

The effectiveness of an online training and support program for family caregivers of people with dementia in China: Randomized controlled trial

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Submitted to: JMIR Aging
on: August 05, 2024

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The effectiveness of an online training and support program for family caregivers of people with dementia in China: Randomized controlled trial

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Abstract

Background: Dementia affects the memory, thinking, behavior, and daily functioning of people, with approximately 55 million people worldwide with dementia as of 2019, increasing by one new case every three seconds. In China, over 90% of people with dementia are cared for at home due to cultural values of filial piety. However, the support system for family caregivers is underdeveloped, leading to various health issues. The World Health Organization's 'iSupport for Dementia' program aims to support family caregivers and reduce their burden. Despite its adoption in 31 countries, iSupport in China is in early development, necessitating localized support programs.

Objective: This study aimed to evaluate the effectiveness of the Chinese version of iSupport, an online caregiving skills training and support program originally developed by the World Health Organization for family caregivers and people with dementia.

Methods: A randomized controlled trial was conducted with 81 Chinese family caregivers of people with dementia, divided into an intervention group (n = 41) and a control group (n = 40). The primary outcome, health-related quality of life, was assessed at baseline (T0), immediately after the intervention (T1, 3rd month), and three months post-intervention (T2, 6th month). Social support, self-efficacy, caregiving burden, and the quality of life and memory and behavior problems of people with dementia were also evaluated. Comparisons were made using a repeated-measures analysis of the variance model.

Results: Sixty-four caregivers completed the study (32 in each group). The intervention group showed significant improvements in mental-related quality of life ($p < 0.05$), self-efficacy ($p < 0.001$), social support ($p < 0.001$), and caregiving burden ($p < 0.001$) compared to the control group. The intervention also significantly improved the quality of life for people with dementia ($p < 0.001$). No significant differences were found between groups regarding the memory and behavior problems of people with dementia ($p > 0.05$).

Conclusions: The online iSupport program significantly improves the quality of life, self-efficacy, and social support of Chinese family caregivers of people with dementia while reducing the caregiving burden. The study suggests that diverse intervention content, including treatment, rehabilitation, and caregiving, alongside continuous support, can alleviate the condition of people with dementia. Clinical Trial: This study is registered in the Australia New Zealand Clinical Trials Registry: <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=381061&isReview=true> ID: ACTRN12621000276853.

(JMIR Preprints 05/08/2024:65076)

DOI: <https://doi.org/10.2196/preprints.65076>

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Original Manuscript

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Abstract

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Conclusions: The online iSupport program significantly improves the quality of life, self-efficacy, and social support of Chinese family caregivers of people with dementia while reducing the caregiving burden. The study suggests that diverse intervention content, including treatment, rehabilitation, and caregiving, alongside continuous support, can alleviate the condition of people with dementia.

Trial Registration: This study is registered in the Australia New Zealand Clinical Trials Registry: <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=381061&isReview=true> ID: ACTRN12621000276853.

Keywords: dementia; family caregivers; iSupport; online training and support program; randomized controlled trial

Introduction

Dementia is a general term for brain diseases that affecting memory, thinking, behavior, and daily functioning. According to the latest data in 2019, there are approximately 55 million people worldwide living with dementia, and this number is increasing at a rate of one new case every three

seconds. The number of people with dementia (PWD) will reach 82 million by 2030¹. As an incurable condition, dementia leaves PWD dependent on family caregivers for daily activities as the disease progresses. 84% of PWD worldwide receive care and treatment at home².

In China, influenced by Confucian culture and filial piety, caring for elderly family members is a significant responsibility protected by law, and over 90% of PWD are cared for at home by family members³. However, compared with developed countries, we have not established a complete support system for family caregivers, which may lead to various health issues that impact their work and daily life and may even threaten the quality of life for PWD. To relieve the enormous care pressure for family caregivers, researchers have suggested that appropriate multidimensional interventions, including psychological education, can significantly reduce caregiver burden and improve caregivers' well-being⁴.

In 2018, the World Health Organization (WHO) launched the 'iSupport for Dementia', an online support program specifically designed for family caregivers of PWD. The program aims to provide resources and support strategies to countries worldwide, enhancing caregivers' skills and reducing their caregiving burden⁵. WHO has highlighted the adaptability of iSupport, allowing dementia caregiving experts in different countries to make appropriate modifications to its content based on their respective cultural contexts. Currently, iSupport is being adopted in 31 countries/regions, and preliminary findings demonstrate its reliable effectiveness in enhancing caregiver capabilities, and improving the quality of life for the PWD⁶. However, in China, the development of iSupport is still in the early stages. Given the significant number of family caregivers for PWD and the underdeveloped caregiver support system in China, it is imperative to develop a localized and personalized caregiver support program such as iSupport and promote its widespread adoption.

Background

As the disease progresses, PWD often experience pronounced psychiatric symptoms in the middle and later stages, such as hallucinations, delusions, and wandering⁷. Family caregivers of PWD bear a significantly higher caregiving burden compared to other diseases. The physical and mental well-being of family caregivers and the quality of care they provide to PWD are crucial in slowing down the progression of the condition and improving the quality of life for PWD. In China, many family caregivers of PWD perceive dementia as a normal part of aging and a stigmatized mental illness. As a result, they often refuse to seek help from professionals or receive intervention support, which may significantly worsen the PWD's condition and even lead to death.

Both WHO and Alzheimer's Disease International (ADI) have increasingly recognized the importance of supporting to family caregivers of PWD¹. In 2017, WHO released the "Global Action Plan on the Public Health Response to Dementia 2017-2025"⁸, which aims to enhance the well-being of PWD and their family caregivers. The plan calls for 75% of member countries to provide support and training for family caregivers by 2025. The National Health Commission Office of China also issued a notice titled "Promotion of Activities for Dementia Prevention and Control among the Elderly (2023-2025)", which highlights the importance of promoting dementia caregiving techniques and reducing the burden on caregivers⁹. Specialized training can be conducted to provide caregivers with targeted support.

Currently, personalized support programs for family caregivers of PWD have been implemented in multiple developed countries and regions. Due to the impact of COVID-19, online support activities can effectively mitigate the risk of infection for caregivers. It has become evident that online activity offers the advantages of time-saving and overcoming geographical limitations, which is more valuable for promotion than offline activities. Loi et al.¹⁰ provided online support for family caregivers through 'START-online' in Australia. Hattink et al.¹¹ utilized a Web-Based Training

Program, named E-learning, to deliver supportive information to family caregivers. Both scholars agreed that personalized support programs can be widely accepted by family caregivers, which also effectively enhance the caregiving knowledge of family caregivers and should be disseminated in multiple regions. However, the support for caregivers of PWD in mainland China is still in its infancy. Apart from high-level hospitals in developed areas providing routine caregiver support, other regions have not yet initiated such support. The training support primarily relied on research programs to intervene with caregivers offline, including group discussions, community nurse home visits, experiential learning, and home caregiving skills training^{12,13}. Only a few hospitals provide skill guidance to family caregivers through WeChat, but these services are relatively limited in scope and dispersed¹⁴. While offline training has been proven effective in reducing caregiver anxiety and depression, its widespread implementation is limited by constraints such as time and distance, making it challenging to achieve large-scale promotion¹⁵.

With the widespread adoption of the internet in China, an increasing number of family caregivers of PWD are turning to the internet to seek support and assistance¹⁶. Therefore, it is necessary to develop an online support program designed for family caregivers in mainland China. In 2020, Chinese scholars collaborated with an Australian team to localize 'iSupport for Dementia', developed by the WHO, for family caregivers of PWD¹⁷.

iSupport is a psychoeducational curriculum, which consists of five modules: (1) Introduction to dementia; (2) Being a carer; (3) Care for me; (4) Providing everyday care; (5) Dealing with behavioral changes. Each module includes a variable number of lessons, with a total of 23 lessons⁵. The project adopts a combined theory and practice approach, incorporating psychological education, cognitive-behavioral therapy, and relaxation techniques into the course to fully engage family caregivers in the learning process. WHO predicts that iSupport has the potential to improve education and awareness of how to handle social and emotional issues that arise in interactions with PWD¹⁸. Portuguese scholars conducted a systematic usability assessment of iSupport and found that over 80% of the participants perceived it as highly applicable, with a system usability score of 89.5, indicating a positive perception of the project's usability among the participants¹⁹. However, the study on the iSupport program in multiple countries has shown inconsistent results, with a predominance of qualitative studies and limited reporting of results from randomized controlled trials, suggesting that the study on iSupport is still in the exploratory stage in different countries. Furthermore, the effect of the iSupport on Chinese family caregivers has not been tested either.

