caregivers” (Callahan et al., 2006, p. 2148).

The Resources for Enhancing Alzheimer’s Caregiver Health (REACH) was a randomized trial studying effective interventions for burnout in AD caregivers. The study analyzed nine interventions and two control conditions across six REACH sites with a sample of 1,222 caregivers. Each REACH site provided interventions that focused on family systems, psychoeducation, group support, skill training, home management adaptations, technological advances, and individual knowledge. After six months, the results showed that the intervention groups had lower burnout rates than the control groups. Nevertheless, not all interventions worked for each caregiver, which is why a broad range of interventions were implemented. Caregivers could then use their training to adapt the interventions to the individual needs of the patient (Wisniewski et al., 2003).

Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II) was a multicomponent intervention that analyzed 92 informal caregivers of AD patients. The REACH intervention led the German healthcare system to realize a gap in its coverage regarding caregiver burnout. The United States REACH program was adapted for the German healthcare system, producing REACH II (Berwig et al., 2017). The multicomponent intervention combined five modules. It was implemented in two sessions per week for a total of 12 sessions. The goal was to reduce caregiver burnout in a short period of time and to teach caregivers effective coping mechanisms. The results of the pre-post study showed that burden decreased slightly in the intervention group even as it increased dramatically in the control group. Caregivers reported that they experienced an increased quality of life through applying the coping mechanisms that they

learned during the intervention period (Berwig et al., 2017).

A “memory club” was an emerging intervention in 2004 for early-stage dementia patients and their caregivers. The 10-session group program educated patients and caregivers about what to expect along their journey (Zarit et al., 2004). The goal was to provide emotional support for both individuals and to allow the patients to be to be educated on their illness. During the sessions, caregivers and patients met in separate groups and then groups combined at the end of the session. During the final session, they used the information they learned to form a cohesive relationship between caregiver and patient. Early evaluations of the “memory club” were positive, though further longitudinal research was needed to determine whether it was effective in preventing burnout (Zarit et al., 2004).

McCurry et al. (2005) investigated sleep disturbance among 36 AD patients and their caregivers. The caregivers who received treatment were provided with a sleep hygiene program and sleep management skill training and were instructed to increase daylight exposure through the use of a light box. The control group only received general education about caring for a dementia patient. McCurry et al. (2005) confirmed that “patients with AD who are experiencing sleep problems can benefit from behavioral techniques (specifically, sleep hygiene education, daily walking, and increased light exposure) that are known to improve sleep in nondemented, institutionalized older adults” (p. 793). While AD patients’ sleep patterns improved, further research needs to be conducted to address caregiver sleep disturbance and the cost-effectiveness of the treatment (Sörensen & Conwell, 2011).

There are several gaps in the research associated with effective interventions for burnout in AD patient caregivers. According to Sörensen and Conwell (2011), more research needs to be conducted to determine the characteristics of caregivers that make them the most vulnerable

to burnout. Sörensen & Conwell (2011) suggested that a pre-intervention assessment be created to identify at risk caregivers before they start experiencing signs and symptoms associated with burnout. Several screening tools have been examined during testing trials, but none have been shown to have validity. Another gap in the literature is understanding the various factors which influence caregiver experience, such as patient characteristics or level of emotional support. More studies “are needed to help us understand why some caregivers thrive while others do poorly or provide poor care” (Sörensen & Conwell, 2011, p. 491).

Conclusion

Alzheimer’s disease has a tragic impact on a patient’s family, friends, and loved ones who face the pressures of providing physical care, emotional support, and financial aid. This literature review has identified practical options and research opportunities that can improve caregivers’ lives and their AD patients’ lives. Pre-intervention assessments need to be developed to identify caregivers who are at risk of developing burnout before they start experiencing signs and symptoms. It is necessary to determine the characteristics of caregivers that make them the most vulnerable to burnout. Further investigation into the emotions and reactions that lead caregivers to institutionalize their loved ones can aid in more successful interventions. Finally, a better understanding of the biological mechanisms of stress as they relate to risk factors among caregivers would help ensure the best possible outcome for both individuals. Until we discover a cure for AD, it is imperative that healthcare professionals, families, and their communities are fully educated on how the disease affects caregivers as well as patients.



Author’s Note Madeline Hekeler

Madeline J. Hekeler (’21) graduated with a degree in Health Sciences and a minor in Honors Interdisciplinary Studies. She currently works as an Emergency Medical Technician in Connecticut. Madeline hopes to go to PA school one day in order to help patients along the continuum of their care and possess the knowledge needed to diagnose, treat, and follow them through their journey. She would like to thank her advisor, Dr. Audrey Burnett; for her unconditional guidance. Without her, this project would not have been possible. Madeline would like to thank her family and friends for always believing in her and for fostering her confidence and passion in pursuing her dreams with no boundaries.

In Loving Memory

My beautiful grandma, my sunshine, who recently lost her battle with Alzheimer’s. Her unwavering strength and grace inspired my research in hopes of helping other families who are suffering as well.

July 27, 1943 - January 11, 2022

My dad, the greatest man I will ever have the privilege of knowing. Thank you for fostering a confidence and passion in me to work hard and pursue my biggest dreams with no boundaries.

February 28, 1960 - February 6, 2022

*You are my sunshine, my only sunshine
You make me happy when skies are gray
You’ll never know dear, how much I love you
Please don’t take my sunshine away*

-Jimmie Davis

Editor's Note

This article is part of a larger work focused on the background/history of Alzheimer's disease, its pathology and modes of transmission, behavioral and natural risk factors, and prevention/treatment options. To access Madeline Hekeler's complete Honors thesis, visit <https://commons.lib.jmu.edu/honors202029/121/>.

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