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The Role of a Social Support System in Alleviating Multidimensional Stress among Family Caregivers of Older Adults with Disability and Dementia: An Exploratory Study

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Abstract: Against the backdrop of global population aging posing severe social challenges, the long-term care needs of older adults with disability and dementia are becoming increasingly prominent, straining healthcare and social welfare systems worldwide. Family caregivers, as the cornerstone of the care system, universally experience profound and multidimensional stress while fulfilling their responsibilities, often at significant personal cost [1]. This exploratory study employed a mixed-methods approach, combining standardized questionnaire surveys and semi-structured in-depth interviews with 30 caregivers. The aim was to preliminarily delineate their stress status across key domains and construct a comprehensive social support framework grounded in Bronfenbrenner's ecological systems theory. The findings indicate that caregivers exhibit alarmingly high-stress levels across physiological (mean sleep quality self-assessment 4.25/5) [2], psychological (mean anxiety/depression tendency 4.10/5) [3], economic (mean care expenditure as a percentage of household income 58.3%) [4], and social (mean social interaction frequency 4.23/5) [5] dimensions. Qualitative data further contextualized these scores, revealing narratives of chronic exhaustion, anticipatory grief, financial precarity, and profound social isolation. Consequently, this study proposes a multi-tiered social support system encompassing micro (individual and family empowerment through skill training and psychological services) [6], meso (community support network construction via respite care and peer groups) [7], and macro (policy safeguards and cultural shifts) [8] levels. It aims to provide preliminary theoretical insights and practical pathways for systematically alleviating caregiver stress and building a resilient, sustainable care ecosystem. The study concludes by acknowledging its sampling limitations and outlining critical directions for future research, including large-scale validation, subgroup analysis, and the integration of digital health technologies [9].

Keywords: Older adults with disability and dementia; Family caregivers; Caregiver stress; Social support; Ecological systems theory; Mixed-methods research

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1. Introduction

The rapidly expanding population of older adults with disability and dementia represents one of the most challenging socio-medical consequences of global demographic shifts [1]. As life expectancy increases, so does the prevalence of age-related chronic conditions, functional limitations, and cognitive impairments such as Alzheimer's disease and other dementias [10]. This demographic trend precipitates a complex and growing demand for long-term care that extends beyond basic activities of daily living to encompass specialized medical attention, cognitive stimulation, and sustained emotional support [4].

Within this landscape, the role of professional care institutions, while indispensable, is often constrained by resource limitations, cultural preferences, and accessibility issues [7]. Consequently, in most cultural and social contexts, particularly those influenced by filial piety norms like in East Asia, family care remains the central pillar of the long-term care system [1]. These family caregivers—typically spouses, adult children, or daughters-in-law—perform a labor of love and duty that is physically demanding, emotionally draining, and financially taxing [2]. Often with little formal training or preparation, they become the de facto frontline workers in a silent epidemic, providing countless hours of unpaid care that sustains their loved ones and offsets immense societal costs [3].

However, the long-term, high-intensity, and emotionally complex nature of caring for a person with co-morbid disability and dementia renders family caregivers a population at high risk for physical and mental exhaustion, a condition widely recognized as "caregiver syndrome" [4]. The stress experienced by caregivers—also referred to in some literature as "caregiver burden"—is well-documented as a multidimensional construct [1,2]. Physiological stress manifests as chronic fatigue, sleep disturbances, and neglect of personal health, leading to higher morbidity rates among caregivers compared to non-caregiving peers [2]. Psychological stress is particularly acute. Caregivers frequently report high levels of depression, anxiety, and a unique form of "anticipatory grief," where they mourn the progressive loss of the person they knew while simultaneously managing the demands of the present relationship [3,5]. Economic stress is a pervasive and often devastating dimension [4,7]. Direct costs and indirect costs from reduced work hours can deplete savings, pushing families toward financial precarity, starkly described as "asset depletion due to care" [4]. Furthermore, social stress arises from the profound social isolation caregivers experience as care duties force withdrawal from social activities and community engagement, leading to atrophied social connections and loneliness [5,8].

To understand this complex phenomenon and design systemic interventions, a theoretical framework is crucial. Among various models, Bronfenbrenner's ecological systems theory offers a uniquely powerful lens [11,12]. It posits that an individual's development and well-being are shaped by a series of nested environmental systems. This perspective forces a shift from viewing caregiver stress as an individual problem to recognizing it as the outcome of a complex interplay between the caregiver and their broader environment, thereby demanding multi-level solutions [11].

