EXPLORING A FACILITATOR-ENABLED VIRTUAL ISUPPORT FOR DEMENTIA PROGRAM IN THE AUSTRALIAN HEALTH AND AGED CARE CONTEXT

By

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Thesis

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Summary

Background: Caring for a person living with dementia (PLWD) at home can be overwhelming. Carers of PLWD reported unmet needs in acquiring dementia care knowledge and skills, symptom management, accessing care services, and peer and emotional support. To strengthen support for carers, the World Health Organisation (WHO) has developed an iSupport for Dementia program, a psychoeducation program for carers. The program aims to improve carers' ability to manage dementia at home and reduce their stress.

Aims: The aims of this PhD thesis were to 1) engage with stakeholders to reach the consensus on activities to be delivered by iSupport facilitators for carers of PLWD in a planned iSupport for Dementia program in Australia and 2) assess the feasibility, fidelity, and preliminary effectiveness of a facilitator-enabled virtual iSupport for Dementia program for informal carers of PLWD in a 6-month intervention period.

Methods: The study used a mixed methods research design in two phases to achieve its aims. Phase 1 applied a modified nominal group technique to reach consensus with stakeholders using survey and workshop discussion/interview methods. Phase 2 applied a 6-month internal pilot randomised controlled trial (RCT) and a qualitative descriptive study design. Quantitative data using surveys were collected at baseline and 6-month. Qualitative data from carer support group meetings were collected during the RCT, and interviews with carers, facilitators and site leaders were collected after the 6-month intervention.

Findings: In phase 1, stakeholders agreed on 16 relevant activities to be delivered by iSupport facilitators to strengthen support for carers in the iSupport program. Three themes identified from qualitative data indicated that stakeholders desire to have iSupport facilitator support at the time of dementia diagnosis, throughout the everyday dementia care journey, and during transition moments.

In phase 2, findings indicated that the study had a 10% recruitment rate and a 70% retention rate in the intervention group at the 6-month. Based on feedback during the pilot study, modifications were made to the main RCT, including providing hard copy books and phone support instead of virtual-only and modifying inclusion criteria to include carers of people with cognitive impairment. Findings show that carers were actively engaged in the program. They also recommended strategies to embed and sustain such a program after the trial. Furthermore, findings indicated that the iSupport program significantly improved the PLWD’s changed behaviours, carers' distress reactions towards changed behaviours and self-efficacy in obtaining respite in the intervention group. The hospital group showed significantly improved self-efficacy for responding to PLWD’s changed behaviour compared to the community aged care group. However, there were no significant differences in carers' QOL, quality of social support, PLWD’s QOL, and carers’ self-efficacy in controlling upsetting thoughts.

Conclusion: The engagement with stakeholders informed the project team of the facilitators’ role and relevant activities to support carers of PLWD in the program. The internal pilot RCT enabled the modification of the main trial, made the main trial feasible, and measured the preliminary effectiveness of the iSupport program. The new knowledge generated from this PhD study has implications for policy and practice development in supporting carers of PLWD in the community.

Keywords: Feasibility studies, Dementia, Quality of life, Caregivers, Self-Efficacy

The DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed................Ying Yu...................................

Date..

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Preface

The work of this thesis was carried out by the author, except:

- Chinese database search was conducted by Dr Jing Wang and Jin Jie He at Xi'an Jiao Tong University, China for Chapter 2 systematic review and meta-analysis,
- Chinese database search was conducted by Dr Jing Wang at Xi'an Jiao Tong University, China; search for studies written in Arabic in the Academic Journal of the Middle East was conducted by Dr Fathimath Shifaza at the College of Nursing and Health Sciences, Flinders University for Chapter 3 systematic review and meta synthesis,
- Participants recruitment, consent and survey data collection: Research assistant Kai Ping Tan, whom Dr Michael Chapman supervised, conducted consenting and survey data collection in Canberra Health Services. Dr Claudia Meyer supervised Raylene Fresie and Heather Williams and completed consent and survey data collection with participants in Bolton Clarke, Australia.
- Workshops and interviews in phase 1: Dr Sarah Hunter at Caring Future Institute, Flinders University, led the discussion of co-design workshops in South Australia. Dr Michael Chapman led workshops and interviews in Canberra Health Service, and Dr Claudia Meyer led workshops and interviews in Bolton Clarke, Australia.
- In phase 2, Dr Shahid Ullah completed randomisation.

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List of Abbreviations

Abbreviations	Explanation
BPSD	psychological and behavioural symptoms of dementia
CI	confidence interval
CINAL	the Cumulative Index to Nursing and Allied Health Literature
C_L	Carer’s letter to the researcher
CNKI	China National Knowledge Infrastructure
ConQual	Confidence in qualitative synthesis findings
ESC	Evaluation to Sign Consent
FP	Facilitator portfolio
GDS	Global Deterioration Stages between Normal Ageing and Alzheimer's Disease
GRADE	the Grading of Recommendations Assessment, Development and Evaluation
G_P	Peer support meeting recording
G_T	WhatsApp messages
I_C	Carer in the iSupport group interview
I_F	Facilitator interview
I_SL	Site leader interview
JBI	Joanna Briggs Institute
JBI QARI	JBI Qualitative Assessment and Review Instrument
MEDLINE	Medical Literature Analysis and Retrieval System Online
MMSE	Mini-Mental State Examination
NDB	The Need-driven Dementia-compromised Behaviour model
PICOs	P=Population, I= Intervention, C= Context, O= Outcome, S= Study
PLST	the Progressively Lowered Stress Threshold model
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
PLWD	People living with dementia
QOL	Quality of Life
QOL-AD-Proxy	Quality of Life in Alzheimer’s Disease family version
RA	Research assistants' documentation
RCTs	Randomised Controlled Trials
RMBPC	Revised Memory and Behaviour Problem Checklist

Abbreviations	Explanation
RevMan	Review Manager
RoB2	Cochrane risk-of-bias tool
ROBINS-I	Risk of Bias In Non-randomised Studies – of Interventions
RUDAS	The Rowland Universal Dementia Assessment Scale
SALHN	Southern Adelaide Local Health Network
SC	Survey comments
SF-12 health survey	QoL: the 12-Item Short-Form Health Survey
SMD	Standardised mean differences
SMMSE	Standardised Mini-Mental State Examination
The COPE Index-QS	Europe Index-Quality of Social Support
WHO	World Health Organisation

List of publications during candidature

Publication related to this thesis

1. **Yu, Y.,** Xiao, L., Ullah, S., Meyer, C., Wang, J., Pot, A. M., & He, J. J. (2023). The effectiveness of internet-based psychoeducation programs for caregivers of people living with dementia: a systematic review and meta-analysis. Aging & Mental Health, 1-17. https://doi.org/10.1080/13607863.2023.2190082

2. **Yu, Y.,** Xiao, L., Ullah, S., Meyer, C., Wang, J., Pot, A. M., & Shifaza, F. (2023). The Experiences of Informal Caregivers of People With Dementia in Web-Based Psychoeducation Programs: Systematic Review and Meta-synthesis. JMIR aging, 6, e47152. https://doi.org/10.2196/47152

3. Xiao, L., **Yu, Y**., Ratcliffe, J., Milte, R., Meyer, C., Chapman, M., Chen, L., Ullah, S., Kitson, A., De Andrade, A. Q., Beattie, E., Brodaty, H., McKechnie, S., Low, L. F., Nguyen, T. A., Whitehead, C., Brijnath, B., Sinclair, R., & Voss, D. (2022). Creating 'Partnership in iSupport program' to optimise family carers' impact on dementia care: a randomised controlled trial protocol. BMC Health Serv Res, 22(1), 762. https://doi.org/10.1186/s12913-022-08148-2

4. **Yu, Y.,** Hunter, S. C., Xiao, L., Meyer, C., Chapman, M., Tan, K. P., Chen, L., McKechnie, S., Ratcliffe, J., Ullah, S., Kitson, A., Andrade, A. Q., & Whitehead, C. (2023). Exploring the role of a facilitator in supporting family carers when embedding the iSupport for Dementia programme in care services: A qualitative study. *Journal of Clinical Nursing*. https://doi.org/10.1111/jocn.16836

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7. **Yu, Y**., Xiao, L., & Chamberlain, D. (2022). Chinese patients' perception of care quality and safety in Australian hospitals. *International Journal of Advanced Health Science and Technology*, *3*(2), 118-126. https://doi.org/https://doi.org/10.35882/ijahst.v3i2.243
8. Xu, D.X., Wang, J., Xiao, L., Wang, J., **Yu, Y**., Ullah, S., 'Informal carers' perceived needs and preferences in implementing WHO iSupport for Dementia program: A cross-sectional study'. Submitted to Journal of Advanced Nursing on 16th Jan 2024

9. Xiao, L., Cheng, A., Xie, C., Chiu, K., **Yu, Y.**, Ullah, S., Wang, J., Xu, D., Pan, X., Zhang, Y.J., & Zhang, A. 'Evaluating an evidence-based iSupport for Dementia program in routine care services: study protocol for a hybrid type II trial' submitted to BMJ Open on 20th March 2024

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1. 'Exploring the role of a facilitator in supporting family carers when embedding the iSupport for Dementia programme in care services: A qualitative study', **oral presentation**, Australian Association of Gerontology (AAG) conference 2023, Gold Coast, Australia.

2. 'The experience of informal caregivers of people with dementia in online dementia psychoeducation programs: a meta-synthesis of qualitative studies', **oral presentation,** Australian Dementia Research Forum 2023, Gold Coast, Australia.

3. 'The effectiveness of internet-based psychoeducational programs for caregivers of people living with dementia: a systematic review and meta-analyses', **poster presentation**, Australian Dementia Forum 2023

4. 'The effectiveness of internet based psychoeducational programs for caregivers of people living with dementia: a systematic review and meta-analyses, **poster presentation**, the International Joint Conference for Healthcare Professionals, Bandos Maldives.