Based on the study experience of iSupport abroad and the necessity of developing online training programs for family caregivers of PWD in China, this study is the first to apply the iSupport program to Chinese caregivers. The study aims to examine the effectiveness of the Chinese version of iSupport among family caregivers of PWD in China through a randomized controlled trial. The findings will provide evidence and support for the widespread implementation of the Chinese version of iSupport, enhancing the caregiving abilities and quality of life for family caregivers of PWD in China. This study is part of a multicenter, multinational study that included the cost-effectiveness, feasibility, and acceptability of caregivers in the iSupport program, which will be reported elsewhere.

Methods

Design

A two-armed, web-based randomized controlled trial (RCT) with Chinese family caregivers of PWD was conducted to explore the effectiveness of the iSupport program between May 2021 and February 2022. The participants were randomized to either the intervention group (using iSupport) or the

control group (using usual care). The intervention was administered over 3 months, and all the participants were followed up for an additional 3 months after the intervention was completed. Measurements for family caregivers of PWD were taken at baseline (T0), at the end of the intervention (T1) (three months after baseline), and three months after the intervention (T2). The trial is registered on the Australian New Zealand Clinical Trials Registry (ANZCTR) website (ACTRN12621000276853). We followed the CONSORT statement to report the trial²⁰, and a CONSORT checklist based on this trial is presented in *Supplementary 1*.

Study setting and participants

The participants were family caregivers of PWD from China. We recruited participants through 11 WeChat communication groups that were self-formed by family caregivers of PWD (Wechat is a major social media platform in China that enables rapid information sharing across the web. It supports multiple group chats, similar to WhatsApp). Initially, we contacted the group administrators and explained the aim, significance, content, implementation process, and potential benefits of the study. Once we obtained the administrators' support, we sent the pre-designed promotional materials to them, and they shared the information with the group members in the WeChat group. We included the family caregivers of PWD based on the following criteria: (a) aged ≥ 18 years; (b) the care recipient was diagnosed with any dementia and cared for home; (c) the family member for PWD (including spouses, children/son-in-law/daughter-in-law and grandchildren), with a caregiving duration of at least 6 months; (d) with the ability to engage in online learning and having access to smartphone, computers or iPads. We excluded the caregivers of PWD who (a) have health conditions that may affect their ability to participate in the study and (b) are currently involved in similar studies.

2.3. Randomization and blinding

After baseline data collection, family caregivers were randomly assigned to either an intervention group or a control group, using a block size of four to ensure equivalent group sizes. Randomization also balanced the distribution of carer-care recipient relationships (spouse versus non-spouse carers) and the severity of dementia diagnosis (mild versus moderate cognitive impairment). Researchers who enrolled family caregivers provided these details to a statistician (JW) responsible for the randomization. The statistician, blinded to the participants, did not participate in the data analysis.

Sample size

In this study, the primary outcome was the health-related quality of life of family caregivers using the 12-Item Short-Form Health Survey (SF-12). The sample size was based on the results of a previous study²¹; the intervention group difference in SF-12 psychologically related score before and after the intervention was 2.389 ± 8.703 , while the control group was -2.528 ± 8.556 . The minimum detectable difference between the two groups was calculated as 4.917. The study involved a repeated measure count of 3, a group count of 2, a pooled variance of 8.631, and a correlation coefficient of 0.510. To detect mean differences between the intervention and control groups with a power of 80% and a two-sample comparison of means for $\alpha = 0.05$, 33 caregivers per group were required in this study (calculated by PASS 15.0.5). Allowing for a dropout rate of 20%, a total of 42 family caregivers per group was planned.

Intervention

Participants in the intervention group were provided a 3-month online support intervention. This intervention included course learning and a series of facilitator activities to promote caregivers' well-being. All interventions were conducted online. After the 3-month intervention period, there was a follow-up period of 3 months. During the follow-up period, participants were allowed to continue to study the online courses and could also discuss in the WeChat group. However, there were no additional facilitator activities. The specific details of the intervention were as follows:

(a) Based on the web-based iSupport learning: the iSupport consists of 5 modules with 23 lessons. The researcher acted as a facilitator to assist participants throughout the iSupport learning process, which included guiding participants through the website registration, helping them develop personalized learning plans, and regularly urging them to learn iSupport. Participants in the intervention group had the flexibility to arrange their own time and were encouraged to log in to the website for self-directed learning at least once a week.

(b) Facilitator activities: (1) Using the WeChat platform: The researchers used WeChat as the primary medium for daily communication with the participants. The participants were invited to join a WeChat group where they were encouraged to share their daily caregiving experiences and seek advice on caregiving-related issues, providing peer support to the participants; (2) Online Q&A: The researchers organized monthly online Q&A sessions to address questions from caregivers about issues learned in iSupport. Before the Q&A sessions, researchers would gather the participants' questions and provide them to the experts. Each Q&A session lasted approximately 45 minutes. After the session concluded, researchers uploaded the text of the Q&A to the website; (3) facilitators regularly encouraged participants to study: Facilitators sent course reminders through WeChat groups every week, reminding participants to study courses in their free time.

Participants in the control group received the usual care support. Researchers maintained regular interaction with participants in the control group through WeChat groups, where they shared relevant caregiving resources for family caregivers, such as accessing resources from the website of the Alzheimer's Disease Chinese (ADC) or receiving healthcare support available to PWD during medical visits. Additional online support was provided in addition to the iSupport program, which aimed to offer comprehensive assistance to participants in the control group. After the completion of the trial, all the iSupport courses and relevant resources were also provided to the caregivers in the control group.

Data collection

All data was collected through a Chinese online survey platform named WJX. Data collection was conducted at three-time points for both the intervention and control groups of family caregivers: baseline data before the intervention (T0), immediately after the intervention (T1, at the 3rd month), and three months after the intervention (T2, at the 6th month). *Table 1* presents the schedule used for the enrolment, interventions and assessments for the participants. All questionnaires were self-reported by the caregivers. Researchers provided one-on-one online guidance to family caregivers for completing the questionnaire and assisted whenever needed. Researchers also provided explanations for items that caregivers may find difficult to understand or were unsure about. After family caregivers had completed the questionnaire, the researchers reviewed it, confirming that there were no incomplete entries made by the caregivers.

Trained researchers conducted all guidance for the questionnaire filling process to ensure the reliability of data collection.

Outcomes

The primary outcome was Health-Related Quality of Life (HRQoL) measured by the 12-item Short-Form Health Survey (SF-12) with two dimensions, namely Mental Component Summary (MCS) and Physical Component Summary (PCS). The SF-12 scale was developed by Ware and Kosinski in 1996²². The MCS included four dimensions: Vitality (VT), Social Functioning (SF), Role-Emotional (RE), and Mental Health (MH). The PCS included Physical Functioning (PF), Role-Physical (RP), Bodily Pain (BP), and General Health (GH). In the 12 items, items 1, 8, 9, and 10 are reverse-scored questions. Each item is scored as follows: the first option is scored as 1 point, the second option as 2 points, the third option as 3 points, and so on. PCS includes items 1, 2, 3, 4, 5, and 8; MCS includes

items 6, 7, 9, 10, 11, and 12. The scoring method for the SF-12 was to add up the scores of the items included in each dimension to obtain the raw score for that dimension and then use the standardization formula to obtain the standardized score for each dimension. The PCS and MCS scores are the sum of the scores of the dimensions in each respective component. The scores ranged from 0 to 100. A higher score indicated a better quality of life. In this study, the Cronbach's α for the MCS and PCS were 0.76 and 0.81, respectively.