Currently, a significant portion of domestic research on supporting family caregivers remains largely theoretical or relies on samples drawn predominantly from major metropolitan areas [6]. There is a conspicuous lack of in-depth, exploratory empirical analyses that delve into the lived experiences of caregivers using small, intensively studied cohorts to generate rich, contextual insights [3]. Therefore, this study aims to address this gap by conducting a rigorous investigation of 30 family caregivers. It seeks to preliminarily reveal their multidimensional stress status using a combination of quantitative and qualitative methods, thereby capturing both the scale and the nuance of their burden [2,3]. Based on these findings, the study endeavors to construct a holistic social support framework grounded in Bronfenbrenner's ecological systems theory [11]. The ultimate objective is to provide preliminary empirical evidence and a directional roadmap for subsequent larger-scale epidemiological studies and the development of targeted, effective support policies and interventions [9,12].

2. Methodology

2.1. Research design

This study employed an exploratory, concurrent mixed-methods design [3]. This approach was selected to facilitate a comprehensive understanding of the phenomenon by obtaining both quantitative data to quantify the magnitude of stress and qualitative data to explore the subjective, lived experiences behind the numbers [2,3].

2.2. Participant recruitment and sampling

A purposive sampling strategy was used to recruit 30 primary family caregivers from a metropolitan area and its surrounding suburbs. The sample size of 30 was determined based on methodological recommendations for mixed-methods exploratory studies, which suggest that such a size is sufficient to achieve qualitative thematic saturation while allowing for meaningful preliminary quantitative description. Participants were eligible if they were the primary unpaid caregiver for an older adult (aged 65+) diagnosed with both a physical disability (requiring assistance with at least two activities of daily living) and a formal diagnosis of dementia [1,10]. Recruitment was conducted through local community health centers, neurology clinics, and caregiver support groups [6]. Informed consent was obtained from all participants prior to data collection.

2.3. Data collection

Quantitative data: A self-administered questionnaire was used to collect demographic information and assess stress across four dimensions. The questionnaire was developed specifically for this study based on a comprehensive literature review, and items were structured using Likert scales (1 = Low/Negative, 5 = High/Positive) and percentage-based questions to ensure clarity and relevance to the caregiver context.

Qualitative data: Semi-structured in-depth interviews were conducted with each participant, lasting approximately 60–90 minutes. All interviews were carried out by trained researchers with backgrounds in psychology or social work to ensure consistency and empathy. The interview guide explored experiences related to each stress dimension, coping mechanisms, and perceived support needs [3,5]. All interviews were audio-recorded and transcribed verbatim.

2.4. Data analysis

Quantitative data were analyzed using descriptive statistics (means, standard deviations) with SPSS software (Version 26.0) to summarize the stress levels. Qualitative data were analyzed using thematic analysis. To ensure coding reliability, two researchers independently coded the transcripts. Any discrepancies were resolved through discussion until consensus was reached. The coded themes were then organized according to the pre-defined stress dimensions and ecological systems levels to facilitate a mixed-methods interpretation.

2.5. Ethical considerations

This study strictly adhered to the ethical principles of the Declaration of Helsinki. Written informed consent was obtained from all participants following a full explanation of the study, and their rights, safety, and well-being were upheld as paramount throughout.

3. Multidimensional data analysis: Exploratory findings from 30 caregivers

To deeply explore the multidimensional stress faced by family caregivers, this study collected and analyzed data from 30 participants. The results, summarized in **Table 1**, preliminarily outline the high-stress manifestations across physiological, psychological, economic, and social dimensions [2,13].

Table 1. Descriptive statistics of multidimensional stress among family caregivers (*n* = 30)

Stress dimension	Specific indicator	Mean	Standard deviation
Physiological stress	Sleep quality self-assessment	4.25	0.71
	Physical fatigue level	4.17	0.75
Psychological stress	Anxiety/depression tendency	4.10	0.68
	Perceived caregiving burden	4.02	0.80
Economic stress	Care expenditure as % of household income	58.3%	18.5%
Social stress	Social interaction frequency	4.23	0.65
	Perceived social support level	3.95	0.72

Note: All indicators are scored on a 1–5 scale unless otherwise noted, with higher scores indicating greater stress or less support. The economic stress indicator is presented as a percentage of household income.

