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ORIGINAL RESEARCH

Development of a Home-Based Holistic Dementia Nursing Intervention Model for Family Caregivers



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Abstract

Background: The number of older adults with dementia in Indonesia continues to increase. However, many family caregivers still have limited knowledge and skills, which can adversely affect both older adults and caregivers. Existing interventions mainly focus on single aspects of care and have not adequately addressed the physical, psychological, social, and spiritual dimensions. Therefore, there is a need for a comprehensive intervention model that holistically meets caregivers' needs.

Purpose: This study aimed to develop a home-based holistic dementia nursing intervention model for family caregivers and identify its key features.

Methods: Three approaches were used for model development: (1) literature review, (2) in-depth interviews, and (3) expert validation. Five articles addressing holistic care dimensions and nursing interventions were included in the review. Fifteen participants took part in the in-depth interviews, and expert validation involved three specialists in the field of geriatrics with specific qualifications. Data were collected between August and September 2022. Analysis was conducted by comparing and synthesizing the findings from the literature review, interviews, and expert validation.

Results: The holistic dementia nursing intervention model for family caregivers consisted of four intervention domains: (1) physical, (2) psychological, (3) social, and (4) spiritual. The model also incorporated three key components: (1) communication processes, (2) organizational processes, and (3) belief systems.

Conclusion: The home-based holistic dementia nursing intervention model for family caregivers offers a potential conceptual framework to comprehensively address the physical, psychological, social, and spiritual needs of both older adults and their caregivers.

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1. Introduction

Dementia is one of the leading causes of death and disability, posing serious health and social challenges (World Health Organization, 2017). Currently, there are no available data in Indonesia regarding older adults with dementia. However, based on data on the number of older adults in Indonesia, it is estimated that the number of older adults with dementia will reach 2 million by 2030 and increase to 4 million by 2050. More than 30% of older adults with dementia in Indonesia are cared for by family members (Alzheimer Indonesia, 2019). Dementia is a terminal, progressive, chronic disease that requires complex care, which can have a negative impact on family caregivers. Therefore, family caregivers require special skills, including knowledge, self-efficacy, and adequate social support, to provide quality care (Leocadie et al., 2020).

A recent Systematic review highlights a gradual increase in the number of interventions for family caregivers caring for older adults with dementia. These interventions involve various approaches, including biological interventions, such as enhancing knowledge and skills in dementia care through online modules (Pleasant et al., 2017), psychological interventions such as psychoeducation on burden (Tawfik et al., 2021), and cognitive-behavioral therapy focused on stress management (Meichsner et al., 2019). Social interventions have involved self-help groups (Laakkonen et al., 2016), while spiritual interventions incorporate mindfulness practices

(Stjernswärd & Hansson, 2017; Tkatch et al., 2017). All interventions had significant results. However, a systematic review of online interventions to reduce the burden on family caregivers found no statistically significant results (Zhao et al., 2019). This outcome is attributed to the superficial nature of the materials provided, which lacked depth in addressing dementia care (Cristancho-Lacroix et al., 2015), and failure to provide comprehensive stress management strategies (Zhao et al., 2019). While psychological and social interventions remain focused on single aspects, it is crucial to provide family caregivers with interventions that address physical, psychological, social, and spiritual needs (Pleasant et al., 2020). Despite the presence of interventions for dementia family caregivers in some countries, such as the USA, South Korea, Germany, Sweden, Spain, and Canada, caregivers in Indonesia still perceive a lack of knowledge and skills in caring for older adults with dementia (Widyastuti et al., 2023).

The nursing interventions provided to date have not fully met the needs of family caregivers. Consequently, there is a need to develop an accessible intervention model for caregivers through holistic care that meets their needs. Holistic care constitutes a comprehensive approach that integrates biological, psychological, social, and spiritual aspects to enhance the patient's condition, encompassing the mind, body, and soul (Jasemi et al., 2017; Papathanasiou, 2013; Ventegodt et al., 2016; Zafeiridi et al., 2018). Holistic nursing helps empower patients to use available resources to enhance their quality of life and adapt to changes (Ventegodt et al., 2016). It empowers family caregivers to use all available resources to improve their quality of life and facilitate adaptation to the roles and impacts of caregiving.

