DEMENTIA CARE: THE UNEXPLORED RELATIONSHIP BETWEEN CAREGIVERS AND DEMENTIA PATIENTS

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ABSTRACT

The modern prominence of mental wellbeing has led healthcare professionals to shift from purely physical treatments toward more holistic approaches that incorporate mental health therapies. However, this is not always the case for dementia patients. Research shows that social interaction and a positive environment can be beneficial in slowing dementia development and progression. Nevertheless, the patient's emotional and psychological state is often sidelined in favour of symptom treatment and third-party statements about their condition. Conversely, health implications of caregiving are often discussed and scrutinised in academic and mainstream settings. Studies indicate that a caregiver's mental state can significantly impact patient wellbeing, with high levels of caregiver anxiety in turn triggering anxiety in the patient as well. Yet, similar patient-focused research is sparse, especially compared to the large cohort studies and systematic reviews done on 'caregiver burden'. This gap in the literature reinforces the underrepresentation of patient experience in research, which aligns with patient reports on loss of agency and stigma post-diagnosis. Additionally, neglecting the reciprocal effects between patient and caregiver conditions highlights ethical and practical limitations in current approaches to dementia care. Acknowledging the interconnection between caregiver and patient is essential for establishing more inclusive and thorough dementia care. Therefore, this review examines inconsistencies in the current literature, exposes methodological and societal causes behind the research gap, and presents strategies to holistically improve dementia care. Addressing these issues ensures that the lives of patients and caregivers alike remain at the forefront of the conversation.

INTRODUCTION

In the last few decades, mental wellbeing has become the focus of a multitude of research endeavours (Foulkes and Andrews, 2023). Studying the effects of socialisation (focusing primarily on social interaction and social isolation) during a person's lifespan has led to increased understanding of the connection between physical health, mortality, and mental wellbeing. As the influence of socialisation becomes increasingly understood, researchers in psychology and healthcare attempt to adapt and further expand on these findings to offer better care to patients with underlying health conditions (Umberson and Karas Montez, 2010); dementia is one of these conditions.

Dementia is the progressive loss of cognitive function to the extent of interfering with and heavily impacting on someone's behaviour, relationships, and everyday activities (National Institute of Aging, 2022). The term encompasses a range of conditions that include but are not limited to: Alzheimer's disease, the most common and known type; frontotemporal dementia, a rare type affecting mostly adults under 60; and vascular dementia, caused by blood vessel damage in the brain. While most dementias do not share disease mechanisms nor a timeline, they all deal with progressive loss of cognitive function (National Institute of Aging, 2022). With around 10 million new dementia cases estimated every year, dementia continues to be an increasing threat to public health because there are no cures available (World Health Organization, 2025). The need to understand the causes, risk factors, and how to treat the condition has increased, pushing researchers in both scientific and social fields to study not only the science behind the disease but its social influence and the dynamics between dementia patients (DPs) and their caregivers.

Studies found that affirmative socialisation with family, other patients, and particularly the patient's caregiver can have positive results in long-term care residents, encouraging an improved sense of belonging and security in their environment (Gillen et al., 2024). However, when it comes to studying psychological impacts worsening or improving the patient's condition, most papers focus on understanding the psychophysical effects that the DP has on their caregiver. The term 'caregiver' can refer to a health professional, a family member, a friend, or a social worker who takes on the needs of someone affected by a condition that limits their health and ability to carry out everyday necessities (National Cancer Institute, 2011). While caregivers are essential in ensuring the wellbeing of a person living with dementia, most research on how to improve dementia care mainly pays attention to the caregiver's burden, rather than looking at the reciprocal effect that patient and caregiver have on each other's health and moods (Connors et al., 2019). Further exploration of this reciprocal relationship is essential to improve dementia care and achieve efficient, long-term solutions (Gillen et al., 2024). The aim of this literature review is to look at the current research imbalance between dementia caregiver (DCG)- and patient-focused studies looking at physical and psychological effects, and the causes behind this research gap.

