# A tailored iSupport virtual group intervention for Chinese dementia carers living in New Zealand: study protocol for a pilot randomised controlled trial

**Researcher team:**

Fei Li: PhD candidate in the School of Nursing, Faculty of Medical and Health Sciences, University of Auckland.

Dr John Parsons: Associate Professor in the School of Nursing, Faculty of Medical and Health Sciences, University of Auckland.

Dr Gary Cheung: Senior Lecturer in psychiatry at the University of Auckland and specialist psychogeriatrician at Auckland DHB.

Abstract

Background: An iSupport programme was developed to provide knowledge, skills training, and support for dementia carers. Current iSupport online programmes trials reported a low adherence rate, and their efficacy is uncertain. To address these research gaps, we developed an iSupport virtual group intervention to improve or maintain the mental well-being of dementia carers based on a participant-centred approach. However, no randomised controlled trial (RCT) has utilised this intervention for Chinese dementia carers. Thus, this study will evaluate the feasibility of this intervention in a pilot RCT.

Methods: This 12-week, single-blind, parallel-group, mixed-methods pilot RCT will evaluate the feasibility of iSupport virtual group intervention in Chinese dementia carers. Twenty-four participants will be included and randomly allocated to the control group (n = 12) and the intervention group (n = 12). The intervention group will receive a 1.5-hour weekly virtual group intervention for 12 weeks, whereas the control group will receive the iSupport manual for self-learning. Feasibility outcomes and preliminary impacts on stress, social support, quality of life, burden, culture, and resilience will be assessed.

Discussion: This pilot study will explore the feasibility of the iSupport virtual group intervention to improve or maintain the mental well-being of Chinese dementia carers. The findings from this intervention study will provide evidence for intervention refinements and will inform the development of a full-powered RCT.

**Key Words:** Dementia, family carers; virtual group intervention; mental wellbeing; a pilot study

# Introduction

Dementia is one of the leading causes of morbidity in the world (GBD 2019 Collaborators., 2021), and the number of people living with dementia (PLwD) is expected to reach 152 million by 2050 (Livingston et al., 2020). The progressive nature of dementia in terms of cognitive and functional impairment indicates that there is an increasing need for assistance in caring for PLwD. Additionally, the long-term care for PLwD is typically dependent on family carers including PLwD’ spouses, children, or other family members(Brodaty & Donkin, 2009). As a result, caring for PLwD is a highly stressful role that may lead to a decline in mental and physical wellbeing, and quality of life (QoL) among dementia carers. A number of dementia carers suffer from a high level of depression(Alfakhri et al., 2018; Jang et al., 2016), anxiety(Messina et al., 2022), burden (Baharudin et al., 2019; Zhang et al., 2018), stress(Messina et al., 2022), strain (Zhang et al., 2018), etc. In addition, less than half of dementia carers reported receiving adequate dementia information when their care recipients were diagnosed with dementia (Gauthier S, Rosa-Neto P, Morais JA, 2021). To minimise negative mental health outcomes and a lack of dementia information, various interventions have been developed for dementia carers, such as multicomponent interventions (Abrahams et al., 2018), online support programmes (Egan et al., 2018; Leng et al., 2020), and psychosocial interventions (Wiegelmann et al., 2021).

The generic version of iSupport was developed by the World Health Organization based on Kitwood’s person-centred care, problem-solving and cognitive behavioural therapy techniques. It provides knowledge, skills training, and support for dementia caregivers (T. A. Nguyen et al., 2021). The iSupport manual has been translated into 11 languages (Hindi, Chinese, Portuguese, Maori, Japanese, Brazilian, Bahasa, Vietnamese, Swedish, Greek, and Dutch) (Baruah et al., 2020; Efthymiou et al., 2022; Egan et al., 2018; Fiordelli & Albanese, 2020; L. Nguyen et al., 2021; Oliveira et al., 2020; Pot et al., 2019; Teles et al., 2020; L. D. Xiao et al., 2022). Furthermore, the online or web-based iSupport programme was developed to address the limited dementia carer workforce in developing countries and to provide an e-platform for dementia carers’ self-learning (Pot et al., 2019). Four ongoing trials (T. A. Nguyen et al., 2021; Pinto-Bruno et al., 2019; Teles et al., 2022; L. D. Xiao et al., 2022) have adopted the web-based iSupport programme to improve dementia carers’ mental wellbeing, social support, self-efficacy, attitude, and quality of life (QoL). These trials are classified into two types: web-based iSupport intervention alone and web-based iSupport intervention with additional support (e-coach, peer-support, or virtual carer support). A study in India using a single web-based iSupport intervention for dementia carers found that except for attitude there were no positive effects on their mental wellbeing, QoL, or self-efficacy for dementia carers (Baruah et al., 2021). A Portuguese study reported the positive effects of the online iSupport intervention on anxiety and environmental QoL (Teles et al., 2022). However, both studies revealed a low retention rate, suggesting they either lacked adequate motivation strategies for the dementia carers when implementing the iSupport programme or lacked sufficient online and offline support for the dementia carers.

Impacted by the COVID-19 pandemic and social restrictions, the internet-based intervention appears to be a safe, feasible, and potentially cost-effective option when providing support for dementia carers (Cuffaro et al., 2020). However, there are several barriers to sustaining long-term adherence to the online intervention, including time constraints, competing priorities, anxiety about spending time on the computer, perception of the limited worth of the intervention(Donkin & Glozier, 2012), disappointment and frustration (Dam et al., 2019). To increase motivation and adherence, several strategies have been proposed based on previous evidence, including supervision, tailoring, prompts, remote feedback, goal setting, and memory aids (Donkin & Glozier, 2012; Harwood et al., 2018; Western et al., 2021). These strategies will be used to develop a virtual group intervention for Chinese dementia carers in this study.

