

The effects of a facilitator-enabled online multicomponent iSupport for dementia programme: A multicentre randomised controlled trial



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ABSTRACT

Background: Multicomponent interventions with carers of people with dementia demonstrate positive effects on the health and quality of life for carers and care recipients. The World Health Organization's iSupport for Dementia is an evidence-based online psychoeducation programme for carers. However, the programme was mainly implemented as a self-learning tool which might have limited its positive effects on carers and care recipients. Evidence for online multicomponent interventions with carers that incorporates the iSupport programme remains unknown.

Objectives: This study aimed to partner with health and social care organisations to evaluate the effects of a facilitator-enabled online multicomponent Chinese iSupport programme, which included psychoeducation using the iSupport programme, facilitator-enabled carer support groups and access to care services.

Design: A multicentre randomised controlled trial.

Settings and participants: Participants were family carers in Australia and greater China. We recruited participants to the study from 1st November 2021 to 30th June 2022.

Methods: The intervention group received the Chinese iSupport programme delivered online. The intervention lasted for 6 months. Our primary outcome was carers' quality of life. Our secondary outcomes were carers' self-efficacy, social support, distress reactions to changed behaviours, care recipients' frequency of changed behaviours, quality of life, unplanned hospital admissions, emergency department presentations and permanent admissions to nursing homes. The outcomes were measured at baseline (T0), 6 months (T1) and 9 months (T2). We applied a multivariate mixed effect linear regression model to capture the group effect, time effect and their interaction.

Results: In total, 266 eligible family carers agreed to participate and were randomly assigned to an intervention group (n = 131) or a usual care group (n = 135). Most carers were women with a mean age of 53 years. The intervention group showed a statistically significant higher score of mental-health-related quality of life (mean

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difference = 4.1, 95 % CI: 1.5, 6.8, $p = 0.002$), self-efficacy in controlling upsetting thoughts (mean difference = 7.1, 95 % CI: 2.2, 12.0, $p = 0.005$) and lower score of distress reactions to changed behaviours (mean difference = -0.1, 95 % CI: -0.3, -0.03, $p = 0.012$) than the usual care group at T1.

Conclusion: The facilitator-enabled online multicomponent Chinese iSupport programme demonstrated positive effects for carers on mental health-related quality of life, controlling upsetting thoughts and distress reactions to changed behaviours of people with dementia.

Trial registration: This study is registered in the Australia New Zealand Clinical Trials Registry on 12th March 2021 (ACTRN12621000276853).

Tweetable abstract: The facilitator-enabled online multicomponent Chinese iSupport programme improved family carers' mental health-related quality of life, control of upsetting thoughts and distress reactions to changed behaviours of people with dementia.

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What is already known

- Multicomponent interventions with carers of people with dementia demonstrate positive effects on their health and quality of life and improved health for their care recipients.
- The World Health Organization's iSupport for Dementia is an online psychoeducation programme for carers but was mainly implemented as a self-learning tool which might have limited its positive effects on carers and their care recipients.
- Evidence for online multicomponent interventions with carers that incorporates the iSupport programme remains unknown.

What this paper adds

- The facilitator-enabled online multicomponent Chinese iSupport programme can be delivered by trained nurses or other care professionals in health and social care organisations.
- The facilitator-enabled online multicomponent Chinese iSupport programme shows positive effects on family carers' mental-health-related quality of life, self-efficacy for controlling upsetting thoughts and distress reactions to changed behaviours of people with dementia.
- The facilitator-enabled online multicomponent Chinese iSupport programme mainly focusing on family carers shows no effect on reducing changed behaviours, quality of life, hospital admissions and emergency department presentations of people with dementia.

1. Background

Globally, over 55 million people live with dementia and a new case arises every 3 s. Caring for this large population and supporting their family carers have become a public health priority (WHO, 2021). To achieve the global dementia action plan goal, and ensure that 75 % of member countries provide support programmes for carers by 2025, the World Health Organization (WHO) developed the iSupport for Dementia, an online psychoeducation programme (WHO, 2021). It includes five modules and 23 units (Supplementary 1): introduction to dementia, being a carer, caring for yourself, providing everyday care and dealing with changed behaviour. In the culturally adapted Chinese iSupport programme, we embedded local information about care services throughout the programme and in a standalone module (Xiao et al., 2022a). Person-centred care is emphasised in case scenarios to enable people with dementia to exercise their autonomy, preferences, choices and meaningful interactions with others in daily care in the iSupport programme (Pot et al., 2019). The programme also incorporates cognitive behavioural therapy to enable carers to develop positive

thoughts, problem-solving skills and self-care behaviours to reduce their stresses (Pot et al., 2019). However, the iSupport programme was mainly implemented as an online self-learning tool and showed inconclusive effects on carers' mental health and quality of life (QoL) (Baruah et al., 2021; Teles et al., 2022).

It is well described in the stress and process framework that care recipient-related factors are primary stressors for carers and have a negative impact on their physical and mental health (Conde-Sala et al., 2010; Pearlin et al., 1990). Changed behaviours, for example repetitive behaviours, wandering, hallucinations and aggression, were the most mentioned factors that determined carers' distress, burden and poor mental health (van der Lee et al., 2014; WHO, 2021). Changed behaviours are also associated with poor QoL of people with dementia (Hurt et al., 2008; WHO, 2021). The main causes and triggers of changed behaviours are unmet care needs of people with dementia and are able to be addressed through interventions with carers (Brodaty and Arasaratnam, 2012). A meta-analysis confirmed that combining psychoeducation, tailored advice for carers by trained interventionists and support for carers to access formal care services demonstrated effects on reducing changed behaviours and carers' distress reactions (Brodaty and Arasaratnam, 2012). Module five of the iSupport programme enables carers to analyse causes and triggers of changed behaviours; thus, it has potential to enable them to reduce changed behaviours, their distress and improve the QoL of care recipients. Moreover, care recipients' demand for care activities also contributes to carers' burden and poor health (van der Lee et al., 2014). Unmet care needs are associated with complications in care recipients which contribute to hospital admissions and emergency department presentations (Anderson et al., 2020). Psychoeducation interventions show effects on improving carers' capabilities to meet their recipients' needs (Cheng et al., 2020) and may prevent up to 40 % avoidable hospitalisations (Anderson et al., 2020). Module four of the iSupport programme focuses on promoting health and functional ability and reducing risks for care recipients; thus, it has potential to enable carers to meet the care needs of their care recipients.

