The Multifaceted Pressures Faced by Family Caregivers of Alzheimer's Disease

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Abstract. Alzheimer's disease (AD) is a well-known neurodegenerative disorder characterized by the accumulation of amyloid β and tau proteins in the brain, leading to progressive cognitive decline and an eventual inability to perform daily tasks. While significant research has focused on the impact of AD on patients, less attention has been given to the challenges faced by their caregivers, who are primarily family members providing crucial support. The gap in research lies in the limited understanding of the multifaceted challenges, encompassing physical, psychological, and financial burdens, experienced by caregivers of AD patients. Although some recent studies have explored coping strategies, there is a lack of a comprehensive examination of how these strategies relate to caregivers' subjective perceptions of burden, and these studies often address specific caregiving situations without delving into the ongoing coping process. This research aims to comprehensively investigate the mental, physical, and financial burdens encountered by caregivers of AD patients and explore potential measures to alleviate these burdens. Specifically, it seeks to shed light on the coping behaviors and resources employed by caregivers, how these relate to their perceived burden, and how these challenges impact their overall well-being, employment, and quality of life. The research will draw from both domestic and international studies, with a focus on recent developments in understanding the challenges faced by caregivers. In summary, family caregivers contend with emotional and role-related conflicts, disrupted routines, missed career prospects, substantial professional care expenses, and diminished social engagement.

Keywords: Alzheimer’s Disease, Family Caregivers, Pressure.

1. Introduction

Alzheimer's disease (AD) is a neurodegenerative disorder known for the build-up of amyloid β outside cells in the shape of plaques and the build-up of highly phosphorylated tau proteins within cells as neurofibrillary tangles, leading to gradual neuronal loss and brain shrinkage [1]. AD typically initiates by impacting the memory of individuals and subsequently advances to impair various cognitive functions throughout the cortex, ultimately resulting in an inability to independently carry out everyday tasks [2-4]. As patients undergo the gradual decline of their cognitive faculties and the loss of their ability to independently manage daily life, they endure immense suffering and stress. While AD is extensively studied and its effects on patients are well-documented, there is a gap in acknowledging the challenges, both physical, psychological and financial, faced by the individuals who provide care to these patients. At present, the primary source of support for individuals with Alzheimer's disease is typically their families [5,6]. These families not only bear the physical responsibilities of caregiving but also grapple with diverse mental and psychological challenges, which can have varying effects on their work, social engagement, and overall quality of life. As a result of these severe life disruptions, it is not surprising that caregivers of Alzheimer's patients often suffer from health problems [7], particularly mental health issues such as depressive symptoms and anxiety [8,9]. Contemporary research, both domestic and international, has consistently demonstrated that caregivers of Alzheimer's patients experience notably lower levels of mental well-being compared to those caring for individuals without Alzheimer's [10]. Depression and anxiety are the primary psychological issues prevalent among families of Alzheimer's patients [11,12]. Additionally, there have been reports of family members experiencing suicidal thoughts [13]. The goal of this research is to comprehensively explore the mental, physical and financial burdens that caregivers bear while looking after AD patients and raise possible alleviating measures. The full exploration of coping

behaviors and resources that could alleviate this sense of burden has not received thorough attention, despite some recent efforts to address caregivers' challenges and resources. For instance, in two recent studies conducted by Ware and Carper in 1982 and S. H. Zarit and J. M. Zarit in 1982, they investigated the effectiveness of strategies used by caregivers to manage the emotional and behavioral issues commonly associated with Alzheimer's disease, such as incontinence, disorientation, memory loss, and repetitive questioning [14,15]. However, while these studies offer valuable insights to caregivers, they haven't established a clear link between these coping skills and how caregivers subjectively perceive their burden. Moreover, these studies are primarily focused on specific situations, shedding limited light on the ongoing coping process amidst the caregiving stress. By examining the multifaceted aspects of these challenges, the research aims to raise awareness of the difficulties faced by caregivers, understand their implications on caregivers' well-being, work, and quality of life, and ultimately contribute to the development of better support systems and resources for these caregivers.