The review will evaluate the current research available regarding caregiver burden caused by DPs and compare it to research looking at the effect of caregivers on DPs. Additionally, current research examining the reciprocal relationship between caregivers and DPs will be considered. Highlighting the literary disproportion that favours caregiver-focused studies over

patient-focused ones will show systemic issues related to the stigma that subsists in society against dementia patients. Consequently, reasons why a dyadic approach to dementia healthcare is advised, and suggestions to improve care quality, preserve patient's quality of life, and avoid the perpetuation of harmful biases against DPs will also be discussed (Gillen et al., 2024).

THE BURDEN OF CAREGIVING

The term 'caregiver burden' is used to encompass all the negative implications observed in caregivers which include adverse physical and psychological health outcomes, as well as financial and interpersonal issues derived from the caregiving responsibilities (Liu et al., 2021). Many comparative studies have examined physiological biomarkers such as sympathetic nervous system activity, metabolism, and immune function, in both caregivers and the general population. They found that DCGs performed worse than the non-caregiver controls. Evidence of advanced immune aging was seen in DCGs, characterised by overproduction of interleukin-6 (IL-6), which is linked to problems like cardiovascular disease (CVD), diabetes, or cancer (Fonareva and Oken, 2014). Additionally, high levels of cortisol are seen more often in caregivers than non-caregivers, which accounts for increased anxiety and depression (Corrêa et al., 2015). Furthermore, there is a significant difference in sleep patterns between the two groups, with DCGs on average rating their sleep quality akin to that of insomniacs (Fonareva and Oken, 2014). This suggests that increased stress levels are a hallmark of dementia caregiving, as a source of both physical and cognitive deficits. When evaluating processing speed, attention, and concentration, DCGs showed lower performance levels than the controls. The presence and likelihood of these cognitive deficiencies is particularly worrying when considering the caregiver's capability to provide care, as most care-related tasks require a certain degree of cognitive power (Fonareva and Oken, 2014).

Another important factor in relation to caregiver burden is the degree of burden based on specific dementia diagnoses. One study showed that caregiver burden is higher in frontotemporal dementias (FTDs) than in Alzheimer's disease (Mioshi et al., 2013). When the three variants of FTD were analysed, it was concluded that disease severity and symptom precarity affected the DCG's reported burden as well (Mioshi et al., 2013). A different study by Huang et al. (2022) found similar results. Caregivers of DPs with Lewy bodies disease reported a higher burden than Alzheimer's DCGs, with FTD caregivers reporting the highest burden overall (Huang et al., 2022). These results are critical when developing dementia-specific care applications, as their efficiency may vary based on how the difference in symptoms affect the DCG.

Caregiver demographic research is also prevalent in the context of family dynamics and caregiving. Looking at family caregivers provides a more personal view into the social and emotional distress experienced by a family member's dementia diagnosis. Family dynamics shift drastically when a parent, spouse, or sibling is diagnosed, especially as the dementia progresses and takes its toll on the patient. Not only does the disease affect direct parental and spousal relationships with the patient, but it also indirectly affects the community around the caregiver: like their spouses or children (Smith et al., 2022). This is especially true when considering that women are three times more likely to be designated caregivers than males (Gurayah, 2015). When looking at caregiver risks, considering gender and race is also relevant. One study showed that it was 3.3 times more likely for black male DCGs to experience financial difficulties related to caregiving than it was for white women. Meanwhile, compared to white women, other racial groups were 37% less likely to experience caregiving-related emotional burden (Liu et al., 2021). This evidence indicates that factors like culture and social environment play an important role in caregiving, not only in how that care is approached, but in who becomes the principal caregiver and why.

The literature presented suggests that there are many ways that caregiving has been (and continues to be) approached in academia. As caregivers are fundamental to the quality of life of those they take care of, these types of studies help to improve support systems for the caregivers, who are affected by dementia diagnoses in tandem with the patients themselves (Liu et al., 2020).

