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Review

Challenges of conducting of online educational programs for family caregivers of people with dementia living at home: An integrative review

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ABSTRACT

Objectives: This integrative review aimed to understand the challenges of conducting online educational programs for family caregivers of people with dementia by focusing on the components and design of them.

Methods: Following Whittemore & Knafl's five-step method, seven databases were systematically searched. The Mixed Methods Appraisal Tool was used to evaluate the quality of the studies.

Results: Of the 25,256 articles identified, 49 studies were included. Limitations in components (including useless or repetitive information, incomplete access to dementia-related information, the impact of components related to culture or ethnicity or gender) and in the format of delivered information (including less interaction, time schedule limitations and preference for traditional forms of delivery of information) make it more challenging to conduct online educational programs. Additionally, implementation constraints such as technical problems, poor computer literacy, and fidelity assessment are challenges that cannot be ignored.

Conclusions: Insight into the challenges of online educational programs for family caregivers of people with dementia can help guide researchers in constructing the optimal online educational program. Incorporating cultural specificity, considering structured construction strategies, optimizing interaction design, and increasing fidelity assessment may contribute to the conduct of online educational programs.

What is known?

- Educational programs for family caregivers of people with dementia are now shifting to an online model. Most studies have emphasized the effectiveness of online educational programs for family caregivers, but it was difficult to determine the optimal online educational program as it was diverse in components and designs.

What is new?

- The results of this review describe the challenges of conducting online educational programs for family caregivers of people with dementia in terms of components, formats, and implementation.
- It is recommended that online educational programs should reflect the culture in their component settings. Standardization-based strategies should be considered in the construction and implementation of online educational programs.

1. Introduction

Dementia is a progressive syndrome involving cognitive deterioration and decline in activities of daily living [1]. The number of people with dementia (PwD) is gradually increasing because of the aging population in China. It was reported that the age-

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standardized prevalence of dementia increased by 5.6% from 1990 to 2016, and the annual total cost of dementia was estimated to reach $1.89 trillion by 2050 in China [2,3]. Caring for PwD is considered as one of the most stressful forms of caring, because it is difficult to manage the behavioral and psychological symptoms of dementia. Thus, the caregiving process generates distress and threatens the quality of life of PwD's caregivers [4,5].

Family-supported home care is the main choice for PwD. Alzheimer's Disease International (ADI) reported that an estimated 95% of PwD lived at home in low and middle-income countries [6]. Family caregivers (also called informal caregivers) refer to spouses, children and children-in-law who care for PwD based on emotional bonds [7]. It is difficult for family caregivers to adapt and cope with changes in memory and behaviors of PwD (e.g., memory loss, delusions, repetitive behaviors and personality changes). They face many challenges, such as misunderstanding of behaviors and conflicts in communication, due to a lack of preparation for dementia care [4,8–10]. Thus, family caregivers are likely to experience depression, anxiety and sleep disturbances during long-term care [11,12].

Some research suggested that educational programs are effective in increasing the knowledge level and coping skills of dementia, as well as in reducing caregivers' burden, depression and stress [13,14]. WHO advocated supporting caregivers of PwD by providing evidence-based training programs as a global plan for dementia [15]. With the development of e-health, online educational programs transcend geographical limitations and expand the dissemination of educational resources to rural and urban communities [16,17]. These online educational programs are flexible and convenient for family caregivers who have difficulty leaving PwD alone at home.

Currently, most reviews laid emphasis on the effectiveness of online interventions for mental health (e.g., depression, anxiety, stress) [18–21]. Different online interventions have either positive or negative effects on family caregivers in terms of burden, stress and anxiety, which may result from various components and designs of those online interventions [18,22]. Due to the diversity of online interventions, it may be difficult for systematic reviews to specifically determine the optimal online education program for family caregivers of PwD. In addition, to some extent, certain compositional and design factors may influence the effectiveness of online educational programs. However, few studies have reported on the challenges posed by the composition and design of online education programs to their implementation. Moreover, the inclusion of only randomized controlled studies (RCT) has limitations on the synthesis of existing online interventions in most reviews. There are many other types of studies published in the online educational intervention besides RCT. They are part of the evidence system and are beneficial for analyzing the components of online educational programs. An integrative review is an approach to synthesizing existing literature, giving a full understanding of the phenomenon [23]. The method was selected because it allows for combining diverse methodologies (experimental and non-experimental studies) and a broad understanding of research problems.

