

Internet-Based Supportive Interventions for Family Caregivers of People With Dementia: A Randomized Controlled Trial

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Abstract

Background: As dementia progresses, patients exhibit various psychological and behavioural symptoms, imposing a significant burden on families and society including Behavioural and psychological symptoms of dementia (BPSD). However, caregivers lack professional care knowledge and skills, making it difficult for them to effectively cope with the diverse challenges of caregiving. Therefore, it is urgent to provide caregivers with professional knowledge and skills guidance.

Objective: Aim: The present study aimed to analyze the impact of Internet-based Online Training on behavioral and psychological symptoms of dementia (BPSD) in patients, and exploring how this training model affects the caregiving abilities and caregiving burden of family caregivers for dementia patients.

Methods: Using a consecutive enrollment method, the Department of Geriatrics at Zhejiang Hospital (Zhejiang, China) recruited 72 informal caregivers of dementia patients. These caregivers were randomly divided into an intervention group and a control group, with 36 participants in each group. The intervention group underwent caregiver skill training via an online platform, whereas the control group initially received face-to-face follow-up guidance and was subsequently offered online training after 6 months. To assess the effectiveness of the intervention program, researchers employed the Neuropsychiatric Inventory-Questionnaire (NPI-Q), the Chinese version of the Zarit Caregiver Burden Interview (CZBI), and the Severe Cognitive Impairment Dementia Scale (SCIDS) for evaluations conducted before the intervention, 3 months after the intervention, and 6 months after the intervention.

Results: Between July 2019 and December 2020, a total of 66 patients successfully completed the intervention and follow-up. After 6 months of intervention, the NPI-Q score of the intervention group was 3.18 ± 3.81 , the ZBI score was 10.97 ± 5.43 , and the SCIDS score was 71.88 ± 4.78 . The NPI-Q score of the control group was 8.09 ± 8.52 , the ZBI score was 30.30 ± 13.05 , and the SCIDS score was 50.12 ± 9.10 . There were statistically significant differences in NPI-Q ($P=0.004$), ZBI ($P<0.001$), and SCIDS scores ($P<0.001$) between the intervention group and the control group. Repeated measures analysis of variance showed that compared with before the intervention, there were statistically significant differences in ZBI ($P<0.001$) and SCIDS ($P<0.001$) scores three months after the intervention, while the difference in NPI-Q ($P=0.105$) scores was not significant. The total scores of NPI-Q ($P<0.001$), ZBI ($P<0.001$), and SCIDS ($P<0.001$) were significantly improved six months after the intervention. In addition, the results of covariance analysis showed that after excluding the time effect, the online training intervention significantly reduced the NPI-Q score ($-2.79(-4.38, -1.19)$, $P<0.001$) of dementia patients and the ZBI score ($-13.52(-15.87, -11.16)$, $P<0.001$) of caregivers, while increasing the SCIDS score ($12.24(9.02, 15.47)$, $P<0.001$).

Conclusions: Conclusion: Online training based on the internet could significantly reduce the level of behavioral symptoms in elderly patients with dementia and alleviate the burden on caregivers, enhancing their caregiving abilities. The research results fully confirmed the effectiveness and feasibility of online training, which was of great significance in providing caregiving

knowledge training for informal caregivers of persons with dementia. Clinical Trial: Trial Registration
Clinical Trial Registe ChiCTR2200057858; <https://www.chictr.org.cn/showproj.html?proj=136442>

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Original Manuscript

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time effect, the online training intervention significantly reduced the NPI-Q score (-2.79(-4.38, -1.19), $P<0.001$) of dementia patients and the ZBI score (-13.52(-15.87, -11.16), $P<0.001$) of caregivers, while increasing the SCIDS score (12.24(9.02, 15.47), $P<0.001$).

Conclusion: Online training based on the internet could significantly reduce the level of behavioral symptoms in elderly patients with dementia and alleviate the burden on caregivers, enhancing their caregiving abilities. The research results fully confirmed the effectiveness and feasibility of online training, which was of great significance in providing caregiving knowledge training for informal caregivers of persons with dementia.

Trial Registration

Clinical Trial Register ChiCTR2200057858; <https://www.chictr.org.cn/showproj.html?proj=136442>

KEYWORDS: dementia; family caregiver; online training; care burden; care ability

INTRODUCTION

Dementia care remains a major public health challenge for global health systems. According to a recent nationwide cross-sectional study [1], 15.07 million individuals aged over 60 years suffered dementia in China. A person with dementia, particularly one with moderate-to-severe dementia, has extensive health and social care needs. The annual total treatment costs of patients with AD in China are predicted to reach US \$507.49 billion in 2030 and US \$1.89 trillion in 2050 [2]. Dementia severity is an important driver of cost and the proportion of mild, moderate, and severe dementia cases living in a country can influence the cost estimates. In China, 70% of dementia patients live at home and are cared for by their spouses, children, or other relatives. According to a survey conducted by Xie Hengge et al [3], there are three major difficulties faced by the families of dementia patients, which mainly are insufficient care capacity, and a lack of care resources, and single treatment services. According to the research report [3], 65.43% of caregivers have no hope of treatment and feel intense psychological pressure; 68.69% of caregivers report that their health has been affected; and 78.39% of caregivers said that their social life is often affected.