Table 1 Time schedule of enrolment, interventions and assessments for participants

	Time point	Enrolment	Allocation	T0/Baseline	Study Period					
					Intervention			Follow-up		
					1st month	2nd month	T1/3rd month	4th month	5th month	T3/6th month
Enrolment	General characteristics	×								
	Eligibility screen	×								
	Informed consent	×								
	Randomization		×							
Interventions	Web-based iSupport learning									
	Facilitator support									
	Online Q&A				×	×	×			
	Peer support									
Assessments	Caregiver QoL: SF-12			×			×			×
	Caregiver self-efficacy: RSCSE			×			×			×
	Caregiver social support: COPE Index-QS			×			×			×
	Dementia- related symptoms: RMBPC			×			×			×
	QoL for PWD: QOL-AD-Proxy			×			×			×

The secondary outcomes were caregiving self-efficacy, social support, and caregiving burden for caregivers; the dementia-related symptoms; and quality of life for PWD. The Revised Scale for Caregiving Self-Efficacy (RSCSE) was used to evaluate caregiving self-efficacy, and consists of three subscales: Self-Efficacy-Obtaining Respite (SE-OR), Self-Efficacy-Managing Disruptive Behaviors (SE-MB), and Self-Efficacy-Controlling Upsetting Thoughts (SE-CT), which was developed by Steffen et al.²³. There were 15 items on the scale. Each item was rated on a scale from 0% to 100%, with higher scores indicating greater confidence in completing the activity. In this study, the Cronbach's α for the SE-OR, SE-MB, and SE-CT subscales were 0.99, 0.99, and 0.98, respectively.

The Carers of Older People in Europe Index-Quality of Social Support (The COPE Index-QS) consisted of 15 items, including subscales for the positive impact of caregiving, the negative impact of caregiving, and quality of social support²⁴. In this study, only the subscale for quality of social support was used. The total score for the scale is the sum of the scores for the 5 items, ranging from 5 to 20. A higher score indicates a better social support. The Cronbach's α for the quality of social support was 0.78 in this study.

The Revised Memory and Behavior Problem Checklist (RMBPC) consisted of two subscales: the frequency of memory and behavior problems in the care recipient and the caregiving burden to these behaviors²⁵. It included 24 items, with each subscale further divided into three dimensions: memory-related problems, disruptive behaviors, and depression. This study used the frequency of memory and behavior problems in the care recipient to measure the dementia-related symptoms of PWD. Likert 5-level score was used in the scale. The frequency of memory and behavior problems subscale for care recipient was categorized as follows: 0 = never occurred, 1 = not in the past week, 2 = 1 to 2 times in the past week, 3 = 3 to 6 times in the past week, 4 = daily or more often, and 9 = do not know/not applicable. This categorization was based on the frequency of problems within the past week, and the family caregivers completed the scale. For the caregiver's burden to these behaviors subscale, items were classified according to the intensity of caregiver distress: 0 = not at all, 1 = a little, 2 = moderately, 3 = very much, 4 = extremely, and 9 = do not know/not applicable. The average score of each subscale was calculated. A higher score on the frequency of memory and behavior problems for the care recipient indicated more severe memory and behavior problems. Similarly, a higher score on the caregiver reaction indicated a higher caregiving burden. In this study, the Cronbach's α were 0.95 and 0.96, respectively.

The Quality of Life in Alzheimer's Disease (QOL-AD)-Proxy scale was used to measure the quality of life in PWD, developed by Logsdon et al.²⁶. Ai et al. translated it and applied the scale in the Chinese population. This scale was suitable for assessing the quality of life of people aged 65 and above with cognitive impairment at various stages. The scale comprised 13 items, each rated on a 4-point Likert scale, with a total score ranging from 13 to 52. Higher scores indicated a better quality of life. In this study, the (QOL-AD)-Proxy was completed by the primary caregiver of the PWD to assess their quality of life. The Cronbach's α was 0.84 in this study.

Data analysis

Data analysis was conducted using IBM SPSS STATISTICS 22.0. The data were analyzed based on intention-to-treat (ITT) principles. Descriptive statistics were used to describe the characteristics of the participants. The baseline outcome variables of the intervention and control groups were compared using the Chi-square exact test (for normally distributed data that is a categorical variable), the Mann-Whitney U test (for non-normal distributed or uneven variance data), and the independent t-test (for normally distributed data that is a continuous variable). Repeated measures analysis of variance was employed to examine the group effect (intervention vs. control), time effect (T0, T1, T2), and interaction effect (group \times time) for all outcome measures.

The study was utilized Python to implement the K-Nearest Neighbor (KNN) algorithm for the multiple imputation of missing values at T1 and T2. KNN involved the fundamental approach of identifying the K nearest neighbors to a given test sample based on a selected distance metric. The algorithm fit on the training set by finding the K samples closest to the test sample, followed by predicting missing values based on these K nearest neighbors.

Ethical considerations

The study was approved by the Ethics Committee of Health Science Center, Xi' an Jiaotong University (Project number: 2017-704) (for the anonymized review). The study was conducted online, and data collection was carried out after the participants signed the informed consent. Each participant was provided with comprehensive details regarding the study, its possible risks and advantages. Involvement was optional, ensuring both privacy and anonymity.

Results

Recruitment and retention

Figure 1 displays the flow of participants through the study. Totally 96 family caregivers were assessed for eligibility, and 81 were randomized to the intervention group or the control group. The smaller sample size than originally planned was due to the COVID-19 restrictions that were implemented before the completion of recruitment. Three participants in the intervention group did not complete their immediate post-intervention assessments, and nine did not complete the three months post-intervention. In the control group, four family caregivers did not complete the post-intervention data collection (T1), and eight participants did not complete their three months post-intervention assessments (T2) because four PWDs died and four caregivers could not be reached.