This current iSupport virtual group intervention contains several strategies to enhance the mental wellbeing of Chinese dementia carers. These strategies include motivation, cultural appreciation, problem-solving skills, dementia information, as well as social support services. The iSupport manual has been translated into Chinese and adapted to Chinese living in Australia. To ensure that this Australian Chinese version of the iSupport manual is suitable for use in New Zealand (NZ), we have checked for its usability with Chinese dementia carers living in NZ. We kept the core structure and content of the iSupport manual but replaced the information on local dementia services.

Although web-based iSupport intervention has been evaluated in several studies, the effects of the iSupport virtual group intervention have not yet been examined. Therefore, a pilot study will be conducted to determine whether the virtual group intervention is suitable for future use. We will collect feasibility data that will contribute to the new knowledge of how to implement this virtual group intervention. The feasibility findings will be used to determine how and in which contexts this intervention may be effective. This study proposes to (i) develop and evaluate the iSupport virtual group intervention for Chinese dementia carers; (ii) explain the intervention process, and (iii) determine the important factors for a future full-powered RCT.

# Methods

## Design

This is a 12-week, prospective, single-blind, parallel-group, mixed-methods pilot RCT comparing two groups: the iSupport virtual group intervention group vs the self-learning group. This pilot study will test the outcome measures and trial procedures, as well as finalise the modes of iSupport virtual group delivery for use in a future fully powered clinical trial.

The CONSORT extension statement checklist for pilot studies (Eldridge et al., 2016) guides the reporting of this study. Figure 1 depicts the CONSORT flow chart showing the study design and trial participants. In addition, this protocol follows the guidelines presented in the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) checklist (A. W. Chan et al., 2013). Table 1 shows the SPIRIT flow diagram of the iSupport virtual group intervention.



Figure 1. CONSORT 2010 flow chart showing the study design and the flow of participants

Table 1. SPIRIT checklist showing time points for enrollment, allocation, intervention, baseline and post-assessment.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Timepoint** | **Enrollment**  | **Baseline assessment****Allocation** | **Week1-Week12** | **Post-assessment** |
| Consent  | × |  |  |  |
| Eligibility  | × |  |  |  |
| Allocation  |  | × |  |  |
| Intervention  |
| iSupport virtual group intervention(Intervention group) |  |  | × |  |
| Self-learning(Control group) |  |  | × |  |
| Quantitative measures |
| PSS |  | × |  | × |
| SF-12 |  | × |  | × |
| CJCS |  | × |  | × |
| ZBS |  | × |  | × |
| SSRS |  | × |  | × |
| RSA |  | × |  | × |
| Qualitative measures |
| Feasibility metrics |  |  | × |  |
| Usability  |  |  | × |  |

Note: CJCS: Cultural Justification for Caregiving Scale; RSA: Resilience Scale for Adults; ZBS: Zarit Burden Scale; SPSS: Social Support Rating Scale; PSS: Perceived Stress Scale; SF-12: 12-Item Short-Form Health Survey

## Study aims

The overarching aim of this pilot RCT is to assess the feasibility of the iSupport virtual group intervention in comparison to the self-learning intervention. To achieve the overarching aim, the following objectives will be evaluated:

*Primary objective*

This study will answer practicability and feasibility questions about recruitment and retention of participants, study procedures, delivery, the intensity of intervention, adherence, data collection, and completion of outcomes measures to ensure that a planned large-scale trial is successful.

*Secondary objective*

This study will evaluate the effect sizes of stress as a primary clinical outcome and social support, resilience, burden, culture, and QoL as secondary outcomes in Chinese dementia carers completing the 12-week intervention.

## Conceptual framework

The conceptual framework underlying the evaluation of the iSupport virtual group intervention is the framework of resilience resources (RRs) (S. Han et al., 2019). This framework was adapted from the ecological model of resilience (Windle & Bennett, 2011) which has been applied to older adults (Bennett et al., 2016) and dementia carers (Donnellan et al., 2015).

To capture the caring challenges, resources and expected outcomes from family carers of PLwD receiving hospice care, Han and colleagues classified a wide range of RRs into three levels, including individual, community, and society. At the individual level, RRs include knowledge, personal control, coping strategies, self-care, and health behaviour. At the community level, RRs include support from family and friends, care facilities, communication with staff, home-like environment, and trust in providers. At the societal level, RRs include laws, culture, insurance, religion, policies, organisational support, and government expenditures. They suggested that this framework can be used to guide the development of new interventions to build RRs for dementia carers, which could result in providing better care, reducing caregiving burden and stress, and improving QOL. The RRs framework will be used in this study to examine the potential RRs for improving the mental wellbeing of Chinese dementia carers.

Based on the concept of RRs (Han et al., 2019), the expected relation between the iSupport virtual group intervention and mental wellbeing among dementia carers is shown in Figure 2. We propose that dementia carers are competent in caring for duty and maintaining their health when they are equipped with resilience resources. At the societal level, culturally appropriate interventions are more acceptable and valuable for dementia carers (Castro et al., 2010; James et al., 2021). At the community level, social support is beneficial for maintaining the mental wellbeing of dementia carers (Giebel et al., 2021; J. Han et al., 2014). In particular, support services tailored to the needs of dementia carers can facilitate their resilience(Donnellan et al., 2017). At the individual level, resilient dementia carers are knowledgeable, have well-supported families, and benefit from sharing knowledge with friends(Donnellan et al., 2015). Furthermore, interventions with knowledge and skills are led by health care clinicians that can ease the burden of caregiving and minimise stress(Given et al., 2008).

The iSupport virtual group intervention has all three of the above-mentioned components (a culturally appropriate intervention, knowledge and skills, and social support) and therefore could potentially improve the RRs and mental wellbeing of dementia carers. First, the intervention is developed based on the dementia carers’ needs and preferences. Next, the intervention will be delivered by health professionals who will provide a culturally and language-friendly intervention. Finally, active engagement in a small virtual group environment will facilitate social interactions amongst the other dementia carers. As a result, iSupport virtual group intervention has the potential to be beneficial for maintaining and/or enhancing the mental wellbeing of dementia carers.