CAREGIVER EFFECTS ON DEMENTIA PATIENTS

The literature looking at negative effects and social aspects of caregiving is abundant. Meanwhile, far fewer studies evaluate how patients experience care. One such study evaluating the effects of DCGs' mental health on the DP's condition focused on the role caregiver state has on the aggravation and onset of depression and anxiety in patients (Hwang and Kim, 2024). These mental health conditions are considered affective neuropsychiatric symptoms (the earliest signs of cognitive decline) and are reported in around 39% of all individuals with dementia (Hwang and Kim, 2024). As caregivers spend so much time with DPs, it is likely that their own mood, coping strategies, and depression can have an effect on worsening patient symptoms. In fact, results showed that (even after adjusting for these conditions as disease factors) DPs were still more likely to have anxiety and depression when their caregiver also experienced these conditions (Hwang and Kim, 2024). Treating and handling depression in DPs is particularly challenging because of its effect on worsening language function (Yoon et al., 2023). Additionally, Hwang and Kim (2024) determined that a DCG's perception of caregiving (in this case a negative one) and their closeness (or lack thereof) with the DP, also influences these neuropsychiatric outcomes.

The relevance of caregiving perception by the DCG was similarly explored by Quinn et al. (2019). Their findings indicated that ratings of lower quality of life by the patients were closely linked to caregiver stress, high levels of perceived social restrictions, and low caregiving competence. This suggests that if a caregiver does not look at their duties in a positive light or becomes too overwhelmed (as often occurs) it can detrimentally affect not only them but their patient too (Quinn et al., 2019). In cases of

familial caregivers these findings are particularly distressing, as caregiving is often associated with feelings of guilt at their behaviour and abuse towards the patient. A study reported that psychologically distressed family caregivers are more likely to respond abusively to their patients (Cooper et al., 2010). This is especially true in cases when the patient's condition has made them abusive as well. Some of the interviewed caregivers relayed shouting and even hitting back when provoked in these instances (Cooper et al., 2010). While these behaviours are likely influenced by the high-pressure conditions of caregiving, it is not justified when it comes to the patients, whether they engaged in abusive behaviours pre-diagnosis or not.

THE UNDERREPRESENTATION OF THE PATIENT'S EXPERIENCE

The shortage of research into other effects of DCGs on their patients is not indicative of patient experience not being a useful field of study, but it points to bigger concerns not only among academics but among the general public. Among the research reviewed, even the studies acknowledging caregiver effect on DPs have been conducted primarily with the intention of improving caregiver outcomes, not patient outcomes (Cooper et al., 2010; Hwang and Kim, 2024). While these outcomes are inherently intertwined, it is troubling that most studies look at the patients only in light of what they reveal about the caregiver, and not because understanding patients matters too. This does not only point to the narrow research discussing negative impacts on the patients, but also to the small volume of studies done on the influence of positive caregiving experiences on a DP (Quinn et al., 2022). The same infrequency appears true for demographic studies looking at patient effects. As discussed in the study by Liu et al. (2021) regarding caregivers, DPs might also suffer consequences because of their gender and race, or by other aspects outside of their dementia. There are also few studies looking at dementia-related neuropsychiatric symptoms and their effect on overall health. In fact, when a DP is diagnosed with anxiety or depression, many health professionals do not look further than their dementia to explain why they now have anxiety or depression (Hwang and Kim, 2024). It can be inferred that this literature gap is based on some of the reasons discussed below.

Primarily, doing studies on people affected by cognitive decline is logistically more difficult. The approaches used to survey, interview, or observe non-cognitively impaired participants often cannot be used with patients with moderate to advanced stages of dementia. However, it is not impossible, as shown by a study using an 'observer-rated ecological momentary assessment' (Gebhard et al., 2024). This method involves the repeated sampling of participant experiences in real time (Shiffman et al., 2008). Thus, using this method, researchers were able to study rates of social interaction among DPs in long-term care, documenting daily routine without making the patients recall the information (Gebhard et al., 2024). Other study designs involving DP interviews have also been employed in assorted research endeavours regarding dementia care (Passos et al., 2012; King et al., 2023). The satisfactory results reported in these studies reflect that research methodology can, and should, be adapted to include DPs.