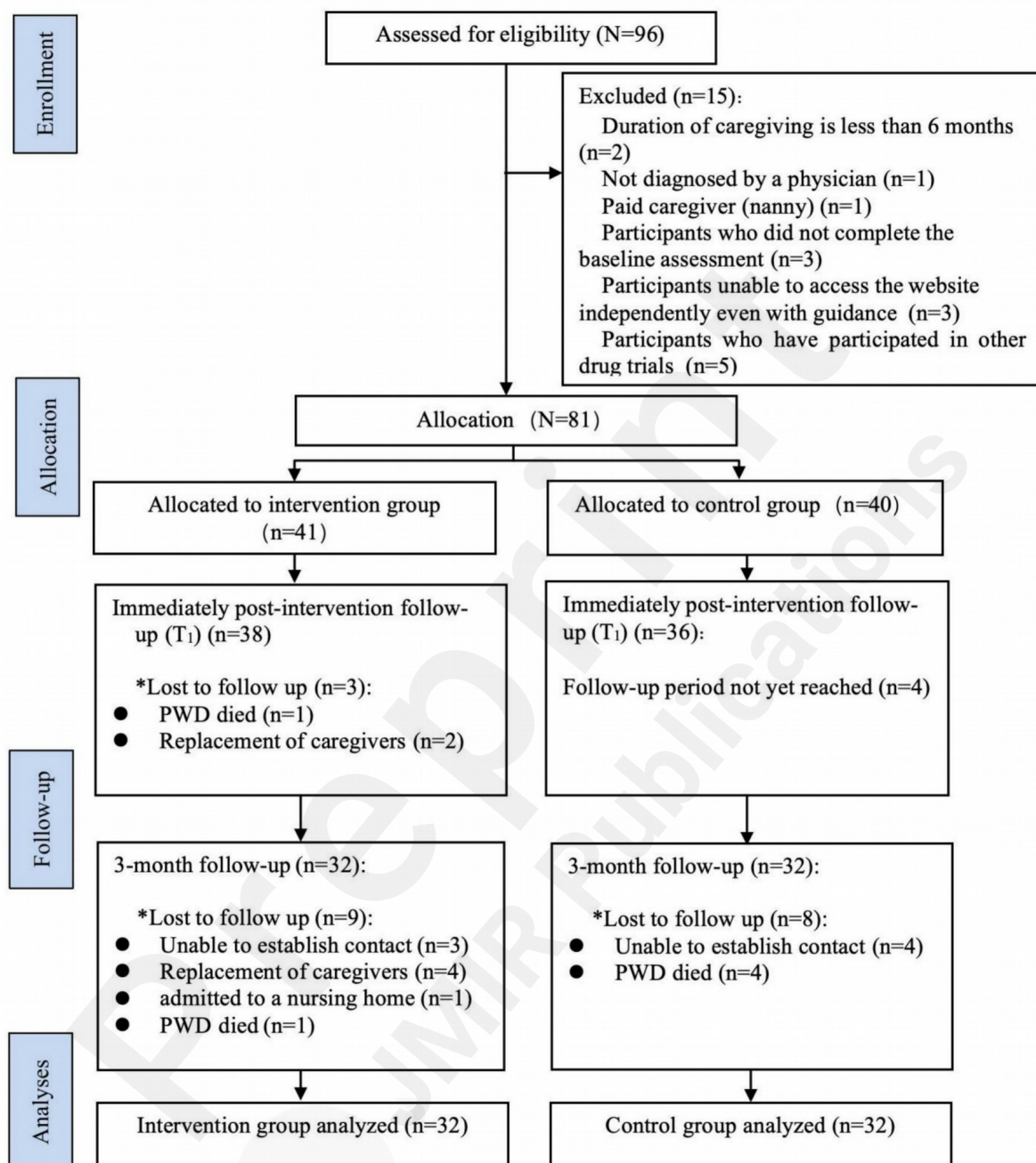


Figure 1 Study flow diagram

Characteristics of the participants

The baseline characteristics of family caregivers are reported in *Table 2*. The mean age of the caregivers was 44.26 (SD = 12.20). Most caregivers (75.3%) were sons or daughters of the care recipients. Most caregivers (66.7%) lived with the PWD, and they spent an average of 9.94 hours per day providing care. No statistically significant differences existed between the intervention and control groups' caregivers in age, gender, relationship with PWD and other characteristics ($p > 0.05$).

Table 3 shows the PWD baseline characteristics. The mean age of the PWD was 73.96 (SD = 10.27). More than half of the PWD had been diagnosed with Alzheimer's disease. There were no statistically significant differences between the intervention and control groups' PWD in age, gender, type of dementia and other characteristics ($p > 0.05$).

Primary outcome

Table 4 and *Figure 2* present the changes in HRQoL in the two groups at T0 (baseline), T1 (at the 3rd month), and T2 (at the 6th month). Family caregivers in the intervention group experienced significant improvements in MCS. The score of the MCS for the intervention group was 46.39 (SD = 8.98) at T2, which was significantly higher than that at T1 (M = 42.15, SD = 11.6), and 37.42 (SD = 11.1) at T0. The score increased over time, especially during T0 to T2 (mean difference = -4.27, SE = 0.95) and T1 to T2 (mean difference = -2.45, SD = 0.55) in the intervention group. At the 6th month (T2), the MCS scores between the intervention and control groups were confirmed to be a statistical difference ($p < 0.05$). No significant difference was observed between the two groups of participants in PCS

Table 2 Caregivers demographic characteristics n (%)

Demographic characteristics		Participants (N=81)	Intervention group (n=41)	Control group (n=40)	t/X ²	p
Age (years)	X±s	44.26±12.20	43.44±13.07	45.10±11.35	-0.610 ^a	0.54
Gender	Male	24 (29.6)	8 (19.5)	16 (40.0)	4.076 ^b	0.05
	Female	57 (70.4)	33 (80.5)	24 (60.0)		
Relationship with PWD	Spouse	6 (7.4)	4 (9.8)	2 (5.0)	7.952 ^c	0.12
	Son	21 (25.9)	6 (14.6)	15 (37.5)		
	Daughter-in-law	5 (6.2)	3 (7.3)	2 (5.0)		
	Daughter	40 (49.4)	22 (53.7)	18 (45.0)		
	Grandchildren	8 (9.9)	6 (14.6)	2 (5.0)		
	Nephew	1 (1.2)	0(0.0)	1 (2.5)		
Live with PWD	No	27 (33.3)	17 (41.5)	10 (25.0)	2.470 ^a	0.15
	Yes	54 (66.7)	24 (58.5)	30 (75.0)		
Caregiving (years), mean (SD)	X±s	3.58±3.82	3.51±4.72	3.65±2.67	-0.161 ^a	0.87
Caregiving (days/week), mean (SD)	X±s	5.90±2.16	5.73±2.13	6.05±2.21	-0.660 ^a	0.51
Caregiving (years), mean (SD)	X±s	9.94±8.44	11.51±9.04	8.32±7.55	1.723 ^a	0.08
Marital status	Married	60 (74.1)	28 (68.3)	32 (80.0)	4.846 ^c	0.13
	Single	13 (16.0)	10 (24.4)	3 (7.5)		
	Divorced	6 (7.4)	2 (4.9)	4 (10.0)		
	Widow	2 (2.5)	1 (2.4)	1 (2.5)		
	Employed	48 (59.3)	24 (58.5)	24 (60.0)		
Employment status	Retired	14 (17.3)	7 (17.1)	7 (17.5)	2.528 ^c	0.48
	Unemployed	10 (12.3)	7 (17.1)	2 (5.4)		
	Others	9 (11.1)	3 (7.3)	6 (16.2)		
	No formal education	1 (1.2)	1 (2.4)	0 (0.0)		
Education	Primary school	1 (1.2)	0 (0.0)	1 (2.5)	6.478 ^c	0.33
	Junior high school	8 (9.9)	5 (12.2)	3 (7.5)		
	Senior high school	10 (12.3)	4 (9.8)	6 (15.0)		
	Vocational education (10 – 12 years)	17 (21.0)	12 (29.3)	5 (12.5)		
	Bachelor's degree	33 (40.7)	14 (34.1)	19 (47.5)		
	Master's degree and above	11 (13.6)	5 (12.2)	6 (15.0)		
Number of chronic conditions	None	60 (74.1)	30 (73.2)	30 (75.0)	2.297 ^c	0.61
	One chronic condition	16 (19.8)	7 (17.1)	9 (22.5)		
	Two chronic conditions	2 (2.5)	2 (4.9)	0 (0.0)		
	Three or more chronic conditions	3 (3.7)	2 (4.9)	1 (2.5)		

Note^a t test; ^b Pearson X² ^c Fisher exact probability



Table 3 PWD demographic characteristics n (%)

Demographic characteristics		PWD (N=81)	Intervention group (n=41)	Control group (n=40)	t/X ²	p
Age (years)	X±s	73.96±10.27	73.51±10.46	74.43±10.18	0.165 ^a	0.692
Gender	Male	28 (34.6)	12 (29.3)	16 (40.0)	1.031 ^b	0.356
	Female	53 (65.4)	29 (70.7)	24 (60.0)		
Education	No formal education	13 (16.0)	5 (12.2)	8 (20.0)	7.712 ^c	0.245
	Primary school	17 (21.0)	11 (26.8)	6 (15.0)		
	Junior high school	14 (17.3)	8 (19.5)	6 (15.0)		
	Senior high school	14 (17.3)	5 (12.2)	9 (22.5)		
	Vocational education (10 – 12 years)	9 (11.1)	7 (17.1)	2 (5.0)		
	Bachelor's degree	12 (14.8)	4 (9.8)	8 (20.0)		
	Master's degree and above	2 (2.5)	1 (2.4)	1 (2.5)		
	Others	2 (2.5)	1 (2.4)	1 (2.5)		
Type of dementia	Alzheimer's disease	41 (50.6)	20 (48.8)	21 (52.5)	0.565 ^c	1.000
	Vascular dementia	9 (11.1)	5 (12.2)	4 (10.0)		
	Mixed dementia	6 (7.4)	3 (7.3)	3 (7.5)		
	Not clear	23 (28.4)	12 (29.3)	11 (27.5)		
Stage of dementia development	Mild	19 (23.5)	11 (26.8)	8 (20.0)	3.784 ^b	0.305
	Moderate	28 (34.6)	15 (36.6)	13 (32.5)		
	Serious	19 (23.5)	6 (14.6)	13 (32.5)		
	Not clear	15 (18.5)	9 (22.0)	6 (15.0)		
Number of chronic conditions	None	39 (48.1)	17 (41.5)	22 (55.0)	3.026 ^c	0.393
	One chronic condition	24 (29.6)	12 (29.3)	12 (30.0)		
	Two chronic conditions	7 (8.6)	4 (9.8)	3 (7.5)		
	Three or more chronic conditions	11 (13.6)	8 (19.5)	3 (7.5)		