Behavioral and psychological symptoms of dementia (BPSD) may occur at any stage of the disease progression, with patients exhibiting at least one type of BPSD. BPSD is highly correlated with caregiver burden. Caregiver factors are some of the causes and triggers of BPSD, and insufficient interaction between caregivers and care recipients may lead to the occurrence or exacerbation of BPSD. For family caregivers, caring for people with dementia is perceived as one of the most stressful experiences. During the long-term progression of the disease, the patient's

independence will decline, which requires more responsibility and supervision time from informal caregivers. Long-term problems of continuously managing activities of daily living [4, 5], behavioral and psychological symptoms [6], and providing emotional, spiritual, and social support place considerable burdens to the family, which can result in mental health problems such as depression. The burden of care can put caregivers at risk of physical and psychological ailments, as well as negatively affect their quality of life, so effective and practical support is essential. Training and supporting family caregivers, especially in the proper management of BPSD, to enhance their ability to cope with BPSD, may help break this vicious cycle [7].

In 2019, informal dementia carers spent over 89 billion hours providing support with activities of daily living (ADLs) about 5 hours per day per person with dementia [8]. **As the most direct contact and participant, the competence of the caregiver has a direct impact on the outcome of BPSD.** However, due to the ongoing COVID-19 pandemic, many support services for dementia caregivers have been reduced, delayed, or even withdrawn, which has substantially increased interest in virtual health services [9]. It is important to create a digital platform that offers invaluable and usable information to caregivers of people living with dementia [10]. In the face of these significant challenges, the WHO developed “iSupport”, an evidence-based e-health intervention designed to help dementia carers provide good care and take care of themselves [11]. Internet-based supportive interventions can provide convenient and efficient support and education to potentially reduce the physical and psychological burden associated with providing care. Internet-based supportive interventions for family caregivers of people with dementia have been reported in the UK [11], India [12], the Netherlands [13], Brazil [14], Germany [15], and other countries, but they are rare in China.

This manuscript presents the findings of a randomized controlled trial (RCT) examining the implementation of an internet-based supportive interventions for home care among patients with dementia in China. The trial is an innovative online support program that was developed to advance the skills, knowledge, and practice of caregivers, in order to enhance self-care skills in individuals with dementia and simultaneously provide invaluable assistance to their caregivers. The experiment also aims to assess the effectiveness of the online support program, and to explore its impact on the caregiving burden and caregiving abilities of dementia caregivers, compared with dementia caregivers who receive routine caregiving interventions after discharge. The primary outcomes of this study consisted of evaluating the severity of neuropsychiatric symptoms in dementia patients, assessing the burden on caregivers, and gauging the capability of caregivers. We hypothesized that internet-based supportive interventions would lead to produce greater

improvement in primary outcomes than routine caregiving interventions after discharge.

MATERIALS AND METHODS

Study design

The trial was designed, planned, and executed by the Department of Geriatrics of Zhejiang Hospital (Zhejiang China). An RCT design was employed to study the feasibility and effectiveness of a nurse-led multidisciplinary team online training and support program. 72 caregivers of dementia patient were recruited from the Geriatric Department of Zhejiang Hospital from July 2019 to December 2020. Recruitment strategy included posting flyers and posters in the geriatric ward. During the patient's hospitalization, the geriatric nurse proposed this protocol to the family caregivers of the dementia patient. Interested participants were provided with a flyer containing contact information for the research and filled out a contact form. The geriatric nurse confirmed inclusion criteria and collected the signed informed consents. The control group intervention measures included regular face-to-face follow-up interviews with caregivers to provide education on dementia care knowledge and skills. These measures were conducted every 3 months after the patient's discharge. All participants were assessed at baseline (T0) and post-intervention (T1, 3 months after T0; T2, 6 months after T0). Once enrolled, participants had access to the online program or follow-up interview for more than six months. All procedures were in accordance with the Helsinki Declaration and the study was approved by the Ethics Review Committee of Zhejiang Hospital. It was registered at the Chinese Clinical Trial Registry (Register number: ChiCTR-2200057858).

Inclusion and exclusion criteria

Selection criteria included: (1) Being a primary, informal caregiver aged at least 18 years; (2) caring for individuals with dementia while living together at home for a minimum of six months; (3) having Internet access via computers or iPads; (4) could read, understand Chinese, and following instructions. Participants were excluded if they had severe visual or hearing impairment that was incompatible with participation as assessed by the study staff.