In the stress and process framework, carer-related factors can positively or negatively impact their physical and mental health (Conde-Sala et al., 2010; Pearlin et al., 1990). Carer self-efficacy, described as carers' beliefs about their capabilities in dementia care, can enable carers to respond to changed behaviours adequately; and therefore, reduce their distress and unhelpful thoughts (Steffen et al., 2002). Psychoeducation intervention (Cheng et al., 2020) and online carer support groups (Parker Oliver et al., 2017) show the effects of improving carers' self-efficacy and social support (Parker Oliver et al., 2017). Moreover, carers' self-efficacy is associated with positive self-appraisal of stressors, problem-solving focused coping styles and positive thoughts about caregiving and improved mental health and health-related QoL for carers (Crellin et al., 2014). However, a meta-analysis of 13 RCTs on online psychoeducation programmes showed no effects on

improving QoL for carers (Yu et al., 2023). QoL is defined as individuals' self-appraisal of their position in life (WHO, 2024) and is strongly influenced by carers' life experiences in coping with care recipient-related factors, carer-related factors and formal and informal support for carers (or system-related factors) (Farina et al., 2017). A meta-analysis showed that multicomponent interventions that combined psychoeducation and support groups delivered by trained interventionists demonstrated effects on improving the QoL of carers (Lee et al., 2020).

Carers usually experience social isolation and unmet needs in socialising and information sharing with others which contribute to carers' burden and poor mental health (Hopwood et al., 2018; van der Lee et al., 2014). Carer support group interventions demonstrated effects on improving carers' QoL (Sun et al., 2022). Moreover, carer support groups can create a safe environment for carers to share their experiences in dementia care, confirm and reinforce their positive thoughts about their caregiver role (Yu et al., 2018). Online carer support groups show effects of reducing carers' stress and burden, especially in the environment where carers have opportunities to access online tailored support and advice from trained facilitators (Hopwood et al., 2018). Incorporating online support groups into the iSupport programme may generate synergy in improving carers' QoL, self-efficacy and social support.

Studies in European countries and Australia confirmed that care services in the health and social care systems were fragmental and affected carers' ability to navigate, access and utilise care services for their care recipients and for themselves to gain emotional support or other forms of support when needed (Jelley et al., 2021; Steiner et al., 2020). Moreover, carers from ethnic minority groups like Chinese-Australian carers experienced additional challenges in accessing care services due to language barriers, different cultural expectations of care services and other social and structural factors in the health and social care systems (Gilbert et al., 2022). These studies underscore the need to incorporate facilitator-enabled access to care services.

So far, two research groups have reported the effects of the iSupport programme using randomised controlled trials (RCTs). In the RCT in India, 151 family carers were recruited via a national advertiser (Baruah et al., 2021). Carers in the intervention group received the online iSupport for self-learning and the intervention lasted 3 months. The trial did not show significant improvements in these outcomes: carers' depression, perceived burden scores, carers' self-efficacy, mastery and self-rated health. Moreover, the trial showed a high attrition rate of 64%. The lack of strategies to engage care service providers and carers in the programme may have contributed to these outcomes. In the Portugal iSupport study with 42 carers, the intervention group also received the online iSupport only (Teles et al., 2022). Notably, carers who were referred by health and social care professionals showed 100% retention compared to 58% retention in carers recruited via social media. This finding underscored the need for partnership with health and social care organisations in delivering the iSupport programme. However, the Portugal iSupport intervention had inconclusive findings on caregiver burden, depression, anxiety, QoL, positive aspects of caregiving and self-efficacy due to a small sample size.

The WHO Western Pacific Region which comprises Australia, greater China and other countries is home to a large population of people with dementia (36% or 20.1 million) and the vast majority of them live in greater China (Jia et al., 2020; WHO, 2021). Nearly 95% of Chinese with dementia are cared for by family carers at home due to the influence of filial piety and Confucianism (Alzheimer's Disease International, 2018; Ma and Saw, 2020). Filial piety is a belief in Chinese culture that adult children need to demonstrate good attitudes and behaviours, for example by respecting, obeying and taking good care of their parents, especially when their parents are old and/or lose their ability to self-care (Lai, 2010). Prolonged exposure to carer burden is associated with poor health and QoL for carers; poor quality of care and poor health for people with dementia; and disease burden on the health

and social care systems (WHO, 2021). Multicomponent interventions with carers demonstrate positive effects on their health and QoL and their care recipients' health. However, evidence on online multicomponent interventions with carers in clinical practice that incorporates the iSupport programme remains unknown. This study addresses the critical gap in dementia care research by reporting the effects of a facilitator-enabled online multicomponent Chinese iSupport programme.

1.1. Conceptual framework

The stress and process framework informed this study (Conde-Sala et al., 2010; Pearlin et al., 1990). In this framework, care recipient-related variables (see Fig. 1) are recognised as primary stressors for carers and determine carers' physical and mental health, socialisation with others and QoL. Moreover, carer-related variables (see Fig. 1) may have positive or negative impact on carers' self-efficacy, social, physical, and mental health and QoL. Based on our literature review, we considered the system-related variables (see Fig. 1) as contextual stressors for carers to maintain health for themselves and their care recipients (Gilbert et al., 2022; Jelley et al., 2021). However, these variables can be modified through non-pharmacological interventions with carers (Cheng et al., 2020).

Our intervention with carers was a facilitator-enabled online multicomponent programme, including psychoeducation using the online iSupport programme, online carer support groups and need-based access to information and services (see Fig. 1). The rationale of combining these three types of non-pharmacological interventions is based on our comprehensive literature review as detailed in the Background section and summarised as follows. First, psychoeducation interventions show positive effects on carers' self-efficacy (Cheng et al., 2020) and mental health (Cheng et al., 2020; Sun et al., 2022; Yu et al., 2023). Second, carer support group interventions demonstrate positive effects on carers' QoL (Sun et al., 2022), self-efficacy and social support (Parker Oliver et al., 2017). Third, multicomponent interventions that included psychoeducation, carer support groups and access to trained facilitators to gain advice show positive effects on carers' QoL (Lee et al., 2020), care recipients' changed behaviours and carers' distress reactions to changed behaviours (Brodaty and Arasaratnam, 2012). Improving the QoL of people with dementia and their carers is the goal of the Global action plan on public health response to dementia (WHO, 2017, 2021) and QoL is a key indicator of clinical significance in carer interventions (Schulz et al., 2002). Therefore, we chose carers' QoL as the primary outcome in this study.

2. Objectives

This study aimed to determine the effects of the Chinese iSupport programme 1) on carers' quality of life, self-efficacy, social support, and distress reactions to changed behaviours; and 2) on care recipients' frequency of changed behaviour, quality of life, unplanned hospital admissions, emergency department presentations and permanent admissions to nursing homes. This study is phase two of a large study that included cultural adaptation of the Chinese iSupport programme in phase one which is reported elsewhere (Che et al., 2024; Xiao et al., 2022b) and the cost-effectiveness of the Chinese iSupport programme and carers' experiences of the iSupport programme in phase two which will be reported in separate papers.