The family resilience model focuses on family strengths to manage stress and foster resilience in adapting to changes while caring for older adults with dementia (Palacio G et al., 2020; Walsh, 2016). This model effectively describes family strengths in managing stress and facilitating adjustment, acceptance, and adaptation to the impacts of caring for older adults with dementia (Fernández-Calvo et al., 2016; Walsh, 2016; Zhou et al., 2021). However, the resilience model lacks a comprehensive description of nursing interventions, thus requiring a holistic care approach for its implementation (Dossey et al., 2005). Furthermore, it does not explain the interaction between nurses and family caregivers in achieving the intervention goals, thereby requiring integration with Imogene King's Goal Attainment Theory (King, 1992). Through this integration, family caregivers can provide safe, high-quality nursing care to older adults with dementia. Nevertheless, there has been limited exploration of the conceptual dimensions of holism and holistic dementia nursing interventions needed by family caregivers in the care of older adults with dementia and in supporting self-care practices. Therefore, this study aimed to develop a home-based holistic dementia nursing intervention model for family caregivers.

2. Methods

2.1. Research design

Three methods were subsequently employed to develop a home-based holistic dementia nursing intervention model for family caregivers: (1) literature review, (2) in-depth interviews, and (3) expert validation (Hamid et al., 2023). Figure 1 illustrates the flow of the methods used to develop the model, the outcomes of each method, and their interrelationships. Several relevant online databases were searched to identify research publications for the literature review. Meanwhile, the qualitative component, conducted through in-depth interviews with family caregivers, followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007). Both guidelines were used to enhance the clarity and rigor in reporting the findings.

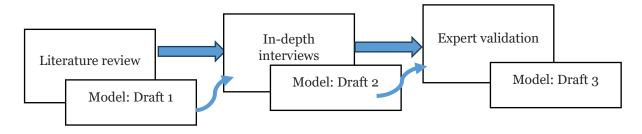


Figure 1. Method flow of model development

2.2. Setting and samples

The literature review in this model development aimed to identify concepts and dimensions of holistic care, as well as forms of interventions based on the holistic dimensions. We conducted a literature search of publications between 2013 and 2023 using four databases, including PubMed, Sage, Scopus, and Google Scholar, with the following search terms: biopsychosocial AND holistic nursing OR holistic care OR holistic practice. The inclusion criteria focused on articles discussing the concepts and dimensions of holistic care, as well as the interventions derived from these dimensions. Included articles were full-text publications written in English or Indonesian and consisted of reviews, concept analyses, and randomized controlled trials.

After synthesizing the literature review findings, we conducted in-depth interviews with family caregivers. The purpose of these interviews was to explore the intervention needs of family caregivers in caring for older adults with dementia and in promoting their own self-care. Fifteen family caregivers from Central Java Province, Indonesia, were selected from five regions: Semarang City, Pemalang, Jepara, Solo, and Magelang. According to Campbell et al. (2020), purposive sampling facilitates a better match between the sample and the research objectives. Therefore, we purposively selected 15 participants. The inclusion criteria were family members who had cared for older adults with dementia for at least six months and assisted them with daily activities. These participants were chosen because they had direct experience in dementia caregiving. According to Hennink et al. (2022), the sample size required to reach saturation in indepth interviews for qualitative studies ranges from 5 to 24. Thus, the selected sample was considered adequate to capture diverse perspectives and achieve data saturation.

In this study, expert validation aimed to obtain feedback on the concepts used in developing the model, which were derived from the literature review and in-depth interviews. We purposively recruited three experts. Inclusion criteria included holding a Ph.D. and having experience in dementia care and model development. In this study, the experts consisted of a geriatric physician, a geriatric nurse, and a gerontological nursing lecturer.

2.3. Measurement and data collection

For the literature review, relevant data, information, and documents matching the keywords were retrieved. Articles aligned with the review objectives were manually selected, and those that did not meet the inclusion criteria were excluded. Articles published in specific journals were retained to prevent duplication. Any discrepancies regarding inclusion or exclusion were resolved through discussion among all team members. Data extraction was performed using Microsoft Excel, capturing relevant information for model development, such as (1) article characteristics, (2) concepts identified from research findings, and (3) nursing interventions based on holistic dimensions. The article selection process is presented in Figure 2.