Recruitment, consent, and baseline data collection

Between July 2019 and December 2020, 72 informal primary caregivers of people with dementia of all subtypes and stages were recruited via the Department of Geriatrics, Zhejiang Hospital. Caregivers meeting the eligibility criteria were informed of initial details about the study

and provided with a subject information sheet. Once potential participants decided to participate, they were asked to sign the informed consent form and were informed of their rights. Baseline information was collected by trained interviewers from participants through the completing standardized questionnaires. During the interviews, trained interviewers were blinded to the group allocations. Participants were randomly allocated on a 1:1 ratio assigned to either the intervention or a waiting list control group after baseline assessment. Randomization was carried out using a random number generator.

In the follow-up period, 3 patients in the intervention group and the control group were lost to follow-up, respectively. In the intervention group, two caregivers accompanied the dementia patients when they relocated to a different city, and another caregiver returned to her hometown after the dementia patient was admitted to a nursing home. In the control group, one caregiver of a dementia patient accompanied the patient for emergency hospital admission due to a fracture, another caregiver failed to continue contact despite repeated appointments, and one caregiver accompanied the patient to a nursing home (Fig.1).

The patients in the control and intervention groups were comparable in terms of their baseline data such as sex, education level, marital status, age, BMI, number of children, number of diseases, and number of long-term medications (Table 1). In this study, caregivers averaged 57.74 years old ($SD=3.93$; range 48–66) and the majority ($n=57$; 86%) were female. Caregivers were most frequently the patients' distant relatives from the countryside (64%) and children (20%); the remainder were spouses (16%). Table 1 presents the demographic characteristics of the sample. Among the study groups, demographic and clinical characteristics did not differ significantly.

Sample size calculation

The experiment was conducted as a parallel-group, randomized, control study design and repeated measures were used. Sample size calculation was based on the primary outcome of CZBI at 6-month after baseline. The detection power was set at 90%, and alpha (two-tailed) was set at 0.05. Preliminary experiments showed that the CZBI of dementia family caregivers was 21.55, with a standard deviation of 9.89, and an auto-correlation between adjacent measurements on the same individual was 0.70. By providing online knowledge and skills training through the internet, the preliminary trial showed that the average CZBI had decreased by 12.5. Using PASS software (version 16.0), the minimum sample size for each group was identified as 27. Considering a potential 10% loss of samples during the study, the final sample size was determined to be 36 individuals per group.

Intervention

The platform aims to provide opportunities for support, education, and sharing experiences among users across Zhejiang province. In order to provide users with convenient access to the course at any time and place, the platform was designed to operate on any Internet-enabled device. In the intervention group, we instructed the informal caregivers of persons with dementia to log in to the platform web page and taught them about the knowledge and skills relevant to home care via the internet. The content on the platform was divided into five different themes, which were: computer cognitive training, language training, reality-oriented therapy, daily life rehabilitation, and care skills training. Computer cognitive training includes concentration (picture-text matching), memory (vocabulary memorization), calculation (simulated shopping), and reaction training (fruit picking). Each training time was 20 minutes and was conducted three times a week. Language training aims to improve communication by focusing on vocalization, recognition, and the application of words. Reality orientation therapy focuses on presenting patients with facts about the time, date, and current environment. The primary objective for daily life rehabilitation is to increase self-care ability. **The 4 themes (cognitive training, language training, reality-oriented therapy, daily life rehabilitation) have been evaluated in a prior study with pending results and this paper focuses mainly on the fifth theme.** The latter theme consisted of 18 lessons (270 minutes) aimed at improving caregiver care skills (Table 2). In order to encourage participants to complete the online course training, the online active screen time was calculated. Once participants completed at least 80% of the training sessions (216 minutes), they would be sent a book ("Long-term Care for Dementia").

The control-comparison group would receive an educational booklet on caring for dementia patients provided by the research team. In addition to this education, the control group would also receive face-to-face follow-up guidance and have the option to receive the same intervention after 6 months. The research team's helpline would also be available 24 hours a day to the control group for caregiver assistance.

Measurement Instruments

Due to the in-person meetings restrictions imposed by the Covid-19 pandemic, caregivers participated in two 10-minute online self-assessed surveys through Questionnaire Star at 3 and 6 months. The primary outcome measures were the Neuropsychiatric Inventory Questionnaire (NPI-Q), the Chinese version of the Zarit Burden Interview (CZBI), and the Sense of Competence in Dementia Care Staff Scale (SCIDS).