3. Methods

3.1. Study design

We undertook a randomised, multicentre, two-arm, parallel-group controlled trial to determine the effects of the Chinese iSupport programme. We registered the trial with the Australia New Zealand Clinical Trials Registry (ID: ACTRN12621000276853) and detailed the trial in a

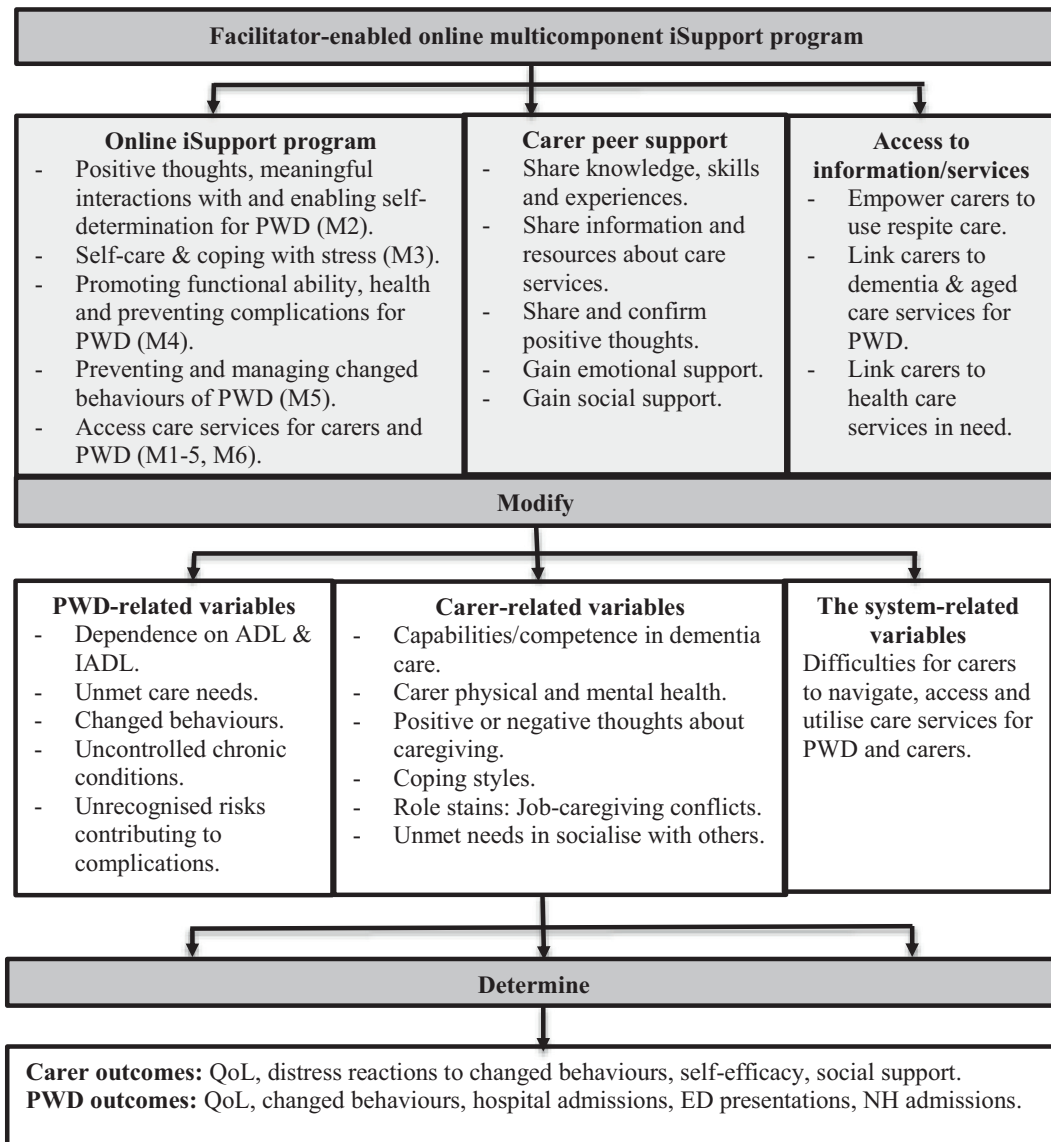


Fig. 1. Conceptual framework underpinning the study.

Note: ADL = activities of daily living; ED = emergency department; IADL = instrumental activities of daily living; M = module in the iSupport manual (see Supplementary file 1); QoL = quality of life; NH = nursing home; PWD = people with dementia.

published study protocol (Xiao et al., 2022a). A CONSORT checklist (see Supplementary 2) and a TIDieR Checklist (Supplementary 3) based on this trial are presented.

3.2. Study setting, participants and randomisation

We recruited carers to the study from not-for-profit community aged care organisations in three Australian sites, Taipei, Hong Kong and Macau; public hospital memory clinics in Beijing and Taipei; and community health centres (public primary health care organisations in mainland China) in Xi'an. The first participant was recruited on 1st November 2021. Inclusion criteria for carers were: (1) primary family carers aged 18 years or over; (2) caring for persons with mild to moderate dementia [a score between 10 and 22 using the Chinese version of the Rowland Universal Dementia Assessment Scale (Storey et al., 2004) or between 10 and 24 using the Chinese Mini-Mental State Examination (Chiu et al., 1994)]; and (3) using the internet and having access to computers or iPads. Exclusion criteria for caregivers were: (1) having self-reported severe mental health conditions or terminal illness; (2) being involved in other studies;

(3) could not read Chinese without assistance; and (4) carers who cared for people in the severe stage of dementia. This group of care recipients usually becomes bed-bound and requires 24-hour care (Alzheimer's Association, 2023). Thus, a formal home care service intervention is needed to relieve carers from physical and mental stresses which is out of the scope of the current iSupport programme.

We calculated the sample size based on the primary outcome of the SF-12 mental component for carers. In an earlier RCT with multicomponent intervention on carers, the researcher reported a Cohen's $d = 0.57$ and standard deviation of 8.63 in the SF-12 mental component (Berwig et al., 2017). Therefore, we estimated that the sample size would be 66 caregivers per arm using a 2-sample comparison of means for $\alpha = 0.05$ at 90% of power. We also estimated a 55% attrition rate in the 9-month trial considering the COVID-19 outbreaks across all study sites and their negative impact on carer recruitment and retention. We estimated a sample size of 204. The trial ended when we completed the planned 9-month follow-up.

We assigned carers randomly to an intervention group or a usual care group after baseline data collection using a randomly generated

block size of 4 to ensure the two groups were of equivalent size. The randomisation also ensured equivalent distribution of the relationship between the carer and care-recipient (spouse carers versus non-spouse carers) and severity of dementia diagnosis (mild versus moderate cognitive impairment). Site-specific researchers who enrolled carers in the study provided these information categories to a senior statistician (SU) for randomisation. The statistician was blinded to participants and not involved in data analysis. The randomisation of carers in the study is presented in Fig. 2.

3.3. Study groups

3.3.1. Usual care group

Carers in the usual care group were supported by the publicly available services and information provided by Alzheimer's Association in their region. They received monthly text messages via WeChat or mobile phone to remind them of the monthly survey we conducted to measure the usage of care resource for cost-effectiveness analysis. The

message also reminded them of the services and information provided by Alzheimer's Association. They had no interaction with the iSupport facilitator.