In-depth interviews followed the guidelines proposed by Jacobvitz et al. (2002). Interview guidelines were developed and structured based on the objectives, and the questions were openended, allowing for in-depth exploration of participants' experiences (Bevan, 2014). The interview guide followed Bevan's phenomenological structure with three domains: contextualization, apprehension of the phenomenon, and clarification of the phenomenon (Bevan, 2014). Sample questions included: "Please tell me about the intervention you expect," "Describe the types of dementia intervention for caregivers that you need in caring for older adults with dementia," and "Can you explain your experience and why such interventions are necessary in dementia care?" Each caregiver participated in a single in-depth interview conducted via Zoom, as the participants had to accompany the older adults they cared for. Interviews were conducted between August and September 2022. During the interviews, only the participant and the researcher were present. The interviews began with open-ended questions and lasted 45-60 minutes.

In this study, three experts from affiliated universities and professional organizations in elderly care were invited. We emailed the draft model and its key concepts to the experts and requested feedback. They provided comments through email and online meetings with the research team.

2.4. Data analysis

The literature review was conducted by reviewing articles that met the predetermined inclusion criteria. Data, information, and documents matching the keywords and inclusion criteria were included in the review.

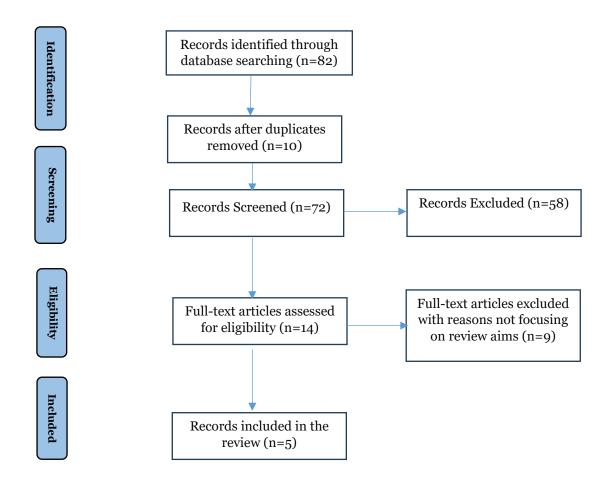


Figure 2. Article selection process for the literature review flow diagram

The Colaizzi method (Colaizzi, 1978) was employed for qualitative data analysis. This approach was selected because it aligns with the primary aim of our initial model development: to identify and clarify the concepts and dimensions of holism and holistic dementia nursing interventions required by family caregivers in caring for older adults with dementia and in supporting their own self-care. The data analysis process involved transcribing each interview, reading the transcripts multiple times to identify emerging themes by highlighting codes within significant quotations and capturing units of meaning, and organizing these units into sub-themes and themes. The findings were then returned to the participants for validation. Notes were added throughout the process. Similarities and differences were identified to construct key concepts for home-based holistic dementia nursing interventions for family caregivers, based on the interrelationships among data from the literature review, in-depth interviews, and expert validation.

To develop the model systematically, data analysis involved comparing and synthesizing the results of the literature review, in-depth interviews, and expert validation. In this way, evidence-based and expert-based knowledge were integrated to achieve the full richness of the model. The integration of these knowledge sources provides a strong foundation for developing an empirical conceptual framework of complex concepts (Creswell & Creswell, 2018).

2.5. Trustworthiness/rigor

Data trustworthiness comprises credibility, dependability, confirmability, and transferability (Polit & Beck, 2014). Credibility was ensured by having the researchers with the necessary knowledge and skills to perform their roles; three authors had previous experience in qualitative research, and two held PhD degrees. Dependability was achieved by maintaining detailed records of the data collection process. Confirmability of the key concepts in the model was established through team review and expert validation. Transferability was supported by providing detailed descriptions of the data collection, analysis, and results.

2.6. Ethical considerations

This study received approval from the Health Research Ethics Committee of the Faculty of Nursing, Universitas Indonesia (Reference No. KET-132/UN2.F12.D1.2.1/PPM.00.02/2022). All participants in interviews and expert validation received both written and oral information about the study. They were informed that their participation was voluntary and that they could withdraw at any time without any consequences. Informed consent was obtained from each participant.

3. Results

It should be noted that the results presented in this article focus on findings relevant to model development.