Note^a t test; ^b Pearson X² ^c Fisher exact probability

Table 4 Impact of the intervention on primary outcome at three time-points test (N=81)

Outcomes	Time point			Group		Time		Group×Time	
	T ₀	T ₁	T ₂	F	p	F	p	F	p
SF-12									
PCS									
Intervention group	46.63±9.37	47.92±8.06	48.19±7.58	0.014	0.908	0.295	0.745	1.314	0.275
Control group	47.81±9.00	47.1±8.61	47.18±9.18						
MCS									
Intervention group	37.42±11.1	42.15±11.6	46.39±8.98	2.300	0.137	7.929	0.001	18.927	□0.001
Control group	40.05±11.89	38.97±9.24	38.01±8.16						

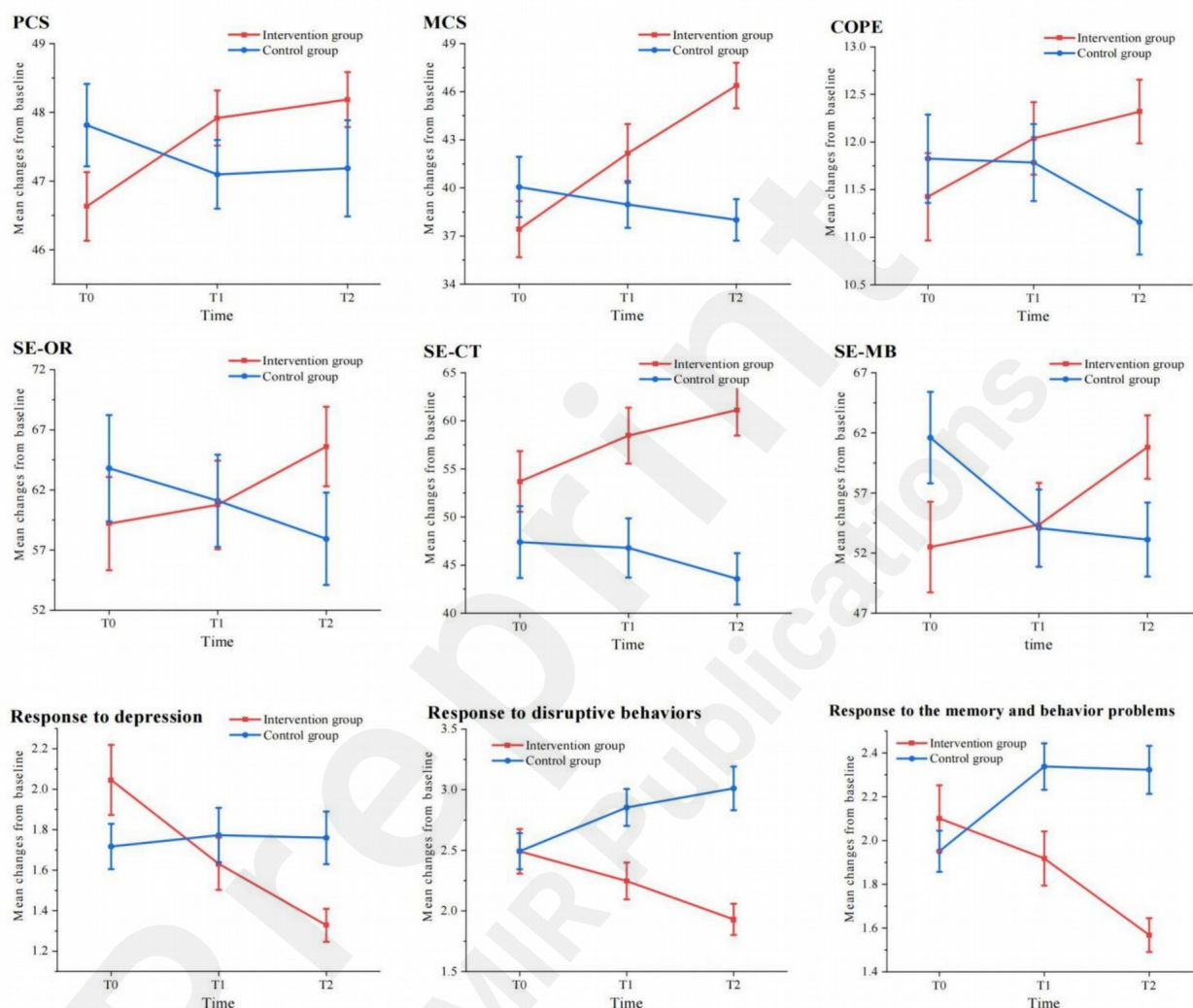


Figure 2 Mean changes form baseline of family caregivers

Secondary outcomes for family caregivers

The secondary outcome measures as shown in *Table 5* and *Figure 2*, the caregiving self-efficacy of SE-OR, SE-MB, SE-CT over time were significantly higher in the intervention group compared to the control group. The intervention group also showed significantly lower scores on the caregiver's response to the memory and behavior problems of PWD at T1 and T2 compared with the control group ($F = 14.730\text{--}32.170$, all $p < 0.001$). Moreover, for social support, significant interaction effects were found ($F = 8.234$, $p < 0.001$).

Secondary outcomes for PWD

No significant differences over time were found for the PWD in the intervention and control groups for the outcome measures of memory-related problems ($p = 0.090$; *Table 6*

and *Figure 3*), disruptive behaviors ($p=0.318$), depression ($p=0.087$) and quality of life ($p=0.241$). However, a statistically significant primary effect for the group factor was observed for quality of life of PWD ($F=5.953$, $p=0.241$), whereas a statistically significant primary effect for the time factor was observed for memory-related problems ($F=9.887$, $p<0.001$) and quality of life ($F=11.593$, $p<0.001$).

Table 5 Impact of the intervention on secondary outcomes for caregivers at three time-points test (N=81)

Outcomes	Time point			Group		Time		Group×Time	
	T ₀	T ₁	T ₂	F	p	F	p	F	p
The COPE Index-QS									
Intervention group	11.43±2.9	12.04±2.41	12.32±2.12	0.419	0.521	1.302	0.278	8.234	0.001
Control group	11.83±2.93	11.79±2.56	11.16±2.16						
RSCSE									
SE-OR									
Intervention group	59.2±24.53	60.76±23.28	65.61±20.96	0.066	0.799	0.229	0.796	7.249	0.001
Control group	63.8±27.92	61.11±24.27	57.94±24.31						
SE-MB									
Intervention group	52.5±23.83	54.36±22.03	60.83±16.68	0.007	0.936	2.389	0.098	13.394	0.001
Control group	61.6±24.06	54.08±20.3	53.13±19.44						
SE-CT									
Intervention group	53.7±19.93	58.46±18.36	61.14±16.81	0.007	0.936	2.389	0.098	13.394	0.001
Control group	47.4±23.64	46.8±19.4	43.58±16.86						
The caregiver's response to the memory and behavior problems of PWD									
Memory-related problems									
Intervention group	2.1±0.96	1.92±0.78	1.57±0.48	6.529	0.015	5.094	0.008	32.170	□0.00
Control group	1.95±0.6	2.34±0.67	2.32±0.69						
Disruptive behaviors									
Intervention group	2.49±1.17	2.25±0.96	1.93±0.82	9.131	0.004	0.399	0.673	19.753	□0.00
Control group	2.49±0.94	2.85±0.96	3.01±1.14						
Depression									
Intervention group	2.05±1.09	1.63±0.82	1.33±0.51	0.266	0.609	7.717	0.001	14.73	□0.00
Control group	1.72±0.71	1.77±0.85	1.78±0.82						

Table 6 Impact of the intervention on secondary outcomes for PWD at three time-points test (N=81)

Outcomes	Time point			Group		Time		Group×T	
	T ₀	T ₁	T ₂	F	p	F	p	F	
The memory and behavior problems of PWD									
Memory-related problems									