The Neuropsychiatric Inventory Questionnaire (NPI-Q) [16] is an observer rating scale that was

used to evaluate participants' neuropsychiatric symptoms across 12 different areas, including delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/emotional lability, aberrant motor behaviors, nighttime behavioral disturbances, and appetite/eating disturbances. Each symptom was evaluated with a basic screening question (to which participants responded). If a positive answer is given to the screening question, a more detailed exploration of specific areas will be conducted. The neurobehavioral manifestations within a domain are collectively rated by caregivers based on frequency (1 to 4) and severity (1 to 3), resulting in a composite domain score (frequency x severity), with higher scores indicating greater severity of symptoms. The total score of NPI is defined as the sum of scores from 12 symptom evaluations, with a maximum score of 144. The Cronbach's α coefficient of the NPI-Q was 0.82, and the test-retest coefficients ranged from 0.66 to 0.98 ($p < 0.001$) [17].

The caregiver burden was measured using the Chinese version of the Zarit Burden Interview (CZBI) [18]. CZBI consists of 22 items that require a Likert-type response ranging from 0 (never) to 4 (almost always), with a total score ranging from 0 to 88. A higher score indicates an increased caregiver burden. The internal consistency value, established by Cronbach's alpha coefficient, was 0.89 and the intraclass correlation coefficient for test-retest reliability of the total score was 0.88.

Sense of Competence in Dementia Care Staff Scale (SCIDS) is designed to evaluate the level of competency among caregivers in providing care for individuals with dementia [19]. The scale consists of 17 items across four subscales: professionalism, relationship-building, care challenges, and sustaining personhood. SCIDS has acceptable to good internal consistency (Cronbach's $\alpha=0.91$) and moderate to substantial test-retest reliability (0.74). The total score of the scale ranges from 17 to 68 points, with higher scores indicating that staff members have a better awareness of dementia care abilities.

Statistical analysis

Outliers were identified using boxplots, and data distribution was assessed by Shapiro-Wilk test. Data were tested for normal distribution or variance homogeneity using appropriate tests before statistical analysis with SPSS20.0 statistical software. Continuous variables that followed a normal distribution were expressed as mean and standard deviation and were compared using an independent t-test between the two groups. Categorical variables were expressed as frequencies and proportions and compared using a chi-square test between groups. In repeated measures analysis of variance, when the assumption of sphericity was violated (evaluated using Mauchly's test), the degrees of freedom value for testing the F-ratio was adjusted using the Greenhouse-Geisser

correction. If there was no interaction effect between time and treatment factors in the repeated measures ANOVA results, the main effects test was used to evaluate the treatment effect. If there was an interaction effect, separate analyses were performed: the within-group effect was evaluated using a one-way repeated measures ANOVA, and the between-group effect was evaluated using a multivariate ANOVA. Bonferroni correction was used for post-hoc multiple pairwise comparisons.

Results

According to the results of repeated measures analysis of variance, as shown in Table 3, it was found that intervention and time had significant statistical effects on the NPI-Q, CZBI, and SCIDS ($P < 0.05$), and the significant interaction effects of group \times time in primary outcome indicators were also found ($P < 0.05$). Since there were significant differences (group \times time effect) in the primary outcome measure, analyses of the individual effects of intervention and time were performed. To verify the significance of intervention effects, multiple comparisons were subjected to the Bonferroni correction for adjustment. The comparison of various data between the intervention group and the control group at different time points was shown in Table 4. After 6 months of intervention, the NPI-Q of caregivers in the intervention group was significantly lower than that of in the control group ($t = -3.020$, $P = 0.004$); at 3 and 6 months after intervention, the care burden (CZBI) of caregivers in the intervention group was significantly lower than that of in the control group ($t_{3\text{ month}} = -2.939$, $P = 0.005$; $t_{6\text{ month}} = -7.858$, $P < 0.001$). The caregiving ability (SCIDS) of caregivers was significantly higher than that of in the control group ($t_{3\text{ month}} = 6.138$, $P < 0.001$; $t_{6\text{ month}} = 12.16$, $P < 0.001$).

Using the Sidak method to conduct multiple comparisons for the individual effects of time on the primary outcome measure (NPI-Q, CZBI, SCIDS), the results were shown in Table 5. In the intervention group, the NPI-Q score showed a decrease over time (Means Difference_{T2-T1} = -1.39, Means Difference_{T3-T1} = -2.79), while the comparison group showed a significant increase at the 3- and 6-month follow-up compared to baseline, with statistically significant differences (Means Difference_{T2-T1} = 1.46, Means Difference_{T3-T1} = 3.64). According to the research results, the severity of NPI in dementia patients tends to worsen over time. However, this study showed that caregiver knowledge and skills training through an information platform significantly delayed the progression of NPI symptoms in dementia patients, indicating the effectiveness of this training method.

The intervention group's CZBI scores showed a significant decrease over time (Means Difference_{T2-T1} = -7.70, Means Difference_{T3-T1} = -13.52), while the control group experienced a significant increase (Means Difference_{T2-T1} = 4.49, Means Difference_{T3-T1} = 10.45). The study revealed that internet-based supportive interventions providing dementia caregivers with knowledge and skills training led to a significant reduction in caregiving burden and were proved to be highly effective.