3.1. Literature review

The initial search identified a total of 82 articles. After removing duplicates and applying the inclusion and exclusion criteria during title and abstract screening, 14 studies were selected for full-text assessment. Of these, five articles were included in the review. The remaining articles were excluded because they did not sufficiently align with the review's objective. The findings of the literature review related to the dimensions of holistic care and holistic nursing interventions are presented in Table 1.

Table 1. Results of data extraction from the reviewed articles

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Author (Year) and Country	Title	Holistic care dimensions	Biopsychosocial-Spiritual Based Interventions
Colvin, A. D., & Bullock, A. N. (2016). USA	A review of the biopsychosocial aspects of caregiving for aging family members	 The physical dimension includes anatomy, as well as the structural and molecular aspects of illness and physical health. The social dimension includes cultural influences, family relationships, the interconnectedness of all individuals, and the importance of social relationships and support (family and peer groups). The psychological dimension includes mental factors, emotional components, behavior as a response to emotions, and stress. 	- Physical intervention: Education (knowledge and skill transfer) - Social intervention: Self-help, Social networking, advocacy, and social action - Psychological intervention: Training in social problem- solving, assisting effective decision- making, encouraging recreational activities
Drury, C., & Hunter, J. (2016).	The hole in holistic patient care	The spiritual dimension involves beliefs, a higher power, giving life	NA
USA		meaning, seeking transcendent meaning, connection to something beyond oneself, peace, faith, hope, love, truth, the need to seek purpose in life, relationships, forgiveness, creativity, and the need for emotional feelings (peace, comfort).	
Jasemi, M., Valizadeh, L., Zamanzadeh, V., & Keogh, B. (2017). Iran	A concept analysis of holistic care by hybrid model	The holistic dimension includes emotions, education, physical needs, culture, and spirituality.	NA
Papathanasiou, I. (2013). Greece	Holistic nursing care: Theories and perspectives	Holism involves biological and multidimensional mental aspects, including body, mind, soul, and spirit.	
Hilcove et al. (2021) USA	Holistic nursing in practice: Mindfulness- based yoga as an intervention to manage stress and burnout	NA	Spiritual intervention: Mindfulness
	Stress and parnout		

3.2. In-depth interviews

All participants were women with a mean age of 44.1 years. Most were married, held a bachelor's degree, and belonged to Javanese or Chinese ethnic groups. The majority were daughters of older adults with dementia who had been caring for them for an average of 4.5 years. During the interviews, participants shared their experiences, thoughts, and insights while caring for older adults with dementia. Four themes emerged from the data: (1) family caregivers' need for training on dementia care and self-care; (2) peer support groups can provide informational and emotional support; (3) the need for stress management to minimize the negative impacts; and (4) the need for spiritual support to increase self-awareness as caregivers.

3.2.1. Theme 1: Family caregivers need training on dementia care and self-care

Participants agreed that family caregivers require training on dementia care and self-care. They emphasized the importance of online training supported by relevant modules and videos. Participants stated:

It's essential to have online training so that we can also accompany older adults while attending the training. We can learn how dementia progresses and how to care for it according to its stages, and care for those in the advanced stage. (Daughter, P1)

Online training about strategies for caring for dementia patients is essential. It allows me to continue accompanying my mother. (Daughter, P11)

We need training modules and videos about caring for older adults that provide caregiving examples. It can help me provide activities suitable for my father's condition. (Daughter, P2)

3.2.2. Theme 2: Peer support groups can provide informational and emotional support Most family caregivers stated that peer support groups offer informational and emotional support. Some participants expressed:

Through a WhatsApp group for family caregivers, I obtain information and strategies for caring for dementia patients, which enhances my knowledge. (Daughter, P2)

On WhatsApp, fellow caregivers can share their experiences of caring for family members with dementia, and it feels relatable. I don't feel alone. I find similarities with other caregivers, which reduces my sadness. (Wife, P7)

3.2.3. Theme 3: Need for stress management to minimize the negative impacts

Participants also expressed the need for stress management to minimize the negative impacts while caring for older adults with dementia. They stated:

Caring for older adults with dementia is extraordinary... the changes in my mom... suddenly getting angry for no reason... it stresses us... that's why we need to find ways to cope with that stress. (Daughter, P8)

Caring for older adults with dementia can cause immense emotional strain and physical fatigue; I need activities that can reduce the exhaustion. (Daughter, P10)

*3.2.4.Theme 4: Need for spiritual support to increase self-awareness as caregivers*Participants stated that they need spiritual support to increase self-awareness as caregivers.

