Development of Online Training Modules on Dementia Care at Home for Family Caregivers

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Abstract:

Introduction: To improve the quality of care and reduce the negative effects of caregiving, modules that address the needs of caregivers must be developed. There hasn't been much progress in Indonesia in creating online training programs for dementia care at home.

Objective: This study aims to develop online training modules on dementia care at home that are especially suited to the needs of family caregivers.

Methods: The modules were developed using the Sidek Module Development Model (SMDM), which consisted of two stages: [a] developing the module drafts and [b] testing and evaluating the modules. The study involved semi-structured in-depth interviews with fifteen family caregivers caring for older adults with dementia that focused on [i] existing problems and challenges that family caregivers face in caring for older adults with dementia, [ii] the needs of family caregivers in caring for older adults with dementia and self-care, and [iii] strategies to meet those needs. The interview results were analyzed using the collaizi method.

Results: Seven modules were developed based on the family needs in this study, including aging processes in older adults, dementia and its impact, communication adapted to the older adults' condition, management of issues arising in older adults with dementia, becoming resilient family caregivers, addressing issues faced by family caregivers, and self-help groups. The module content validity scores ranged between 90.73% and 94.73% based on the respective aspects of the modules, with an overall content validity score of 92.79%.

Conclusion: The findings suggest that the online training modules on dementia care at home for family caregivers are appropriate and applicable for online training programs aimed to improve the knowledge and abilities of caregivers in providing self-care and care for older adults with dementia.

Keywords: Caregiving, Dementia, Older adult, Family caregiver, Module development, Online training.

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1. INTRODUCTION

Caring for older adults with dementia positively and negatively impacts family caregivers [1]. In 2016, it was estimated that there were 1.2 million caregivers for older adults with dementia in Indonesia; this number is projected to increase to 2 million in 2030 and 4 million by 2050 [2]. Cognitive function loss, neuropsychological symptoms, and functional impairment in older adults with

dementia can trigger emotional stress, physical exhaustion, social isolation, and financial burden that contribute to the reduced physical and mental health of family caregivers [3-5]. Caring for older adults with dementia can have positive impacts if the caregivers feel valuable and satisfied with their caregiving role, there is a loving relationship between the caregivers and the person they care for, and the needs of the family caregivers are met [6].

Caregivers of older adults with dementia require long-term assistance due to their increased dependence on daily activities, making family caregivers a vulnerable group to the effects of caregiving. Family caregivers who provide care to older adults with dementia without adequate preparation and lack the necessary knowledge and skills to handle dementia-related situations may result in negative consequences and low caregiving quality. Additionally, family caregivers often face difficulties planning for future care needs [7, 8]. Caring for older adults with dementia is a unique form of care, requiring specific needs, such as knowledge, skills, self-efficacy, training, and adequate social support to provide quality care and increase confidence and competence among family caregivers [5, 9-12]. This highlights the importance of interventions to support family caregivers in providing care to older adults with dementia at home. Family caregivers must have the basic knowledge and skills to provide quality care to older adults with dementia.

Family caregivers have limited access to educational resources, resulting in a lack of knowledge and caregiving skills. Most information on dementia care is provided in English [13]. Research in Indonesia indicates that family caregivers are still limited in their knowledge and caregiving skills when caring for older adults with dementia, hindering their ability to provide quality care [8]. Thus, online training would be an essential tool for caregivers to aid older adults with dementia [14]. Currently, no Indonesian language training modules meet the needs of family caregivers of older adults with dementia in Indonesia. This study aimed to develop online training modules on dementia care at home for family caregivers.

2. METHODS

This study developed the modules using the Sidek Module Development Model (SMDM) (2005), a comprehensive model for developing high-quality modules. Under this approach, the module development consisted of two phases, each with specific objectives.

2.1. The First Phase was Developing the Module Draft, Encompassing Nine Steps [15] as Follows

2.1.1. First Step: Setting up the Goals

This step included explaining the goals and targets of the module development. This module aims to enhance family caregivers' knowledge and skills in caring for older adults with dementia and self-care to improve the quality of care, reduce caregiver burden,

enhance cognitive function in older adults, and decrease mistreatment of older adults with dementia [15-17].