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1. Chief Investigator, NHMRC 2022 TCR Cultural Ethnic and Linguistic Diversity in Dementia Research Grant (No.2024551) $1,555,078.05. Project title: A 'culturally tailored iSupport model' for carers of people with dementia

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Glossary

Term	Definition
Caregiver burden	Refers to the carer's perceived emotional, social, and financial consequences of care provision over time (Liu et al., 2020).
Changed behaviours	A term that describes psychological and behavioural symptoms of dementia, such as apathy, confusion, agitation, and depression (Perera et al., 2017)
Dementia	A progressive condition associated with a gradual decline in brain function present as memory loss, difficulty with speech, personality change and functional decline (Australian Institute of Health and Welfare (AIHW),2023a).
Informal carer	Unpaid carers can be family, friends, or neighbours (AIHW, 2023a). In this thesis, this term is exchangeable with family carers.
Implementation fidelity	The degree of the program is delivered as intended, while adaptation refers to the process by which implementers bring deliberate changes to the original design to fit with contextual factors (Pérez et al., 2016; Von Thiele Schwarz et al., 2019).
iSupport facilitator	Health and social care professionals employed by service providers. Their responsibilities are supporting carers of PLWD based on individual needs, facilitating monthly online carer support meetings, and interacting with carers on WhatsApp groups.
iSupport program	The iSupport psychoeducation program builds on a person-centred dementia care approach, emphasising the program facilitator's support (World Health Organization, 2017). The iSupport is an interactive internet-based program that contains education components of dementia knowledge and coping strategies to help informal carers understand dementia and enable each carer to develop capabilities for self-management of dementia at home.
Person-centred dementia care	It emphasises PLWD's individual needs, values, and beliefs to promote high standards of dementia care and consumer engagement in the health system (Kitwood, 1993).
Psychoeducation	An educational program with theoretical, psychological, and behaviour training about dementia care to increase carers' capability to cope with challenges (Cheng et al., 2020; Dumont et al., 2016).
Quality of life	An individual's perception of their life expectations in the context of their culture and value systems (World Health Organization, 2020).
Self-efficacy theory	A social cognitive or social learning theory emphasises the person's ability to learn, and environmental factors influence learning. Perceived self-efficacy means the belief in the capability of completing the assigned task (Bandura, 1986).
Transitional care	A person moves between different healthcare settings or levels of care within the same setting (Groenvynck et al., 2021).
Virtual iSupport program	Virtual iSupport program in this study means iSupport for Dementia program and facilitator support were offered virtually, via internet and video conferences.

1 Background

1.1 INTRODUCTION

Dementia currently affects over 50 million people worldwide and is projected to reach 83 million by 2030, and the number will increase three-fold and reach 152 million by 2050 (World Health Organization (WHO), 2023). In 2021, nearly half a million Australians were living with dementia, and over 70% of them were cared for by informal or family carers in the community (Dementia Australia, 2021). Caring for a person living with dementia (PLWD) at home can be overwhelming and often impacts carers' physical and psychological wellbeing, resulting in decreased quality of life (QOL) for both carers and PLWD. Carers of PLWD reported unmet needs in acquiring dementia care knowledge and skills, sharing experiences with peers, accessing care services, symptom management, physical care for PLWD, and emotional support at home (Clemmensen, Lauridsen, et al., 2021; Mazurek et al., 2019). Supporting carers of PLWD is critical to maintaining or improving both carers and PLWD's QOL while decreasing the impact of the burden of dementia on families and the health and social care systems. However, interventions that support carers' needs were diverse, and the effectiveness of this support was inconclusive (Cheng et al., 2020; Huggins et al., 2023). Moreover, evidence on incorporating the program into Australian health and aged care services to strengthen support for carers of PLWD is scant. Therefore, research on dementia caregivers' support is much needed to build an evidence base to better support them in the Australian community.

To address the dementia burden, the Australian Government established the Medical Research Future Fund (MRFF) Dementia Ageing and Aged Care Mission funding to enhance dementia research (MRFF, 2023). The 'Creating 'partnership in iSupport program' to optimise carers' impact on dementia care' is one of the 2020 MRFF-funded projects. The iSupport for Dementia program was originally developed by WHO (2017) to support the international community to achieve the WHO's Global Action Plan on the public response to dementia care. The WHO iSupport program was adapted to the Australian context by Xiao et al. (2021) before the project. This PhD study reported in this thesis is part of the large project mentioned above.

This PhD study was conducted with two community aged care organisations and two tertiary hospitals across Australia between September 2021 and October 2023. The two age care organisations provide community and residential aged care services. They collectively support more than 100,000 clients in Australia. Phase 1 of the PhD study explored the activities to be delivered by the iSupport facilitators and their role and responsibility in a planned iSupport for Dementia program by engaging with stakeholders. Phase 2 of the PhD study was an internal pilot randomised controlled trial (RCT) study that evaluated the feasibility, fidelity, and preliminary effectiveness of the facilitator-enabled virtual iSupport for Dementia program and explored the strategies to embed and sustain such a program after the trial. In this thesis, the term ‘informal carers’ is interchangeable with ‘family carers’, and means unpaid carers for PLWD such as family, friends, or neighbours (AIHW,2023a). This study focused on carers of all types of dementia.

This chapter presents the background of this PhD study entitled ‘Exploring a Facilitator-enabled Virtual iSupport for Dementia Program in the Australian Health and Aged Care Context’. The chapter discusses the definition of dementia, changed behaviour as one of the signs and symptoms of dementia, and its impact on individuals and the health and social care system in section 1.2. Section 1.3 introduces the iSupport for Dementia program and the role of the iSupport facilitator. Section 1.4 presents the study's aims and objectives. Section 1.5 provides the rationale of the study. Section 1.6 discusses the significance of the study. Section 1.7 presents an outline of the remaining chapters of this thesis, and section 1.8 presents a summary of the chapter.

1.2 DEMENTIA DEFINITION AND ITS IMPACT

1.2.1 Definition and progression

Dementia is a progressive condition associated with a gradual decline in brain function, which is present as memory loss, difficulty with speech, personality change, and functional decline (Innes, 2020). It can affect people of any age. The general progression of dementia can be described as three stages, including early, middle and late-stage dementia, depending on the symptoms presented (Dementia Australia, 2020; WHO, 2021a). According to the WHO (2021a), a common symptom of earlier stage or mild dementia is often overlooked, including forgetfulness or becoming lost in familiar places. Symptoms of middle-stage or moderate dementia include difficulty in communication, increased confusion and experiencing behavioural changes such as wandering or repetitive behaviours. Late-stage or severe dementia is close to total dependence, with apparent signs of confusion and escalated behavioural changes such as aggression (WHO, 2021a). Although the symptoms of dementia may be similar in PLWD, the impact on an individual and their carers can be very different.

1.2.2 Changed behaviours in dementia

Changed behaviours is a term used to describe common dementia symptoms such as apathy, confusion, agitation (i.e., wandering or vocal disruption) and depression (Perera et al., 2017; Pond et al., 2019). Alternate terminology used is described as psychological and behavioural symptoms of dementia (BPSD) or neuropsychiatric symptoms in PLWD. Changed behaviour is the preferred terminology because not all behaviours of PLWD result from physiological changes in the brain but rather their unmet needs (Cunningham et al., 2019). Moreover, advocates raised concerns about the negative influence of terminology on beliefs towards PLWD, such as BPSD (Burley, Casey, et al., 2021). Although there is no consensus on which terminology is preferred, researchers and PLWD agreed that language use needs to be person-centred. Therefore, this thesis uses changed behaviours instead of BPSD to describe behaviour change in PLWD.

Changed behaviours are highly prevalent; up to 90% of PLWD experience changed behaviours at some stage (Burley, Chenoweth, et al., 2021). Changed behaviours can be perceived differently by people around PLWD, depending on the presentation. For example, some PLWD may present as withdrawing from social activity. In contrast, others may be aggressive and agitated, the latter often perceived as more challenging, although both symptoms are changed behaviours. Cohen-Mansfield (2000) summarised four theoretical models that aimed to understand changed behaviours in PLWD and to better support PLWD, including: 1) the direct impact of the dementia-biological model, 2) the behavioural model, 3) the Need-driven Dementia-compromised Behaviour model (NDB), and 4) the Progressively Lowered Stress Threshold model (PLST).

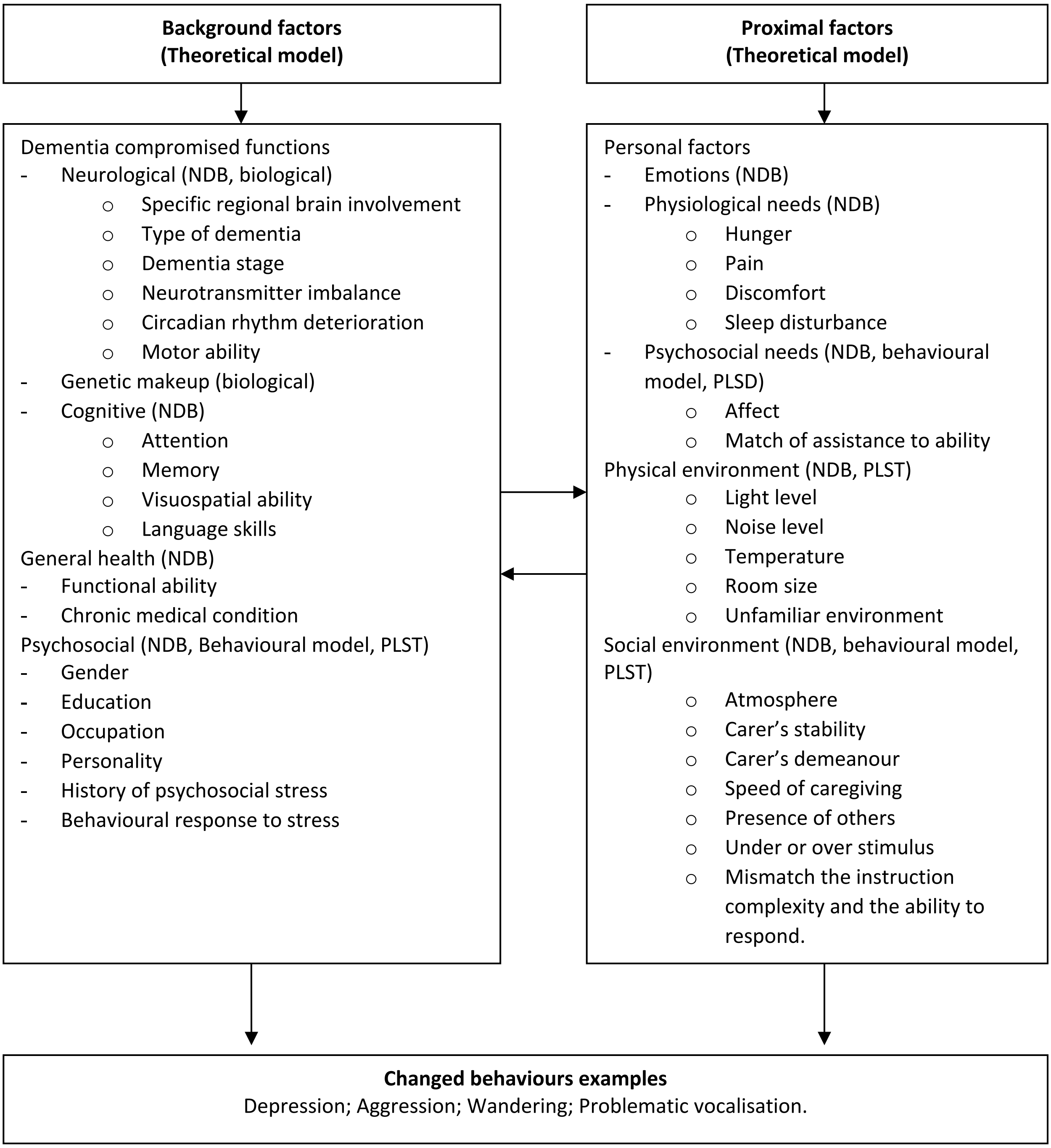
The direct impact of the dementia-biological model explains that the changed behaviour in dementia results from genetic risk factors or physiological changes in the brain (Cohen-Mansfield, 2013; Scassellati et al., 2020; Tible et al., 2017), in this model, the specific changed behaviours in PLWD are linked to dementia-related brain lesions and changes in neurotransmission, neuromodulation, and corticolimbic system (Tible et al., 2017). For example, PLWD may experience difficulties understanding spoken words (Wernicke aphasia) or recognising faces (prosopagnosia) if the temporal lobe of the cerebral cortex is affected. In contrast, problems with frontal lobes may result in loss of movement, withdrawal, expressive dysphasia or repetitive behaviours (Hobson, 2019). Common interventions based on the biological model are pharmacological treatments, such as anti-depressants, mood stabilisers or antipsychotics, to treat and manage behaviours or balance neurotransmitters (Tible et al., 2017). However, not all changed behaviours respond to pharmacotherapy, nor should it be the first line of management; non-pharmacological behavioural and psychological interventions should be considered first (Macfarlane & Cunningham, 2021; Pond et al., 2019).