I need a spiritual approach to remind myself that I'm caring for someone with dementia. I need to accept the condition and our role as caregivers so that we can handle it well. (Daughter, P14)

Older adults with dementia have emotional swings. When mom gets angry, it irritates us too, so we need spiritual guidance. It is because praying and worshipping can be an outlet for our emotions while caring for the elderly. (Daughter, P6)

Based on in-depth interviews with family caregivers, key concepts from the interviews and the literature review were integrated to refine the model.

3.3. Expert validation

The experts held Ph.D degrees and had experience in dementia care for older adults, as well as in model development through affiliated universities and professional organizations. The revised model was presented and explained, and feedback was requested. Overall, the experts agreed with the key concepts. They suggested adding more narrative explanations to the concepts:

Caregivers of older adults with dementia need comprehensive and holistic interventions, including physical, psychological, social, and spiritual components, so that they can provide optimal care for older adults and practice self-care. (SS, geriatric nurse in hospital)

3.4. Home-based holistic dementia nursing intervention model for family caregivers

A home-based holistic dementia nursing intervention model for family caregivers was developed through the integration of literature review findings, qualitative data, and expert validation. Figure 3 presents the model. The model incorporates the family resilience framework, which consists of belief systems, organizational processes, and communication processes (Walsh, 2016), integrated with holistic care interventions. Meanwhile, the nurse-caregiver relationship is developed based on King's Middle Range Theory of Goal Attainment (King, 1992), emphasizing communication, respect, and trust. The final model integrates the family resilience model, the Theory of Goal Attainment, literature review findings, qualitative insights, and expert validation. It is important to note that only the most recent version of the model is presented in this article.

The final model includes four components. First, physical interventions are integrated into the communication process, which includes clear information, emotional sharing, and problem-solving, and are facilitated through dementia education. Second, psychological interventions are embedded within the communication process, which consists of clear information, emotional sharing, and problem-solving, facilitated by stress management. Third, social interventions are integrated with both the organizational process, which provides informational support such as advice, information, and materials, as well as emotional support in the form of attention and appreciation, attachment, and communication, facilitated through self-help groups. Fourth, spiritual interventions are integrated with the belief system, including perceptions, the meaning of caregiving, positive views, and spirituality, and are facilitated through spiritual mindfulness. The model's framework is presented in Figure 3.

4. Discussion

The home-based holistic dementia care intervention model for family caregivers integrates the family resilience model, which includes belief systems, organizational processes, and communication processes (Walsh, 2016), with holistic care interventions. The literature review in this study identified four dimensions of holism: physical, psychological, social, and spiritual (Jasemi et al., 2017; Papathanasiou, 2013). The physical dimension includes anatomy, structural and molecular disease agents, and physical health, offering potential knowledge and skill transfers (Colvin & Bullock, 2016). Family caregivers of older adults with dementia often lack adequate knowledge, which makes them feel unprepared for caregiving and leads to physical strain. Previous research has reported that family caregivers experience numerous negative physical consequences due to caregiving, including elevated cholesterol and insulin levels, heart attacks, hypertension, diabetes, arthritis, headaches, acid reflux, fatigue, decreased immune and neuroendocrine responses, and sleep disturbances (Colvin & Bullock, 2016).

The model developed in this study presents physical interventions that integrate communication processes, including clear information, emotional sharing, and problem-solving, delivered through training to support older adults with dementia. Findings from the in-depth interviews highlighted the need for online training modules and videos on dementia care to help family caregivers cope with caregiving burdens. Training for family caregivers has been shown to

positively influence their physical well-being while caring for older adults with dementia (Birkenhäger-Gillesse et al., 2020). Furthermore, training associated with caregiving tasks, combined with counseling and health education interventions, enhances the quality of care and reduces caregiver burden (Martínez-Santos et al., 2021).