On the other hand, the constant assumption throughout these papers that improved caregiver outcomes will automatically improve patient quality of life highlights a very one-sided view of dementia healthcare (Cooper et al., 2010; Hwang and Kim, 2024; Mioshi et al., 2013). Evidence shows that both professionals and the general public have a skewed view of what dementia is and what it means for the people that experience it both directly (as the patient) and indirectly (as their loved ones or caregivers). According to a report by Alzheimer's Disease International (2024) that sampled 40,000 people in 166 countries, 65% of healthcare professionals believe that dementia is a normal part of the ageing process. Moreover, 80% of people from the general public share this belief, while 25% of respondents also believe that dementia is not a preventable condition. These findings paint a dire picture about how dementia is perceived by society, and such beliefs often lead to stigma (Alzheimer's Disease International, 2024).

Dementia-related stigma can take many forms, including self, public, courtesy, affiliate, and structural stigma, perpetuated by institutions and systemic policies. This is particularly relevant in the context of this review. In fact, society tends to look at DPs as 'a burden on families', as 'a danger to themselves', or as 'weak and incompetent' (Alzheimer's Disease International, 2024, pp.15-21). In the case of self-stigma, even the patients themselves start to believe they are an 'embarrassment' and feel 'ashamed' because of their dementia (Alzheimer's Disease International, 2024, pp.21-94). This often leads to stress, social isolation, and self-discrimination, further aggravating their condition (Alzheimer's Disease International, 2024). Studies have disproven that cognitively impaired people are incapable of exercising autonomy, showing that while patients may lose logical abilities, they can still retain social and creative capacity for agency (Boyle, 2014). This research shows that certain societal conceptions, including but not limited to discrimination against DPs and loved ones, lack of dementia knowledge, and inaccurate representation of DPs to the general public, reflect the literature gap explored in this review (Devenney et al., 2024).

A DYADIC APPROACH TO DEMENTIA CARE

The aim of this review was to shed light on the current state of research regarding the relationship between DPs and DCGs. As evidenced, there *is* a gap when it comes to the volume of caregiver-focused studies compared to patient-focused studies, likely because of methodological difficulties and stigmatised attitudes regarding the cognitive capabilities of DPs.

However, one aspect of this relationship that thus far remains unacknowledged is the reciprocity that exists in these relationships. In recent years, studies have taken what has been referred to as a 'dyadic approach' which advocates for putting DPs and DCGs under the same lens to study them as a unit: as a *dyad* (Gillen et al., 2024). This approach relies on simultaneous involvement of both DPs and DCGs when discussing care and developing communication strategies reliant on relationship

dynamics (Balvert et al., 2024). Consequently, dyadic interventions offer an opportunity to create more inclusive environments both in research and in real-life applications.

The Senses Framework, as developed by Nolan et al. (2006), represents a good way to promote this interconnected approach. As it acknowledges the experiences of all parties involved, in this case caregivers and patients, it serves as a guide to illustrate what needs are being met for both. The Senses include security, continuity, belonging, purpose, fulfilment, and significance. When these needs were fulfilled for both the DPs and DCGs, notable improvements to their conditions were seen. For DPs, reduced neuropsychiatric symptoms, like aggression and agitation, were observed. Improved management of these symptoms is essential for reducing caregiver burden. Additionally, with enhanced communication with relatives and community support, the DCGs appeared more secure and at peace within their role, leading to improvements in their stress levels (Gillen et al., 2024). Other studies also showcase that reciprocal approaches might have more benefits in the long run especially when paired with technological advances like companion robots, which encourage a socially interactive environment without further burdening the caregiver (Gebhard et al., 2024).

CONCLUSION

This review has discussed dementia patients and caregivers both as individuals and as a dyad, in the hope of showcasing the current state of research regarding these groups and as a call to improve upon it. An examination of psychophysical effects on both DCGs and DPs has been carried out, methodological and societal reasons why a literature gap exists have been dissected, and potential improvements to current care methods have been discussed. Taken together, the research has evidenced that dementia caregivers and patients are not independent of one another and that neither academia nor the general public must regard them as such. It is paramount that dementia care evolves not just medically with new therapies, but socially and ethically by improving research efforts, taking a dyadic approach, and restoring dignity and agency to those most often silenced.

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