The second model, the behavioural model, suggests that changed behaviour in PLWD is due to the decline in rule-governed behaviour and the increase in contingency-maintained behaviour. For example, an environmental stimulus (i.e., meeting strangers) will only induce an emotional reaction (i.e., frightened, screaming) as dementia progresses (Fisher et al., 2007). The interventions based on the behavioural model focus on the prevention of changed behaviours (i.e., reduce confusion by providing more cues in the environment), maximise reinforcement (reward appropriate behaviours) and control stimuli (i.e., slowly introduce strangers) (Cohen-Mansfield, 2013; Tible et al., 2017).

The Need-driven Dementia-compromised Behaviour model (NDB) emphasises a person's needs, changing the standard view of dementia-related behaviour as 'disruptive' or disturbing (Algase et al., 1996; Kolanowski, 1999). Within the NDB Model, dementia-related changed behaviours express unmet needs; for example, a PLWD may communicate their needs via behaviour such as aggression, wandering or problematic vocalisation instead of ordinary verbal communication (Cho et al., 2021; Colling, 1999). It reflects the interaction of background factors (i.e., dementia-compromised function, health state or personality) and proximal factors (i.e., physiological needs or environment) (Kolanowski, 1999). Interventions based on the NDB model focus on PLWD's needs, for example, using music or structured activities to address the unmet needs of boredom or sensory deprivation and pain relief medication to address unmet needs of pain (Cohen-Mansfield, 2013).

Another commonly cited model is the Progressively Lowered Stress Threshold model (PLST). This model suggests that PLWD have a decreased threshold for stress tolerance (i.e., change routine) and environmental stressors (i.e., invasion of personal space), which has a significant impact on PLWD's behaviour (Hall & Buckwalter, 1987; Pickering et al., 2022). According to the PLST model, stressors accumulate during the day until the stress threshold is exceeded and may cause changed behaviour, such as anxiety and restlessness in PLWD (Hall & Buckwalter, 1987). Interventions in the PLST model suggest environmental modification to decrease or increase the stimulation to meet an individual's needs (Pickering et al., 2022).

Changed behaviours in dementia are multifaceted, and while these models explain changed behaviours, they are likely not exclusive. Blending all the factors from the above models to better understand the changed behaviour, a summary of the underlying factors of changed behaviour can be found in Figure 1-1.



Background factors (Theoretical model)

Dementia compromised functions
- Neurological (NDB, biological)
  - Specific regional brain involvement
  - Type of dementia
  - Dementia stage
  - Neurotransmitter imbalance
  - Circadian rhythm deterioration
  - Motor ability
- Genetic makeup (biological)
- Cognitive (NDB)
  - Attention
  - Memory
  - Visuospatial ability
  - Language skills

General health (NDB)
- Functional ability
- Chronic medical condition

Psychosocial (NDB, Behavioural model, PLST)
- Gender
- Education
- Occupation
- Personality
- History of psychosocial stress
- Behavioural response to stress

Proximal factors (Theoretical model)

Personal factors
- Emotions (NDB)
- Physiological needs (NDB)
  - Hunger
  - Pain
  - Discomfort
  - Sleep disturbance
- Psychosocial needs (NDB, behavioural model, PLSD)
  - Affect
  - Match of assistance to ability

Physical environment (NDB, PLST)
  - Light level
  - Noise level
  - Temperature
  - Room size
  - Unfamiliar environment

Social environment (NDB, behavioural model, PLST)
  - Atmosphere
  - Carer's stability
  - Carer's demeanour
  - Speed of caregiving
  - Presence of others
  - Under or over stimulus
  - Mismatch the instruction complexity and the ability to respond.

Changed behaviours examples

Depression; Aggression; Wandering; Problematic vocalisation.

Figure 1-1 Theoretical model for changed behaviours in dementia
(Cohen-Mansfield, 2013; Fisher et al., 2007; Hall & Buckwalter, 1987; Kolanowski, 1999; Tible et al., 2017)

1.2.3 Experience of people living with dementia

Cognitive decline directly alters PLWD's ability to recognise, interpret, and respond to their surroundings (Zwijsen et al., 2016). Therefore, people usually misinterpret PLWD' needs, preferences, and behaviours. It is imperative to understand that the underlying life experiences that formed PLWD will never change (Hutmacher, 2021). Diagnosed with dementia can be shocking, with a deep sense of losing identity and loss of control (van

Wijngaarden et al., 2019). PLWD desire to have a shared journey while living with dementia; however, they often feel alone and unable to share their struggles (van Wijngaarden et al., 2019). There are a growing number of PLWD worldwide who are sharing their first-hand experience of living with dementia despite the difficulty they are facing. Many PLWD are determined to live life fully, restore their identity, and advocate for a cultural shift in dementia care (Swaffer, 2021; Talbot et al., 2020). They desire to remain actively engaged in meaningful activities that positively impact other people's lives (Swaffer, 2021; Talbot et al., 2020) and live quality, independent lives in a safe environment as well as manage their dementia symptoms (Harding et al., 2019). To achieve this, community care services need to be refined to meet evolving expectations, with the support of family carers.

1.2.4 Health and social care system impacts

Dementia impacts individuals, as outlined above, and heavily impacts health and social care systems. Dementia is the leading cause of the burden of disease and the second leading cause of death in Australia (Australian Institute of Health and Welfare (AIHW),2023a). Dementia symptoms and changed behaviours also contributed to approximately 30% of overall dementia cost (Burley, Chenoweth, et al., 2021) and are the primary factor for hospital admission (Matsuoka et al., 2019). A study from the United Kingdom identified that PLWD living in the community had a higher hospital admission rate and was associated with an increased health system burden (Afonso-Argilés et al., 2020). In Australia, between 2021 and 2022, more than 25,700 hospitalisations were due to dementia, and 94,500 hospitalisations with dementia, PLWD stayed five times longer than the average hospitalisation (AIHW, 2023a). The latest available health and aged care expenditure was in 2018-2019, estimated to be nearly three billion Australian Dollars related to dementia, including A$1.7 billion (56%) contributing to residential aged care services, followed by A$596 million (20%) towards community-based aged care services and A$383 million (13%) hospital services (AIHW, 2023a). More than half the Informal carers of PLWD in Australia provided an average of 60 or more hours of unpaid care every week, contributing to the Australian economy by supporting PLWD to remain home (AIHW, 2023a).

1.2.5 The Impact of dementia care on family carers' health and wellbeing

The AIHW (2023a) estimated there were between 137,600 and 354,200 family carers of PLWD in the community in 2022. Caring for PLWD can be physically and emotionally demanding and can have a significant impact on carers' health, wellbeing and QOL. WHO defines QOL as an individual's perception of their life expectations in the context of their culture and value systems (WHO, 2020). Research shows that family carers of PLWD reported worse health-related QOL than non-PLWD carers (Karg et al., 2018; Lippe et al., 2021). Carers of PLWD often spend at least five hours per day for each PLWD to assist in daily living activities such as dressing and undressing, meal preparation, bathing and other household tasks (Rathnayake et al., 2020; WHO, 2021b). Furthermore, carers of PLWD often reported burden, a subjective feeling of negative impact on their functioning due to the caregiving role (Williams et al., 2019) and stress, a term used to describe carers' emotional reaction due to PLWD's condition or care tasks that are beyond their ability to cope (Dombestein et al., 2020; Morrisby et al., 2019). In Australia, around 31% of carers of PLWD felt worried and depressed, and 6.7% of them were diagnosed with a stress-related illness (AIHW, 2023a). Carers' burden and stress are often directly or indirectly caused by the care recipient's condition, the carer's situation, and the health and social care system.

A carer’s level of burden and stress is directly related to the extent of the PLWD's condition (i.e., changed behaviours and number of medications), dependent level (i.e., driving status and physical function), and level of support carers received (i.e., PLWD's service levels) (Connors et al., 2020b). Changed behaviours in PLWD can also trigger carers' sense of losing their emotional bond with the PLWD, contributing to their own unmet needs which may be experienced as depressive symptoms or poor mental health (Chang et al., 2021). Moreover, emotional challenges of carers may also relate to social isolation, stigma, losing their identity, their companion (i.e., PLWD gradually lose their memory and communication ability, leading to carer grieving), role change (i.e., husband and wife versus carer and care recipients), and work-care conflicts due to care responsibilities (Fletcher, 2020; Hazzan et al., 2022; Innes, 2020; Waligora et al., 2019). Additionally, other factors such as living standards, support service availability and financial difficulties also significantly correlated with carers' anxiety and depressive symptoms, whereas adequate support can reduce carer's burden and stress (Connors et al., 2020b; Fekete et al., 2019).

Carers often need to navigate the health and social care systems to identify available services, financial support, their carer rights, and trustworthy yet understandable information relevant to their situation; the process often causes stress to carers (Bressan et al., 2020).

However, according to current government policy, carers are not viewed as recipients of aged care services, and their support is mainly based on the assessed needs of the PLWD. Carers' confidence and capability to care for PLWD at home is often described as self-efficacy, defined as their belief in their capability to complete the care tasks (i.e., managing changed behaviours)(Bandura, 1986). Caregivers with high self-efficacy tend to believe they have mastered specific skills to deal with challenges. Research shows that carers' confidence level, social support, and positive thinking ability correlate with caregivers' mental health and wellbeing (Arenella & Steffen, 2020; Bekhet & Garnier-Villarreal, 2020). However, many carers of PLWD indicated that they lack knowledge of dementia progression, symptom management and skills for the provision of daily care (Alves et al., 2019; Bressan et al., 2020; Rathnayake et al., 2020). Moreover, carers of PLWD reported unmet needs, including peer support, emotional support and available respite services (Bressan et al., 2020; Steenfeldt et al., 2021). Inadequate services, poor communication between service providers, and delays in recognising changed behaviours were also reported by carers (Braun et al., 2019). Carers also expressed the need for support from knowledgeable, trained health professionals (Fitzgerald et al., 2019).