3.3.2. Intervention group

The intervention group received these supports: 1) The facilitator encouraged carers to assess their learning needs and select at least 20 learning units relevant to them in the "My plan" section. Carers had autonomy to change their study plan, control their learning pace and not to complete the plan based on their needs and circumstances during the 6-month intervention period. The length of each unit varies with an estimated 1–2 h required for a carer to complete a unit. We measured their completion of the 20-unit studying plan as part of intervention fidelity data for analysis and for informing future studies on the average completion of learning units; 2) the trained facilitator assigned carers to peer support groups of 6–8 people and facilitated a monthly carer peer support meeting lasting 45–60 min using WeChat or WhatsApp. The meetings created opportunities for carers to share their study progress,

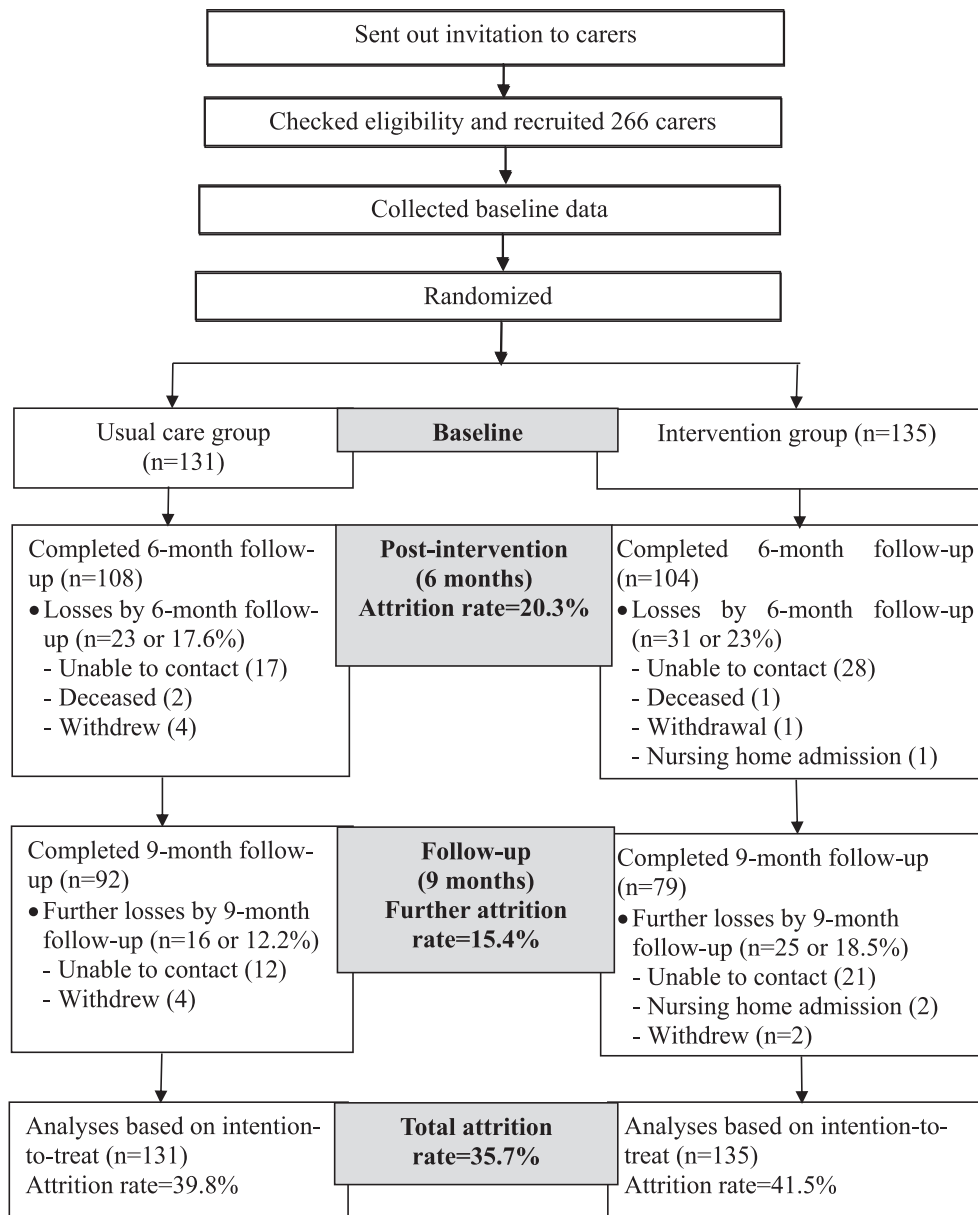


Fig. 2. Flow of carers through the RCT.

experiences in applying knowledge to own care activities, or to access resources and care services. Both of the App platforms share similar functionalities, for example, enabling the facilitator to conduct and record the group meetings, and are easy for carers to join video meetings via their smartphone, send text messages or share relevant materials with members in the same group. Like other social platforms, the limitations of these Apps include the sharing of mobile phone numbers or WeChat IDs in the group with the third party. These limitations were considered in the study and members in the carer group signed informed consent to not releasing information outside the group; 3) the trained facilitator also created carer support groups in WeChat or WhatsApp to enable carers to talk or send text messages to carers in the same group to strengthen social support; and 4) the trained facilitator analysed group interactions weekly and sent a short summary message to enhance caregivers' understanding of dementia care. Of the eight trained facilitators, four were registered nurses, three were social workers and one was an allied health professional.

3.4. Instruments

Our primary outcome was QoL of carers. Our secondary outcomes were carers' self-efficacy, social support, distress reactions to changed behaviours, care recipients' frequency of changed behaviours, QoL, unplanned hospital admissions, emergency department presentations and permanent admissions to nursing homes.

The Chinese version of the 12-Item Short-Form Health Survey (SF-12) comprises 12 items that measure two domains: mental health-related QoL and physical health-related QoL. Higher scores indicate better QoL. The Chinese version exhibits satisfactory internal consistency, as indicated by a Cronbach's α of 0.78 (Xiao and Kuang, 2014).

We applied the Chinese version of the Revised Scale for Caregiving Self-efficacy (Au et al., 2009), which comprises 3 subscales with 15 items: self-efficacy for obtaining respite, responding to changed behaviours, and controlling upsetting thoughts about caregiving. The instrument demonstrates adequate internal consistency (Cronbach's α of 0.89–0.91). Higher scores indicate better self-efficacy.

We used the Carers of Older People in Europe Index—Quality of Social Support (The COPE Index-QS) to measure carers' perceived social support (Moholt et al., 2018), which includes 5 items describing support from family, friends and care service providers. It has adequate internal consistency (Cronbach's α = 0.77) in the Chinese version used in our pilot study. Higher scores indicate better social support.

We applied the Chinese version of the Revised Memory and Behaviour Problem Checklist (RMBPC) which includes 24 items to measure the frequency of changed behaviours of people with dementia and carers' distress reactions to those behaviours. It shows an internal consistency of 0.81 for the frequency of changed behaviour and 0.89 for responding to the behaviour and construct validity (Fuh et al., 1999). Lower scores represent less frequency of changed behaviours and less carer distress.

We used the Quality of Life in Alzheimer's Disease (QOL-AD)—Proxy to measure the carer's perspective of the QoL of the person living with dementia they care for. The scale includes 13 items using a 4-Likert scale (Ai, 2011). The instrument shows a high internal consistency (Cronbach's α = 0.87). Higher scores represent better QoL of the person with dementia.