Intervention group	3.97±1.08	4.28±0.91	4.31±1.06	0.027	0.871	9.887	□0.001	2.480	0
Control group	4.04±0.92	4.44±0.71	4.37±0.94						
Disruptive behaviors									
Intervention group	2.56±0.97	2.6±1.04	2.41±0.85	0.139	0.712	2.426	0.095	1.161	0
Control group	2.45±1.07	2.73±1.1	2.61±1.08						
Depression									
Intervention group	2.88±1.00	2.85±1.06	2.67±0.97	2.304	0.137	0.841	0.435	2.519	0
Control group	2.37±1.04	2.6±1.00	2.54±1.07						
QOL-AD									
Intervention group	25.23±5.39	25.98±4.51	23.96±3.71	5.935	0.02	11.593	0.001	1.450	0
Control group	23.55±5.43	22.86±4.90	21.53±4.58						

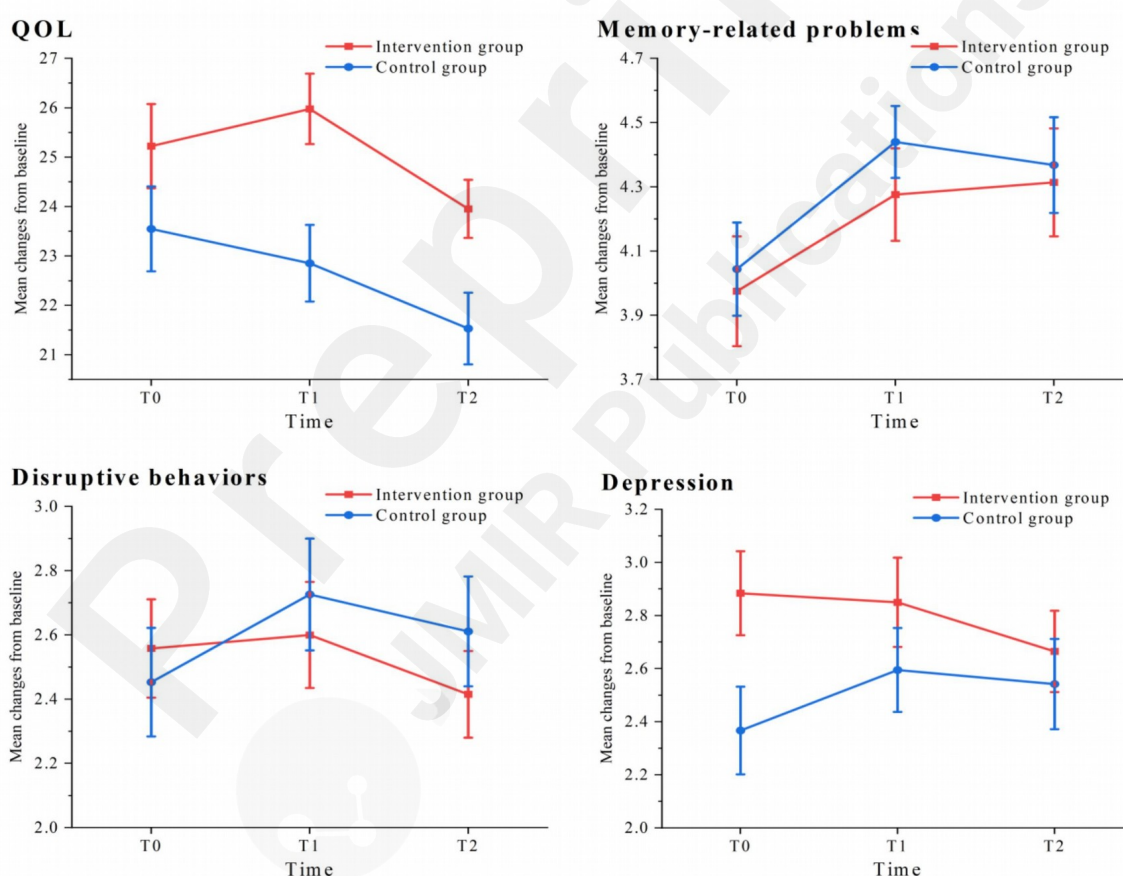


Figure 3 Mean changes form baseline of PWD

Discussion

Principal Results

To the best of our knowledge, this study is the first to evaluate the effectiveness of the web-based WHO iSupport program among Chinese family caregivers of PWD. The adoption of multiple data collection time-points in this study was implemented to assess

whether outcomes were improved and whether any changes observed were sustained over time. Our results indicated that WHO iSupport program enhanced the mental component summary of HRQoL, caregiving self-efficacy and social support of caregivers, which can also improve the quality of life of PWD. Although it did not decrease the memory and behavior problems of PWD, the caregiver's response to those problems of PWD has been improved.

Our first key finding was that the mental component summary of HRQoL among participants in the intervention group was significantly improved. This result is supported by a recent study¹¹, suggesting that educational support to caregivers delivered via online platforms, information handbooks, and chats can improve health outcomes for caregivers. Specifically, tailored interventions have been found to be significantly more effective in improving health-related behaviors compared to non-tailored interventions²⁷. However, there were no statistically significant differences in the PCS and MCS between the intervention and control groups. This finding is consistent with previous web-based studies with an intervention duration of 3-4 months^{11,28}. The PCS of HRQoL for caregivers is closely linked to their physical health status. It is important to note that significant changes in the caregiver's physical health through short-term support interventions can be challenging to achieve. Torkamani et al.²⁹ reported no statistically significant differences in the quality of life between the two groups of caregivers of PWD after a three-month web-based intervention. However, a remarkable enhancement in the caregivers' quality of life was observed when the intervention persisted for six months. Furthermore, the enhanced mental-health-related QoL in our study contrasted with the study by Teles et al.³⁰ in Portugal, where only the iSupport manual was part of the intervention, and the results showed no impact on the quality of life of caregivers. The results of our study and the study by Teles et al. indicated the necessity of integrating the iSupport manual with additional intervention contents, such as the assistance of facilitators and healthcare workers, given the positive factors influencing caregivers' quality of life³¹.

The study indicated that the web-based iSupport program effectively improved self-efficacy in family caregivers of PWD. This result is similar to the prior study³², which found that virtual education programs increased family caregiver's self-efficacy over follow-up compared with controls. There are four ways to achieve self-efficacy: enactive mastery experience, vicarious experience, verbal persuasion, and physiological and affective states to improve self-efficacy³³. We tailored the personalized intervention plans for participants based on their individual needs, assisting them in acquiring dementia knowledge, which helps them gain enactive mastery experience. We also encouraged participants to communicate with peers via the WeChat, enabling them to obtain vicarious experience. Professionals provided support and assistance to participants through verbal persuasion, physiological and affective support. However, no statistically significant effect was observed for the group factor and time factor for the three dimensions of self-efficacy, but the mean scores of the SE-OR, SE-MB, and SE-CT showed a non-significant increase. This result is consistent with a recent study from India⁴. This observation could be attributed to the relatively short duration of the intervention and insufficient professional support. While this study provided professional support for

family caregivers, it was only provided to participants at a scheduled time each month due to limited human resources. Studies have shown that involving clinicians in interventions and providing online contact with a professional can improve outcomes and increase participant retention^{4,34}. In terms of study design for future trials, more online professional guidance could be provided to participants. Moreover, the intervention duration could also be extended.

The present study also revealed the benefits of social support for caregivers, evinced as an increase in social support for the intervention group vs. the control group after their 3-month and 3-month follow-up. This result is consistent with a recent systematic review, which found that providing web-based interventions for caregivers significantly improved their social support³⁵. Support from family members and friends can effectively alleviate the stress experienced by caregivers, which could promote their psychological well-being and alleviate their caregiving burden³⁶. Although social support is important for family caregivers, they often choose to ignore the help due to various factors such as time constraints and stigmatization. Therefore, researchers should prioritize guiding caregivers to recognize their need for support and enhancing their opportunities to access social support when formulating intervention strategies³⁷. In this study, we not only provided peer support and professional assistance through WeChat for participants, but also encouraged them to actively seek support during their learning ("The journey together" & "Involving others"). Furthermore, participants may have concerns about personal privacy breaches and potential security risks, leading them to refuse to communicate with unfamiliar individuals. Therefore, it is recommended that personal account login passwords and nicknames be incorporated to protect participants' privacy.