Overall, given the diversity of the components and design of online educational programs, understanding their challenges facilitates providing evidence for developing more effective online training interventions. Then, other types of literature besides RCT can be useful to fully understand online educational programs. Therefore, the objective of this integrative review was to explore the challenges of conducting online educational programs in terms of their components and designs for family caregivers of PwD.

2. Methods

2.1. Design

Following Whittemore & Knafl's method, the integrative review was conducted in five steps: problem identification, literature search, data evaluation, data analysis, and presentation [23]. This review followed the PRISMA 2020 guidelines [24] and had been registered on PROSPERO (registration number: CRD42021230389).

2.2. Problem identification

The problem is identified: What are the challenges of conducting online educational programs for family caregivers of PwD in terms of the components and design of the programs?

2.3. Literature search

Literature meeting the following criteria were included: (a) participants were family caregivers of PwD who provide unpaid care, such as spouses, relatives, and friends, (b) educational programs were structurally delivering information and skills through online approaches, such as e-learning courses and web-based intervention. Exclusion criteria were: (a) editorials, trial registration materials, technical notes, and secondary studies, (b) articles that only described the development process of an application content without the evaluation of the program effects, and (c) articles written in languages other than English. Multiple electronic databases were used to search relevant literature, including PubMed, Web of Science, Embase, CINAHL, Cochrane Library, PsycINFO and Education Resources Information Centre. We retrieved the literature from the inception of the database to July 2022.

The keywords were related to dementia, family caregivers as well as online educational program. The search strategies are (dementia OR Alzheimer's disease OR "cognit* impair*") AND (family caregivers OR informal caregivers OR carer* OR caretaker* OR relative* OR spouse) AND (online OR web OR internet OR technology OR telephone OR e-health OR e-learning OR application OR electronic OR telecomputing) AND (education OR training OR intervention OR learning OR program OR support OR therap* OR course OR curriculum OR evaluation). Additional literature was identified through the references of included studies. An E-alert of each database was established to track the newly published studies. The literature was screened by two authors (Y. W. and Y. X.) independently. If there was a doubt, the third author (Y. D.) was consulted. Fig. 1 shows the literature screening process.

2.4. Quality appraisal

Given there was no restriction on the types of studies included in this review, the Mixed Methods Appraisal Tool (MMAT, 2018 version) was used to evaluate five different types of study designs (qualitative studies, RCT, non-randomized studies, quantitative descriptive studies, and mixed methods studies). MMAT included two screening questions and 25 criteria, 5 criteria for each type of study design. All included studies passed the two screening questions that determined whether the study was appropriate for assessment with MMAT. Each criterion was rated as "yes," "no," or "can't tell" [25]. The assessment results according to each criterion would be assigned * to represent the quality of each study. The tool measured the quality of studies in terms of study design, data collection, data integrity, confounding factors, and interpretation of results. Two authors (Y. X. and W. X.) independently performed the quality assessment. If there was a discrepancy, a discussion was made with the author (Y. W.).