We also collected data relating to self-reported unplanned hospital admissions, emergency department presentation and permanent admission to nursing homes for the care recipients monthly occurring during the 6-month intervention using the Chinese version of the Resource Utilization in Dementia (RUD) Lite Questionnaire (Wimo et al., 1998) at baseline and 6 months during the trial. The information collected via the RUD Lite Questionnaire was verified by site-specific research assistants.

3.5. Data collection and data analysis

Data were collected through self-administered online surveys at baseline (T0), 6 months (T1, post-intervention) and 9 months (T2, 3-month follow-up). Site-specific researchers were available to help carers with the survey when they required. The online survey data were exported into the IBM SPSS 28.0 by two site-specific researchers in each study site to eliminate errors. A researcher (RH), who was blinded to group assignments and was not involved in data collection, undertook data analysis. The data analysis processes and outcomes were cross-checked by a senior biostatistician (SU) in the team. We applied an intention-to-treat approach according to group assignments. The missing values were filled using multiple imputations. Participants' characteristics were presented as mean and standard deviation for continuous data and as percentages for categorical data. The two sample independent *t*-test and standard Chi-square test for association with continuity correction, where appropriate, were used to explore the significant differences in individuals' characteristics between intervention and usual care groups. We transformed raw scale scores of the SF-12 to 0–100 scale and calculated means for the physical component summary scores and mental component summary scores. All *p* values less than 0.05 were considered statistically significant from the two-sided test.

A multivariate mixed-effect linear regression model (two-level $\bar{\sigma}$ random slope model) was conducted for each outcome due to the hierarchical structure of the data (outcome occurs for each participant with repeated time points). We started with fixed effects to capture the group effect (the intervention or usual care group), time effect (baseline, 6 and 9 months), and group by time interaction. We then undertook multivariate modelling by adding variables considered clinically important or statistically significant from the univariate model to adjust for confounding effects between variables. Our analysis included random intercepts and slopes to capture individual trajectories over time, ensuring a robust interpretation of the observed changes in outcome variables and helping us differentiate between true changes and statistical artefacts such as regression to the mean. A mixed-effect Poisson regression model was also applied to calculate the incidence rate ratio for hospital admission and emergency department presentations of people with dementia between intervention and usual care groups.

3.6. Fidelity monitoring

Strategies used to ensure study fidelity are as follows. First, a Steering Committee was established to govern the project according to the study protocol. Second, we developed selection criteria for facilitators to deliver the intervention as follows: health or social care professionals who were employed by the partner organisations in the project; obtaining a Bachelor degree or above and having at least one year of experience in the care of people with dementia. Third, we provided a training programme for facilitators to ensure they understood and were able to carry out the programme. The programme included theoretical, practical and coaching components and was delivered via online training, self-study and regular debriefing sessions as detailed in Supplementary file 4. Fourth, we developed an implementation manual for trained facilitators and research assistants to standardise interventions and data collection. Fifth, all facilitators and research assistants were required to keep a facilitator portfolio and intervention diary respectively and submit to the site-specific leaders, who were chief investigators/senior researchers, to review as part of project auditing. In addition, the completion of the required iSupport learning units by carers in the intervention group was measured via the website, which had a functionality to determine the learner's completion of each unit. The completion was also confirmed by facilitators through monthly meeting with carers.

3.7. Ethical considerations

This study was approved by Flinders University Human Research Ethics Committee (date: 22-09-2021; Project number: HEL2782-5). Participating organisations distributed the information pack to potential carer participants. Potential participants were advised to contact a site-specific researcher via a text message or phone call if they were interested in the study. The researcher confirmed their eligibility and discussed informed consent with them. Each participant provided written consent and was assigned a unique code to safeguard identities whilst allowing for reidentification during data analysis. Data were stored electronically on the Flinders University research drive for data analysis and data sharing. Each participant received a total of \$500AUD gift card in Australia or a lower value gift card in other study sites to acknowledge their contributions to the study.

4. Results

4.1. Socio-demographic characteristics of participants

In total, 266 eligible carers agreed to participate in the study and were randomly assigned to the intervention group ($n = 131$) or the usual care group ($n = 135$). The number of carers recruited from each study site is presented in Supplementary file 5. Participants' socio-demographic characteristics are outlined in Table 1. The majority of carers were women ($n = 205, 77\%$) and their average age was 53 years. The majority were adult child carers (196 or 73.7%), lived in the same house (176 or 66%) with care recipients, were still in paid work (134 or 50%), had an above high school education level, experienced financial stress (155 or 58%), spent 35 h per week on care activities and received casual or no help from other family members (165 or 62%). There were no statistically significant differences in socio-demographic characteristics between the intervention and usual care groups. The socio-demographic characteristics of care recipients in the study are presented in Table 2. The majority were female (169 or 64%) with an average age of 78 years. The majority had an education level at high school or below (186 or 70%). About half had Alzheimer's disease (128 or 48%) and half had another type of dementia (138 or 52%); most were in a moderate stage of dementia (232 or 87%). There were no statistically significant differences in socio-demographic characteristics of care recipients between the intervention and usual care groups.

All carers completed the data collection at baseline (T0). Between the baseline and 6 month follow-up, 54 participants (or 20.3%) were lost to follow-up including 23 participants in the usual care group and 31 participants in the intervention group (see Fig. 2). Between 6 month and 9 month follow-ups, 41 participants (15.4%) were lost to follow-up including 16 in the usual care group and 25 in the intervention group. In sum, 95 participants were lost in the 9-month trial with an attrition rate of 35.7%. The attrition rate in the intervention group was 41.5% which is higher than the 39.8% attrition rate in the usual care group. The main reason for the losses in the follow-up was unable to contact participants during the COVID-19 outbreaks. Other reasons included unable to commit to the study due to busy carer duty; unwilling to fill in the long survey form; and unable to see the value in participating in the study as the care recipients were in a stable condition.

4.2. Carer mental-health-related QoL

In the multivariate mixed effect model, the mean difference in mental-health-related QoL between the intervention group and the usual care group at 6 months post-intervention was 4.1 (95% CI: 1.5, 6.8) and was statistically significant ($p = 0.002$) (see Table 3; Supplementary 6 Fig. 2A). This result supports that the intervention can improve carers' mental-health-related QoL. However, the between-group difference was not statistically significant at 9 months. In the within-group comparison, the intervention group showed a statistically significantly

Table 1
Demographic characteristics of carers.