1.2.6 Support for carers of a person living with dementia

Different forms of support are available and aim to decrease caregiver burden and improve their psychological wellbeing and QOL. The recommendations for carers of PLWD support include education, skill training, information provision, psychosocial support, and physical support (Bressan et al., 2020; Gao et al., 2022; WHO, 2017). Cheng et al. (2020) classified support into the following: 1) psychoeducation; 2) psychotherapy; 3) support groups; 4) respite; 5) training of carer recipient; 6) multicomponent interventions (i.e., combine psychoeducation and support groups) and 7) miscellaneous interventions (i.e., exercise, communication training or spiritual care). Among all these support interventions, psychoeducation and multicomponent interventions have broader and more significant effects on reducing caregiver depression and enhancing self-efficacy and QOL (Cheng et al., 2020). A psychoeducation program in dementia is an educational program that contains theoretical, psychological and behavioural training about dementia care to increase carers' knowledge, skills, and strategies to cope with dementia care challenges (Cheng et al., 2020). Traditionally, psychoeducation programs are run in small face-to-face groups. Virtual or internet-based psychoeducation programs are worth exploring as they offer more flexibility and are not restricted by time and space. Psychoeducation programs can be provided with supporting groups. Supporting groups for carers of PLWD can offer them the opportunity to socialise, exchange experiences, and support each other in similar situations. Research shows that appropriate peer or social support can improve carers psychological wellbeing and knowledge acquisition (Lauritzen et al., 2022; West & Hogan, 2020). A well-run virtual carer support group has a similar positive effect to a face-to-face support group (Etxeberria et al., 2020; Han et al., 2020). Virtual carer support groups may particularly benefit those who have difficulty travelling.

In addition to psychoeducation programs, carers also desired tailored information and emotional support from a health professional (Steenfeldt et al., 2021). A support worker or key workers role was developed in community aged care settings to better support carers, and their responsibility is varied in the literature, covering the areas of case management, counselling, care management or specialist Admiral Nurse Service (Goeman et al., 2016; Renehan et al., 2017). The main emphasis of the support worker role in the literature was assisting carers in navigating, accessing and utilising care services for PLWD (Kiely et al., 2021; Reilly et al., 2015). A previous study conducted by Gridley et al. (2019) to evaluate the role of their Admiral Nurse (a specialist nurse in dementia established in the UK), who delivered a carers emotional support and training showed a positive change in the carers confidence and competence over time. Thus, expanding the existing support worker role is necessary to support carers of PLWD in addressing their education and emotional support needs.

1.3 INTRODUCTION TO THE ISUPPORT FOR DEMENTIA PROGRAM

1.3.1 WHO ISupport for Dementia program

The WHO iSupport for Dementia is an evidence-basedpsychoeducation program that contains educational components of dementia knowledge and coping strategies to help family carers of PLWD develop capabilities for self-management of dementia at home (WHO, 2019). It is presented as an internet-based program and an electronic book manual, which can be printed as hard copies. The WHO iSupport for Dementia program was developed to support the international community in achieving the WHOs goal described as 75% of countries will provide support and training programmes for carers and families of people with dementia by 2025 (WHO, 2021b, p. 182), and to achieve the WHO's Global Action Plan on the public response to dementia care (WHO, 2017). Compared to other psychoeducation programs, the WHO iSupport is more comprehensive as it includes the carer of PLWD from early stage to the late stage. The program is also flexible and allows member countries to adopt the program into their context. Studies across the globe confirmed that the WHO iSupport for Dementia psychoeducation program would enable carers to develop dementia care knowledge, skills and attitudes while offering them self-care and stress reduction strategies (Fiordelli & Albanese, 2020; Oliveira et al., 2020; Soraia Teles et al., 2020; Xiao et al., 2021). Therefore, the project adapted the Australian version of the iSupport for Dementia program to implement a facilitator-enabled intervention.

1.3.2 The Australian iSupport for Dementia program

The WHO iSupport for Dementia program was culturally adapted to the Australian context (Xiao et al., 2021). The Australian iSupport for Dementia program has an additional learning module and Australian based care resources compared to the original WHO program, with new learning units about Australian aged care services to meet the carers' expectations for the program in Australia (Xiao et al., 2021). It contains six modules and 30 units (Table 1-1). Each module presents a topic related to dementia care and provides interactive exercises with instant feedback for carers. When appropriate, the program introduces dementia care resources and services with weblinks for carers.

Table 1-1 Overview of Australian iSupport for Dementia

Module	Units
1. Introduction to dementia	1. What is dementia? 2. Timely diagnosis of dementia has many benefits. 3. Using memory aids in your care activities. 4. How to respond to repetitive behaviour. 5. How to avoid conversations that may trigger changed behaviour.
2. Being a carer	1. The journey together. 2. Improving communication. 3. Supported decision-making. 4. Involving others.
3. Caring for yourself	1. Reducing stress in everyday life. 2. Making time for pleasant activities. 3. Thinking differently.
4. Providing everyday care	1. Eating and drinking-more pleasant mealtimes. 2. Eating, drinking and preventing health problems. 3. Toileting and continence care. 4. Personal care. 5. An enjoyable day.

Module	Units
5. Dealing with changed behaviour	1. Introduction to person-centred care approach. 2. Aggression. 3. Changes in mood or interest. 4. Difficulty sleeping. 5. Delusions and hallucinations. 6. Walking and getting lost. 7. Changes in judgement.
6. Consumer-directed aged care and dementia care (New unit about Australian aged care services)	1. Making informed choices in dementia care. 2. Services that are available for younger onset dementia. 3. Carer support. 4. Dementia Behaviour Management Advisory Service. 5. Home care packages. 6. Relinquishing the carer role.

1.3.3 iSupport facilitators in the present study

It was suggested that the iSupport for Dementia program can be linked to a coach or a support group to meet individual needs in different country's context (Pot et al., 2019). Previous online psychoeducation programs offered facilitator's support via various format such as using the application (Blom et al., 2015), email (Boots et al., 2018), messaging (Gustafson et al., 2019), telephone (Hicken et al., 2017) or telegram group chat (Mollaei et al., 2021) to provide information, guide discussions, provide feedback or deliver education content. Some programs utilised facilitators to monitor or moderate discussion forums (Brennan et al., 1995; Cristancho-Lacroix et al., 2015) or only answer questions if asked (Gustafson et al., 2019).

In Australia, the iSupport facilitator is employed to support carers virtually by delivering the Australian iSupport for Dementia program and facilitate virtual peer support group meetings. The term 'iSupport facilitator' is used to distinguish the current study from existing support workers or key worker role in the literature. As discussed above, the main emphasis of the support worker role in the literature was assisting carers to navigate, access and utilise care services for PLWD (Kiely et al., 2021; Reilly et al., 2015). Whereas iSupport facilitators in this study were health and social care professionals employed by the service providers to deliver the iSupport for Dementia program as an intervention. ISupport facilitators are also interventionists in addition to their clinical role. This role could be a newly established role or an existing role with expanded responsibilities. Therefore, it is imperative to work with stakeholders to explore the activities to be delivered and role and responsibilities of the iSupport facilitators in phase 1 and evaluate whether they could adhere to their roles and responsibilities when delivering the iSupport program in phase 2.

1.4 AIMS AND OBJECTIVES

This two-phase PhD study had two aims and seven objectives detailed in the following:

Aim 1: Phase 1: Engage with stakeholders to reach a consensus on activities to be delivered by iSupport facilitators for carers of PLWD in a planned iSupport for Dementia program.

Objective 1: To reach a consensus on the activities to be delivered by iSupport facilitators to strengthen support for carers of PLWD in the planned iSupport program in hospital and community aged care settings.

Objective 2: To reach a consensus on the iSupport facilitator's roles and responsibilities when embedding the Australian iSupport for Dementia program in care services in hospital and community aged care settings.

Aim 2: Phase 2: To assess the feasibility, fidelity, and preliminary effectiveness of a facilitator-enabled virtual iSupport for Dementia program for informal carers of PLWD.

Objective 3: To determine the feasibility of the participant recruitment and factors affecting the recruitment.

Objective 4: To determine the attrition rate and factors contributing to the attrition.

Objective 5: To monitor intervention fidelity and factors affecting the fidelity.

Objective 6: To explore strategies to embed and sustain the facilitator-enabled iSupport program after the trial.

Objective 7: To determine the intervention effectiveness with the given sample size at six months.

1.5 THE RATIONALE OF THE STUDY

1.5.1 Gaps in meeting carers' needs in dementia care

As discussed in the previous section, dementia caregiving can have a detrimental impact on carers' and PLWD's health, wellbeing and QOL, as well as placing pressure upon health and social care systems. Carers of PLWD can be socially isolated, with limited interaction with peers to share experiences and support each other, and may have limited information to help them navigate the health and social care services (Clemmensen, Hein Lauridsen, et al., 2021).

Studies also revealed that carers required tailored support in monitoring dementia progress and related symptoms, managing comorbidities, medical treatment and transitions between care settings for PLWD (Bamford et al., 2021; Smith et al., 2021). It was shown that carers were at a high risk of poor health due to role strain and inability to cope with emotional and psychological stress arising from their carers' role (Seidel & Thyrian, 2019), therefore, requiring substantial self-care knowledge, skills, and support from care services. Thus, the importance of interventions and programs that support carers of PLWD in meeting their needs was highlighted, with the facilitator-enabled virtual iSupport program introduced to address the gap in meeting carers' needs in dementia care. Furthermore, a virtual intervention may offer more flexibility and accommodate a broader range of carers of the PLWD population, such as working carers or carers who cannot travel.

1.5.2 Gaps in understanding a facilitator's roles and responsibilities in complex intervention programs for carers of PLWD

Studies on dementia care providers' roles in supporting carers in hospital and community aged care settings are rare. The facilitator's role in dementia care is diverse and lacks a universal definition of role and responsibility (Goeman et al., 2016). Inadequate evidence limits quality and safety improvement in clinical practice, with single methodology research designs also limiting the exploration of co-design of dementia care intervention, indicating the need for such a study to fill the practice gap (Goeman et al., 2019; Goh et al., 2022). The inconclusive effectiveness of the supporting programs and limited complex intervention programs for carers of PLWD conducted in Australia also means more multicomponent interventions need to be evaluated in the Australian context.