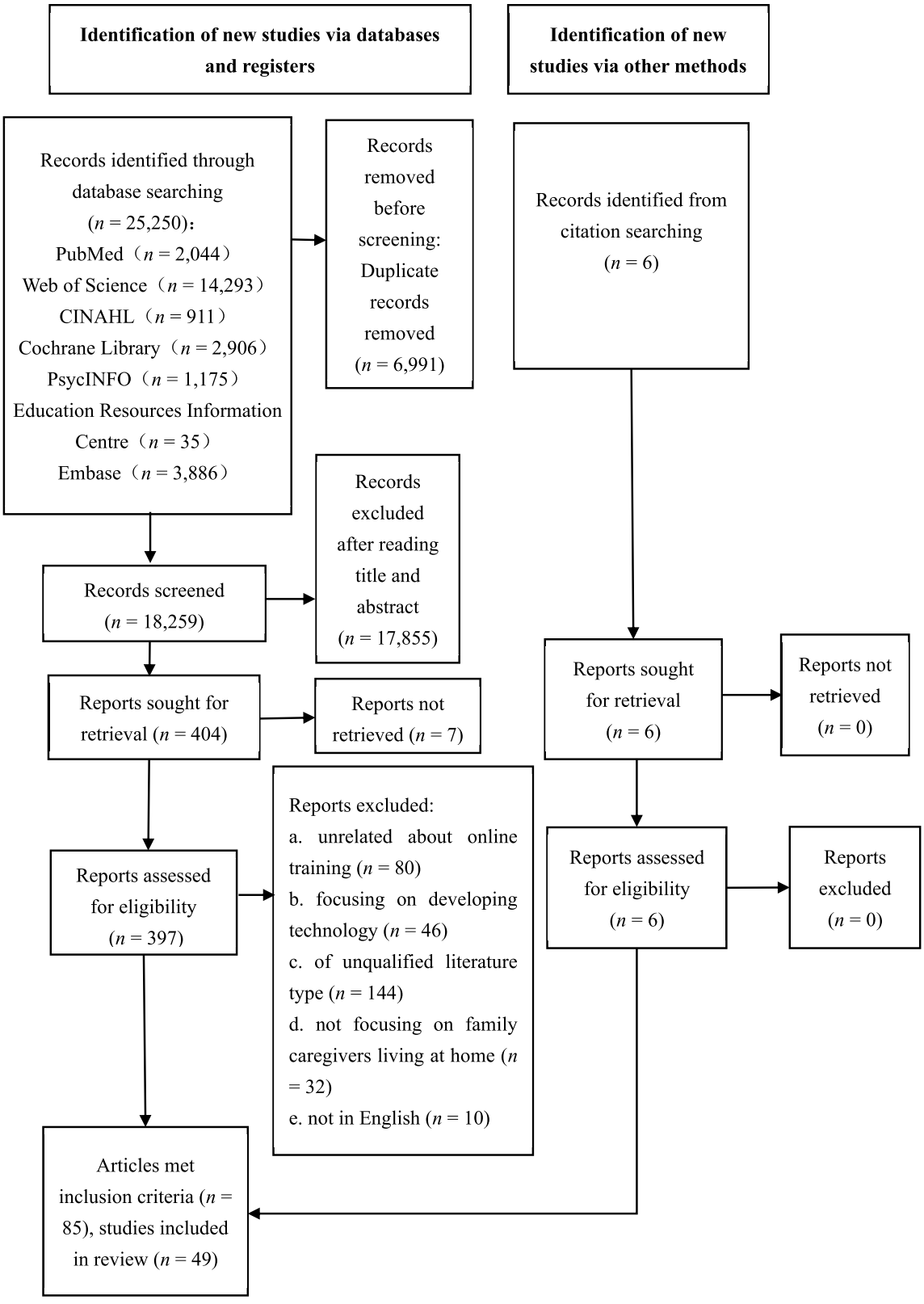

Fig. 1. Flow diagram of literature search.

2.5. Data analysis

The data of quantitative and qualitative studies were extracted and synthesized in the same way following a data-based convergent synthesis design [26]. Qualitative data were analyzed and integrated through content analysis. Quantitative data were also synthesized because the review focused on intervention components. Template for the Intervention Description and

Replication – the telehealth intervention guideline (TIDieR-telehealth) was developed to allow information on telehealth interventions to be fully considered and described in the systematic review. In this review, the TIDieR-telehealth checklist was used to standardize the components and design of online educational programs for further classification and comparison [27]. Extracted data included first author, publication year, country, study design, participants and samples, intervention description (components, format and fidelity analysis), outcomes, major findings and barriers. Two authors (Y. W. and Y. X.) performed data extraction and data synthesis independently. If there were disagreements, the results were determined by the third author (Y. D.) after discussion.

3. Results

3.1. Characteristics of the included studies

Eighty-five papers covering 49 studies were included (some studies were demonstrated in a series of papers). The included studies consisted of 19 RCTs [28–46], 10 non-RCTs [47–56], 4 descriptive quantitative studies [57–60], 4 qualitative studies [61–64] and 12 mixed-methods studies [65–76], see Appendix A. These studies were conducted in America ($n = 25$), Netherlands ($n = 4$), Canada ($n = 2$), France ($n = 1$), India ($n = 1$), China ($n = 1$), Australia ($n = 3$), United Kingdom ($n = 2$), Spain ($n = 1$), Greece ($n = 1$), Ireland ($n = 1$), Korea ($n = 1$), Iran ($n = 1$) and multiple European countries ($n = 5$).

One study included caregivers of people with early dementia [30]; one study only included spouse caregivers for moderate-to-severe dementia [45]; one involved family caregivers for people with young-onset Alzheimer's disease or frontotemporal degeneration [73]. Participants were limited to male caregivers of PwD in one study [34]. Other studies addressed family caregivers of PwD as participants.

The quality of the included studies was various. Randomization was not clearly performed in 9 RCTs. More than 5% of participants in 25 RCTs and non-RCTs did not consistently complete the online training, but only nine of these studies conducted intentional analyses of missing values. In 4 non-RCTs, potential confounding factors such as the severity of dementia in PwD and length of care by family caregivers may have influenced their results. In the qualitative studies, one study did not report the analysis methods and result interpretation. Regarding the mixed study, the correlation between quantitative and qualitative results was barely explained in six studies.