Characteristics	Total (n = 266)	IG (n = 131)	UG (n = 135)	p
Gender: n (%)				
Male	61 (22.9)	27 (20.6)	34 (25.2)	0.375 ^a
Female	205 (77.1)	104 (79.4)	101 (74.8)	
Age (years): mean (SD)	52.9 (14.4)	52.9 (15.1)	53.0 (13.8)	0.935 ^b
Relationship with patient: n (%)				
Spouse	53 (19.9)	26 (19.8)	27 (20.0)	0.715 ^a
Adult child carers	196 (73.7)	95 (72.5)	101 (74.8)	
Others	17 (6.4)	10 (7.6)	7 (5.2)	
Duration on carer role (years): median (IQR)	3 (2–5)	3 (1–5)	3 (2–5)	0.317 ^c
Marital status: n (%)				
Married	152 (57.1)	75 (57.3)	77 (57.0)	0.972 ^a
Unmarried/divorced/widowed	114 (42.9)	56 (42.7)	44 (43.0)	
Live in the same house: n (%)				
Yes	176 (66.2)	86 (65.6)	90 (66.7)	0.861 ^a
No	90 (33.8)	45 (34.4)	45 (33.3)	
Religion: n (%)				
Yes	88 (33.1)	38 (29.0)	50 (37.0)	0.164 ^a
No	178 (66.9)	93 (71.0)	85 (63.0)	
Employment status: n (%)				
Employed	134 (50.4)	65 (49.6)	69 (51.1)	0.808 ^a
Unemployed/retired	132 (49.6)	66 (50.4)	66 (48.9)	
Education level: n (%)				
High school and below	73 (27.4)	35 (26.7)	38 (28.1)	0.794 ^a
Above high school	193 (72.6)	96 (73.3)	97 (71.9)	
Financial pressure: n (%)				
Yes	155 (58.3)	76 (58.0)	79 (58.5)	0.934 ^a
No	111 (41.7)	55 (42.0)	56 (41.5)	
Hours on care weekly: median (IQR)	35 (14.0, 84.0)	35 (14.0, 84.0)	35 (15.0, 84.0)	0.850 ^c
Family members' help: n (%)				
Substantial help	101 (38.0)	46 (35.1)	55 (40.7)	0.345 ^a
Casual help or no help	165 (62.0)	85 (64.9)	80 (59.3)	

Substantial help: providing 24 h or daytime or nighttime care.

^a Chi-Square test.

^b *t*-Test.

^c Mann Whitney *U* test.

increased mean score from 43.3 at baseline to 46.2 at 6 months which supports the improved mental-health-related QoL in the intervention group. However, there was no statistically significant change in mental-health-related QoL in the usual care group.

4.3. Carer physical-health-related QoL

The mean difference in physical-health-related QoL between the intervention group and the usual care group was not statistically significant at 6 months or at 9 months (see Table 3; Supplementary 6 Fig. 2B). In the within-group comparison, both groups showed no statistically significant change in physical-health-related QoL from baseline to 6 months, but a statistically significantly lower mean score from baseline to 9 months (-3.5 in the intervention group and -2.3 in the usual care group) which indicates declined physical-health-related QoL in a 3-month follow-up after intervention.

4.4. Caregiving self-efficacy

4.4.1. Self-efficacy for obtaining respite

The mean difference in self-efficacy for obtaining respite between the intervention group and the usual care group was not statistically significant (see Table 3; Supplementary 6 Fig. 2C). In the within-group comparison, both groups showed no significant change in the mean score from baseline to 6 months. However, both groups showed a declined mean score from baseline to 9 months and the change was statistically significant in the intervention group, but not in the usual care

Table 2
Demographic characteristics of people with dementia.

Characteristics	Total (n = 266)	IG (n = 131)	UG (n = 135)	p
Gender				
Male	97 (36.5)	42 (32.1)	55 (40.7)	0.141 ^a
Female	169 (63.5)	89 (67.9)	80 (59.3)	
Age (years), mean (SD)	78.4 (10.1)	79.5 (9.9)	77.4 (10.2)	0.088 ^b
Religion				
Yes	98 (36.8)	50 (38.2)	48 (35.6)	0.659 ^a
No	168 (63.2)	81 (61.8)	87 (64.4)	
Education level				
High school and below	186 (69.9)	92 (70.2)	94 (69.6)	0.915 ^a
Above high school	80 (30.1)	39 (29.8)	41 (30.4)	
Type of dementia				
Alzheimer's disease	128 (48.1)	63 (48.1)	65 (48.1)	0.993 ^a
Other types	138 (51.9)	68 (51.9)	70 (51.9)	
Stages of dementia ^a				
Mild	34 (12.8)	18 (13.7)	16 (11.9)	0.645 ^a
Moderate	232 (87.2)	113 (86.3)	119 (88.1)	

Mild dementia was based on MMSE score of 21–24; moderate dementia was based on MMSE score of 10–20.

^a Chi-Square test.

^b t-Test.

group. The results support that the intervention group showed a significant decline in self-efficacy for obtaining respite in a 3-month follow-up after intervention.

4.4.2. Self-efficacy for responding to changed behaviours of people with dementia

The mean difference in self-efficacy for responding to changed behaviours between the intervention group and the usual care group was not statistically significant at 6 months or at 9 months (see Table 3; Supplementary 6 Fig. 2D). The results indicate that the iSupport programme had no effect on self-efficacy for responding to changed behaviours. In the within-group comparison, there was no statistically significant change in the mean score in either group.

4.4.3. Self-efficacy for controlling upsetting thoughts about caregiving

The mean difference in self-efficacy for controlling upsetting thoughts about caregiving between the intervention group and the usual care group at 6 months was 7.1 (95% CI: 2.2, 12.0) and was statistically significant ($p = 0.005$) (see Table 3; Supplementary 6 Fig. 2E). This result supports that the iSupport programme can improve carers' self-efficacy for controlling upsetting thoughts about caregiving. However, the between-group difference was not statistically significant at 9 months. This result indicates that the intervention effect did not sustain in a 3-month follow-up after the intervention. In the within-group comparison, there was no statistically significant change in the mean score in either group.

4.5. Social support

The mean difference in perceived social support between the intervention group and the usual care group was not statistically significant at 6 months or at 9 months (see Table 3; Supplementary 6 Fig. 2F). The results support that the iSupport programme had no effect on improving social support for carers. In the within-group comparison, there was no statistically significant change in the mean score in either group.

4.6. Frequency of changed behaviours of people with dementia

The mean difference in the frequency of changed behaviours between the intervention group and the usual care group was not statistically significant at 6 months or at 9 months (see Table 3; Supplementary 6 Fig. 2G). The results support that the iSupport programme had no effect on reducing the frequency of changed behaviours. In the

within-group comparison, there was no statistically significant change in the mean score in either group.

4.7. Carers' distress reactions to changed behaviours of people with dementia

The mean difference in carers' distress reactions to changed behaviours between the intervention group and the usual care group at 6 months was -0.1 (95% CI: $-0.3, -0.03$) and was statistically significant ($p = 0.012$) (see Table 3; Supplementary 6 Fig. 2H). The result supports that the iSupport programme can reduce carers' distress reactions to changed behaviours. However, the between-group difference was not significant at 9 months. This result indicates that the effect did not sustain in a 3-month follow-up after the intervention. In the within-group comparison, there was no statistically significant change in the mean score in either group.

4.8. QoL for people with dementia

The mean difference in the QoL between the intervention group and the usual care group was not statistically significant at 6 months or at 9 months (see Table 3; Supplementary 6 Fig. 2I). In the within-group comparison, there was no statistically significant change in the mean score in the intervention group at 6 months, but a declined mean score at 9 months that was statistically significant. There was no statistically significant change in the mean score in the usual care group at 6 months or at 9 months.