3.1. Physiological stress: A state of chronic depletion

Quantitative data clearly indicate that the participating caregivers are in a state of significant health depletion. The mean sleep quality self-assessment score was notably high at 4.25, complemented by a mean physical fatigue level of 4.17. Interview data provided a poignant context to these numbers. One spouse caregiver, a 72-year-old woman, shared, “I haven’t had a full night’s sleep in three years. He wanders, and I’m always listening. Even when I do sleep, it’s with one ear open. I’m more tired now than I’ve ever been in my life.” The fatigue was consistently attributed to the 24-hour uninterrupted vigilance required for safety (particularly for those with dementia) and the physically strenuous nature of tasks like transferring, bathing, and managing incontinence. This relentless cycle leads to the widespread neglect of the caregivers’ own health issues, with many reporting cancelled personal medical appointments.

3.2. Psychological stress: The invisible weight

Beyond the physical toll, the psychological burden on caregivers was profound. Both quantitative measures were alarmingly high: anxiety/depression tendency (mean 4.10) and perceived caregiving burden (mean 4.02). The qualitative interviews uncovered the complex emotional underpinnings of these scores. Caregivers commonly described experiencing a profound sense of loss—“anticipatory grief”—for the person their loved one used to be. An adult daughter expressed, “I’m mourning my mother every single day, but she’s still right here. It’s a confusing and lonely pain.” This long-term emotional drain is compounded by feelings of helplessness and frustration in the face of the disease’s irreversible progression and the often-combative behaviors that can accompany dementia. The burden is not just of work, but of continuous emotional management and loss.

3.3. Economic stress: The brink of financial precarity

The economic pressure demonstrated both pervasiveness and severity. On average, care-related expenditures consumed 58.3% of total household income, a figure that underscores the substantial financial sacrifice. The large standard deviation (18.5%) indicates significant variation in economic resilience, with some families facing near-total financial absorption. Several interviewees reported that ongoing costs for medication, specialized nutrition, adult diapers, and occasional temporary institutional respite stays were rapidly depleting family savings. One working-age son lamented, “I had to cut my hours to part-time. Between that and the extra costs, my family’s future—my kids’ college fund—is being spent on today’s care. We’re one major expense away from crisis.” This narrative highlights how caregiving becomes a primary factor risking “asset depletion due to care” and intergenerational poverty.

3.4. Social stress: The shrinking world

In the social dimension, caregivers’ reported social interaction frequency was very high (mean 4.23, indicating low frequency), and their perceived level of social support was also low (mean 3.95). This data confirms that high-intensity care duties severely compress caregivers’ personal time and space, leading to the systematic atrophy of their social networks. A common theme in interviews was the loss of friendships and social identity. “My friends stopped inviting me because I always said ‘no.’ Now, they don’t call at all. You become invisible,” shared one caregiver. Simultaneously, they universally felt a lack of tangible support from relatives, friends, and the community. Promises of help often went unfulfilled, and a lack of understanding about dementia from their social circle led to stigma and judgment, intensifying their sense of isolation and exacerbating the overall stress experience.

In summary, this exploratory study preliminarily suggests that the stress experienced by family caregivers is not merely a collection of individual challenges but a complex, high-intensity, and interconnected system of pressures across multiple life domains. These findings provide valuable data references and clear intervention points for subsequently constructing a targeted, multi-level support system.

4. Theoretical framework: Application of ecological systems theory

This study employs Urie Bronfenbrenner’s ecological systems theory as the core foundation for constructing the support framework. This theory provides a macro, systemic perspective for understanding the caregivers’ situation, positing that an individual’s development and well-being are profoundly influenced by a series of nested environmental systems. Applying this theory to the family caregiver context allows for a deconstruction of their environment into multiple interacting levels:

The microsystem involves the immediate environment of direct, regular interactions. For the caregiver, this includes the care recipient, core family members (spouse, children, siblings), and potentially close friends. Stress at this level arises from the dyadic relationship with the care recipient, intra-family conflicts over care responsibilities, and the lack of practical help from immediate kin.

The mesosystem encompasses the linkages and processes between two or more micro-settings. This includes the connections between the family and the caregiver’s workplace, their social network, their religious community, and local community service centers (e.g., clinics, senior centers). A weak mesosystem is characterized by poor communication between, for example, the family and healthcare providers, or a lack of supportive policies at the workplace that acknowledge caregiving responsibilities.

The exosystem comprises settings that do not directly involve the caregiver as an active participant but in which events occur that affect them. This includes local government health departments, social service agency policies, and the parents’ workplace (if the caregiver is an adult child). For instance, a budget cut in a local respite care program (exosystem) directly increases the burden on the caregiver, even though they have no control over the decision.