Figure 2 Conceptual framework of the iSupport virtual group intervention

## Ethics consideration

This study will only commence once ethics approval has been granted by the Health and Disability Ethics Committee. This trial has been registered in the Australian New Zealand Clinical Trial Registry (Registered number: 383702).

## Participants

This study will include Chinese dementia carers in accordance with the criteria below:

*Inclusion criteria:*

* aged 18 years (self-identified) or older AND
* members of Dementia Auckland, Age Concern Auckland, Dementia Canterbury, or Dementia Wellington AND
* provide practical support with domestic and/or personal activities to the person with dementia for a minimum of 4 hours per week AND
* be able to converse in Mandarin or Cantonese AND
* internet users.

*Exclusion criteria:*

* carers with visual communication disorders or hearing disorders that may interfere with their ability to participate in the study AND/OR
* unable to provide informed consent.

## Recruitment

Participants will be recruited through Dementia Auckland, Age Concern Auckland, Dementia Canterbury, and Dementia Wellington. The poster and Participant Information Sheet will be distributed to these organisations to inform potential participants. Potential participants will be instructed to call or email the researcher (Fei) who will explain the purpose of the research and study activities. Those who express an interest will be scheduled for a virtual assessment to determine their eligibility. If eligible, written consent will be obtained, and the baseline assessment will be conducted via Zoom.

## Sample size

Power calculations are not recommended for a feasibility trial(Lancaster et al., 2004).

A total of 24 participants will be recruited, with 12 people in each arm. This number is consistent with the recommendations for pilot and feasibility studies, where the samples of 10 to 20 participants per arm have been deemed adequate for assessing the feasibility outcomes(Dobkin, 2009; Plow et al., 2013).

## Randomisation

Following the baseline assessment, the participants will be randomly assigned into one of two groups (experimental group or control group) by using a computer-generated list. Random allocation will incorporate randomised blocks of 4 participants to ensure a balanced design at any time during the trial. Block randomisation will be performed centrally by a principal investigator (A/P John) who is not involved in the day to day running of the trial. The allocation sequence will be concealed from the researcher enrolling participants by each allocation being contained in an opaque, sealed, sequentially numbered envelope. Each new participant will be given their allocation after consent to take part has been given and baseline assessments have been made.

## Blinding

An independent research assistant will undertake the baseline and post-intervention assessments and will be blinded to participants’ treatment allocation and without any involvement in the intervention.

## Interventions

*Control condition*

Dementia carers in the control group will receive a minimal active intervention. The intervention consists of self-learning the iSupport manual with practical information about caring for PLwD. A hard copy and the PDF version of the iSupport manual will be sent to the carers two weeks before starting the intervention. Participants will have unlimited access to the iSupport manual.

*Intervention condition*

The Chinese version of the iSupport manual has been culturally adapted for Chinese dementia carers living in New Zealand, and it will be used in this study. This manual contains five themes spread across 23 sessions: (1) what is dementia? (one session), (2) being a carer (four sessions), (3) caring for me (three sessions), (4) providing everyday care (five sessions), and (5) dealing with challenging behaviours (10 sessions). For the iSupport virtual group intervention, only 11 sessions will be used.

The intervention development was informed by the findings of a qualitative study interviewing Chinese dementia carers about their meaningful activities, digital ability, unmet needs, and usability of the Chinese version of the iSupport manual. These findings were used to tailor the iSupport virtual group intervention and to design the format of intervention delivery. In addition, the included participants will be required to choose 11 lessons from the iSupport manual at the baseline assessment. The 11 lessons chosen by all the participants will be combined and prioritised by the research team. The 12 lessons of the iSupport virtual group intervention will be finalized from the findings of the interviews and 11 chosen lessons.

This iSupport virtual group intervention will consist of a 1.5-hour session per week for 12 weeks. The intervention group will be divided into two groups with 5-7 people in each group. Two trained facilitators (an Age Concern Auckland staff and a volunteer) will be assigned to each group. Each session follows a similar format, consisting of a presentation about the main topic of the session, small exercises (e.g., mindful breathing), questions & answers, a summary of the lesson plus homework (e.g., preparing questions for the upcoming session), and evaluation. In addition, each session will involve a peer who was an experienced dementia carer or a health professional (such as a nursing practitioner or psychiatrist).

Participants in the intervention group will receive 12 sessions of the iSupport virtual group intervention over a 12-week period following baseline assessment and randomisation. In addition, participants will receive all training materials (the Chinese version of the iSupport manual and the iSupport virtual group intervention participant guide) for self-learning two weeks before starting the intervention. Participants will be encouraged to attend the iSupport virtual group intervention to benefit as much as possible. It is anticipated that dementia carers will be able to complete the whole intervention in 3 months. Before starting each session, they will be contacted by a facilitator via phone or Zoom. Additionally, dementia carers may contact the facilitators, if necessary, at any point of the intervention. The roles of the facilitator are to encourage participants to continue with the intervention, and to explain anything that is not clear to dementia carers during the intervention. Adherence to the intervention will be monitored using a spreadsheet before the start of each session.

Zoom will be used to deliver the iSupport virtual group intervention. Thus, all participants from the intervention group can engage in the intervention from anywhere in NZ. Before starting the intervention, all the participants will watch a training video on how to use Zoom. In addition, the facilitators will offer an experimental course to ensure that all participants are familiar with Zoom meetings. One day before the intervention, participants will receive a text reminder of the Zoom link and ID.

Participants are free to withdraw from the study at any time and without any explanation. If participants are unwilling or unable to comply with the required study procedures, the research team may withdraw them from the study. To promote participant retention and complete follow-up, all the participants will receive written feedback regarding the assessments performed.

## Fidelity

To maximise intervention fidelity, a standardised training programme will be developed and provided by the research team to train the facilitators. A researcher (Fei) will complete the intervention checklist to quantify the number, frequency, length, and content of the sessions provided to each pair. She will also audio record intervention sessions and transcribe a sample to monitor the facilitators' adherence to the intervention.