2.1.2. Step 2: Identifying related Theories, Reasons, Philosophies, Concepts, Targets, and required Duration

This step included a literature review. Specific target groups and the timing of module implementation were precisely determined to ensure appropriate and accurate module development.

2.1.3. Step 3: Need Analysis

A need analysis was conducted among the target group committed to using the developed modules. In-depth interviews with 15 family caregivers were conducted by RHW [primary researcher trained in qualitative research] to explore the challenges faced by caregivers in caring for older adults with dementia, their needs in providing care and self-care, and strategies to meet those needs. We used purposive sampling to recruit participants from Central Java Province. The inclusion criteria included family caregivers who had familial ties with older adults with dementia, resided in the same household, provided care for over four hours weekly spanning more than six months, and engaged in daily companionship activities. Trust relationships were established with all participants before conducting the study, and their consent was obtained. Participants were informed of the research objectives, and their confidentiality was assured. After obtaining consent, the interviews were carried out using the pre-determined interview guides. The interviews began with open-ended questions and lasted between 45 to 60 minutes.

All interviews were conducted in Bahasa Indonesia and audiotaped with permission from the participants. The recordings were transcribed by RHW, and the transcripts were subsequently coded and analyzed by RHW, JS, and ER. The Collaizi method [18] was employed to analyze the data qualitatively. The Collaizi method examines the transcript once more, selecting important quotes related to the phenomenon; determines the significance of important statements; combines constructed meanings to create themes and theme clusters creates a thorough explanation of the fundamental elements or structure of the phenomena; after that, a description of the phenomenon's basic structure is produced; and the analysis is finished with participant input being used to validate the study's findings. Furthermore, the trust-worthiness of the data was also ensured, including reliability, dependability, confirmability, and transfer-ability. To ensure the credibility of this research, participants were asked to review the research results. Dependability was ensured by transparently documenting every research step taken from the beginning of the research to the development and reporting of findings. Records of the research path were kept throughout the study for five years. Confirmability was done by presenting

the research results to all members of the research team to ensure that there was no bias in analyzing the data. All research members approved the results of the study. Transferability is achieved by presenting and explaining all research findings in a narrative so that readers can easily and clearly understand the results of the research and can apply the research results elsewhere [19].

2.1.4. Step 4: Setting Objectives for Each Module

The objectives for each module were determined based on the needs analysis in Step 3. These objectives were made realistic and measurable, including the targets, knowledge, skills, attitudes to be achieved, and the required timeframe. The objectives were also observable and measurable.

2.1.5. Step 5: Selecting Module Contents

This step was conducted by identifying module contents required by family caregivers based on the needs analysis results in Step 3.

2.1.6. Step 6: Choosing Strategies for Implementing the Modules

In this step, strategies were identified to ensure the implementation of the modules in line with the needs analysis in Step 3.

2.1.7. Step 7: Selecting Logistics

A list of module materials, such as images/figures to clarify module contents, was created to facilitate module implementation.

2.1.8. Step 8: Choosing Media

This was achieved by choosing media that engage, stimulate, and motivate participants to understand the operational aspects of the modules, specifically in the form of e-modules.

2.1.9. Step 9: Drafting the Module

After completing all steps, the module drafts were prepared based on the results from Steps 1 to 8.

2.2. Phase 2 Involved Module Testing and Evaluation. The Module Drafts were Piloted to Assess their Validity and Reliability, Encompassing the Following Steps

2.2.1. Step 1: Conducting a Pilot Study to Evaluate the Module

A pilot study was conducted among family caregivers who met the same inclusion criteria and resided in circumstances similar to those in the primary study. However, these participants were not included in the main study. The pilot study assessed module readability by testing language appropriateness and level, identifying potential grammatical errors, and evaluating the relevance of module contents to the needs of family caregivers [15-17].

2.2.2. Step 2: Assessment of Content Validity and Reliability of the Modules

In this study, two steps were undertaken to evaluate validity and reliability. Step 1 involved three experts in geriatric care specializing in dementia in Indonesia: a geriatrician, a geriatric nurse, and a nursing lecturer. In Step 2, the reliability of the modules was assessed among family caregivers of older adults with dementia in the pilot study. The results of content validity are presented in Table.