The macrosystem is the most extensive external layer, consisting of the overarching cultural values, social norms, ideological beliefs, economic structures, and national laws and policies of a given society. The macrosystem defines the broader context of caregiving, such as the strength of filial piety norms, the societal perception of dementia, the existence of a national long-term care insurance system, and labor laws regarding family leave.

The multidimensional stress experienced by caregivers is dynamically generated and sustained through the complex interaction within and between these system levels. Therefore, an effective and sustainable support framework cannot focus on a single level but must intervene simultaneously across the micro-, meso-, and macro-levels (with exosystem influences addressed within macro-level policy interventions) to fundamentally alter the caregivers' ecosystem and alleviate their burden.

5. Constructing a multi-tiered social support system

Based on the aforementioned theoretical framework and the exploratory data analysis, we propose a comprehensive and actionable multi-tier intervention support system.

5.1. Microsystem intervention: Empowering caregivers and strengthening the family unit

The core goal of intervention at this level is to enhance the coping capacity, knowledge, and internal resilience of the individual caregiver and their immediate family unit.

Systematic capacity building and skill training: Addressing the widespread skills anxiety and lack of preparedness, evidence-based, easily understandable training materials and courses should be developed and widely promoted. These should cover disease-specific knowledge (e.g., understanding dementia progression), practical daily care skills (e.g., safe transferring techniques, managing behavioral symptoms), and emergency response protocols. Utilizing online platforms and mobile health (mHealth) applications can significantly enhance accessibility and provide just-in-time learning.

Multi-level psychological empowerment and support: To tackle the high prevalence of psychological exhaustion, accessible professional psychological support resources must be integrated at the community level. This includes establishing mindfulness-based stress reduction (MBSR) groups, cognitive-behavioral therapy (CBT) workshops tailored for caregivers, and a dedicated, widely-publicized caregiver psychological support hotline. These services provide safe emotional outlets and equip caregivers with professional emotional management tools to combat depression, anxiety, and grief.

Internal support restructuring within the family system: Addressing the low perceived social support from within the family, professional social workers or family therapists can be utilized to facilitate "family care meetings." These structured meetings help families clarify responsibility sharing, communicate openly about challenges, and develop fair, realistic, and sustainable care plans, thereby activating the family's internal support potential and reducing conflict.

5.2. Mesosystem intervention: Building a supportive community and collaborative service network

Intervention at this level is dedicated to constructing a resource-integrated, functionally complementary, and easily accessible supportive community ecology around the caregiver.

Establishing integrated community support hubs: It is recommended to integrate existing but often fragmented community resources to establish “Community Caregiver Support Hubs” or “Neighborhood Care Centers.” These hubs would provide a one-stop shop for services including information and referral, benefits counseling, legal advice, support group meetings, and training workshops, drastically reducing the time and energy cost for caregivers seeking help.

Developing institutionalized and diversified respite services: To directly address the severe physical fatigue and social isolation of caregivers, accessible and affordable respite services must be promoted as a core intervention measure. This involves developing a spectrum of short-term services, including in-home respite (trained aides coming to the home), adult day care centers, and short-term overnight stays in residential facilities. Respite care provides caregivers with the essential, guilt-free breaks necessary for self-care, medical appointments, and social reconnection.

Cultivating peer support and volunteer service networks: Systematically cultivate and facilitate peer-led caregiver mutual support groups, both in-person and online, where caregivers can share experiences, advice, and emotional comfort with those who truly understand. Concurrently, recruit, train, and coordinate volunteers (e.g., younger retirees, university students) to form teams that provide practical, non-clinical help like friendly visitation, companionship for the care recipient, and assistance with light household chores or grocery shopping.

5.3. Macrosystem intervention: Establishing protective policies and an inclusive culture

Intervention at this level aims to build a solid, enabling, and inclusive external environment for caregivers through top-level institutional design, legal safeguards, and socio-cultural campaigns. This includes actions typically situated in the exosystem, which are driven by macro-level policies.

Strengthening policy and financial support: To directly alleviate the crushing economic pressure on families, the exploration and establishment of a universal, publicly funded Long-Term Care Insurance (LTCI) system should be accelerated. This system would help cover the costs of professional care and respite services. Furthermore, the feasibility and implementation of direct financial subsidies or tax credits for low- and middle-income caregiving families should be rigorously studied and enacted.