To minimise the potential bias, the following actions will be taken: (1) All research team members will be oriented to basic research principles and effective communication. (2) Two facilitators will receive a 2-hour training session to fully comprehend the intervention and the study.

## Adverse events

Participants are not likely to experience any risk of unexpected adverse events because this is a non-drug intervention trial. In addition, no adverse reactions were reported in the previous trial of iSupport interventions for dementia carers (Baruah et al., 2021; Teles et al., 2022). For this reason, adverse events will not be routinely collected for this trial.

## Outcome measures

Outcome measures will include feasibility outcomes and person-centred outcomes.

1. Feasibility outcome

Under the suggestion given from a recent scoping systematic review (Learmonth & Motl, 2018), feasibility data in this study will be collected in four metrics, including resources, process, management, and scientific feasibility (see Table 2).

Table 2. Outline the feasibility metrics

|  |  |
| --- | --- |
| **Metric**  | **Measured variables**  |
| *Resource feasibility* |
| Time | * Time to complete the assessments and consent and the time to enrol participants as documented in the study-specific database
 |
| Appropriateness ofeligibility criteria  | * Details of reasons individuals are excluded from participation as documented in the study enrolment logs
 |
| Adherence  | * Review of session attendance logs
 |
| Retention  | * The percentage of participants enrolled in the study who completed the intervention was determined by an audit of study enrolment logs
 |
| *Process feasibility*  |
| Recruitment  | * The feasibility of recruiting approaches as documented in the study enrolment logs
 |
| Determine ease of randomisation | * The willingness of participants to be randomised to the intervention group as documented in the study randomisation logs
 |
| *Management feasibility*  |
| Treatment fidelity  | * Facilitator training: Age Concern staff and volunteers will provide evaluation and feedback on the training workshop.
* Intervention delivery: active feedback from the participants could be used to refine the group intervention for the full study.
* Supervision of group facilitators: The frequency, duration and acceptability of online supervision will be assessed through active feedback from the group facilitators.
 |
| *Scientific feasibility*  |
| Safety | * Safety will be assessed through the review of any adverse events, including distress, etc, that occur during the intervention. These events will be self-reported by participants.
 |

1. Person-centred outcome measures

The person-centred outcomes will be used to assess the relevance and acceptability of outcome measures for use in a future definitive RCT, as well as to inform the selection of the primary outcome measure for a future trial. The measures of perceived stress, carer burden, culture, QoL, resilience, and social support are shown in table 3.

Table 3 Person-centred outcome measures

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Outcome of interest** | **Outcome measure**  | **Items**  | **Scores**  | **Intra-class correlation****coefficient**  | **Cronbach’s α** |
| Perceived stress  | PSS(Lee, 2012) | 14  | 0-70 | 0.83(Huang et al., 2020) | 0. 71 to 0.88 (Li et al., 2021; She et al., 2021) |
| Carer burden  | ZBS(Bédard et al., 2001) | 12 | 0-48 | 0.99(T. S. . Chan et al., 2005) | 0.88(Tang et al., 2017) |
| Culture | CJCS(Dilworth-Anderson et al., 2004) | 10 | 10-40 | 0.85(Xiong et al., 2011) | 0.87 to 0.88 |
| QOL | SF-12(Ware et al., 1996) | 12 | 0-100 | 0.67 to 0.82(Lam Bsc et al., 2013) | 0.91(Shou et al., 2016) |
| Resilience  | RSA(Friborg et al., 1996) | 33 | 33-165 | 0.706 to 0 .902(Yao et al., 2013) | 0.903(C. Gao & Yang, 2016) |
| Social support  | SSRS(S. Xiao, 1994) | 10 | 10-40 | 0.92(L. Gao et al., 2009) | 0.74(Xia et al., 2012) |

Note: CJCS: Cultural Justification for Caregiving Scale; RSA: Resilience Scale for Adults; ZBS: Zarit Burden Scale; SSRS: Social Support Rating Scale; PSS: Perceived Stress Scale; SF-12: 12-Item Short-Form Health Survey

## Data collection

A researcher assistant will conduct Zoom interviews with dementia carers at baseline before randomisation and postintervention. In addition, two facilitators will collect qualitative data about the feasibility of implementing the intervention during the 12- week intervention.

## Data management

Data management is detailed more fully in the Data Management Plan. A researcher (Fei) will be in charge of data management including data entry. All original hard copies of the study data, including consent forms, questionnaires, and field notes will be kept under lock and key in a secure location within the University of Auckland which will be retained for 6 years. The interview data will be stored on the University of Auckland managed storage in an ‘institutional Dropbox’ without any names or identifying information. In addition, identifiable data will be removed before analysis. Only the research team will have access to de-identified data for analyses. After that, the data will be erased. The researcher (Fei) will be responsible for overseeing the entire study and ensuring that the timelines are met, the data are cleaned and accurate, and any missing values are identified.

## Data analysis

Data analysis will include quantitative and qualitative methods.

*Qualitative analysis*

A semi-structured interview about the participants’ experiences of the iSupport virtual group intervention will be conducted on individuals from the intervention group. The semi-structured interviews will be audio-recorded and transcribed. Thematic analysis based on a general inductive method will be used to analyse the qualitative data within NVivo-12 (Thomas, 2006). The themes will likely be structured around the topics in the interview guide (general opinions about the intervention; motivation of intervention involvement; positive aspects of the intervention; challenges or opportunities for intervention improvement; likelihood to utilise a similar programme in the future). The findings will be used to inform the intervention development for further RCTs.

*Quantitative analysis*

The main analysis will be the person-centred outcome measures. Descriptive statistics will be calculated for demographics, questionnaires, and feasibility data. The baseline characteristics will be presented descriptively for dementia carers. Descriptive statistics of the mean /median, standard deviation /and interquartile ranges will be used to analyse continuous variables, while categorical data will be calculated in numbers and percentages. To estimate data variability, between-group differences for all primary and secondary outcomes will be adjusted for baseline values, age, gender, and education.