In terms of caregiving ability (SCIDS), the performance of the intervention group's caregivers significantly improved in the 3- and 6- month follow-ups, with statistically significant differences compared to before intervention (Means Difference_{T2-T1}=5.79, Means Difference_{T3-T1}=12.24). Conversely, the caregiving ability of the control group's caregivers declined during the same period (Means Difference_{T2-T1}=-6.70, Means Difference_{T3-T1}=-8.64). This result indicated that providing knowledge and skills training to informal caregivers of persons with dementia through information technology platforms can effectively enhance their caregiving skills.

Discussion

The restrictions of the Covid-19 pandemic have had profound effects on dementia patients and their caregivers. This study shows that internet-based support and education have a positive impact on family caregivers. The intervention can reduce the NPI scores of dementia patients, enhance the dementia care skills of informal caregivers, and ease the care burden for caregivers. With the progression of dementia, caregivers not only have to deal with many behavioral, daily living, and safety issues, but also lack the professional knowledge and skills to address diverse caregiving challenges. This not only causes them to experience anxiety and depression but also brings care and financial burdens to their families and society. Online interventions based on internet technology are highly flexible and suitable for family caregivers, as their schedules are largely consumed by caregiving and they may not have time to attend in-person learning sessions (due to travel and time constraints).

Patients diagnosed with dementia often struggle with a gradual deterioration of emotional regulation and an increased likelihood of displaying behavioral and psychological symptoms. This is closely linked to the decline in cognitive function associated with the condition. Research on caregiver burden indicated that Behavioral and Psychiatric Symptoms of Dementia (BPSD) are strongly correlated with caregiver burden [20]. The prevalence of dementia in Chinese society is expected to increase in the next 40 years. Family members remain the primary caregivers and bear a heavy burden. BPSD not only has a significant impact on the health and quality of life of patients but also brings enormous physical and psychological burden to caregivers. In this study, the intervention group had significantly lower NPI scores than the control group after 6 months of intervention. The results indicated that internet-based supportive interventions for dementia caregivers can effectively improve BPSD symptoms in dementia patients. This result is consistent with those of previous studies [21, 22]. BPSD symptoms are a prevalent issue among elderly individuals with dementia. These symptoms often occur repeatedly and can present at varying stages of the disease. Previous

research [23] has demonstrated that the emergence of BPSD symptoms is associated with an increased risk of accelerated progression of dementia, reduced cognitive function, and a quicker decline in cognitive abilities in individuals with dementia. Our research has to some extent reduced the incidence and severity of behavioral and emotional symptoms. The meta-analysis results of Minmin Leng [24] also show that internet-based supportive interventions have potential benefits for the neurological and psychiatric symptoms of patients with dementia.

The research results showed that after 6 months of intervention, the total score of caregiving ability for the intervention group caregivers was significantly higher than that of the control group ($P < 0.05$), indicating that online supportive intervention for dementia informal caregivers can significantly improve their caregiving ability. Providing care for patients with dementia is an incredibly difficult task, and caregivers may struggle with a lack of essential resources, including knowledge, skills, and social support. In this context, the development of knowledge and skills to support family caregivers is essential. The online caregiver training intervention plan for dementia caregivers in this project covers the basic knowledge that caregivers should possess. It systematically explains the causes, clinical manifestations, and progression of dementia, promoting caregivers' understanding. Mastering knowledge is a prerequisite for improving skill levels [25]. In caring for dementia patients, knowing about the disease can help caregivers better care for patients. Only when caregivers have a correct understanding of the illness can they truly empathize with patients and provide them with appropriate care. This study adopted online training to enhance caregivers' caregiving skills from four aspects: knowledge, skills, self-emotional management, interpersonal relationships, and resource utilization. In terms of intervention form, online knowledge and skills training is more flexible in terms of time, allowing caregivers to choose their free time to increase their participation. The result is similar to the study by Soraia Teles et al [26].

After comparing the CZBI scores of two groups of caregivers at different time points, we concluded that within 6 months after the intervention, the CZBI scores of caregivers in the intervention group were significantly lower than those in the control group ($P < 0.05$). The findings demonstrated that the internet-based supportive intervention had a significant impact on alleviating the burden of care for dementia. This result is consistent with those of two studies [26, 27]. The meta-analysis carried out by Kieren J. Egan [28] and the systematic review conducted by Michelle Pleasant [29] have also demonstrated online training programs supportive intervention for informal caregivers of persons with dementia were highly effective in reducing their burden. When informal caregivers have mastered basic care knowledge and skills, their confidence in caring for patients is enhanced, uncertainty is reduced, and understanding of patients is improved. This knowledge and

skills can reduce the burden on caregivers and can enable them to care for patients more effectively. Using home care resources could help maintain health status, minimize symptom relief, and reduce avoidable hospitalizations [30]. This study offers a solution to the challenges faced by informal caregivers by providing them with training through online programs. They gain knowledge and skills that allow them to adjust their caregiving schedules flexibly to accommodate the needs of individuals with dementia. This approach not only empowered informal caregivers but also optimized the use of home care resources, making care provision more effective.