2.3. Ethical Considerations

The ethical approval of this study was obtained from the Human Ethics Committee of the Faculty of Nursing, Universitas Indonesia, Indonesia [approval number #KET-132/UN2.F12.D1.2.1/PPM.00.02/ 2022]. The purpose of the study was communicated to the participants and they were contacted based on pre-arranged criteria. As a result, after obtaining the participant's consent, information about the purpose, methods, inconveniences, harms, advantages, and expectations of the study was provided in the content.

Table 1. Overview of online training modules for dementia care at home for family caregivers.

Themes	Sub-themes	Modules and Sub-topics
Family caregivers' perceptions of dementia	- Dementia is a disease of the aging process.	Module 1: Aging process in older adults Subtopics: - Impact of aging on various bodily systems - Types of diseases resulting from the aging process
	- Dementia is caused by contributing factors (Parkinson's, stroke, stress, loneliness)	Module 2: Dementia and its impacts Subtopics: - Definition of dementia - Brain function changes in older adults with dementia - Types of dementia - Stages of dementia - Impacts of dementia

(Table 1) contd.....

Themes	Sub-themes	Modules and Sub-topics
Communication issues with older adults with dementia	- Barriers to communication with older adults with dementia	Module 3: Communication adapted to the older adults' conditions Subtopics: - Communication concepts - Ways to communicate with older adults with dementia
Problems experienced by older adults due to dementia	- Daily activity impairments in older adults with dementia	Module 4: Problem management in older adults with dementia Subtopics: - Daily activity impairments in older adults with dementia and their management - Physical problems in older adults with dementia and their management - Behavioral and psychological symptoms of dementia and their management
Problems experienced by older adults due to dementia	- Physical problems in older adults with dementia	Module 4: Problem management in older adults with dementia Subtopics: - Daily activity impairments in older adults with dementia and their management - Physical problems in older adults with dementia and their management - Behavioral and psychological symptoms of dementia and their management
Problems experienced by older adults due to dementia	- Behavioral and psychological symptoms of dementia	Module 4: Problem management in older adults with dementia Subtopics: - Daily activity impairments in older adults with dementia and their management - Physical problems in older adults with dementia and their management - Behavioral and psychological symptoms of dementia and their management
Older adults' needs related to dementia.	- Physiological needs of older adults with dementia	Module 4: Problem management in older adults with dementia Subtopics: - Daily activity impairments in older adults with dementia and their management - Physical problems in older adults with dementia and their management - Behavioral and psychological symptoms of dementia and their management
Older adults' needs related to dementia.	- Non-physiological needs of older adults with dementia (psychological, recreational, spiritual, and social needs)	Module 4: Problem management in older adults with dementia Subtopics: - Daily activity impairments in older adults with dementia and their management - Physical problems in older adults with dementia and their management - Behavioral and psychological symptoms of dementia and their management
Family caregivers' efforts for older adults with dementia	- Fulfillment of psychological, recreational, spiritual, and social needs	Module 4: Problem management in older adults with dementia Subtopics: - Daily activity impairments in older adults with dementia and their management - Physical problems in older adults with dementia and their management - Behavioral and psychological symptoms of dementia and their management
Family caregivers' efforts for older adults with dementia	- Fulfillment of health needs	Module 4: Problem management in older adults with dementia Subtopics: - Daily activity impairments in older adults with dementia and their management - Physical problems in older adults with dementia and their management - Behavioral and psychological symptoms of dementia and their management
Family caregivers' efforts for older adults with dementia	- Fulfillment of physical needs	Module 4: Problem management in older adults with dementia Subtopics: - Daily activity impairments in older adults with dementia and their management - Physical problems in older adults with dementia and their management - Behavioral and psychological symptoms of dementia and their management
The meaning of caring for older adults with dementia	- Duty to care for older adults	Module 5: Becoming Resilient Family Caregivers Subtopics: - Resilient dementia caregivers - Family caregivers' resilience - Interventions enhancing resilience through spiritual mindfulness
The meaning of caring for older adults with dementia	- Filial duty	Module 5: Becoming Resilient Family Caregivers Subtopics: - Resilient dementia caregivers - Family caregivers' resilience - Interventions enhancing resilience through spiritual mindfulness
The meaning of caring for older adults with dementia	- Spiritual meaning in caring for older adults	Module 5: Becoming Resilient Family Caregivers Subtopics: - Resilient dementia caregivers - Family caregivers' resilience - Interventions enhancing resilience through spiritual mindfulness
Acceptance process in playing the role of caregivers for older adults with dementia	- Denial	Module 5: Becoming Resilient Family Caregivers Subtopics: - Resilient dementia caregivers - Family caregivers' resilience - Interventions enhancing resilience through spiritual mindfulness
Acceptance process in playing the role of caregivers for older adults with dementia	- Depression	Module 5: Becoming Resilient Family Caregivers Subtopics: - Resilient dementia caregivers - Family caregivers' resilience - Interventions enhancing resilience through spiritual mindfulness
Acceptance process in playing the role of caregivers for older adults with dementia	- Acceptance	Module 5: Becoming Resilient Family Caregivers Subtopics: - Resilient dementia caregivers - Family caregivers' resilience - Interventions enhancing resilience through spiritual mindfulness
Family caregivers' hopes for themselves	- Characteristics of Resilient Caregivers	Module 5: Becoming Resilient Family Caregivers Subtopics: - Resilient dementia caregivers - Family caregivers' resilience - Interventions enhancing resilience through spiritual mindfulness
Problems experienced by family caregivers while caring for older adults with dementia	- Family caregiver burden in caring for older adults with dementia	Module 6: Management of problems arising in family caregivers Subtopics: - Family caregiver burden - Factors causing family caregiver burden - Stress management
Family caregivers' efforts for self-care while caring for older adults with dementia	- Stress management	Module 6: Management of problems arising in family caregivers Subtopics: - Family caregiver burden - Factors causing family caregiver burden - Stress management
Support received by family caregivers while caring for older adults with dementia	- Supports from fellow caregivers	Module 7: Self-Help Group Subtopics: - Concepts of self-help group concepts - Ways to conduct self-help groups