The secondary objective is to estimate the effect of the iSupport virtual group intervention on every person-centred outcome. Based on the intent-to-treat principle, all analyses will be performed using IBM SPSS (Statistical Package for the Social Sciences) software, version 27.0, The level of statistical significance will be set at P < 0.05.

## Confidentiality

Participant confidentiality will be ensured by allocating participants a unique identification number to correspond to treatment data in the computer files. If information is disclosed during the study that could pose a risk of harm to the participant or others, the researcher will discuss this with the facilitators and where appropriate report accordingly.

# Discussion

This is the first study to perform the iSupport virtual group intervention in a sample of Chinese dementia carers in order to verify its effect on mental wellbeing. The iSupport virtual group intervention has the potential to be a cost-effective intervention that could be easily delivered in the community during the COVID-19 pandemic. If the results confirm our hypothesis, this study could inform the full-scale RCT to assess the effectiveness of this intervention.

# Dissemination and translation of findings

The findings of the trial will be submitted to peer-reviewed journals and presented at all levels of academic conferences.

# Study timeline

The proposed timeline for the study is shown below (Table 4).

Table 4 Timeline of study milestones

|  |  |
| --- | --- |
| **Study Phases and Milestones**  | **Duration**  |
| Recruitment  | May -June 2022 |
| Baseline assessment  | July 2022 |
| Intervention Process evaluation  | August- October 2022  |
| Post-assessment  | November-December 2022  |
| Analysis the data | January -March 2023 |

# Acknowledgements

The research team thanks Prof. Lily Xiao for her support in the cultural adaptation and the use of the Chinese version of the iSupport manual.

# Competing interests

There are no competing interests declared by the authors.

# Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

# Abbreviations

**PLwD:** people living with dementia

**QoL**: quality of life

**RCT:** randomised control trial

**SPIRIT**: Standard Protocol Items: Recommendations for Interventional Trials

**RRs**: resilience resources

**NZ:** New Zealand

# References:

Abrahams, R., Liu, K. P. Y., Bissett, M., Fahey, P., Cheung, K. S. L., Bye, R., Chaudhary, K. & Chu, L. W. (2018). Effectiveness of interventions for co-residing family caregivers of people with dementia: Systematic review and meta-analysis. *Australian Occupational Therapy Journal*, *65*(3), 208–224. https://doi.org/10.1111/1440-1630.12464

Alfakhri, A. S., Alshudukhi, A. W., Alqahtani, A. A., Alhumaid, A. M., Alhathlol, O. A., Almojali, A. I., Alotaibi, M. A. & Alaqeel, M. K. (2018). Depression Among Caregivers of Patients With Dementia. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, *55*, 004695801775043. https://doi.org/10.1177/0046958017750432

Baharudin, A. D., Din, N. C., Subramaniam, P. & Razali, R. (2019). 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*, *19*(4), 1–12. https://doi.org/10.1186/S12889-019-6868-0/TABLES/5

Baruah, U., Varghese, M., Loganathan, S., Mehta, K., Gallagher‐Thompson, D., Zandi, D., Dua, T. & Pot, A. M. (2020). A pilot randomized controlled trial on iSupport in India: Results on the use of the online program and its effectiveness. *Alzheimer’s & Dementia*, *16*(S7), 38912. https://doi.org/10.1002/alz.038912

Baruah, U., Varghese, M., Loganathan, S., Mehta, K. M., Gallagher-Thompson, D., Zandi, D., Dua, T. & Pot, A. M. (2021). Feasibility and preliminary effectiveness of an online training and support program for caregivers of people with dementia in India: a randomized controlled trial. *International Journal of Geriatric Psychiatry*, *36*(4), 606–617. https://doi.org/10.1002/gps.5502

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A. & O’donnell, M. (2001). The Zarit Burden InterviewA New Short Version and Screening Version. *The Gerontologist*, *41*(5), 652–657. https://doi.org/10.1093/GERONT/41.5.652

Bennett, K. M., Reyes-Rodriguez, M. F., Altamar, P. & Soulsby, L. K. (2016). Resilience amongst Older Colombians Living in Poverty: an Ecological Approach. *Journal of Cross-Cultural Gerontology*, *31*(4), 385–407. https://doi.org/10.1007/S10823-016-9303-3/FIGURES/2

Brodaty, H. & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217. https://doi.org/10.31887/DCNS.2009.11.2/HBRODATY

Castro, F. G., Barrera, M. & Holleran Steiker, L. K. (2010). Issues and Challenges in the Design of Culturally Adapted Evidence-Based Interventions. *Annual Review of Clinical Psychology*, *6*, 213. https://doi.org/10.1146/ANNUREV-CLINPSY-033109-132032

Chan, A. W., Tetzlaff, J. M., Altman, D. G., Laupacis, A., Gøtzsche, P. C., Krleža-Jerić, K., Hróbjartsson, A., Mann, H., Dickersin, K., Berlin, J. A., Doré, C. J., Parulekar, W. R., Summerskill, W. S. M., Groves, T., Schulz, K. F., Sox, H. C., Rockhold, F. W., Rennie, D. & Moher, D. (2013). SPIRIT 2013 statement: Defining standard protocol items for clinical trials. *Annals of Internal Medicine*, *158*(3), 200–207. https://doi.org/10.7326/0003-4819-158-3-201302050-00583

Chan, T. S. ., Lam, L. C. . & Chiu, H. F. . (2005). Validation of the Chinese version of the Zarit Burden Interview. *Hong Kong Journal of Psychiatry*, *15*(1), 9+.