2. Pressure Analysis

2.1. Physiological Pressure

Individuals afflicted by Alzheimer's disease possess a distinctive trait: their tendency to generate conflicts with their caregivers, especially during moments of emotional turbulence. An insightful study led by Rabins et al. brought to light a remarkable prevalence of physical outbursts, constituting a staggering 75 percent of incidents, alongside occurrences of striking, accounting for 50 percent of the six prevailing behavioral manifestations manifested within Alzheimer's patients [16]. However, it's crucial to recognize that the implications of these behavioral disruptions extend far beyond familial dynamics, permeating into the caregivers' sphere. This disruptive influence frequently ushers in a profound upheaval of caregivers' daily routines, necessitating a recalibration to the unpredictable cadence dictated by the patient's condition. This turbulent reconfiguration inevitably takes its toll on caregivers' immune resilience, rendering them susceptible to heightened vulnerability. Concurrently, caregivers find themselves grappling with a complex interplay of physical fatigue, an overwhelming sense of powerlessness, and pervasive despondency [17]. These three burdens interweave and often trigger a cascade of supplementary symptoms, contributing to an all-encompassing physiological strain. Strikingly, the patients themselves, grappling with memory confusions, bodily incontinence, and suspicion-fueled cataclysmic emotional responses rooted in cognitive disarray, add another layer of complexity. This intricate tapestry of factors magnifies the caregiver's challenge as they navigate the patients' compelling need for assistance. As a result, caregivers persevere in their unwavering commitment, tending to the needs of their emotionally delicate and wary loved ones, even as these very relatives gradually lose recognition of their caregivers' identities. This ceaseless dedication to care, intertwined with the weight of profound psychological and emotional burdens, inherently presents a formidable and overwhelming challenge in the pursuit of equilibrium. Yet, amidst these trials, caregivers continue to exemplify the essence of compassion and resilience.

2.2. Psychological Pressure

In the context of grappling with the arduous task of caring for Alzheimer's patients, caregivers are burdened not only by the accumulation of relentless physical fatigue but also by a myriad of profound psychological challenges. As they dedicate extended periods of time to the care of Alzheimer's patients, their participation in their pre-existing social circles undergoes a marked decline, leading to a pervasive sense of social isolation that lingers over time. This isolation, stemming from the curtailing of social interactions, fosters a disconnect from their original social spheres. Consequently, caregivers find themselves estranged from their once-familiar circles, bereft of opportunities to forge new connections, partake in recreational pursuits, or fulfill personal aspirations and hobbies. This scarcity of fulfilling interactions invariably exerts a discernible impact, often manifesting as psychological distress and, regrettably, depression. The repercussions extend beyond the caregiver's

social world, casting a long shadow over their personal trajectories. For working adults, well-established career paths are disrupted, making it unfeasible to sustain extended absences from the workplace or fulfill assignments remotely, particularly when caregiving necessitates a constant, physical presence. In the case of students who shoulder the responsibility of caring for elderly family members independently, the burden of heightened academic workloads, coupled with the strains of economic pressures, frequently undermines their ability to channel their full energy into their educational pursuits. This, at times, culminates in academic disengagement and even the disheartening prospect of discontinuing their education. In tandem with these structural disruptions, caregivers grapple with an unrelenting undercurrent of guilt, powerlessness, and an ever-present sense of self-recrimination. Observing their loved ones navigate the constraints of their waning temporal horizons imparts a prevailing sense of despondency. This pervasive despair is further compounded by dwindling self-assurance and morale, heightened by the pervasive fear of depleting their own finite physical and emotional resources. At times, caregivers may even find themselves ensnared in a web of self-directed aversion, entrapped in the painful cycle of self-blame and internal strife. A study featured in the Journal of the American Medical Association, meticulously conducted by experts from the Alzheimer's Association, the American Geriatric Society, and the American Academy of General Psychiatry, underscores the extensive emotional tumult caregivers endure. The study illustrates that at minimum, half of all caregivers confront substantial emotional distress, a burden that casts a profound shadow, impacting both their physical and mental well-being. For these caregivers, witnessing the gradual erosion of their loved ones' capabilities represents a poignant, protracted farewell to the individuals they once were. They grapple with the discordance of encountering physically identical yet fundamentally transformed personas. As the cognitive faculties of the afflicted individuals succumb to the ravages of Alzheimer's disease—culminating in memory loss, heightened paranoia, and physical frailty—caregivers find themselves immersed in a wellspring of helplessness. Instances of patient non-cooperation, coupled with the caregiver's own difficulty in managing their emotions, frequently provoke regret. These complex circumstances render the task of caregiving emotionally trying. Moreover, the patient's withdrawal from social interactions and the assumption of an increasingly unfamiliar persona serve to estrange caregivers from their own relatives and friends, exacerbating their own feelings of isolation. This perpetual cycle of unwavering dedication juxtaposed with minimal progress gives rise to distress, frustration, and an insidious fear that their sacrifices might ultimately be in vain. This internal turmoil intensifies, leaving caregivers vulnerable to heightened anxiety, depression, insecurity, and, at the extreme, thoughts of self-harm. In a study conducted by Cohen and Eisdorfer et. al., the attributional style responses of caregivers with depression were compared to those who were not depressed. Among the 22 primary caregivers residing with the patients, a total of 12 individuals, accounting for 55%, met the DSM-III criteria for unipolar depression (with 5 meeting this criteria) or adjustment disorder with depressive symptoms (with 7 meeting this criteria). Among this subgroup, 10 were spouses, comprising eight women and two men, while two were adult daughters. Remarkably, none of the caregivers who lived separately from the patients exhibited clinical signs of depression. Upon analysis, it was evident that the caregivers living with the patients displayed considerably higher depressive symptoms, as gauged by the Beck Depressive Inventory. These findings were aligned with expectations, highlighting a notable and significant disparity in the depressive symptomatology between caregivers dwelling with the patients and those residing elsewhere. In essence, caregivers emerge as concealed sufferers of depression, often invisible behind their mantle of dedication and support. This underscores the imperative for heightened awareness and vigilance concerning their own psychological and physical well-being, as well as the pressing need for a broader societal recognition of the monumental challenges they undertake.