1.5.3 Gaps in undertaking an internal pilot RCT in complex intervention programs for carers of PLWD

The challenges of conducting a complex intervention are well recognised in the literature, and it is recommended to conduct a pilot study before or with the main study (Kathryn et al., 2021) . Participant recruitment and retention is a major challenge that results in a longer study or a premature end of the study (Briel et al., 2016; Rodríguez-Torres et al., 2021; Walters et al., 2017). Previous systematic reviews reported that virtual intervention had a higher participant attrition rate than face-to-face intervention with uncertain causes (Gonzalez-Fraile et al., 2021), indicating the necessity for feasibility and fidelity studies to ensure the success of the large scale main study. Previous studies also indicated that the results of the effectiveness of virtual interventions in dementia care were inconsistent (Leng et al., 2020), indicating the need for further research in the area.

1.6 SIGNIFICANCE

This study aligns with the National priority areas in the Dementia, Ageing and Aged Care Mission Roadmap (MRFF, 2023). It creates an innovative person-centred care approach built on reciprocal partnerships between care service providers and carers (Xiao et al., 2020). This PhD study has several significant points. First, studies on facilitator-enabled virtual psychoeducation programs are scarce. This is the first study to test a virtual psychoeducation program for PLWD. Synthesised findings from systematic reviews at the literature search stage would improve the understanding of the effectiveness of the virtual psychoeducation program and carers’ needs and experiences in these programs. This knowledge would significantly influence the intervention strategies and evaluation of the iSupport for Dementia program in the Australian context.

Second, knowledge generated from phase 1 of the PhD study about the activities and iSupport facilitator’s role and responsibilities in the planned intervention is new and different from existing services. This new knowledge is significant as it can genuinely reflect end-users' needs through engagement with stakeholders and inform the establishment or improvement of the care services in hospital and community aged care settings.

Third, knowledge generated from phase 2 of this PhD study (internal pilot study) is essential to the success of the large MRFF-funded project, as it would significantly influence the implementation of the main RCT and further embed and sustain such program after the trial. The findings can also benefit similar study planning in the future, especially involving PLWD carers in the community.

Fourth, the facilitator-enabled virtual iSupport program is anticipated to reduce carers' stress and enable carers to manage dementia at home safely, consequently improving carers' and PLWD's QOL. The knowledge generated from this study related to the effectiveness of such multicomponent intervention is significant, as it has the potential to inform government and policymakers for future community dementia care service planning, for example, using virtual services to support carers in rural and remote areas.

Finally, further significance of this study is to foster international collaborations via the WHO iSupport community. These collaborations will allow Australia to adopt a multilingual version of the iSupport program from different countries. International collaborations are an innovative and cost-effective way to implement a program that can better support informal carers from culturally and linguistically diverse communities in Australia.

1.7 THESIS OUTLINE

The following section outlines the contents of the thesis chapters. This thesis contains nine chapters.

Chapter 1: Background - This chapter describes the definition of dementia, its signs and symptoms, and its impact on PLWD, their family carers and the health and social care system. This chapter also details the unmet needs of the family carer of PLWD, and the support required for carers of PLWD in the community. Chapter 1 also introduces the iSupport for Dementia program and how this PhD study uses the Australian version of the program to support carers of PLWD in the community through an iSupport facilitator. This chapter provides the rationale for the study by identifying gaps in the services and literature. The aims, objectives, and significance of the study are also presented in this chapter.

Chapter 2: Systematic review and meta-analysis - This chapter contains a published systematic review and meta-analysis of quantitative studies conducted between June and December 2021, reporting existing virtual or internet-based psychoeducation programs. The review showed that internet-based psychoeducational programs can improve some aspects of carers' mental and emotional wellbeing, especially when the program has a facilitator. However, the effects of programs on self-efficacy, anxiety, burden and QOL for carers remain inconclusive. This chapter also contains a summary of the included RCTs' feasibility. This systematic review prompted another systematic review to explore and synthesise carers' experiences in these studies, leading to Chapter 3.

Chapter 3: Systematic review and meta-synthesis - This chapter contains a published systematic review and meta-synthesis of qualitative evidence conducted between July 2021 and January 2022. The results of this systematic review confirmed that carers had positive experiences in high-quality and carefully designed virtual psychoeducation programs. To meet broader carers' education and support needs, program developers should consider information quality and relevancy, the support offered, individual needs, flexibility in delivery, and connectedness between peers and program facilitators.

Chapter 4: **Research methodology and method -** This chapter presents the research design including the study methodology, method and associated ethical considerations. In this chapter, different methodologies and methods used in phases 1 and 2 are presented. The study used a mixed methods experimental design to achieve the study's aims and objectives. Study phase 1 uses the consensus method through a modified nominal group technique, uses a pre-workshop survey, workshop discussion or interview and post-workshop survey method. Study phase 2 uses an internal pilot RCT and qualitative descriptive study design that collects qualitative data during the RCT (i.e., meeting record) and after the RCT using interviews. This chapter also contains a synthesis of stress and health theory, presenting the theoretical framework underpinning the present study. This theoretical framework, which guided the entire study, synthesises carer's stress into three categories: care recipient-related, carer-related and system-related factors, and the support that may mitigate these stresses.

Chapter 5: Findings phase 1 - the activities to be delivered and iSupport facilitators' roles and responsibilities in the iSupport program - This chapter presents phase 1 findings which address the first study aim. Findings of objective 1 is presented on stakeholders' consensus on the activities to be delivered in iSupport program. Stakeholders agreed on 16 relevant activities to be delivered by iSupport facilitators to strengthen support for carers in the virtual iSupport program. This chapter also presents findings on objective 2 that explore the iSupport facilitator's role and responsibilities. These findings form part of a published article. Findings indicate that stakeholders desire to have iSupport facilitator support present 1) at the time of dementia diagnosis, 2) throughout the everyday dementia care journey and 3) during transition moments.

Chapter 6: Findings phase 2 - Feasibility, fidelity, and strategies to embed and sustain iSupport program - This chapter addresses the second study's aim and objectives 3, 4, 5 and 6. This chapter presents the characteristics of participants and data analysed for the study objectives. Findings indicated that the study had a 10% recruitment rate and a 70% retention rate in the intervention group at 6 months. Based on feedback during the pilot study, modifications were made to the main RCT, including providing carers with hard copy books and phone support and modifying inclusion criteria to include carers of people with cognitive impairment, rather than only a diagnosis of dementia. Findings show that carers in the intervention group were actively engaged in the program. At the end-of-6-month intervention, data from participant interviews recommended strategies to embed and sustain such a program after the trial. The quantitative and qualitative findings are displayed, integrated, and narratively presented according to 1) feasibility of participant recruitment; 2) study retention and attrition and associated factors; 3) intervention fidelity; 4) strategies to embed and sustain the facilitator-enabled iSupport program after the trial.

Chapter 7: Findings phase 2 - Exploring program effectiveness - This chapter reports phase 2 findings related to the 6-month effectiveness of the facilitator-enabled virtual iSupport program, addressing study objective 7. This chapter contains the characteristics of participants in the intervention and usual care group. Findings indicated that the iSupport program significantly reduced the PLWD’s changed behaviours, carers' distress reactions to the changed behaviours and significantly improved carers’ self-efficacy in obtaining respite in the intervention group. The hospital group showed significantly improved self-efficacy for responding to PLWD’s changed behaviour compared to the community aged care group. However, there were no significant differences in carers' QOL, quality of social support, PLWD’s QOL, and carers’ self-efficacy in controlling upsetting thoughts. In this chapter, quantitative and qualitative findings are displayed, integrated, and presented in a narrative discussion of three findings of Intervention and support aimed at reducing stress related to 1) care recipient's factors, 2) carer factors and 3) system factors.

Chapter 8: Discussion - This chapter presents further integration of the data, through critical analysis and synthesis of quantitative and qualitative findings from phases one and two of the study. The discussion aligns to the seven objectives of the study: 1) the activities to be delivered by iSupport facilitators to strengthen support for carers of PLWD in the planned iSupport program in hospital and community aged care settings; 2) the iSupport facilitator's roles and responsibilities; 3) feasibility of the participant recruitment and factors affecting the recruitment; 4) participants retention and attrition; 5) intervention fidelity; 6) strategies to embed and sustain the facilitator-enabled iSupport program after the trial; and 7) the intervention effectiveness impact on care stressors.

Chapter 9: Conclusion - This chapter summarises all key findings and highlights all original contributions of new knowledge in this thesis. Chapter 9 presents the strengths and limitations of the systematic review, phases 1 and 2 of the study. It outlines implications for policy, clinical practice, education, and recommendations for future research. It concludes that the present PhD study addressed all study aims and objectives and offers valuable new evidence to the dementia care research field.

1.8 SUMMARY

This chapter overviewed dementia and its impact on PLWD, their family carers, and the health and social care system. Dementia is a progressive condition, and PLWD is often highly dependent on their family carers to remain living at home. Caring for PLWD can significantly impact carers' health and wellbeing through increased caregiver burden, resulting in increased stress and decreased QOL. PLWD wish to live independently with family care support for as long as possible, but this requires adequate support for carers. Facilitator-enabled virtual iSupport for Dementia program is an innovative, evidence-based care intervention in Australia to strengthen the support for family carers of PLWD in the community. This support utilises an iSupport facilitator to support carers virtually using Australian iSupport for Dementia psychoeducation programs. This chapter also presented the study's aims, objectives, rationale for the study, significance, and thesis outline.

2 Systematic Review and meta-analysis

2.1 INTRODUCTION

The present study intends to use the facilitator-enabled virtual iSupport psychoeducation program to enhance the support for family care of PLWD in the community. The background literature search identified the need for a systematic review to explore existing knowledge of the effectiveness of virtual or internet-based psychoeducation programs. This chapter presents the systematic review and meta-analysis of quantitative studies conducted between June and December 2021 and published in the Journal of Aging & Mental Health in 2023. Section 2.2 presents the publication. Some words in the publication are changed to ensure the consistency of terminologies used in this thesis. For example, Change 'online' to 'internet-based' and 'PwD' to 'PLWD'. Some references were updated using the present thesis EndNotes library; therefore, the format might differ slightly from the published article. Section 2.3 presents a synthesis of the feasibility and fidelity of the studies included in the review, followed by a summary of this chapter in section 2.4.

This section presents a publication from this thesis published in Aging & Mental Health as an open-access article. The first author's contribution to this paper was leading and coordinating the systematic review, 70% to research design, 90% to data collection and analysis and 70% to writing and editing.