Limitations

This study has limitations. First, due to time constraints, the effects of the intervention program in this study were evaluated for only 6 months, and long-term follow-up will be conducted in the future. Second, since manpower, funding, and time constraints prevented long-term research, this study was conducted with a small sample size only. Third, we measured outcomes and exposures using self-reported questionnaires, so reporting errors were possible. Despite these limitations, our plan is still noteworthy because it is one of the few online interventions that have a significant impact on fostering positive emotions towards caregiving and reducing the burden on informal caregivers of persons with dementia patients. Sofia Bastoni's research [31] has found that monitoring devices are rapidly developing and are seen as promising technologies. This includes monitoring health and safety in homes, as well as providing outdoor location identification for dementia patients. In the future, we will conduct in-depth research on integrating wearable devices and other mobile information collection terminals into this information platform to achieve real-time monitoring of the health status of dementia patients.

Conclusions

The long-term care system in China predominantly relies on informal family care. Family caregivers are the mainstay of elderly care at present in China, and their caregiving capacity directly affects the quality of family care. The lack of caregiver competence affects the quality of care because family caregivers lack basic knowledge and relevant skills in caregiving. The Chinese eldercare system relies heavily on informal care provided by family members due to filial piety. China has many patients with dementia due to having a huge population base. Family caregivers are the mainstay of elderly care in China currently [32], and their ability to provide care directly affects the quality of home-based care. Caregivers for dementia patients often face reality inadequate caregiving skills and desire for support. As a family caregiver, one needs to possess a variety of

knowledge and skills. This comprises an understanding of the ailment in question, being adept at solving problems creatively and possessing techniques for maintaining psychological well-being. Informal caregivers play a crucial role in the care of individuals with dementia. Therefore, it is imperative to have interventions in place that not only support them but also alleviate their burden. Major technological advancements should be leveraged to optimize the time and effectiveness of the dementia care workforce [33]. As a cost-effective, convenient, and accessible intervention, web-based solutions have emerged to support informal caregivers. The advantage of online support training lies in breaking the limitations of time and space, providing a feasible solution for the popularization of support services. During the COVID-19 pandemic, our research project provided digital resources through online support and training to informal caregivers of persons with dementia, which improved the caregivers' skills and alleviated their burden.

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1. Jia L, Du Y, Chu L, Zhang Z, Li F, Lyu D, et al. Prevalence, risk factors, and management of dementia and mild cognitive impairment in adults aged 60 years or older in china: a cross-sectional study. *The Lancet Public Health* 2020-01-01;5(12):e661-e671. [doi:[https://doi.org/10.1016/S2468-2667\(20\)30185-7](https://doi.org/10.1016/S2468-2667(20)30185-7)] [Medline:33271079]
2. Jia J, Wei C, Chen S, Li F, Tang Y, Qin W, et al. The cost of alzheimer's disease in china and re-estimation of costs worldwide. *Alzheimers Dement* 2018-04-01;14(4):483-491. [doi:10.1016/j.jalz.2017.12.006] [Medline:29433981]
3. Report on the family survival status of alzheimer's disease patients in china (2019). China, Association, For, S A, Disease. 2020-1. URL: http://weixin.moreedge.cn/bps_2019/index.php [accessed 2023-06-23]
4. Drummond N, McCleary L, Garcia L, McGilton K, Molnar F, Dalziel W, et al. Assessing determinants of perceived quality in transitions for people with dementia: a prospective observational study. *Can Geriatr J* 2019-03-01;22(1):13-22. [doi:10.5770/cgj.22.332] [Medline:31501679]
5. Spigelmyer PC, Schreiber JB. A pilot study: resistive behavior in the context of informal caregiver-assisted activities of daily living. *Geriatr Nurs* 2019-07-01;40(4):399-404. [doi:10.1016/j.gerinurse.2019.01.005] [Medline:30878279]
6. Baharudin AD, Din NC, Subramaniam P, Razali R. The associations between behavioral-psychological symptoms of dementia (bpsd) and coping strategy, burden of care and personality style among low-income caregivers of patients with dementia. *Bmc Public Health* 2019-06-13;19(Suppl 4):447. [doi:10.1186/s12889-019-6868-0] [Medline:31196141]
7. Lu X, Ye R, Wu J, Rao D, Liao X. Comparing behavioral and psychological symptoms of dementia and caregiver distress caused between older adults with dementia living in the community and in nursing homes. *Front Psychiatry* 2022-01-20;13:881215. [doi:10.3389/fpsy.2022.881215] [Medline:35651819]
8. Global status report on the public health response to dementia. Organizaton WH. 2021/09/01. URL: www.who.int/publications/i/item/9789240033245 [accessed 2023/03/08]
9. Ramirez M, Duran MC, Pabiniak CJ, Hansen KE, Kelley A, Ralston JD, et al. Family caregiver needs and preferences for virtual training to manage behavioral and psychological symptoms of dementia: interview study. *Jmir Aging* 2021-02-10;4(1):e24965. [doi:10.2196/24965] [Medline:33565984]
10. Fan Q, DuBose L, Ory MG, Lee S, Hoang MN, Vennatt J, et al. Financial, legal, and functional challenges of providing care for people living with dementia and needs for a digital platform: interview study among family caregivers. *Jmir Aging* 2023-09-05;6:e47577. [doi:10.2196/47577] [Medline:37526513]
11. Windle G, Flynn G, Hoare Z, Masterson-Algar P, Egan K, Edwards RT, et al. Effects of an e-health intervention 'isupport' for reducing distress of dementia carers: protocol for a randomised controlled trial and feasibility study. *Bmj Open* 2022-09-21;12(9):e64314. [doi:10.1136/bmjopen-2022-064314] [Medline:36130751]
12. Baruah U, Varghese M, Loganathan S, Mehta KM, Gallagher-Thompson D, Zandi D, et al. Feasibility and preliminary effectiveness of an online training and support program for caregivers of people with dementia in india: a randomized controlled trial. *Int J Geriatr Psychiatry* 2021-04-01;36(4):606-617. [doi:10.1002/gps.5502] [Medline:33491811]
13. Christie HL, Dam AEH, van Boxtel M, Köhler S, Verhey F, de Vugt ME. Lessons learned from an effectiveness evaluation of inlife, a web-based social support intervention for caregivers of people with dementia: randomized controlled trial. *Jmir Aging* 2022-12-07;5(4):e38656. [doi:10.2196/38656] [Medline:36476485]