2.3. Financial Pressure

When addressing the care of individuals afflicted with Alzheimer's disease, the impact is not confined solely to the patients themselves; it extends to the financial predicament of their caregivers

as well. This complex situation can be comprehended through several crucial lenses. First and foremost, the burden of medical and medication expenses weighs heavily on caregivers. The demands of Alzheimer's necessitate consistent medical oversight and pharmacological intervention, thereby entailing costs for medication, medical evaluations, and laboratory tests that cannot be disregarded. As the condition advances, these expenditures tend to amass over time, thereby imposing a strain on the caregivers' fiscal stability. Secondly, the cost of professional care cannot be underestimated. With the disease's progression, patients often require more comprehensive and specialized attention, prompting the recruitment of caregivers, nursing professionals, or trained aides. However, the associated costs including remuneration, training, and insurance for these specialized individuals incrementally accrue, exacerbating the financial onus on caregivers. In circumstances where the caregiver's own family lacks significant savings, the situation can be even direr. Moreover, the caregiving responsibility can lead to caregivers relinquishing potential job opportunities. The substantial commitment of time and energy required to tend to patients can lead caregivers to relinquish full-time employment, and in more drastic cases, compel them to abandon their careers. Notably, many caregivers grapple with financial planning on their own. A staggering third of caregivers experience significant reductions in their earnings from work, and a fifth are forced to withdraw from the workforce due to exhaustion—both physical and mental—resulting in profound financial concessions. These scenarios cast a prolonged shadow over the financial trajectories of caregivers. Simultaneously, catering to the unique requirements of patients often necessitates adjustments within the home environment, encompassing structural modifications, acquisitions of medical equipment, and integration of assistive tools. However, these supplementary costs directly impinge on household budgets, accentuating the financial encumbrance borne by caregivers. Psychological and societal costs constitute another facet of this issue. Beyond grappling with substantial mental and emotional stress, caregivers are susceptible to physical and psychological ailments that engender augmented medical expenses. Moreover, the all-encompassing demands of caregiving can detract from satisfaction in other spheres of life, including social engagements and leisure activities. In parallel, the obligations linked to Alzheimer's care can hinder caregivers' retirement plans, exerting a direct impact on their pension accumulations and long-term financial planning. Consequently, this perpetuates a cycle of economic instability. In summation, Alzheimer's disease engenders a multifaceted economic toll that goes beyond mere medical expenses. It encompasses lost career opportunities, expenses incurred by professional caregiving, shifts within familial dynamics, and psychological as well as social repercussions. In order to alleviate the burdens borne by caregivers, it is imperative to offer them tailored support, comprehensive resources, and pertinent information that safeguards both their fiscal and mental well-being.