Citation: Yu, Y., Xiao, L., Ullah, S., Meyer, C., Wang, J., Pot, A. M., & He, J. J. (2023). The effectiveness of internet-based psychoeducation programs for caregivers of people living with dementia: a systematic review and meta-analysis. Aging & Mental Health, 1-17. https://doi.org/10.1080/13607863.2023.2190082

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CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

PUBLICATION 1

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	Yu, Y., Xiao, L., Ullah, S., Meyer, C., Wang, J., Pot, A. M., & He, J. J. (2023). The effectiveness of internet-based psychoeducation programs for caregivers of people living with dementia: a systematic review and meta-analysis. Aging & Mental Health, 1-17. https://doi.org/10.1080/13607863.2023.2190082
Section of thesis where publication is referred to	Chapter 2: systematic review and meta-analysis

Student's contribution to the publication	70	%	Research design
	90	%	Data collection and analysis
	70	%	Writing and editing

Outline your (the student's) contribution to the publication:

Ying's contribution to the publication include: conceptulisation, data search, screening, data extraction, data analysis and write the original manuscript.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

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2.2 THE EFFECTIVENESS OF INTERNET-BASED PSYCHOEDUCATION PROGRAMS FOR CAREGIVERS OF PEOPLE LIVING WITH DEMENTIA: A SYSTEMATIC REVIEW AND META-ANALYSIS

2.2.1 Abstract

Objective: This systematic review and meta-analysis aimed to identify the characteristics of internet-based psychoeducational programs for caregivers of people living with dementia and to synthesise program effectiveness.

Method: We searched 5 English and 4 Chinese databases in June 2021 with no time limit applied. The characteristics of the studies reviewed were described in a narrative summary. Meta-analysis was applied to synthesise the pooled effects where data were available.

Results: A total of 14,352 articles were identified from the database search, and the final review included 19 articles. Reported Interventions comprised educational, psychological, and behavioural training relevant to dementia care. Program duration ranged from 3 weeks to 12 months. Meta-analysis of 13 RCTs showed that internet-based psychoeducational programs had a significant effect on reducing caregivers' depressive symptoms (SMD -0.19; 95% CI -0.03 --0.35) and stress (SMD -0.29; 95% CI -0.03 - -0.54). However, these programs did not show an effect on quality of life, anxiety, burden or self-efficacy in caregivers.

Conclusion: Internet-based psychoeducational programs can improve some aspects of caregivers' mental health and emotional wellbeing. The effects of programs on self-efficacy, anxiety, burden and quality of life for caregivers remain inconclusive.

Keywords: dementia, caregivers, psychoeducation, quality of life, depression, self-efficacy, caregiver burden, COVID-19

2.2.2 Introduction

Dementia currently affects 55 million people worldwide, and this number is projected to reach 152 million by 2050 (WHO, 2021b). Most people living with dementia (PLWD) are cared for by family caregivers at home (WHO, 2021b). It is well-researched that caring for PLWD at home is physically stressful for caregivers due to the nature of the disease, which requires 24-hour supervision, assistance with activities of daily living and management of a treatment regime for chronic conditions (WHO, 2021b). Caring for the PLWD is also a source of psychological stress for caregivers (WHO, 2021b). The inability of caregivers to cope with physical and psychological stress contributes to their poor health, wellbeing and quality of life (QOL) (Farina et al., 2017). Psychoeducation is a major category of nonpharmacological interventions and is widely used to reduce caregivers' stress

(Frias, Garcia-Pascual, et al., 2020). In this review, we describe the definition of psychoeducation as educational programs designed to improve caregivers' capabilities in providing daily care activities for people with dementia and in coping with stress (Cheng et al., 2020). This definition includes psychoeducation-a, programs without mentioning psychological theories, and psychoeducation-b, or programs with psychotherapeutic components (Cheng et al., 2020).

Internet-based psychoeducation has been used increasingly in the past decade due to its flexibility and low costs (Egan et al., 2018). The prolonged COVID-19 outbreak has interrupted most face-to-face education programs for caregivers, and internet-based psychoeducation has advantages for overcoming COVID-19-related challenges (WHO, 2021b). In this review, we considered the definition of internet-based education by Singh and Thurman (2019) and the definition of psychoeducation by Cheng et al. (2020). We describe the internet-based psychoeducation for caregivers of PLWD as an educational program that is (1) designed to improve caregivers' capabilities in providing daily care activities for PLWD and in coping with stress; (2) delivered in an internet-based environment using the internet; (3) has flexible and accessible internet-based learning activities without physical or virtual location restrictions (or asynchronous programs); and (4) may or may not have facilitators to interact with caregivers. Previous systematic reviews on internet-based interventions for caregivers were not explicitly focused on psychoeducation but considered all types of interventions or did not undertake meta-analysis (Egan et al., 2018; Hopwood et al., 2018; Leng et al., 2020; Zhao et al., 2019). This systematic review and meta-analysis address this gap in the dementia care literature.

Psychoeducation for dementia caregivers is informed by stress and coping theories (Cheng et al., 2020; Frias, Garcia-Pascual, et al., 2020). Among various stress and coping theories, we found that the 'stress and health process' model described by Conde-Sala et al. (2010) was most relevant to this review as it explains the source of stress, negative impacts on caregivers and interventions (i.e., psychoeducation) that mitigate these negative impacts. This model was a combination of the stress process models introduced by Pearlin et al. (1990) and Schulz et al. (2002) which highlight the intervention effect on stressors (Conde-Sala et al., 2010). The 'stress and health process' model informed the design of program analysis and understanding of the relationships between sources of stress, effects on caregivers' health and wellbeing, and chosen outcomes. According to Conde-Sala et al. (2010), variables affecting caregiver health and wellbeing include caregiver contextual factors (i.e., ability to provide dementia care, family relationships, co-residing status, gender and time spent on care activities); care recipient factors or primary stressors (i.e., changed behaviours, dependence and multimorbidity); and other factors or secondary stressors (i.e., family conflict and financial difficulties). Interventions that can improve caregivers' symptoms of stress, such as anxiety, depression, isolation, burden and physical health, include nonpharmacological interventions (i.e., psychoeducation, social support and social resources) and treatment (i.e., pharmacological treatment)(Conde-Sala et al., 2010). Previous systematic reviews on the effectiveness of psychoeducation included all types of program delivery (i.e., face-to-face, telephone and internet-based delivery) (Cheng et al., 2020; Frias, Garcia-Pascual, et al., 2020). Systematic reviews on internet-based psychoeducation specifically are scarce. The lack of synthesis of research evidence in this increasingly demanding area of caregiver support may affect the development of evidence-based policy and practices.

Previous systematic reviews showed that dementia care education can mitigate caregiver contextual factors by equipping them with capabilities to handle daily care activities effectively and to develop positive thoughts towards dementia care (Jensen et al., 2015; Klimova et al., 2019). Studies also confirmed that dementia care education improved caregivers' self-efficacy (Easom et al., 2020). Dementia caregivers' self-efficacy is their belief that they can control upsetting thoughts, respond to changed behaviours and obtain respite care (Crellin et al., 2014; Steffen et al., 2002). Caregivers' self-efficacy is related to their QOL (Crellin et al., 2014; Farina et al., 2017). Based on these known relationships between dementia care education and outcomes on caregivers regarding contextual factors, a systematic review and meta-analysis need to include self-efficacy and QOL of caregivers' and caregivers' responses to stressful care situations in the outcome measures.

The most commonly mentioned changed behaviours are apathy, confusion, agitation (i.e., wandering or vocal disruption) and depression (Perera et al., 2017; Pond et al., 2019). These are often associated with other factors besides physiological changes in the brain, such as health and environmental factors (i.e., comfort, inclusion, identity, attachment and occupation) (Cunningham et al., 2019; Kitwood, 1998; Kitwood & Kitwood, 1997). Although there is no consensus regarding the preferred terminology to describe this group of symptoms, there is general agreement that the language used needs to be dementia-friendly (Wolverson et al., 2021). Therefore, consistent with the view of the WHO, we prefer to use the term 'changed behaviours' instead of medical terminology such as BPSD or neuropsychiatric symptoms in PLWD (Burley, Chenoweth, et al., 2021; Wolverson et al., 2021).

In the 'stress and health process' model, changed behaviours are the primary stressors contributing to caregiver stress and burden (Conde-Sala et al., 2010). Stress is described as the caregivers' emotional reactions to challenging situations beyond their abilities and resources to cope (Conde-Sala et al., 2010), while burden is described as a subjective feeling of negative impact on caregivers' functioning (Williams et al., 2019). Caregiver burden can be conceptualised into objective burden (i.e., physical task due to the dependence of the PLWD and the level of changed behaviours) and subjective burden (i.e., emotional distress due to caregivers' negative reactions to these behaviours) (Alexandra Feast et al., 2016; Poon, 2019). Changed behaviours in PLWD cause increased objective burdens, impact family relationships, and contribute to caregiver subjective burdens (Conde-Sala et al., 2010; Williams et al., 2019). Up to 88% of PLWD in community care settings showed changed behaviours (Poon, 2019). However, most caregivers showed limited knowledge about preventing and managing changed behaviours (Chiu et al., 2015). The relationship between primary stressors and caregivers' health and wellbeing indicates that the changed behaviours in PLWD and caregivers' stress and burden need to be measured in a systematic review and meta-analysis.

Research shows that other primary stressors, such as PLWD's physical and cognitive function decline, were directly associated with increased caregiver burden and the latter was associated with caregivers' anxiety and depressive symptoms (Armstrong et al., 2019; Morlett Paredes et al., 2017). Furthermore, other factors, such as social support, economic living standards, dyadic relationship factors and length of caring experience, also significantly correlated with carers' anxiety and depressive symptoms (Fekete et al., 2019; Watson et al., 2019). In other words, greater caregiver burden was associated with caregivers' psychological wellbeing measured as anxiety and depression.

Caregiver burden, carers' psychological wellbeing and carer's self-efficacy are all interrelated and directly linked to carers and care recipients' QOL (Farina et al., 2017; Holopainen et al., 2019). Caregivers with high self-efficacy are related to their beliefs that they have mastered certain skills to deal with challenges (Bandura, 1993; Steffen et al., 2002). WHO defines QOL as an individual's perception of their life expectations in the context of their culture and value systems (WHO, 2020). Research shows that caregivers of PLWD reported worse health-related QOL compared to non-PLWD carers (Karg et al., 2018; Lippe et al., 2021). Caregivers' self-perceived QOL is also linked to primary stressors such as the severity of PLWD's condition, level of changed behaviours, and other factors, for example, the level of social support caregivers received (Frias, Cabrera, & Zabalegui, 2020; Pessotti et al., 2018).

Informed by the 'stress and health process' model described by Conde-Sala et al. (2010), the caregivers' psychological wellbeing outcome measures in this review focused on anxiety, depression and caregivers' burden. In line with a previous systematic review, other outcome measures for QOL and self-efficacy were included as they directly or indirectly affect the caregiver's health and wellbeing (Crellin et al., 2014). The review questions were: (1) what are the characteristics of internet-based psychoeducational programs for caregivers of PLWD living at home? and (2) what is the effectiveness of internet-based psychoeducational programs for informal caregivers of PLWD living at home?

2.2.3 Methods

This review followed the Cochrane Handbook for Systematic Reviews of Interventions (Higgins et al., 2021) and Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021). The systematic review protocol was registered with PROSPERO. The registration number is CRD42021257562.