Cuffaro, L., Di Lorenzo, F., Bonavita, S., Tedeschi, G., Leocani, L. & Lavorgna, L. (2020). Dementia care and COVID-19 pandemic: a necessary digital revolution. *Neurological Sciences 2020 41:8*, *41*(8), 1977–1979. https://doi.org/10.1007/S10072-020-04512-4

Dam, A. E. H., Christie, H. L., Smeets, C. M. J., van Boxtel, M. P. J., Verhey, F. R. J. & de Vugt, M. E. (2019). Process evaluation of a social support platform ‘Inlife’ for caregivers of people with dementia. *Internet Interventions*, *15*, 18–27. https://doi.org/10.1016/J.INVENT.2018.09.002

Dilworth-Anderson, P., Goodwin, P. Y. & Williams, S. W. (2004). Can Culture Help Explain the Physical Health Effects of Caregiving Over Time Among African American Caregivers? *The Journals of Gerontology: Series B*, *59*(3), S138–S145. https://doi.org/10.1093/GERONB/59.3.S138

Dobkin, B. H. (2009). Progressive Staging of Pilot Studies to Improve Phase III Trials for Motor Interventions. *Neurorehabilitation and Neural Repair*, *23*(3), 197–206. https://doi.org/10.1177/1545968309331863

Donkin, L. & Glozier, N. (2012). Motivators and Motivations to Persist With Online Psychological Interventions: A Qualitative Study of Treatment Completers. *J Med Internet Res 2012;14(3):E91 Https://Www.Jmir.Org/2012/3/E91*, *14*(3), e2100. https://doi.org/10.2196/JMIR.2100

Donnellan, W. J., Bennett, K. M. & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health*, *19*(10), 932–939. https://doi.org/10.1080/13607863.2014.977771

Donnellan, W. J., Bennett, K. M. & Soulsby, L. K. (2017). Family close but friends closer: exploring social support and resilience in older spousal dementia carers. *Aging & Mental Health*, *21*(11), 1222–1228. https://doi.org/10.1080/13607863.2016.1209734

Efthymiou, A., Karpathiou, N., Dimakopoulou, E., Zoi, P., Karagianni, C., Lavdas, M., Mastroyiannakis, A., Sioti, E., Zampetakis, I. & Sakka, P. (2022). Cultural Adaptation and Piloting of iSupport Dementia in Greece. *Studies in Health Technology and Informatics*, *289*, 184–187. https://doi.org/10.3233/SHTI210890

Egan, K. J., Pinto-Bruno, Á. C., Bighelli, I., Berg-Weger, M., van Straten, A., Albanese, E. & Pot, A. M. (2018). Online Training and Support Programs Designed to Improve Mental Health and Reduce Burden Among Caregivers of People With Dementia: A Systematic Review. *Journal of the American Medical Directors Association*, *19*(3), 200-206.e1. https://doi.org/10.1016/J.JAMDA.2017.10.023

Eldridge, S. M., Lancaster, G. A., Campbell, M. J., Thabane, L., Hopewell, S., Coleman, C. L. & Bond, C. M. (2016). Defining feasibility and pilot studies in preparation for randomised controlled trials: Development of a conceptual framework. *PLoS ONE*, *11*(3), 1–22. https://doi.org/10.1371/journal.pone.0150205

Fiordelli, M. & Albanese, E. (2020). Preparing the ground for the adaptation of iSupport in Switzerland. *Alzheimer’s & Dementia*, *16*(S7), 38915. https://doi.org/10.1002/alz.038915

Friborg, O., Hjemdal, O., Rosenvinge, J. H. & Martinussen, M. (1996). A new rating scale for adult resilience: what are the central protective resources behind healthy adjustment? *International Journal of Methods in Psychiatric Research*, *12*(2).

Gao, C. & Yang, L. (2016). Reliability and validity of adult Resilience Scale in nursing staff. *China Health Care & Nutrition*, *26*(6), 1536–1539. https://d.wanfangdata.com.cn/periodical/zgbjyy-kp201606248

Gao, L., Chan, S. W. & Mao, Q. (2009). Depression, perceived stress, and social support among first-time Chinese mothers and fathers in the postpartum period. *Research in Nursing & Health*, *32*, 50-58 (in Chinese). https://doi.org/10.1002/nur.20306

Gauthier S, Rosa-Neto P, Morais JA, W. C. (2021). World Alzheimer Report 2021: Journey through the diagnosis of dementia. *London, England: Alzheimer’s Disease International.* https://www.alzint.org/resource/world-alzheimer-report-2021/

GBD 2019 Collaborators. (2021). Global mortality from dementia: Application of a new method and results from the Global Burden of Disease Study 2019. *Alzheimer’s & Dementia: Translational Research & Clinical Interventions*, *7*(1). https://doi.org/10.1002/trc2.12200

Giebel, C., Lord, K., Cooper, C., Shenton, J., Cannon, J., Pulford, D., Shaw, L., Gaughan, A., Tetlow, H., Butchard, S., Limbert, S., Callaghan, S., Whittington, R., Rogers, C., Komuravelli, A., Rajagopal, M., Eley, R., Watkins, C., Downs, M., … Gabbay, M. (2021). A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. *International Journal of Geriatric Psychiatry*, *36*(3), 393–402. https://doi.org/10.1002/GPS.5434

Given, B., Sherwood, P. R. & Given, C. W. (2008). WHAT KNOWLEDGE AND SKILLS DO CAREGIVERS NEED? *Journal of Social Work Education*, *44*(sup3), 115–123. https://doi.org/10.5175/JSWE.2008.773247703

Han, J., Jeong, H., Park, J. Y., Kim, T. H., Lee, D. Y., Lee, D. W., Ryu, S.-H., Kim, S.-K., Yoon, J. C., Jhoo, J., Kim, J. L., Lee, S. B., Lee, J. J., Kwak, K. P., Kim, B.-J., Park, J. H. & Kim, K. W. (2014). Effects of social supports on burden in caregivers of people with dementia. *International Psychogeriatrics*, *26*(10), 1639–1648. https://doi.org/10.1017/S1041610214001331