3. Discussion

3.1. Measures to Counter Financial Burden

For family members and caregivers of individuals with Alzheimer's disease, the financial strain outlined earlier primarily stems from their reduced work income and the expenses associated with patient and caregiver care, whether incurred within medical and nursing facilities or due to independent care. To address the substantial financial burdens faced by Alzheimer's patients and their families, a range of strategic measures can be implemented. First, pursuing financial aid programs offered by government entities and non-profit organizations tailored explicitly for caregivers is essential. These initiatives might encompass partial medical cost coverage, temporary respite care options, or financial assistance to support caregivers who need to reduce their work hours or leave their jobs altogether. Second, striving for comprehensive health insurance, which includes coverage of expenses related to Alzheimer's disease, can significantly alleviate the financial load. Additionally, caregivers should explore whether their employers offer benefits such as flexible work arrangements, paid family leave, or caregiver support programs. Third, engaging short-term care services can temporarily alleviate caregiver stress, providing them with an opportunity to rest while professionals

temporarily assume caregiving responsibilities. This approach not only helps caregivers retain employment but also affords them personal time, thereby mitigating potential income losses. Fourth, participation in support groups and counseling services can indirectly contribute to diminishing healthcare costs by creating a platform for caregivers to share experiences, acquire coping strategies, and receive guidance on managing stress. Fifth, caregivers should actively seek financial advice and education tailored to their specific circumstances, encompassing understanding available benefits, formulating a caregiving budget, exploring options for long-term care insurance, and crafting a contingency plan for unexpected financial needs. Lastly, local community centers, senior facilities, and non-profit organizations frequently offer free or low-cost resources, including informative workshops, support groups, and recreational activities, which provide caregivers with opportunities for self-care and relaxation.

3.2. Limitations of Evaluation Methods

Furthermore, it is important to acknowledge the limitations of the aforementioned evaluation methods. Within the assessment process, the critical factor is the severity of the Alzheimer's patient's condition—a French Alzheimer's health insurance study demonstrated that the group with the most severe symptoms received full coverage under the French National Insurance for social security, while those with milder degrees had complementary insurance [18]. Moreover, in northern California, due to the accessibility of state-funded Alzheimer's disease diagnosis and treatment centers, patients may receive early diagnosis, though an extended treatment duration inevitably raises associated costs [19]. Consequently, when considering the economic strain on Alzheimer's patients and their families, it is imperative to encompass not only the varying economic demands of patients and caregivers throughout the treatment journey, the need for supplemental medical resources both inside and outside the household, and ongoing medical assessments, but also regional policies affecting patients. A comprehensive analysis of these factors provides a more accurate understanding of the economic pressures they encounter.

4. Conclusion

In conclusion, the analysis underscores the multi-dimensional pressures faced by caregivers of Alzheimer's patients, highlighting physiological, psychological, and financial challenges. Physiologically, caregivers contend with disruptions in daily routines, immune resilience, and emotional strain due to patients' behavioral manifestations. Psychologically, caregivers endure social isolation, career disruptions, and pervasive distress, often leading to depression. Financially, caregivers grapple with medical expenses, professional caregiving costs, lost job opportunities, and supplementary household burdens. These multifaceted stressors collectively impact caregivers' well-being and financial stability, necessitating tailored support mechanisms. To further explore the intricacies of Alzheimer's patients and caregivers' pressures, future research should delve into the long-term impact of caregivers' psychological distress and depression on their overall health. Investigating interventions and support systems that effectively mitigate the psychological and emotional toll on caregivers is crucial. Additionally, studies could delve into the financial ramifications on caregivers' retirement plans and long-term financial well-being, potentially leading to policy recommendations aimed at alleviating economic burdens. Furthermore, comprehensive assessments should consider regional variations in healthcare policies and accessibility, allowing for tailored support strategies that address unique challenges faced by caregivers across different locales. Exploring the efficacy of different caregiving models, such as community-based programs or technology-assisted solutions, could yield insights into enhancing caregivers' resilience and well-being. In sum, understanding the multifaceted pressures on Alzheimer's patients and their caregivers requires a holistic approach that encompasses physiological, psychological, and financial dimensions. This paper anticipates forthcoming academic investigations focusing on several key areas: the enduring consequences of psychological distress experienced by caregivers, the evaluation of

interventions and support systems for their effectiveness, the financial implications on caregivers' retirement preparations, regional disparities in caregiving-related challenges, and emerging developments in alternative caregiving approaches.

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