3. RESULTS

A total of 15 family caregivers were recruited for in-depth interviews in Phase 1 of Step 3, aiming to assess the caregivers' needs related to self-care and care for older adults with dementia. The topics covered in the training modules in Phase 3 are presented in Table **1**.

Based on the need analysis that is shown on Table **1**, there are seven modules the caregivers' needs related to self-care and care for older adults with dementia. Those are: module 1 (Aging process in older adults); module 2 (Dementia and its impacts); module 3 (Communication adapted to the older adults' conditions; module 4 (Problem management in older adults with dementia); module 5 (Becoming Resilient Family Caregivers); module 6 (Management of problems arising in family caregivers); and module 7 (Self-Help Group).

In the second phase, the modules were piloted and evaluated. This project involved 15 family caregivers and three experts in geriatrics, including a geriatrician, a geriatric nurse, and a lecturer of geriatric nursing. Content validity results and expert review of dementia care training modules for family caregivers are presented in Table **2**.

Table 2. Content validity and expert evaluation of the developed modules on dementia care at home for family caregivers.

No.	Statements	Content Validity (%)	Expert Assessment
1	The dementia care training modules for family caregivers meet the required components of dementia care.	92.07	Agreed
2	The dementia care training modules for family caregivers are suitable for the target population, namely caregivers of older adults with dementia.	90.73	Agreed
3	The contents of the dementia care training modules for family caregivers can be effectively implemented/practiced.	93.10	Agreed
4	The contents of the dementia care training modules for family caregivers meet the required needs.	93.40	Agreed
5	The contents of the dementia care training modules for family caregivers can enhance knowledge and skills to improve the quality of care for older adults with dementia.	94.73	Agreed

No.	Statements	Content Validity (%)	Expert Assessment
6	The contents of the dementia care training modules for family caregivers educate participants on more beneficial ways of thinking	92.73	Agreed
-	Overall score	92.79	Accepted

Table **2** shows that the overall content validity score is 92.79%, with content validity scores ranging from 90.73% to 94.73% across the various aspects of validity.