For PWD, the memory and behavior problems did not show significant time by group interactions; only memory-related problems showed a significant decrease over time. In this study, the intervention played a minimal role in reducing the disruptive behaviors and depression of PWD. Although iSupport offered extensive methods for family caregivers on how to cope with the behavioral changes of PWD, these methods did not have a "therapeutic" effect but rather focus on "coping". Therefore, those conditions of PWD were not alleviated. Behavioral and psychological symptoms of dementia (BPSD) are the most complex and stressful symptoms faced by PWD and their family caregivers³⁸. In the absence of medical intervention, the BPSD among PWD is likely to deteriorate progressively. The existing treatments include drug therapy and non-drug therapy. During the inclusion of participants in this study, there was no requirement for PWD to be undergoing medication treatment, and no non-pharmacological interventions for PWD were provided during the intervention, which may be a reason for the lack of significant improvement in the memory and behavior problems of PWD. The WHO guidelines of "Risk reduction of cognitive decline and dementia" state that both non-pharmacological and pharmacological treatments play an important role in alleviating BPSD symptoms of PWD¹⁸. Therefore, future studies should guide family caregivers in acquiring knowledge about pharmacological treatment and incorporate non-pharmacological interventions in which PWD can participate.

Although PWD did not experience a reduction in BPSD, there was a significant decrease in the caregiving burden across three dimensions of the PWD's memory and behavior problems during the three-month intervention and three-month follow-up, which deduced that caregiving burden did not directly correlate with the severity of the PWD's symptoms. Proper psychological training continued to be efficient in reducing the caregiving burden for families with people suffering from severe dementia. Facilitators provided comprehensive support and guidance to them throughout, helping them apply knowledge to practice. Participants in the intervention group were introduced how to deal with ten common BPSD in PWD, including aggressive behavior, depression, anxiety and so on, which contributes to enhancing caregivers' coping abilities, boosting their confidence in managing the BPSD of PWD and alleviating their negative emotions²⁷. However, alleviating BPSD in PWD is not an overnight process. Family caregivers need to put the knowledge they have learned into practice, which takes time and requires more practice. Therefore, in subsequent interventions, researchers should focus on helping participants translate theory into practice and apply what they have learned to help PWD reduce their BPSD symptoms.

For the quality of life for PWD, a statistically significant decrease in the group factor and time factor was observed, but it did not show a significant time by group interaction. This result is consistent with Birkenhäger-Gillesse et al.³⁹. The Quality of Life Group of the World Health Organization has shown that the quality of life of individuals is influenced by various factors, including the physical component, psychological component, social relationships, and cultural contexts⁴⁰. In our study, most PWD did not only suffer from dementia but also had other chronic diseases, with 51.9% of them having at least one chronic disease. Chronic disease may also hurt the quality of life for PWD. Song et al. have confirmed that sleep disturbances in PWD are associated with a lower quality of life⁴¹. Kang et al.⁴² have shown that the depression level of PWD was positively correlated with the quality of life. Therefore, improving PWD's quality of life requires comprehensive consideration of all aspects. In future studies, researchers could comprehensively provide participants with caregiving knowledge to enhance the quality of life for PWD, helping them address the physiological, psychological, and external factors influencing their lives. Simultaneously, the learning content should be practical, straightforward, and presented in a manner that is easy to understand. Enhancing the readability of the learning content can also be achieved through video, audio, and image, which may facilitate participants in applying the theoretical knowledge learned to their daily caregiving practices.

Limitations

The limitations of this study include the following. First, due to the impact of COVID-19, the recruitment of participants is exclusively conducted through online platforms. Despite having sufficient family caregivers WeChat groups available for recruitment, the process has proven much more challenging than anticipated. Researchers never had face-to-face contact with caregivers, resulting in their lack of strong trust. Some caregivers refused to participate in the project due to the privacy and stigma concerns. However, even so, the results still show a positive impact on the participants, providing a good reference for

future studies that adopt online interventions due to the inability to conduct face-to-face interventions. Second, most participants resisted participating in video meetings and preferred receiving personalized support from healthcare professionals through text or voice messages on WeChat, which may be attributed to participants feeling a sense of embarrassment or hesitation when interacting with researchers they have never met before. While these messages can provide support for caregivers, they may impact the effectiveness of peer and professional support. Therefore, before the beginning of the study, researchers should arrange face-to-face ice-breaking activities for the participants, reducing their concerns and fostering their trust in each other. Finally, most participants learn the iSupport courses through their mobile phones. The Chinese iSupport website was initially developed based on computer devices and was not adapted for mobile, which may potentially reduce participants' learning experience. Therefore, the improvements and modifications to the website will be made based on caregivers' feedback. In the future, iSupport can be transformed into audio and video versions, providing support for more family caregivers that meets their personalized needs, which may enhance the accessibility of the Chinese version of iSupport.

Conclusions

iSupport is an online and self-guided program developed by the WHO. It aims to provide education, skills training, and social support to caregivers who are experiencing stress, burden, and mild to moderate symptoms of depression or anxiety. iSupport could enhance the mental health of HRQoL, social support, self-efficacy and caregiving burden of family caregivers, while also assisting in alleviating the decline of quality of life for PWD after 3 months of follow-up. However, the impact of iSupport on the memory and behavior problems of PWD is limited, and requires further investigation. Our results suggest that researchers should extend the study period for participants and provide them with tutors to enhance the intervention's effectiveness in future research. When providing online interventions for family caregivers, researchers should integrate treatment, rehabilitation, and caregiving to delay the progression of PWD and reduce the caregiving burden. Additionally, our results suggest optimizing online intervention models, such as protecting participants' privacy and adding audio-visual resources, to increase participants' trust and applicability.

Acknowledgments

This study was supported by the National Social Science Fund of China (grant number 20XRK004) and the National Foundation for Australia-China Relations through National Foundation for Australia-China Relations 2020-21 Competitive Grants Program (NFACR216). We would like to thank all the family caregivers who participated in this study.

Authors' Contributions

DX contributed to writing—original draft, writing—review & editing, project administration, investigation, and formal analysis. JH contributed to writing—original draft, writing—review & editing, project administration, formal analysis, and investigation. JW contributed to writing—review & editing, supervision, conceptualization, funding acquisition, and methodology. JW contributed to visualization,

resources, and project administration. LX contributed to methodology, and project administration. CG contributed to resources. JM contributed to software.

Conflicts of Interest

None declared.