14. Ottaviani AC, Monteiro DQ, Ferreira CC, Barham EJ, Oliveira D, Da CK, et al. Isupport-brasil: preliminary results of the usability and acceptability assessment by caregivers of people who have dementia. *Front Med (Lausanne)* 2022-01-20;9:981748. [doi:10.3389/fmed.2022.981748] [Medline:36059826]
15. Meichsner F, Theurer C, Wilz G. Acceptance and treatment effects of an internet-delivered cognitive-behavioral intervention for family caregivers of people with dementia: a randomized-controlled trial. *J Clin Psychol* 2019-04-01;75(4):594-613. [doi:10.1002/jclp.22739] [Medline:30597537]
16. Kaufer DI, Cummings JL, Ketchel P, Smith V, MacMillan A, Shelley T, et al. Validation of the npi-q, a brief clinical form of the neuropsychiatric inventory. *J Neuropsychiatry Clin Neurosci* 2000-03-01;12(2):233-239. [doi:10.1176/jnp.12.2.233] [Medline:11001602]
17. Wang T, Xiao S, Li X, Wang H, Liu Y, Su N, et al. Reliability and validity of the chinese version of the neuropsychiatric inventory in mainland china. *Int J Geriatr Psychiatry* 2012-05-01;27(5):539-544. [doi:10.1002/gps.2757] [Medline:21769938]
18. Ko KT, Yip PK, Liu SI, Huang CR. Chinese version of the zarit caregiver burden interview: a validation study. *Am J Geriatr Psychiatry* 2008-06-01;16(6):513-518. [doi:10.1097/JGP.0b013e318167ae5b] [Medline:18515696]
19. Schepers AK, Orrell M, Shanahan N, Spector A. Sense of competence in dementia care staff (scids) scale: development, reliability, and validity. *Int Psychogeriatr* 2012-07-01;24(7):1153-1162. [doi:10.1017/S104161021100247X] [Medline:22340666]
20. Chen YJ, Su JA, Chen JS, Liu CH, Griffiths MD, Tsai HC, et al. Examining the association between neuropsychiatric symptoms among people with dementia and caregiver mental health: are caregiver burden and affiliate stigma mediators? *Bmc Geriatr* 2023-01-16;23(1):27. [doi:10.1186/s12877-023-03735-2] [Medline:36646996]
21. Birkenhager-Gillesse EG, Achterberg WP, Janus S, Kollen BJ, Zuidema SU. Effects of caregiver dementia training in caregiver-patient dyads: a randomized controlled study. *Int J Geriatr Psychiatry* 2020-11-01;35(11):1376-1384. [doi:10.1002/gps.5378] [Medline:32662184]
22. Gharavi Y, Stringer B, Hoogendoorn A, Boogaarts J, Van Raaij B, Van Meijel B. Evaluation of an interaction-skills training for reducing the burden of family caregivers of patients with severe mental illness: a pre-posttest design. *Bmc Psychiatry* 2018-03-27;18(1):84. [doi:10.1186/s12888-018-1669-z] [Medline:29587690]
23. Eikelboom WS, van den Berg E, Singleton EH, Baart SJ, Coesmans M, Leeuwis AE, et al. Neuropsychiatric and cognitive symptoms across the alzheimer disease clinical spectrum: cross-sectional and longitudinal associations. *Neurology* 2021-09-28;97(13):e1276-e1287. [doi:10.1212/WNL.00000000000012598] [Medline:34413181]
24. Leng M, Zhao Y, Xiao H, Li C, Wang Z. Internet-based supportive interventions for family caregivers of people with dementia: systematic review and meta-analysis. *J Med Internet Res* 2020-09-09;22(9):e19468. [doi:10.2196/19468] [Medline:32902388]
25. Farran CJ, McCann JJ, Fogg LG, Etkin CD. Developing a measurement strategy for assessing family caregiver skills: conceptual issues. *Alzheimers care today* 2009-01-20;10(3):129-139. [doi:10.1097/ACQ.0b013e3181b15d82] [Medline:20179779]
26. Teles S, Ferreira A, Paul C. Feasibility of an online training and support program for dementia carers: results from a mixed-methods pilot randomized controlled trial. *Bmc Geriatr* 2022-03-01;22(1):173. [doi:10.1186/s12877-022-02831-z] [Medline:35232389]
27. Shadarevian J, Chan C, Berndt A, Son C, Gregorio M, Horne N, et al. Creating a toolkit with stakeholders for leveraging tablet computers to support person-centred dementia care in hospitals. *J Rehabil Assist Technol Eng* 2020-01-01;7:1811153023. [doi:10.1177/2055668320960385] [Medline:33282336]
28. Egan KJ, Pinto-Bruno AC, Bighelli I, Berg-Weger M, van Straten A, Albanese E, et al. Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: a systematic review. *J Am Med Dir Assoc* 2018-03-01;19(3):200-206. [doi:10.1016/j.jamda.2017.10.023] [Medline:29306605]
29. Pleasant M, Molinari V, Dobbs D, Meng H, Hyer K. Effectiveness of online dementia caregivers training programs: a systematic review. *Geriatr Nurs* 2020-11-01;41(6):921-935. [doi:10.1016/j.gerinurse.2020.07.004] [Medline:32703628]
30. Naess G, Kirkevold M, Hammer W, Straand J, Wyller TB. Nursing care needs and services utilised by home-dwelling elderly with complex health problems: observational study. *Bmc Health Serv Res* 2017-09-12;17(1):645. [doi:10.1186/s12913-017-2600-x] [Medline:28899369]
31. Bastoni S, Wrede C, Da Silva MC, Sanderman R, Gaggioli A, Braakman-Jansen A, et al. Factors influencing implementation of ehealth technologies to support informal dementia care: umbrella review. *Jmir Aging* 2021-10-08;4(4):e30841. [doi:10.2196/30841] [Medline:34623314]
32. Krings MF, van Wijngaarden J, Yuan S, Huijsman R. China's elder care policies 1994-2020: a narrative document analysis. *Int J Environ Res Public Health* 2022-05-18;19(10):6141. [doi:10.3390/ijerph19106141] [Medline:35627677]
33. . 2023 alzheimer's disease facts and figures. *Alzheimers Dement* 2023-04-01;19(4):1598-1695. [doi:10.1002/alz.13016] [Medline:36918389]

