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Exploring Resilience In Dementia Caregivers: A Comprehensive Review Study

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Abstract

Dementia is a progressive neurocognitive disorder that results in significant functional decline, requiring extensive support from family caregivers. These caregivers often experience substantial psychological, emotional, and physical stress due to prolonged caregiving responsibilities. This systematic review explored the key determinants of resilience among family caregivers of individuals with dementia, aiming to understand how personal attributes, relational factors, and caregiving demands influence resilience and overall caregiver well-being. A structured search of major academic databases identified relevant quantitative, qualitative, and mixed-methods studies that examined resilience within dementia caregiving contexts. The evidence showed that higher resilience was commonly associated with older caregiver age, male gender, stronger caregiver–care recipient relationships, lower levels of social isolation, fewer behavioural and neuropsychiatric symptoms in the care recipient, lower neuroticism, and a greater sense of competence in managing caregiving responsibilities. Interestingly, widely assumed protective traits such as self-efficacy, optimism, and self-esteem did not demonstrate consistent associations with resilience across the included studies. Caregivers supporting individuals with mild to moderate dementia tended to display relatively higher resilience, suggesting that resilience may fluctuate depending on the stage and severity of the condition. Despite these insights, notable gaps remain in the existing literature, there is limited use of standardized tools to measure caregiver resilience, and many studies fail to clarify whether higher resilience reflects true adaptive ability or reduced care demands in earlier stages of dementia. Research also lacks long-term follow-up, clear reporting of dementia severity and comparison across caregiver groups such as spouses and adult children. The review emphasizes the need for longitudinal research, standardized tools to measure resilience, and culturally sensitive interventions that can better support caregivers across diverse populations and caregiving environments.

Keywords: Dementia, resilience, competence, self-efficacy, coping strategies, burden, stress, anxiety.

Introduction

Dementia has been described since ancient times, as a progressive disorder marked by memory loss and behavioral changes. Over centuries, understanding evolved from viewing it as a natural part of ageing to recognizing it as a pathological condition affecting the brain-mind relationship where neuronal degeneration leads to detoriation in cognitive function such as memory, reasoning, and judgement. This decline also extends to conation, with marked reduction motivation, initiation and goal directed behavior.[13]

Dementia is a syndrome resulting from various diseases that progressively damage nerve cells and impair brain function, often leading to cognitive decline beyond what is considered typical for aging. The prevalence of Dementia is increasing. The number of people living with Dementia worldwide is currently estimated at over 50 million and will almost triple by 2050 as per World Health Organization, 2023.[22] Currently Dementia is the seventh most common cause of death among all disease and a major contributor to disability and dependency among the older people.[21] The faster growth in dementia prevalence is seen in China, India and other countries of South Asia.[1] As Dementia progresses, debilitating behavioral and psychological symptoms of dementia such as agitation, aggression, depression and apathy also emerge.[15]

Globally, there are over 2.5 billion informal caregivers. (Subsequently referred to as caregivers).[2] The informal care givers commonly family members sustain much of dementia care. They face progressive cognitive, behavioral and functional challenges in PLWD, increasing risk of burden, depression and poor health. Yet many caregivers maintain functioning and report positive adaptation, this heterogeneity has focused attention on resilience as a protective construct to understand and promote caregiver wellbeing.[22] The work of care giving requires much time and is often stressful, placing the care giver at risk both physically and psychologically. Care giver tasks can adversely affect the wellbeing of caregivers, particularly those who are unable to adapt to stressful situations.[10]

There is growing interest in the concepts of resilience and how this can impact both the quality of care provided and care givers wellbeing.[11] Resilience may be defined as the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional and behavioral flexibility and adjustment to external and internal demands".[4]

The review of literature for the present study is organized under the following headings:

- Studies related to the prevalence of Dementia
- Studies related to key determinants or factors of resilience among family caregivers of individuals with dementia
- Studies related to Relationship of caregiver resilience, their subjective wellbeing and quality of life based on demographic profile

World Health Organization (2023) and Alzheimer's Disease International (2021), conducted study on prevalence of Dementia. The number of people living with Dementia worldwide is currently estimated at over 50 million and will almost triple by 2050. According to WHO and ADI, caregiving for persons with dementia is widely recognized as a highly demanding role that places caregivers at significant psychological, emotional, and physical risk. the progressive nature of dementia leads to increasing dependence, behavioural disturbances, and long-term caregiving stress, making caregiver resilience a critical factor for sustainable care.[23,1]

Bekhet and Avery (2018) conducted a study which described resilience from caregivers' perspectives as the ability to adapt positively despite emotional exhaustion, uncertainty, and role strain.[3]

Anu et al., 2023 conducted a study which revealed greater burden, particularly in advanced stages of dementia with wandering and behavioural symptoms, is associated with poorer caregiver well-being.[2]