3.2. Challenges related to components of online educational programs

Although the online educational programs offered in the included studies varied in terms of content, 7 types of components can be identified, namely, facts of dementia, caregiving strategies, management of behavioral and psychological symptoms of dementia, caring for daily living activities, safety at home, family caregivers' self-care, as well as seeking social support. Some studies have found challenges with the current delivery of content through qualitative interviews or follow-up assessments. A total of three studies mentioned the presence of useless or repetitive information in online education programs [43,47,70]. Seven studies pointed out that family caregivers have limited access to dementia-related information. Family caregivers desired more detailed information, such as stage-specific dementia information, attention to more difficult behaviors and complex issues, end-of-life planning and local resource [46,49,67,69,73,74]. Five studies perceived that more culturally, ethnically, or gender-related components may influence the delivery of online educational programs [28,34,39,54,76]. Even so, the results showed that 4 studies explored the impact of online educational programs on family caregivers' knowledge relating to dementia [35,47,50,67], with 3 of them finding positive improvements.

3.3. Challenges related to the format of delivering information

The online educational programs for family caregivers of PwD were mainly run in the form of online modules (including video or text-based materials, online discussion groups, sitcoms, and audio formats), interactive modules and personalized support modules. The results found little interaction among family caregivers and a lack of opportunities to interact with professionals in the interactive modules [30,35,39,58,59,63,67,69,70,74]. In addition, some family caregivers did not have time to participate in online education programs whether synchronous or self-help delivery forms [57,68,70,73]. Some other family caregivers preferred paper-based materials or in-person contact [68,70,73]. Unfortunately, the one-on-one delivery format was difficult to implement widely [57]. Only 6 of 24 studies found improvements in burden from online educational programs, and these 6 studies were rich in interactive modules, such as caregiver communities, discussion groups, interaction with instructors, and supervisor reminders [32,41,48,51,53,76].

3.4. Challenges related to implementation of online educational programs

Five major challenges related to the implementation were identified in this study, including technical problems, poor computer literacy, information storage and management, high dropout rates, and fidelity assessment. First, technical problems were identified in 9 studies, such as busy signals, visual problems caused by poor contact and unclear site navigation [31,36,43,47,63,69,71,72,75]. Second, poor computer literacy of family caregivers was also a barrier to program implementation [38,65,68,69]. Online programs are more flexible to use for young family caregivers with internet access. Thirdly, storing, managing and updating information on the online platform was a major challenge [36,49,62,74]. For example, the WeChat software used in the Han et al.'s study was unable to store files for long periods of time [49]. One study proposed that the inaccessibility or unavailability of some resources during the COVID-19 epidemic was also a limitation to implementing the intervention [65]. Fourth, low family caregiver recruitment rates and high dropout rates were also commonly found [28,30,33,35,39,51]. Eighteen studies tracked those who did not complete online educational programs for various reasons, which included lack of interest or time, illness or death of the elderly, and lack of technology [29–31,34–36,39,43,46,50,51,53,55–57,66,68,76]. Fifth, we discovered that fidelity assessment was rare in studies. Only 3 experimental studies noted the fidelity assessment of the program [36,45,72]. Loi used a standard checklist to develop fidelity assessments for each aspect of the program [72]. Other studies mentioned only some measures to improve or maintain fidelity, such as supervision during the intervention and training of implementers or participants prior to the intervention. Most studies did not describe the specific process of implementing and assessing fidelity in detail.

4. Discussion

The integrative review identified the challenges of conducting online educational programs for family caregivers of PwD. Forty-

nine studies were included through a comprehensive and systematic literature search. In general, most of these online educational programs were delivered in western countries. The findings of this review revealed online educational programs' challenges related to components (useless or repetitive information, incomplete access to dementia-related information, and impact of components related to culture, ethnicity or gender), formats (less interaction, time schedule limitations and preference for traditional forms of information delivery), as well as implementation (technical problems, poor computer literary, and fidelity assessment).

It was worth noting that non-personalized components were found in some programs. This further prompts the supplier to clarify the information needs of family caregivers. Most studies recommend segmenting family caregivers' information needs in line with the severity of dementia and providing the appropriate components [77–79]. However, family caregivers' personality styles and culturally different understanding of dementia may affect family caregivers' needs even when caring for people with dementia at the same stage of the disease [80]. In addition, developing components required consideration of gender. Male caregivers tend to prefer problem-solving-focused strategies over emotion-focused strategies [67,81]. Moreover, family caregivers of PwD in China prefer problem-focused coping strategies in the early or controllable stages of the disease [82]. We propose the development of online training programs should consider characteristics of traditional Chinese culture and consist of view teaching problem-solving strategies as the main focus and emotion-focused strategies as a supplement.