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Supplementary Files

Multimedia Appendixes

Flowchart of study participants.

URL: <http://asset.jmir.pub/assets/57664aec92a29c48d1aa83d237cd3b51.png>

Table1 Sample characteristics.

URL: <http://asset.jmir.pub/assets/a9cd95823559c7f8d97b06aac17a468c.docx>

Overview of intervention modules.

URL: <http://asset.jmir.pub/assets/c2cdb40669b0f59dd04f12a207b4f0f5.docx>

Comparison of 3 scores between two randomly assigned groups with key outcomes.

URL: <http://asset.jmir.pub/assets/9b8476755dbe02d4061741adbf629892.docx>

Comparison of 3 scores between the two groups at different time.

URL: <http://asset.jmir.pub/assets/e5d5d19955af471e7e4e868c68e9a1fa.docx>

Time for multiple comparisons of the individual effects of NPI-Q, Zarit, SCIDS.

URL: <http://asset.jmir.pub/assets/9b7c8aad5d1630e6f93e9bacd245f452.docx>

CONSORT???????s

JMIR Aging 50847 CONSORT-EHEALTH (V 1.6.1) Submission Form.
URL: <http://asset.jmir.pub/assets/cb6da43eef3ba9c67ad15306afc4c592.pdf>

CONSORT (or other) checklists

URL: <http://asset.jmir.pub/assets/dade6d26d1767e49c4b08085a5d27461.pdf>

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Intervention screenshot.