Ong et al. (2017) and Cao and Yang (2020) demonstrated that both perceived emotional support and instrumental support buffer the negative impact of caregiving burden on mental health and resilience.[17]

Gomez et al., 2020; Duangjina et al.(2024) conducted a Cross-cultural studies from Spain and Asian populations further confirm the universal role of family cohesion, coping skills, meaning-making, and adaptive belief systems in strengthening resilience of care giver with person with Dementia.[11]

Quinn et al.2019;Martyr et al. 2023 conducted IDEAL cohort studies highlighted that resilience is also shaped by caregivers' psychological resources, including optimism, sense of coherence, and positive appraisal of the caregiving role.[19]

Jia et al. (2025) conducted a study which further demonstrated that family resilience mediates the relationship between caregiver burden and sense of coherence, emphasizing the importance of family-level interventions.[14]

Encinas et al. (2024) conducted a systematic review on Effectiveness of structured psychoeducational interventions for dementia caregivers, from this review it was established that structured psychoeducational programs improve caregivers' knowledge, coping confidence, and stress management. Mindfulness-based interventions, ranging from brief formats to extended programs, effectively reduce stress and enhance emotional regulation and resilience.[9]

Saber and Rahimian (2024) done a broader intervention review on enhancing caregiver resilience which supports multi-component resilience-enhancing programs highly effective for caregiver of person with dementia.[14]

Methods

Search Strategy

A comprehensive literature search was conducted by the author across four electronic databases: PubMed (MEDLINE), PsycINFO, CINAHL, and Web of Science. The search term was selected to focus the search on resilience: dementia, caregiving, and resilience

- Dementia terms: dementia, Alzheimer, cognitive impairment, neurocognitive disorder
- Caregiver terms: caregiver, family care giver, informal care giver
- Resilience terms: resilience, adaptation, coping, psychological strength, protective factor

The title and abstract retrieved by the search were assessed by the author and were included if they met the following criteria: Studies examining resilience (or closely related constructs) in adult caregivers of persons with dementia, quantitative, qualitative, or mixed-methods designs, published in peer-reviewed journals, available in English and Bengali language. Studies focusing exclusively on professional caregivers, studies examining resilience of caregivers of persons with other conditions without specific dementia and Studies not directly measuring or examining resilience were excluded from the review.

Factors associated with Dementia

The review identified multiple factors associated with resilience levels in dementia caregivers, organized into Protective factors and Risk factors:

1. Protective Factors (Positively associated with resilience)
    a. **Demographic characteristics:** Age, gender, and education showed mixed results. Some studies reported higher resilience in younger caregivers, while others found older caregivers demonstrated greater adaptation. Gender effects were inconsistent, though several studies suggested women caregivers utilized different resilience strategies than men.[6]
    b. **Social support** (family, friends, and community) social support represented one of the most robust. Both emotional support (empathy, understanding) and instrumental support (practical assistance) contributed to caregiver adaptation. Quality of support relationships mattered more than quantity.[17]
    c. **Coping strategies:** Problem-focused and meaning-focused coping were consistently associated with higher resilience. Caregivers who engaged in active coping, sought information, reframed challenges positively, and found meaning in their caregiving role reported better adaptation. Conversely, avoidant coping and emotional suppression were linked to lower resilience.[18]
    d. **Self-efficacy and problem solving:** Care givers reporting confidence in managing tasks show higher resilience.[11]
    e. **Care recipient relationship:** Caregivers reporting positive relationships demonstrated greater resilience, while those with conflicted relationships experienced additional challenges. However,

some caregivers described relationship reconciliation or deepening through the caregiving experience.[10]

f. **Spirituality:** Faith-based resources emerged as significant resilience factors, particularly in certain cultural contexts. Spiritual beliefs provide meaning, hope, buffering against caregiving stress.[6]

2. Risk factors (Negatively Associated with resilience):
   a. **Severity of Dementia and care giver burden:** Greater behavioural symptoms and high care needs associated with lower resilience.[16]
   b. **Financial strain:** Various study revealed that income was related to resilience specially with low and middle income group.[21]
   c. **Education:** Care givers with less education (less than 6 years) experienced higher levels of care giver burden and associated with low level of resilience.[8]
   d. **Stigma:** Few studies reported that stigma was related to care giver burden. Discrimination and stigma towards older family members or person with Dementia, reported by family care givers. The care givers not disclose the illness to neighbours or strangers in order to avoid social stigma and prejudice.[5]

Measuring Resilience: Resilience was assessed using diverse instruments

Scale development: New scales are being developed to measure both the psychological and social aspects of resilience, as well as different types of caregiver burden.

Assessing resilience in different contexts: Studies are exploring the resilience of caregivers of individuals with early onset versus late onset dementia to identify potential differences.