4.9. Unplanned hospital admissions, emergency department presentations and permanent admission to nursing homes in the 6-month intervention

During the 6-month intervention period, 29 care recipients (22.1%) in the intervention group and 36 (26.7%) in the usual care group experienced unplanned hospital admissions. The difference of incidence rate ratio between the two groups was not statistically significant (Supplementary 7). Moreover, 31 care recipients (23.7%) in the intervention group and 29 (21.5%) in the usual care group experienced emergency department presentations. The difference of incidence rate ratio between the two groups was not statistically significant. In addition, 3 care recipients (2.3%) in the intervention group and none in the usual care group were permanently admitted to nursing homes.

4.10. Compliance with the trial registration

All carers who finished the 6-month intervention completed at least 20 learning units. Moreover, all carers in the intervention group attended either monthly peer support meetings or were contacted by the iSupport facilitator to discuss their needs if they missed meetings. All iSupport facilitators completed monthly portfolios, submitted them to the site-specific leader for review and gained feedback. All iSupport facilitators complied with weekly interactions with carers via text messages to motivate them to learn from the iSupport programme and support peers. We made a few minor changes to the trial registration detailed as follows. First, we included primary family carers aged 18 years or over which included carers who did not live in the same house with their care recipients to this study. The reason for making this change was due to difficulties in recruiting carers to the study during COVID-19 outbreaks. Second, a senior statistician (SU) who was blinded to participants and not involved in data analysis provided randomisation and we did not use an independent clinical trial management centre to provide randomisation services to the study. This was due to budget limitations to pay for the service.

5. Discussion

Findings from our study revealed that the online multicomponent Chinese iSupport programme intervention delivered by trained nurses

Table 3
Changes in outcomes at six and nine months.

Outcome measures	Groups	Baseline	6 M	9 M	Within-group effect		Between-group effect				
					6 M vs. baseline (95 % CI)	9 M vs. baseline (95 % CI)	Differences at 6 M (95 % CI)	Cohen's d	p	Differences at 9 M (95 % CI)	p
Carer QoL: MCS	IG	43.1	46.2	44.9	3.2 (0.7, 5.7) ^a	1.4 (-1.1, 3.9)	4.1 (1.5, 6.8)	0.398	0.002 ^a	1.2 (-1.5, 3.8)	0.391
	UCG	42.9	42.5	43.6	-0.5 (-2.8, 1.8)	0.7 (-1.6, 3.5)					
Carer QoL: PCS	IG	46.2	45.8	43.9	-1.1 (-3.4, 1.1)	-3.5 (-5.8, -1.3) ^a	1.4 (-0.9, 3.6)	0.106	0.236	1.1 (-1.2, 3.4)	0.337
	UCG	44.9	44.8	42.6	-1.7 (-2.2, 1.9)	-2.3 (-4.3, -0.3) ^a					
CSE: respite	IG	66.4	67.0	63.3	-1.9 (-7.3, 3.6)	-6.9 (-12.4, -1.5) ^a	4.4 (-1.3, 10.2)	0.163	0.129	-0.03 (-5.8, 5.7)	0.991
	UCG	65.5	63.0	63.1	-3.7 (-8.7, 1.2)	-4.3 (-9.3, 0.7)					
CSE: behaviours	IG	60.0	65.1	63.3	4.5 (-0.3, 9.2)	0.2 (-4.6, 4.9)	3.8 (-1.4, 8.9)	0.178	0.154	-1.3 (-6.4, 3.9)	0.663
	UCG	63.5	61.8	62.7	-2.7 (-7.1, 1.7)	-1.9 (-6.3, 2.4)					
CSE: upsetting	IG	62.9	66.3	61.2	3.7 (-1.0, 8.5)	-3.5 (-8.3, 1.2)	7.1 (2.2, 12.0)	0.325	0.005 ^a	0.9 (-4.1, 5.8)	0.734
	UCG	61.4	60.1	58.3	-0.8 (-5.1, 3.5)	-1.8 (-6.1, 2.5)					
Social support	IG	2.5	2.6	2.6	0.1 (-0.02, 0.2)	0.1 (-0.04, 0.2)	0.1 (-0.1, 0.2)	0.095	0.259	0.01 (-0.1, 0.2)	0.929
	UCG	2.6	2.6	2.6	-0.04 (-0.2, 0.1)	0.03 (-0.1, 0.2)					
Behaviour Frequency	IG	1.6	1.6	1.6	-0.04 (-0.2, 0.2)	0.1 (-0.1, 0.2)	0.01 (-0.2, 0.2)	0.111	0.911	0.1 (-0.1, 0.3)	0.252
	UCG	1.5	1.5	1.5	-0.1 (-0.2, 0.1)	-0.1 (-0.2, 0.1)					
Reactions Frequency	IG	0.5	0.4	0.5	-0.1 (-0.2, 0.03)	0.1 (-0.01, 0.2)	-0.1 (-0.3, -0.03)	-0.279	0.012 ^a	-0.01 (-0.1, 0.1)	0.800
	UCG	0.5	0.5	0.6	0.1 (-0.04, 0.1)	0.1 (-0.01, 0.2)					
QoL of PWD	IG	2.1	2.0	1.9	-0.1 (-0.1, 0.1)	-0.1 (-0.2, -0.01) ^a	0.03 (-0.1, 0.1)	0.063	0.501	-0.02 (-0.1, 0.1)	0.728
	UCG	1.9	1.9	2.0	-0.02 (-0.1, 0.1)	0.02 (-0.1, 0.1)					

Note: (1) Abbreviations: UCG = usual care group; IG = iSupport group; M = months; MCS = mental composite summary score; PCS = physical component summary score; QoL = quality of life; CSE = caregiver self-efficacy; PWD = people with dementia. (2) Adjusted for confounding variables including gender, age, relationship with patient, marital status, duration in care role, live in the same household with PWD or not, religion, employment status, education level, financial pressure and family members' help.

^a The mean difference is statistically significant in the mixed-effect linear regression model.

or other care professionals showed a positive effect on mental-health-related QoL, self-efficacy for controlling upsetting thoughts and carers' distress reactions to changed behaviours. However, findings from our study also indicate that the programme had no effect on other outcome variables. The positive effect on carers' mental-health-related QoL in our study is similar to the UK START study (mean difference = 4.1) (Livingston et al., 2013), and is slightly lower than the German REACH II study (effect size = 0.57) (Berwig et al., 2017). Notably, these previous multicomponent interventions were delivered by trained interventionists in an in-home and face-to-face mode. Perceived time burden by carers has been widely reported in the literature (Farina et al., 2017) and was viewed as the main reason for carers choosing not to participate or withdraw from dementia research (Mundy et al., 2020). Thus, the remote delivery of the Chinese iSupport programme is very important for adult child carers who are still in the paid workforce.