Improving legal safeguards and workplace flexibility: Relevant regulations should be actively promoted to legally clarify the rights and status of family caregivers. Legislation guaranteeing paid “family care leave” for employed caregivers, akin to parental leave, should be explored and advocated for. Additionally, encouraging or mandating workplace policies that support flexible working hours and remote work options can help employed caregivers better balance their competing responsibilities.

Guiding social and cultural advocacy and eliminating stigma: Nationwide public education campaigns should be launched, utilizing community publicity, mainstream media cooperation, and social media influencers to disseminate accurate knowledge about disability and dementia, challenge myths, and eliminate social stigma. The goal is to foster a societal climate that not only recognizes the immense contribution of family caregivers but also actively offers support, understanding, and inclusion, shifting the narrative from a private family problem to a shared societal responsibility.

6. Discussion and outlook

The core value of the framework proposed in this paper lies in the organic integration of the multidimensional stress status, revealed through a mixed-methods exploratory study, with a comprehensive multi-level theoretical intervention system derived from ecological systems theory. The preliminary survey of 30 caregivers not only quantified the pervasiveness and severity of stress across domains but, crucially, provided rich qualitative evidence that contextualized these numbers and pointed toward targeted intervention needs. The proposed micro, meso, and macro-level interventions are designed to act synergistically, recognizing that empowering a caregiver (micro) is insufficient if they return to an unsupportive community (meso) and a policy vacuum (macro).

However, it must be unequivocally stated that the main limitation of this study is its small, non-probability sample size (*n* = 30) drawn from a specific geographical area. Therefore, the statistical generalizability (external validity) of the quantitative findings is limited. The qualitative insights, while deep and illuminating, are not representative of the entire population of caregivers.

Based on these limitations and contributions, future research should proceed along several critical pathways:

Large-scale validation and subgroup analysis: The primary next step is to verify the robustness and prevalence of these exploratory findings through larger-scale, nationally representative surveys. Furthermore, conducting comparative analyses of stress profiles, coping mechanisms, and support needs across different subgroups is essential. Key comparisons include spousal caregivers versus adult-child caregivers, male versus female caregivers, urban versus rural caregivers, and those caring for individuals at different stages of dementia. Such analyses are crucial for developing precision support policies.

Development and evaluation of targeted interventions: Support strategies need to move beyond one-size-fits-all models. Future research should be dedicated to designing, implementing, and rigorously evaluating personalized intervention programs. For example, testing the efficacy of a specific financial subsidy scheme for low-income caregivers, or evaluating the impact of a standardized, 8-week mindfulness training program on reducing psychological stress in a controlled trial.

Longitudinal studies: There is a pressing need for longitudinal research that follows caregivers over time. Such studies can track the evolution of stress as the care recipient's condition progresses, identify critical tipping points where intervention is most needed, and assess the long-term outcomes of various support services on caregiver health and institutionalization rates of care recipients.

Deep integration of technology (gerontotechnology): The exploration of technology represents a frontier full of potential. Future work should investigate the development and implementation of innovative solutions such as remote health monitoring systems, GPS tracking for wander prevention, smart home assistive devices, and comprehensive online support platforms that offer training, peer connection, and service coordination. These technologies hold immense promise for improving care efficiency, enhancing safety, and reducing caregiver burden, particularly in resource-scarce rural and remote areas.

7. Conclusion

Family caregivers are the indispensable, yet often overlooked, assets for sustaining the entire social long-term care system. Through an exploratory mixed-methods study of 30 caregivers, this research preliminarily revealed the alarmingly high-stress status they endure across physiological, psychological, economic, and social dimensions. The narratives of exhaustion, grief, financial strain, and isolation provide a human face to the quantitative scores. Accordingly, this study constructed a "micro-meso-macro" social support framework, grounded in Bronfenbrenner's ecological systems theory, to address these challenges at their root causes.

Although the sample is limited and the findings are exploratory, this study provides valuable preliminary insights and a coherent blueprint for understanding and mitigating caregiver stress. It shifts the focus from the caregiver as the locus of the problem to the caregiver within an ecosystem that requires reinforcement. The ultimate success of any such support system, however, relies not on isolated efforts but on determined, cross-sector collaboration among government agencies, healthcare systems, community organizations, employers, and all sectors of civil society. This must be coupled with continuous policy innovation, adequate funding, and the diligent implementation of services. Only through such integrated, sustained, and systemic efforts can we hope to gradually build a resilient, compassionate, and sustainable care ecosystem—one where caregivers can maintain their own health, dignity, and well-being while selflessly giving their love and fulfilling their responsibilities.

Disclosure statement

The author declares no conflict of interest.

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