2.2.3.1 Search strategies

The following English databases were searched: the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, Medical Literature Analysis and Retrieval System Internet-based (Medline), the Cochrane Library, and Scopus. The following Chinese databases were also searched: China National Knowledge Infrastructure (CNKI), Wang Fang Data, Weipu Data and Chao Xing Data. The search strategies are presented in Appendix 1. The search strategy was developed in line with the PICO framework (see Table 2.1), with no time limit applied. All keywords were identified around internet-based psychoeducation for informal caregivers of PLWD, and a Boolean search was conducted by combining the keywords. A librarian was consulted for the database search.

Table 2-1 Systematic review and meta-analysis keywords

Population	Intervention	Context	Outcome
Informal caregivers of people living with dementia	Internet-based dementia carer education	Homecare settings	Effectiveness
Carer or Caregiver or caretaker or family or friend or spouse or adult children or acquaintance or neighbour or neighbour or home nursing people with dementia or Alzheimer's disease or mild cognitive impairment	Internet or internet-based or e-health or telecomputing or tech or health or computers or software or electronic or digital Intervention or program or course or psychoeducation or training or support or cognitive therapy or psychological or platform or e-learning or telemedicine or telehealth or application or interface or APP		Randomised control trials; pre- and post-intervention test

2.2.3.2 Inclusion and exclusion criteria

All interventional studies that reflect our operational definition of internet-based psychoeducation programs for informal caregivers of PLWD were included. Traditional face-to-face or telephone-delivered dementia education programs or programs using digital video discs (DVD) or a booklet were excluded. Synchronised internet-based education, which mimics the physical classroom or DVD programs delivered through the internet, was also excluded as this type of program showed little flexibility in program delivery and was often restrained by time and space. Studies were excluded if they were not written in English or Chinese language. The inclusion and exclusion criteria are presented in Table 2.2

Table 2-2 Systematic review and meta-analysis inclusion and exclusion criteria

	Inclusion	Exclusion
P	Informal caregivers	Formal caregiver paid caregiver, people living with dementia
I	Internet-based psychoeducation defined in this systematic review	Traditional face-to-face, internet-based face-to-face (e.g., videoconference only), CD-ROM, booklet, internet-based delivered video, delivered via telephone, not education-focused
C	Dementia care in the community	Not related to dementia care, not in the community setting
O	Effectiveness of internet-based psychoeducation program	Feasibility studies, descriptive statistics, implementation descriptions, cost-effectiveness analysis
S	RCTs, pre- and post-intervention test studies	Qualitative studies, not written in English language or Chinese language

Note. P=Population, I= Intervention, C= Context, O= Outcome, S= Study

2.2.3.3 Data collection process

All searched records were imported to Endnote 20 and Covidence, with duplicates removed (The EndNote Team, 2013; Veritas Health Innovation, 2021). Four reviewers (YY, LX, CM, SU) screened the English language title and abstracts to identify whether a study met the inclusion criteria. Two reviewers (JW and JH) screened the Chinese language titles and abstracts. After the title and abstract screening, the reference list of each selected article was manually scanned. Full-text papers were uploaded to Covidence to determine further eligibility by all reviewers (YY, LX, CM, SU screened English language articles and YY, LX, JW screened Chinese language articles). All reviewers met regularly to discuss and resolve any disagreements.

2.2.3.4 Assessment of risk of bias

The risk of bias in the selected article will be assessed according to the criteria recommended by the Cochrane Handbook. Two reviewers conducted the assessment of the risk of bias. RCTs were assessed according to the Cochrane risk-of-bias tool (RoB2) (Higgins et al., 2021). It is set to address the bias arising from 1) the randomization process, 2) intervention deviation, 3) missing outcome data, 4) measurement of outcome, and 5) selection of the report result. Each domain contains questions, and based on the answer to the question, the risk of bias of each domain will be ranked as being "low", "some concern", or "high", and an overall assessment of the quality of each study will be undertaken.

Non-randomised intervention studies were assessed according to the ROBINS-I tool (Sterne et al., 2021). The categories of bias it sets to assess include confounding bias, selection bias, information bias and reporting bias. The ROBINS-I tool provides a domain-level risk-of-bias judgement of 'low', 'moderate', 'serious' or 'critical', with an additional option of 'no information'. Two reviewers undertook an independent quality appraisal of the selected studies, with any disagreement resolved through consensus.

2.2.3.5 Data extraction

A standardised Cochrane data extraction sheet was used to extract the following data: 1) author, publication year, and country; 2) participants' characteristics, sample size; 3) internet-based psychoeducation or training details including content, duration, facilitator details 4) study setting, design, and methods, 5) data collection time points, outcome measurement tools and outcome and 6) main findings.

2.2.3.6 Data synthesis and analysis

Characteristics of internet-based psychoeducation components, outcomes of RCTs that are not suitable for meta-analysis and outcomes of non-RCTs were presented as a descriptive summary. Where appropriate, a meta-analysis of results from included RCTs was undertaken using Review Manager (RevMan) to estimate the effect of the internet-based psychoeducation program on care outcomes (The Cochrane Collaboration, 2014). It was also run through the 'meta-package in the R program by a second reviewer to ensure the robustness of the results (Balduzzi et al., 2019). The authors of included RCTs were contacted to request original data when reported data were unsuitable for meta-analysis. Heterogeneity, including samples, settings and methodological heterogeneity was analysed before performing a meta-analysis. Standardised mean differences (SMD) with a 95% confidence interval (CI) were calculated for continuous data. The statistical heterogeneity between studies was examined using I^2 statistics. The included studies' results were pooled, a random-effects model was applied for studies that showed heterogeneity, and a fixed-effects model was applied for studies showing homogeneity. Sub-group analysis was planned when studies could be grouped into a program with peer support, a program with a facilitator, and a program duration of 3 months or 6 months. However, these subgroup analyses were not performed due to insufficient data.

2.2.3.7 Assessment of publication bias

We planned to test funnel plot asymmetry for publication bias, but this was not achievable due to the small number of RCTs identified.

2.2.3.8 Assessment of evidence quality

The overall quality of evidence for each outcome was rated using the Grading of Recommendations Assessment, Development and Evaluation (GRADE, see Appendix 2) (McMaster University and Evidence Prime, 2021). The GRADE system rates the evidence in 4 levels: High quality, moderate quality, low quality and very low quality based on study limitations, results inconsistencies, indirectness, imprecision and reporting bias (Guyatt et al., 2008).

2.2.4 Results

2.2.4.1 Search process

A total of 14352 articles were identified from the databases (English language database n=13347; Chinese language database n=1005). Covidence automatically removed duplicates (n=7655). A total of 526 (English language n= 515, Chinese language n= 11) full-text articles were retrieved after the title and abstract screening (English language n= 6041, Chinese language n=655). After assessing the eligibility of the full-text articles, 19 studies written in the English language were included in this review. The study selection process is displayed in Figure 2-1.

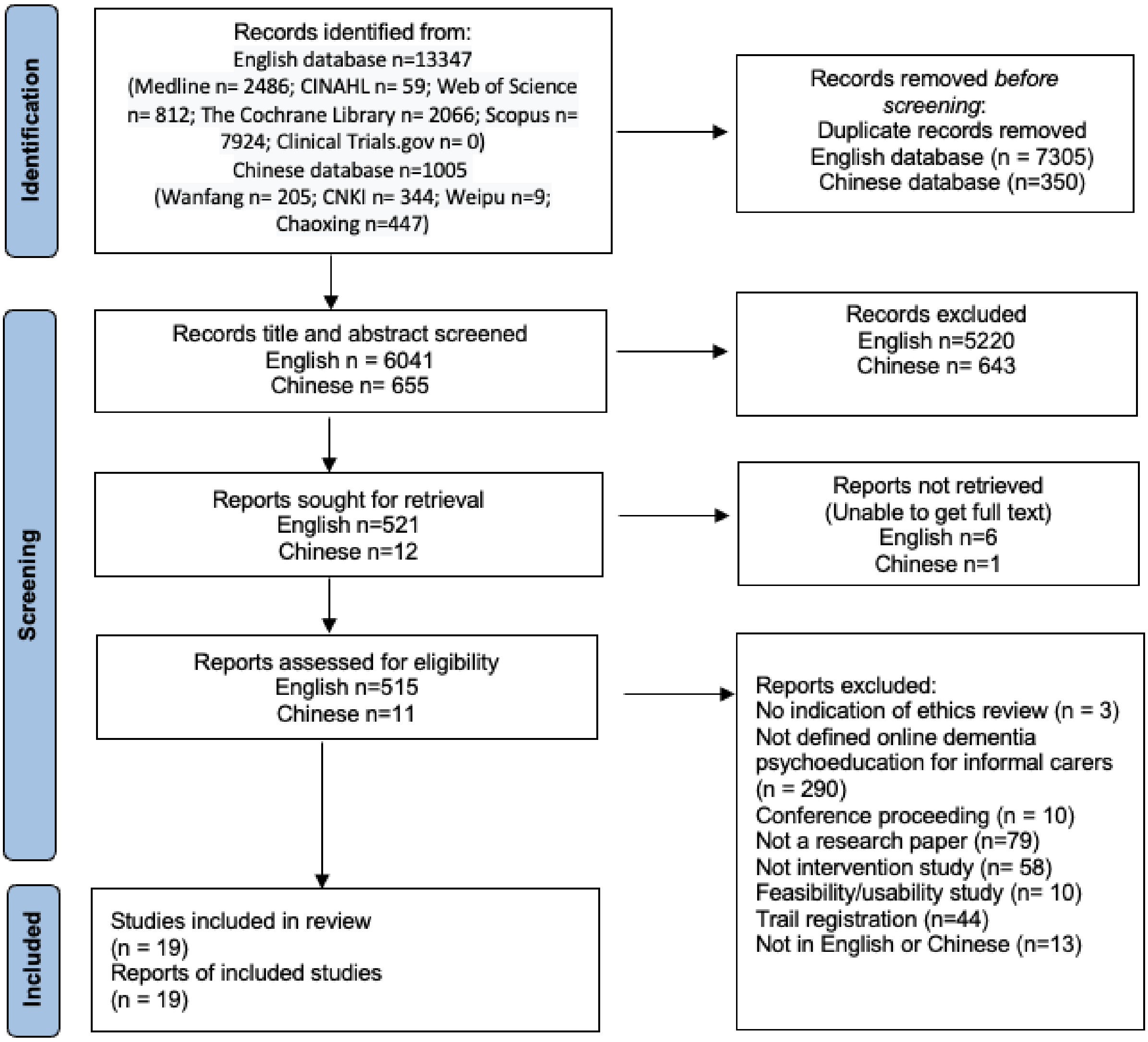
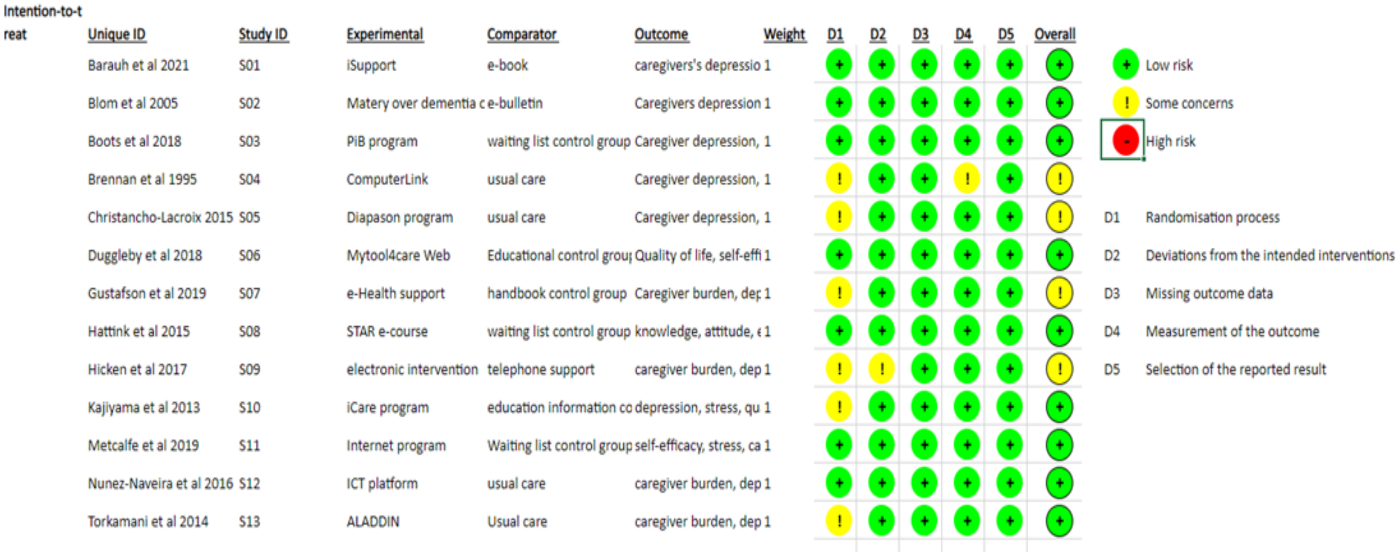