The majority of studies utilized the following standardized scales to assess resilience:

a. The ResQ-Care-Dem questionnaire to assess the psychological aspects and social aspects of care giver resilience.
b. Zerit Burden Interview (ZBI-7) well suited for measuring caregiver burden among dementia caregivers.
c. Caregiver self-efficacy scale (CSES) to assess the self-efficacy in caregiving.
d. The Gain in Alzheimer Care Instrument (GAIN) Questionnaire to assess positive outcome in dementia care giving.

Developing intervention

1. **Social support:** Some studies were supported an evidence of the association between social support and career resilience. Individual's relationship with family, friends were connected to lower level of Depression and it is a protective factor of resilience.
2. **Formal support:** This review identified that carer who identified formal support had better outcome, higher resilience and lower burden. Few studies also supported that carers reported that their quality of life will be far better if they could get help from formal care giver.[19]
3. **External life:** The Author investigated that there was an impact of external life outside the career e.g. maintaining interest in hobbies, having time to themselves, engaging social and recreational activity, part taking in activities were beneficial for improving resilience of caregiver.[13]
4. **Living arrangement:** It is also supported by the few studies that carer who resides separately from PWD have lower burden and better resilience.[9]
5. **Psychoeducation and skill training:** Multiple reviews find that structured psychoeducational programs which teach about dementia progress, behaviour management, communication technique, problem solving and self-care strategies can improve caregiver knowledge, reduce distress and increase resilience of caregiver.[9]

6. **Brief Stress reduction programmes:** Mindfulness meditation (from brief single session formats to 8 week programmes) produce reductions in stress, anxiety and it is appear useful as both short term relief and as part of longer resilience programmes.[15]
7. **Multi component resilience programmes:** Research also suggest that Multi component resilience programmes offline, online, telephonic show promising effect on care giver strain, coping, effective for positive resilience.[20]

Relationship of caregiver resilience, their subjective wellbeing and quality of life based on demographic profile

Age:
Martyr et al, (2023) conducted a cross-sectional study on resilience on care givers of mild to moderate dementia which comprised 1222 caregivers of PWD, from this study it was concluded that greater resilience was associated with being older. Older caregivers sometimes reported better emotional adaptation, possibly due to life experience.[16]

Gender:
From few studies it was revealed that female care givers perceived more stress, depression and burden than male care givers.[19,21]

Education:
Some researchers conducted a research which also emphasizes education/SES. It showed the association between higher education with higher resilience.[7,10]

Religion/Spirituality:
Few studies reported that spirituality as a protective factor and most consistently associated with greater resilience, lower psychological burden and better coping abilities.[3,12]

Personality characteristics:
Researchers conducted a study on self-efficacy, coping, burden and quality of life among family caregivers of person with dementia in Singapore, showed that Personality characteristics like self-efficacy, competence, confidence, self-control were associated with fewer depressive symptoms and increased psychological health.[13,18]

Gaps in current research

1. Standardized resilience measurement: Many trails report burden, stress, depression rather than resilience. It is important to introduce validated caregiver resilience instruments
2. There is a need for more research to understand whether the resilience observed in some caregiver cohorts is due to the individuals' resilience or the relatively lower care demands in those specific situations.
3. The effectiveness of resilience based interventions requires further testing. Also require more studies on how to scale effective interventions in low resource and culturally diverse setting.
4. Long term follow up is also needed to assess durability of resilience gain at least studies with 6 to 12 months follow up
5. Since the degree of Dementia was not indicated in the literature review thus it is quite difficult to find out whether the resilience experienced by the carers differed as per the degree of Dementia.
6. Most of the studies measure the resilience of caregivers but it was difficult to distinguish the characteristics of the resilience of spouse and other carer's especially young adult child. This demonstrates the necessity of conducting more detailed studies on the resilience of spouse career and adult children carers.

Conclusion

This systematic review demonstrates that resilience among caregivers of persons with dementia is influenced by a complex interplay of demographic characteristics, psychosocial resources, and the clinical severity of dementia. Caregivers generally exhibited higher resilience when they were older, male, or caring for individuals with fewer functional impairments and neuropsychiatric symptoms. Protective factors such as strong social support, positive dyadic relationships, lower neuroticism, and greater perceived competence consistently strengthened adaptation. In contrast, high caregiving burden, financial strain, stigma, and limited education were associated with reduced resilience.

Overall, the evidence indicates that caregivers of individuals with mild to moderate dementia demonstrate comparatively high resilience, possibly due to lower care demands at earlier disease stages. However, substantial gaps remain, particularly in the use of standardized resilience measures, the limited number of longitudinal studies, and the scarcity of culturally tailored interventions. Future research should focus on developing validated resilience assessment tools, evaluating long-term outcomes, and designing scalable, context-sensitive programs that enhance caregivers' coping abilities, well-being, and quality of life across all stages of dementia.

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