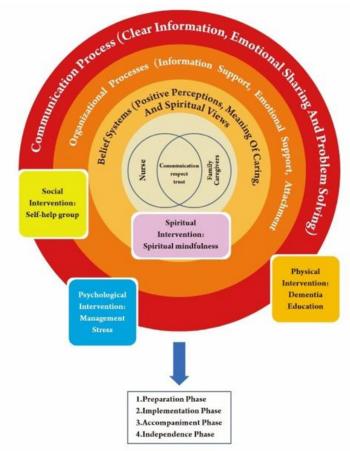


Figure 3. Final model of the home-based holistic dementia nursing intervention for family caregivers

Findings from the literature review showed that the social dimension comprises cultural influences, family relationships, interconnectedness among people, the importance of relationships, and social support (family and peer groups) (Colvin & Bullock, 2016). The model developed in this study presents social interventions that integrate organizational processes, such as informational support through advice, information, and materials, and emotional support through attention, appreciation, and attachment, with communication processes (clear information, emotional sharing, and problem-solving) delivered through self-help groups. Indepth interviews revealed that family caregivers receive both informational and emotional support from fellow caregivers of older adults with dementia. Previous research has shown that online peer group interventions facilitate caregivers in sharing experiences, offering support, exchanging information, enhancing self-esteem and sense of unity, fostering well-being, and motivating them to continue caregiving (Lauritzen et al., 2019; Sitges-Maciá et al., 2021).

The literature review also found that the psychological dimension includes mental factors, emotional components, behaviors as an emotional response, and stress (Colvin & Bullock, 2016). The model developed in this study demonstrates that psychological interventions integrate communication processes (clear information, emotional sharing, and problem-solving) through stress management. In-depth interviews indicated that participants needed stress-management strategies to mitigate the negative impacts of caregiving. Psychoeducation through stress management has been shown to promote problem-focused coping, encourage social support seeking, reduce symptoms of depression and anxiety, mitigate dysfunctional thoughts, and enhance self-efficacy in controlling negative thoughts among family caregivers of older adults with dementia (Cheng et al., 2019; Wiegelmann et al., 2021).

The spiritual dimension identified from the literature review includes beliefs, higher powers, giving meaning to life, seeking transcendental meaning, connection to something beyond oneself, peace, trust, hope, love, truth, the need to seek life's purpose, relationships, forgiveness, creativity, and the need for emotional feelings (peace, comfort) (Drury & Hunter, 2016). In-depth interviews revealed that adopting a spiritual approach enhances self-awareness and acceptance when caring for older adults with dementia. This dimension helps family caregivers adapt to the caregiving process by attributing meaning to their experiences through connections with higher powers (Zhou et al., 2021). Spiritual meaning can positively contribute to spiritual coping and reduce caregiver burden (Kevern & Stifoss-Hanssen, 2020). Research has also indicated that mindfulness practices can reduce caregiver burden (Kevern et al., 2012). Mindfulness, embraced by various religions worldwide, addresses multiple problems and serves as a religious practice aimed at fostering a closer connection with God or the Creator, while supporting physical and psychological health through a spiritual approach (Cho et al., 2021). Mindfulness is a phenomenological concept that refers to a state of mind (awareness, adjustment, acceptance) resulting from meditation or contemplation. Spiritual mindfulness can be applied across different religious beliefs (Mutter, 2014).

5. Implication and limitation

This study contributes to the development of interventions that address physical, psychological, social, and spiritual aspects, thereby adding value by producing a comprehensive model tailored to the needs of family caregivers. Moreover, this model may help reduce barriers faced by family caregivers in Indonesia, as reported in previous research (Widyastuti, 2023). Although different methods were used to develop the model, the study included only family caregivers from one region in Indonesia. Participants from other regions or countries who might offer diverse perspectives were not included. Future studies should examine the model among caregivers from various regions in Indonesia and internationally to better understand their perspectives and, if necessary, revise or expand the model.

6. Conclusion

The home-based holistic dementia nursing intervention model for family caregivers offers a potential conceptual framework to enhance the quality of care for older adults with dementia and support caregivers' self-care. The model encompasses physical, psychological, social, and spiritual components, with three key elements integrated within these interventions. Further research is recommended to validate the model through empirical studies and real-world implementation. External validity may be strengthened by replicating the study with caregivers of older adults with other health conditions.

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Author contribution

All authors contributed to the study conception and design (RHW, JS, ER), data collection (RHW), data analysis (RHW, JS, ER), and manuscript preparation and revision (RHW, JS, ER).

Conflict of interest

The authors declare no potential conflict of interest concerning this research, authorship, and/or publications of this article.

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