4. DISCUSSION

The researchers used the Sidek module develop-ment model due to its integrated and comprehensive nature with specific and systematic steps in developing a module and testing its validity and reliability [15,17,20]. This design also emphasizes pilot studies to identify the strengths and weaknesses of the module. Pilot studies provide information regar-ding the module quality, such as content alignment, activity suitability, language appropriateness and level, and grammar. The overall insights gained during the pilot study contribute to the development of the module itself [15, 16]. Other studies also employed the Sidek model in module development, such as mindfulness modules [21], counseling modules [20], and holistic learning guidance modules [22], all of which show promising results. However, these modules should be administered by professional nurses trained in dementia care to enhance the well-being of family caregivers and optimize their effectiveness.

The results of this study showed an overall content validity score of 92.79%. This score is considered high, above the recommended threshold of 70% [20]. In addition, the content validity scores based on each validity aspect ranged from 90.73% to 94.73%. Therefore, the content validity scores of each dementia care training module for family caregivers are highly validated, indicating high overall content validity. Hence, these modules can be delivered to the target population, namely family caregivers of older adults with dementia. Since the modules have achieved high content validity and reliability, they are expected to assist the targeted population of family caregivers in enhancing self-care and care for older adults with dementia.

Needs-based processes using qualitative approach conducted through in-depth interviews help develop module contents that are needs-based, valid, and culturally appropriate. Family caregivers caring for older adults with dementia in Indonesia have faced significant barriers to caring for older adults with dementia. Research highlights a lack of knowledge and skills regarding the care of older adults with dementia. Previous qualitative research in Indonesia has shown inadequate knowledge and skills of family caregivers in caring for older adults with dementia. Family caregi-vers viewed dementia as a natural part of aging, leading to delayed access to healthcare services [8]. The needs analysis from this study indicated that topics related to the process of aging, dementia, and its impacts are required by family caregivers to develop the understanding that dementia is an illness process and not a normal part of aging.

In this paper, we report that tips on communication in older adults with dementia will also be included in the module. The results of the systematic review that has been carried out show that increasing the knowledge, attitudes and skills of family caregivers in communicating with older adults with dementia can increase the understanding of family caregivers of the condition of the elderly, provide instructions that can be understood by the older adults with dementia and overcome behavioral symptoms in the older adults with dementia. Good communication between family caregivers and older adults with dementia can also improve caregiving readiness, self-efficacy, positive aspects of caregiving, confidence in communicating with older adults with dementia, higher respect and empathy for older adults with dementia, and increased ease of caregiving [23].

The strength of this study is that it is the first in-depth qualitative investigation to identify Becoming Resilient Family Caregivers in caring for older adults with dementia. The results showed that the theme the meaning of caring for older adults with dementia; the acceptance process in undergoing the role of caregiver of older adults with dementia; and family caregivers' expectations of themselves about the characteristics of resilient caregivers became the basis for developing the module topic on Becoming a Resilient Family Carer. Walsh describes an adaptation model of family resilience that includes making meaning out of adversity, having a positive outlook, flexibility, and connectedness to each other and the community [24]. Considering these facts, there is a need to develop modules that incorporate evidence-based strategies to improve the quality of care by family caregivers in caring for older adults with dementia and performing self-care holistically.

CONCLUSION

The study findings suggest that online training modules on dementia care at home for family caregivers are valid and reliable for caring for older adults with dementia. From both theoretical and practical perspectives, these research findings will have important implications for dementia care at home.

ABBREVIATION

SMDM = Sidek Module Development Model

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The ethical approval of this study was obtained from the Human Ethics Committee of the Faculty of Nursing, Universitas Indonesia, Indonesia (approval number #KET-132/UN2.F12.D1.2.1/PPM.00.02/ 2022).

HUMAN AND ANIMAL RIGHTS

All human research procedures are followed in accordance with the ethical standards of the committee responsible for human experimentation [institutional and national] and with the Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

Informed consent was obtained from all participants.

STANDARDS OF REPORTING

STROBE guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The data used to support the findings of this study are included in the article and may also be obtained from the appropriate author [J.S] upon request.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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