Han, S., Chi, N.-C., Han, C., Oliver, D. P., Washington, K. & Demiris, G. (2019). Adapting the Resilience Framework for Family Caregivers of Hospice Patients With Dementia. *American Journal of Alzheimer’s Disease & Other Dementias®*, *34*(6), 399–411. https://doi.org/10.1177/1533317519862095

Harwood, R. H., van der Wardt, V., Goldberg, S. E., Kearney, F., Logan, P., Hood-Moore, V., Booth, V., Hancox, J. E., Masud, T., Hoare, Z., Brand, A., Edwards, R. T., Jones, C., das Nair, R., Pollock, K., Godfrey, M., Gladman, J. R. F., Vedhara, K., Smith, H. & Orrell, M. (2018). A development study and randomised feasibility trial of a tailored intervention to improve activity and reduce falls in older adults with mild cognitive impairment and mild dementia. *Pilot and Feasibility Studies*, *4*(1), 1–12. https://doi.org/10.1186/S40814-018-0239-Y/FIGURES/2

Huang, F., Wang, H., Wang, Z., Zhang, J., Du, W., Su, C., Jia, X., Ouyang, Y., Wang, Y., Li, L., Jiang, H. & Zhang, B. (2020). Psychometric properties of the perceived stress scale in a community sample of Chinese. *BMC Psychiatry*, *20*(1), 1–7. https://doi.org/10.1186/S12888-020-02520-4/TABLES/4

James, T., Mukadam, N., Sommerlad, A., Guerra Ceballos, S. & Livingston, G. (2021). Culturally tailored therapeutic interventions for people affected by dementia: a systematic review and new conceptual model. *The Lancet Healthy Longevity*, *2*(3), e171–e179. https://doi.org/10.1016/S2666-7568(21)00001-5

Jang, S.-I., Bae, H.-C., Shin, J., Jang, S.-Y., Hong, S., Han, K.-T. & Park, E.-C. (2016). Depression in the Family of Patients With Dementia in Korea. *American Journal of Alzheimer’s Disease & Other Dementiasr*, *31*(6), 481–491. https://doi.org/10.1177/1533317515628048

Lam Bsc, E. T. P., Lam, C. L. K., Fhkam, F., Fong, D. Y. T., Huang, W. W., Mtcm, B., Chau, A. L., Kong, H. & Lam, T. P. (2013). Is the SF-12 version 2 Health Survey a valid and equivalent substitute for the SF-36 version 2 Health Survey for the Chinese? *Journal of Evaluation in Clinical Practice*, *19*(1), 200–208. https://doi.org/10.1111/J.1365-2753.2011.01800.X

Lancaster, G. A., Dodd, S. & Williamson, P. R. (2004). Design and analysis of pilot studies: recommendations for good practice. *Journal of Evaluation in Clinical Practice*, *10*(2), 307–312. https://doi.org/10.1111/J..2002.384.DOC.X

Lee, E. H. (2012). Review of the Psychometric Evidence of the Perceived Stress Scale. *Asian Nursing Research*, *6*(4), 121–127. https://doi.org/10.1016/J.ANR.2012.08.004

Leng, M., Zhao, Y., Xiao, H., Li, C. & Wang, Z. (2020). Internet-Based Supportive Interventions for Family Caregivers of People With Dementia: Systematic Review and Meta-Analysis. *J Med Internet Res 2020;22(9):E19468 Https://Www.Jmir.Org/2020/9/E19468*, *22*(9), e19468. https://doi.org/10.2196/19468

Li, Y., Li, Y., Li, J., Zhang, F., Bai, G., Gema, C., Pingcuo, Z. & Suolang, Q. (2021). Application of the Chinese version of the Stress Perception Scale in representative community adult population. *Chinese Mental Health Journal*, *35*(1), 67-72 (in Chinese).

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., … Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, *396*(10248), 413–446. https://doi.org/10.1016/S0140-6736(20)30367-6

Messina, A., Lattanzi, M., Albanese, E. & Fiordelli, M. (2022). Caregivers of people with dementia and mental health during COVID-19: findings from a cross-sectional study. *BMC Geriatrics*, *22*(1), 1–9. https://doi.org/10.1186/S12877-022-02752-X/TABLES/3

Nguyen, L., Murphy, K. & Andrews, G. (2021). *A Game a Day Keeps Cognitive Decline Away ? A Systematic Review and Meta ‑ Analysis of Commercially ‑ Available Brain Training Programs in Healthy and Cognitively Impaired Older Adults*. *0123456789*.

Nguyen, T. A., Tran, K., Esterman, A., Brijnath, B., Xiao, L. D., Schofield, P., Bhar, S., Wickramasinghe, N., Sinclair, R., Dang, T. H., Cullum, S., Turana, Y., Hinton, L., Seeher, K., Andrade, A. Q., Crotty, M., Kurrle, S., Freel, S., Pham, T., … Brodaty, H. (2021). Empowering dementia carers with an iSupport virtual assistant (e-DiVA) in Asia-Pacific regional countries: Protocol for a pilot multisite randomized controlled trial. *JMIR Research Protocols*, *10*(11). https://doi.org/10.2196/33572

Oliveira, D., Jacinto, A. F., Gratao, A. C. M., Ottaviani, A. C., Ferreira, C. R., Monteiro, D. Q., Barham, E. J., Orlandi, F. de S., de Cruz, K. C. T., Correa, L., Zazzeta, M. & Pavarini, S. C. I. (2020). Translation and cultural adaptation of iSupport in Brazil. *Alzheimer’s & Dementia*, *16*(S7), 38917. https://doi.org/10.1002/alz.038917

Pinto-Bruno, Á. C., Pot, A. M., Kleiboer, A., Droes, R. M. & Van Straten, A. (2019). An online minimally guided intervention to support family and other unpaid carers of people with dementia: Protocol for a randomized controlled trial. *JMIR Research Protocols*, *8*(10). https://doi.org/10.2196/14106