Moreover, the composition of an online educational program was diverse. Most of the studies only evaluated the program as a whole and were unable to determine the effects of different components on mental health. The Multiphase Optimization Strategy (MOST) was used to build, optimize, and evaluate e-health interventions to determine which components of the intervention were effective [80]. The MOST method can be considered to establish multi-component online education programs.

Interactivity is one of the important features of online training and is a good way to obtain personalized support. The review discovered that peer interaction was delivered in half of the studies and was considered as a credible online component in other studies [83]. In addition, setting up rich interactions seems to improve the burden on family caregivers. However, family caregivers may be reluctant to publicly disclose and browse distressing experiences, resulting in low utilization of components related to peer interaction. To better serve diverse preferences, it may be a feasible option to allow family caregivers to share information anonymously and hide this component at their discretion. Professional consultation and guidance are also expected by family caregivers, who may have access to tailored information in the process of contact [84]. While family caregivers have great trust in the information provided by health professionals, their time and energy may be limited, and long-term and extensive one-on-one support services will be difficult to maintain. Therefore, the ability of online platforms to store information can be utilized. Information such as expert advice texts and lecture videos were stored so that family caregivers could read and watch them at any time [85]. However, some family caregivers seem to prefer paper-based materials to face-to-face counseling and education [68]. A learning module that combines video and written materials may appeal to more family caregivers.

This review detected less assessment of online education programs regarding fidelity in practice. Accurate assessment of fidelity can promote replicability and internal validity of studies [86,87]. With the emphasis on translating evidence into practice, fidelity assessments can provide reliable decisions for studies to be conducted in real practice settings based on the protocol standards [88]. High dropout rates were found in this review and similarly in other studies [85,89]. A comprehensive assessment of fidelity, rather than being limited to monitoring adherence, has the potential to clarify and analyze the in-depth reasons for high dropout rates in the implementation of online educational programs. As a result, it was suggested that the implementation fidelity assessment framework proposed by Carroll et al. [90] and the 6 guidelines for fidelity assessment proposed by Ginsburg et al. [91] could be employed to improve the quality of the programs.

5. Conclusion

The purpose of this integrative review is to analyze the challenges of conducting online educational programs for family caregivers of PwD from the perspective of the components and design. This review summarized the following three conclusions. First, cultural differences may affect the understanding of education related to dementia care. This is why it is important to develop culturally specific online education. Second, standardized, structured-based strategies can be considered for use when structuring online educational programs in order to analyze the effectiveness of the various components. Third, the interactivity should be dynamic, and the activities should take into account the family caregiver's preferences. Fourth, future studies should focus on using fidelity assessment models to conduct comprehensive fidelity assessments of programs and develop fidelity enhancement strategies. To further improve the quality of future studies, it is suggested that further improvements be made in the areas of randomization and blinding, handling of missing data, and reporting of quantitative and qualitative data integration.

6. Implications

During the COVID-19 pandemic, it is a new challenge for family caregivers to manage PwD confined to the home [92]. The advantages of online intervention are highlighted during this period. This is because the construction of an online educational program points the way for later empirical research to improve the health status of family caregivers and PwD. The popularity of the Internet is an indispensable element for the implementation of online educational programs. Users of online medical services in China have reached 215 million, and the proportion of Internet users aged 50 and above had increased to 26.3% by December 2020 based on the 47th China Statistical Report on Internet Development [93]. This provides an opportunity for the promotion of the online training and education program. Moreover, future research needs to take into account the electronic literacy and information needs of family caregivers, and explore how long educational interventions achieve significant learning outcomes among family caregivers.

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CRediT authorship contribution statement

Yuting Wen: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing. **Yurong Xing:** Conceptualization, Methodology, Formal analysis, Investigation, Resources, Writing - review & editing, Visualization. **Yaping Ding:** Conceptualization, Methodology, Validation, Resources, Data curation, Supervision, Writing - review & editing. **Wenhui Xu:** Methodology, Software, Formal analysis,

Investigation, Visualization, Writing - review & editing. **Xiaoxiao Wang:** Methodology, Software, Validation, Visualization, Investigation, Resources, Writing - review & editing.

Declaration of competing interest

All authors state that there is no conflict of interest.

Data availability statement

The datasets used and analyzed during the current study are available from the corresponding author upon reasonable request.

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Appendices. Supplementary data

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