Our study identified that the facilitator-enabled Chinese iSupport programme demonstrated a positive effect on self-efficacy for controlling upsetting thoughts at 6 months. Our finding in this self-efficacy domain differs from the iSupport RCT in India by Baruah et al. (2021) which showed no intervention effect on carers' self-efficacy. The difference suggests the need to combine other intervention components with the iSupport programme to optimise effects on carers' self-efficacy. Moreover, in our study, the mean difference between the intervention group and the usual care group at 6 months was higher than that reported by Law and Kwok (2019) in Hong Kong with Chinese carers (7.1 vs. 5.5). Notably, the multicomponent intervention for carers in the study by Law and Kwok (2019) was delivered by trained physiotherapists in an in-home face-to-face mode. The comparison reveals that the remote delivery of a facilitator-enabled iSupport programme can generate better outcomes for carers' self-efficacy in controlling upsetting thoughts post-intervention.

Our study demonstrated a positive effect on carers' distress reactions to changed behaviours at 6-month post-intervention. This outcome might be attributed to carers' learning from scenarios presented in the iSupport module five and iSupport facilitator-enabled peer support meetings that enabled carers to share experiences in thinking differently about changed behaviours. This finding aligns with a recent study by Rice et al. (2022) using a remote delivery mode of a

multicomponent intervention (or telehealth) for carers. Our study also concurs with two other multicomponent intervention studies delivered in an in-home face-to-face manner (Berwig et al., 2017; Law and Kwok, 2019), although those studies demonstrated a higher effect size than that in our study. The difference underscores the need to provide individualised support for carers to develop problem-solving skills in managing changed behaviours.

We found no intervention effect on carers' physical-health-related QoL which was also supported by previous multicomponent interventions (Berwig et al., 2017; Livingston et al., 2013). The reasons contributing to the outcome may be that carers experienced objective burden such as long hours on care activities but were unable to access practical support such as respite care and other aged care services (Conde-Sala et al., 2010; Farina et al., 2017; Pearlin et al., 1990). In our study, carers spent over 35 h per week on care activities. Notably, most carers in our study were adult child carers who were still in paid employment; thus, they might be physically overloaded with care activities and their paid work. Moreover, carers might not be able to use formal care services to relieve the objective care burden as government subsidised respite care and other aged care services were underdeveloped in mainland China (Jia et al., 2020), difficult to access for Chinese-Australian carers due to language barriers (Xiao et al., 2022a), or shut down in Taiwan, Hong Kong and Macau during the COVID-19 outbreaks. A systematic review confirmed that carers experienced worse support and increased burden due to the COVID-19 related shutdown of care services (Gaigher et al., 2022). Such situations might also have explained the lack of intervention positive effects on carers' self-efficacy for obtaining respite care and on social support for carers in our study.

Our study did not show intervention positive effects on the frequencies of changed behaviours of people with dementia, which was demonstrated in the study by Berwig et al. (2017) in the 3-month follow-up after intervention. The differences may imply the need to add need-based in-home individualised sessions to allow the interventionist to observe changed behaviours, analyse causes and triggers and train the carer to develop problem-solving skills using various techniques, for example

instructions, demonstrations and roleplaying. A systematic review by Meng et al. (2021) revealed that a standardised intervention without individualised support for carers showed no intervention effect on the frequency of changed behaviours.

We found no intervention effects on the care recipients' QoL, hospital admissions and emergency department presentations, suggesting that the care needs of care recipients might not have been addressed in our study. The similar result was also found in the UK START study (Livingston et al., 2013). Two systematic reviews on carer-care recipient dyadic psychological or communication interventions reported intervention effects on improving the QoL of people with dementia (Hockley et al., 2023; Poon, 2022) which underscore the need to design interventions that address individualised factors affecting the QoL.

We found that the positive effects shown at 6 months did not sustain at follow-up 3 months later (9 months), although we confirmed through multivariate mixed-effects regression models that those changes at 6 months were true, rather than statistical artefacts such as regression to the mean. However, the previous two multicomponent interventions reported effects after the completion of interventions at 3-month (Berwig et al., 2017) and even 6-year time points (Livingston et al., 2020). The differences may indicate that the online delivery mode of a facilitator-enabled multicomponent iSupport programme has limitations in assessing carers' individual needs, coaching them to develop problem-solving skills and enabling them to demonstrate their skills to gain feedback in their care environment, compared to these in-home face-to-face multicomponent interventions.

The total attrition rate in our study at the 6-month follow-up was 20.3 % which is higher than the German REACH II study (12 %) and the UK START study (13 % at 8 months) (Berwig et al., 2017; Livingston et al., 2013). Notably, in our study, the higher attrition rate was found in the usual care group (23 %). The differences of the attrition rate in the intervention group between our study (17.6 %) and the German REACH II study (13 %) or the UK START study (12 %) are relatively small, which might be explained as the loss of contact with participants due to COVID-19 related reasons, however we were unable to verify the reasons due to the COVID-19 lockdowns. Indeed, the withdrawal rate in our study was 1.8 % and smaller than the German REACH II study (8.5 %) and the UK START study (3.8 %).

6. Strength and limitations

Our study shows some strengths. First, the effects of the multicomponent intervention were tested in real-world conditions in the eight study sites where Chinese family carers share similar cultures in dementia care. Therefore, the trial is close to a pragmatic trial as described by Loudon et al. (2015), and the intervention is more likely to be embedded into routine care services after the trial. Second, our study achieved the recruitment goal and participant retention despite COVID-19 outbreaks across all study sites during the trial.

Our study has some limitations. First, carers who participated in the study represent those who have internet access and are capable of using social platforms to communicate with others. Therefore, findings cannot be generalised in the carer population who do not use internet or social platforms. Second, variations in health and social care systems (settings) and aged care and health care providers (organisations) introduced confounding variables that could influence the outcomes. Furthermore, the attrition rate in the usual care group was larger than that in the intervention group, which might have affected the outcomes in the study. In addition, this study was undertaken during the COVID-19 pandemic. Therefore, the outcomes of the study may differ from those prior to or after the COVID-19 pandemic era.

7. Conclusions

Our study provides crucial evidence to the international community that an online delivery mode of a multicomponent intervention incorporating the culturally adapted WHO iSupport programme can improve carers' mental health demonstrated by improved mental-health-related QoL, reduced upsetting thoughts and distress in dementia care. Our study also demonstrates that cross-national collaboration in the study is possible due to shared challenges in dementia care and shared culture in the care of family members living with dementia. Our findings have implications for policy makers to invest funding to allow health and social care organisations to deliver the evidence-based Chinese iSupport programme to family carers of people with dementia in a wider community. Our findings also suggest that health and aged care organisations will need to embed the evidence-based Chinese iSupport programme in routine care services to improve mental health for family carers of people with dementia and stabilise home-based dementia care. In addition, our findings also indicate the need to prepare the health and aged care workforce to deliver the evidence-based iSupport programme through education and training programmes.

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CRediT authorship contribution statement

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Data availability

The data that support the findings of this study are available by email lily.xiao@flinders.edu.au upon reasonable request.

Declaration of Competing Interest

No conflict of interest has been declared by the authors.

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