Plow, M., Moore, S. M., Kirwan, J. P., Frost, F., Katzan, I., Jaeger, S. & Alberts, J. (2013). Randomized controlled pilot study of a SystemCHANGETM weight management intervention in stroke survivors: rationale and protocol. *Trials*, *14*(1), 1–7. https://doi.org/10.1186/1745-6215-14-130/PEER-REVIEW

Pot, A. M., Gallagher-Thompson, D., Xiao, L. D., Willemse, B. M., Rosier, I., Mehta, K. M., Zandi, D., Dua, T., Albanese, E., Batsch, N., Baruah, U., Edwards, K., Egan, K., Gallagher-Thompson, D., Guerra, M., Holroyd-Leduc, J., Kwok, T., Mehta, K., Prins, M., … Zandi, D. (2019). iSupport: a WHO global online intervention for informal caregivers of people with dementia. In *World Psychiatry* (Vol. 18, Issue 3, pp. 365–366). John Wiley & Sons, Ltd. https://doi.org/10.1002/wps.20684

She, Z., Li, D., Zhang, W., Zhou, N., Xi, J. & Ju, K. (2021). Three versions of the perceived stress scale: Psychometric evaluation in a nationally representative sample of chinese adults during the covid-19 pandemic. *International Journal of Environmental Research and Public Health*, *18*(16). https://doi.org/10.3390/ijerph18168312

Shou, J., Ren, L., Wang, H., Yan, F., Cao, X., Wang, H., Wang, Z., Zhu, S. & Liu, Y. (2016). Reliability and validity of 12-item Short-Form health survey (SF-12) for the health status of Chinese community elderly population in Xujiahui district of Shanghai. *Aging Clinical and Experimental Research*, *28*(2), 339–346. https://doi.org/10.1007/S40520-015-0401-9/TABLES/6

Tang, B., Yu, Y., Liu, Z., Lin, M., Chen, Y., Zhao, M. & Xiao, S. (2017). Factor analyses of the Chinese Zarit Burden Interview among caregivers of patients with schizophrenia in a rural Chinese community. *BMJ Open*, *7*(9), e015621. https://doi.org/10.1136/bmjopen-2016-015621

Teles, S., Ferreira, A. & Paúl, C. (2022). Feasibility of an online training and support program for dementia carers: results from a mixed-methods pilot randomized controlled trial. *BMC Geriatrics*, *22*(1), 1–17. https://doi.org/10.1186/s12877-022-02831-z

Teles, S., Ferreira, A., Seeher, K., Fréel, S. & Paúl, C. (2020). Online training and support program (iSupport) for informal dementia caregivers: Protocol for an intervention study in Portugal. *BMC Geriatrics*, *20*(1), 1–13. https://doi.org/10.1186/s12877-019-1364-z

Thomas, D. R. (2006). Method Notes A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*. https://doi.org/10.1177/1098214005283748

Ware, Jj., Kosinski, M. & Keller, S. (1996). A 12-Item Short-Form Health Survey. *Medical Care*, *34*(3), 220–233. https://doi.org/10.1097/00005650-199603000-00003

Western, M. J., Armstrong, M. E. G., Islam, I., Morgan, K., Jones, U. F. & Kelson, M. J. (2021). The effectiveness of digital interventions for increasing physical activity in individuals of low socioeconomic status: a systematic review and meta-analysis. *International Journal of Behavioral Nutrition and Physical Activity*, *18*(1), 1–21. https://doi.org/10.1186/S12966-021-01218-4/FIGURES/6

Wiegelmann, H., Speller, S., Verhaert, L. M., Schirra-Weirich, L. & Wolf-Ostermann, K. (2021). Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review. *BMC Geriatrics 2021 21:1*, *21*(1), 1–17. https://doi.org/10.1186/S12877-021-02020-4

Windle, G. & Bennett, K. M. (2011). Caring relationships: How to promote resilience in challenging times. In In M. Ungar (Ed.) (Ed.), *The Social Ecology of Resilience:A Handbook of Theory and Practice* (pp. 219–232). New York, NY: Springer.

Xia, L.-X., Liu, J., Ding, C., Hollon, S. D., Shao, B.-T. & Zhang, Q. (2012). The relation of self-supporting personality, enacted social support, and perceived social support. *Personality and Individual Differences*, *52*(2), 156–160. https://doi.org/10.1016/j.paid.2011.10.002

Xiao, L. D., Wang, J., Ratcliffe, J., Ullah, S., Brodaty, H., Brijnath, B., Chang, H. ( R., Wang, H., Chang, C., Kwok, T. & Zhu, M. (2022). A nurse‐led multicentre randomized controlled trial on effectiveness and cost‐effectiveness of Chinese i <scp>S</scp> upport for dementia program: A study protocol. *Journal of Advanced Nursing*, *December 2021*, 1–10. https://doi.org/10.1111/jan.15216

Xiao, S. (1994). The theoretical basis and applications of Social Support Rating Scale (SSRS). *J Clinical Psychiatry*, *4*(02), 98-100 (in Chinese).

Xiong, Q., Wang, H., Wang, H. & Chen, B. (2011). Sociocultural beliefs on caregiver for the elderly in Chinese rural area. *Chinese Journal of Gerontology*, *31*(4), 669–671.

Yao, G., Liu, Y., Li, S. & Liang, W. (2013). Reliability and Validity of Resilience Scale for Adults in Nurses. *Chinese General Practice*, *16*(17), 1536-1539 (in Chinese). https://doi.org/10. 3969 /j. issn. 1007 － 9572. 2013. 05. 026

Zhang, M., Chang, Y.-P., Liu, Y. J., Gao, L. & Porock, D. (2018). Burden and Strain among Familial Caregivers of Patients with Dementia in China. *Issues in Mental Health Nursing*, *39*(5), 427–432. https://doi.org/10.1080/01612840.2017.1418034