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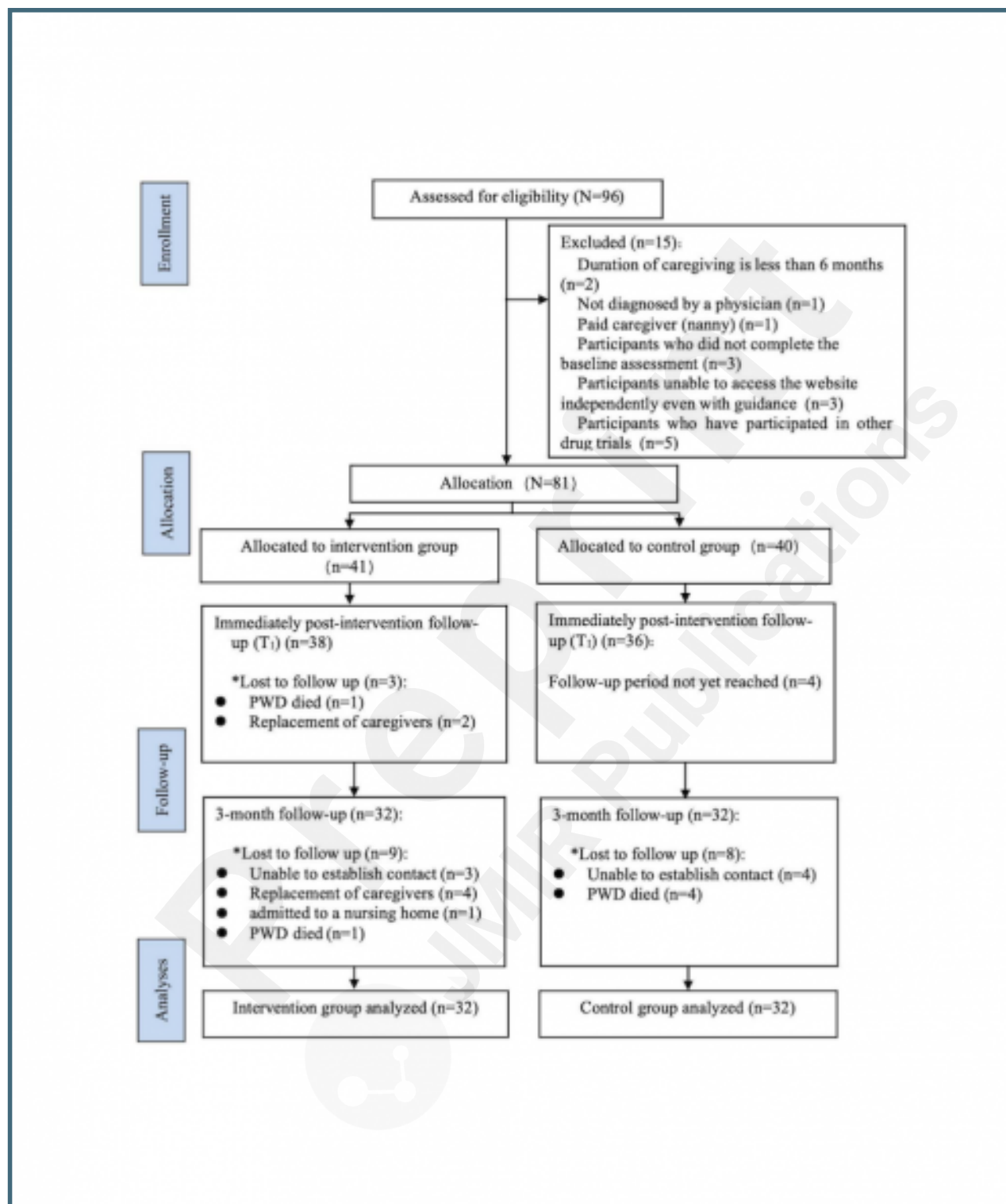
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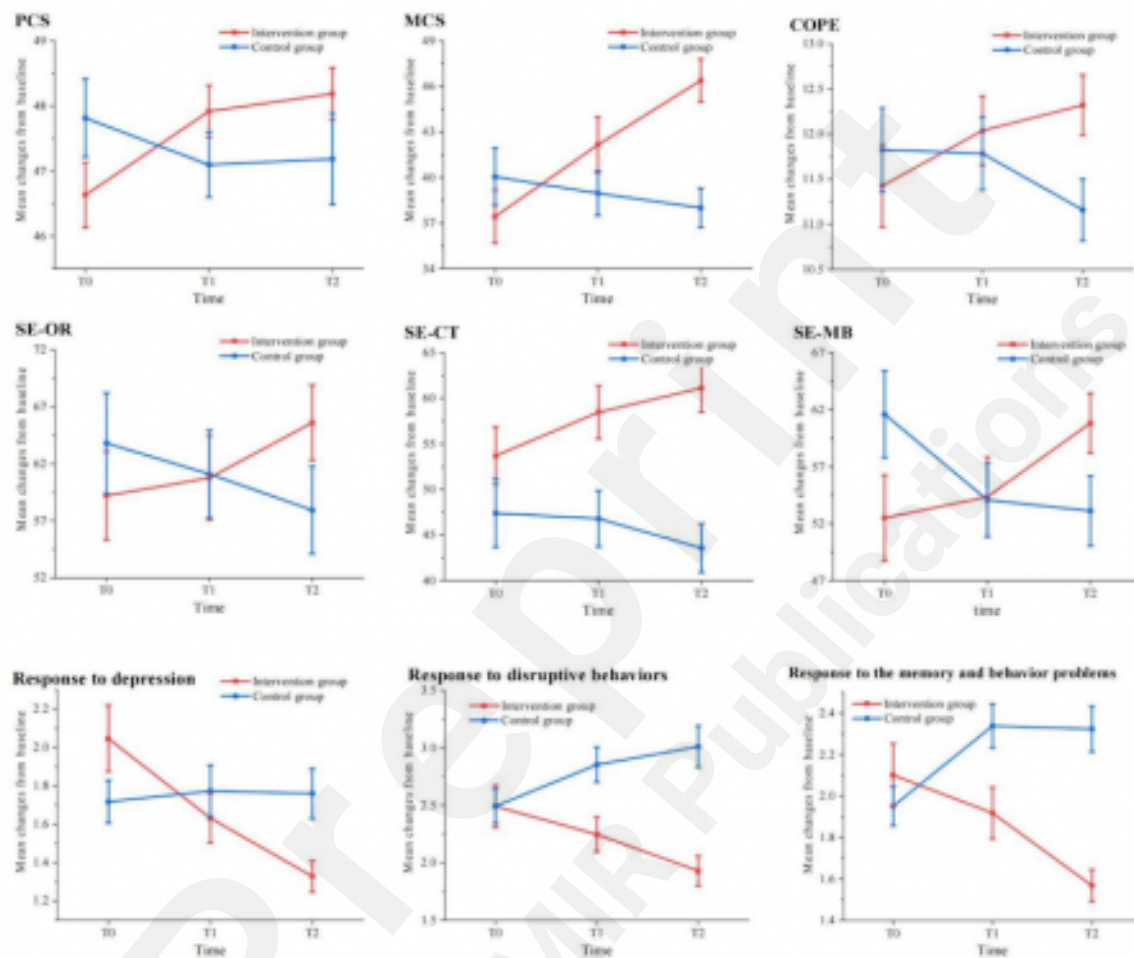
Supplementary Files

Figures

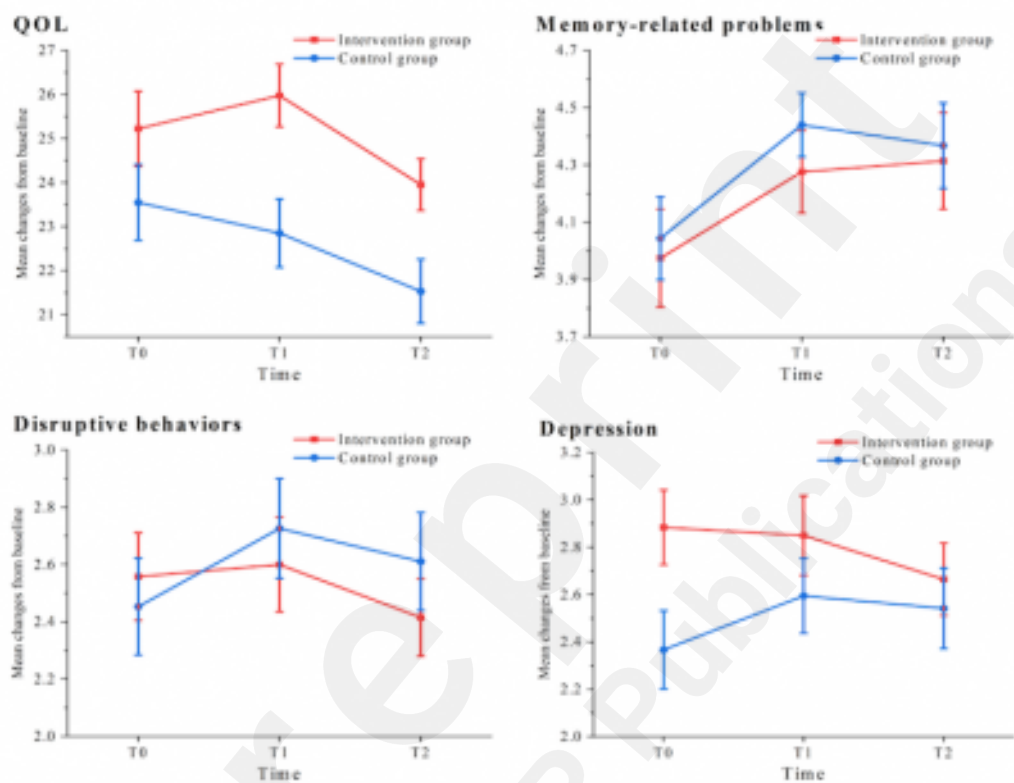
Study flow diagram.



Mean changes form baseline of family caregivers.



Mean changes form baseline of PWD.



CONSORT (or other) checklists

Supplementary 1.

URL: <http://asset.jmir.pub/assets/a1a2b2e966c5c38cfd8263a388481a9c.pdf>