Figure 2-1 Systematic review and meta-analysis articles searching PRISMA flow chart

2.2.4.2 Risk of bias

All selected RCTs were assessed based on the intention-to-treat effect, which is displayed in Figure 2.2. Five out of 13 RCTs did not provide details of the randomisation process, and thus, there is uncertainty about the allocation sequence and allocation concealment (Brennan et al., 1995; Gustafson et al., 2019; Hicken et al., 2017; Kajiyama et al., 2013; Torkamani et al., 2014). All 13 RCTs had no significant baseline differences between intervention and control groups. Of 13 RCTs, 10 interventions were not blinded to participants (Baruah et al., 2021; Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Hicken et al., 2017; Kajiyama et al., 2013; Metcalfe et al., 2019; Nunez-Naveira et al., 2016; Torkamani et al., 2014), while three RCTs were not blinded to researchers (Cristancho-Lacroix et al., 2015; Duggleby et al., 2018; Torkamani et al., 2014). All selected studies had a pre-formulated study protocol either through trial registration (Baruah et al., 2021; Blom et al., 2015; Boots et al., 2018; Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Kajiyama et al., 2013; Metcalfe et al., 2019) or ethics approval (Brennan et al., 1995; Duggleby et al., 2018; Gustafson et al., 2019; Hicken et al., 2017; Nunez-Naveira et al., 2016; Torkamani et al., 2014). The overall risk of bias assessment showed 4 RCTs to have some concerns (Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Hicken et al., 2017), while all other RCTs were considered to have a low risk of bias. All non-RCT studies were assessed as low risk of bias (see figure 2.3). Of 19 studies, 18 were funded through government grants.



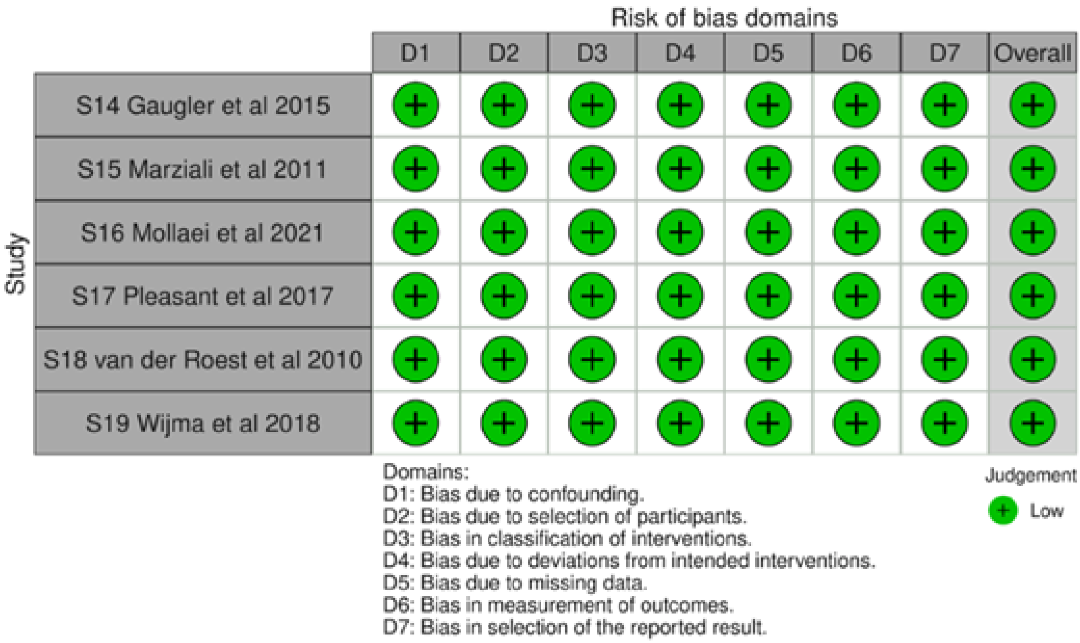
Intention-to-treat

Unique ID	Study ID	Experimental	Comparator	Outcome	Weight	D1	D2	D3	D4	D5	Overall
Barauh et al 2021	S01	iSupport	e-book	caregivers's depressio	1	+	+	+	+	+	+
Blom et al 2005	S02	Matery over dementia c	e-bulletin	Caregivers depression	1	+	+	+	+	+	+
Boots et al 2018	S03	PiB program	waiting list control group	Caregiver depression,	1	+	+	+	+	+	+
Brennan et al 1995	S04	ComputerLink	usual care	Caregiver depression,	1	!	+	+	!	+	!
Christancho-Lacroix 2015	S05	Diapason program	usual care	Caregiver depression,	1	!	+	+	+	+	!
Duggleby et al 2018	S06	Mytool4care Web	Educational control grou	Quality of life, self-effi	1	+	+	+	+	+	+
Gustafson et al 2019	S07	e-Health support	handbook control group	Caregiver burden, de	1	!	+	+	+	+	!
Hattink et al 2015	S08	STAR e-course	waiting list control group	knowledge, attitude,	1	+	+	+	+	+	+
Hicken et al 2017	S09	electronic intervention	telephone support	caregiver burden, dep	1	!	!	+	+	+	!
Kajiyama et al 2013	S10	iCare program	education information co	depression, stress, qu	1	!	+	+	+	+	+
Metcalfe et al 2019	S11	Internet program	Waiting list control group	self-efficacy, stress, ca	1	+	+	+	+	+	+
Nunez-Naveira et al 2016	S12	ICT platform	usual care	caregiver burden, dep	1	+	+	+	+	+	+
Torkamani et al 2014	S13	ALADDIN	Usual care	caregiver burden, dep	1	!	+	+	+	+	+

+	Low risk
!	Some concerns
-	High risk

D1	Randomisation process
D2	Deviations from the intended interventions
D3	Missing outcome data
D4	Measurement of the outcome
D5	Selection of the reported result

Figure 2-2 Systematic review and meta-analysis-Risk of Bias Assessment for RCTs



Risk of bias domains

Study	D1	D2	D3	D4	D5	D6	D7	Overall
S14 Gaugler et al 2015	+	+	+	+	+	+	+	+
S15 Marziali et al 2011	+	+	+	+	+	+	+	+
S16 Mollaei et al 2021	+	+	+	+	+	+	+	+
S17 Pleasant et al 2017	+	+	+	+	+	+	+	+
S18 van der Roest et al 2010	+	+	+	+	+	+	+	+
S19 Wijma et al 2018	+	+	+	+	+	+	+	+

Domains:
D1: Bias due to confounding.
D2: Bias due to selection of participants.
D3: Bias in classification of interventions.
D4: Bias due to deviations from intended interventions.
D5: Bias due to missing data.
D6: Bias in measurement of outcomes.
D7: Bias in selection of the reported result.

Judgement
+ Low

Figure 2-3 Systematic review and meta-analysis-Risk of Bias assessment of non-RCT studies

2.2.4.3 Characteristics of selected studies

No studies reported in the Chinese language met the selection criteria. Among the 19 selected studies, 13 were RCTs, and six had a pre- and post-intervention design. Studies were conducted in the United States (n= 6), the Netherlands (n= 4), Canada (n= 2), France (n=1), India (n= 1) and Iran (n= 1). Four studies were collaborations between European countries (Denmark, Poland, and Spain n=1; United Kingdom (UK), Spain and Greece n=1, France and Germany n=1 and UK and the Netherlands n=1). Selected studies are presented in Table 2-3.

All studies included participants who were informal caregivers of PLWD. The average age of informal caregivers was between 50 and 70 years old. Most informal caregivers were female, with only two studies reporting a greater proportion of males than females (Baruah et al., 2021; Wijma et al., 2018). The relationship between informal caregivers and care recipients varied from spouses, parents/children, and siblings to friends.

Table 2-3 Systematic review and meta-analysis-characteristics of selected studies

Author Year Country	Study design settings data collection time	Participants	Intervention	Comparison	Outcome measure (instrument)	Main findings
S01 Baruah et al, 2021 India	RCT India wide Data collection: Baseline 3 months	- Informal caregiver of PLWD, - > 18 years old, - lives in India, - have access to internet Sample size= 55 IG=29, CG =26 Mean age =46.5 Males =54%	iSupport Internet-based dementia education program	Education only e-book on the brochure	**Primary outcomes** - Caregiver burden (ZBI [score 0-88, ↓=better]) - Depression (CES-D10 [score 0-30, ↓=better]) **Secondary outcomes** - Person-centred attitude (ADQ: [score 18-90, ↑=better]) - Self-efficacy (RIS Eldercare Self-efficacy; PMS [score 7-35, ↑=better]) - QOL (EuroQOL Visual Analog Scale [score 0-100, ↑=better])	- There was no significant difference in caregiver burden, depression, self-efficacy and QOL. - Significant higher positive attitude towards dementia in the IG. - Poor education program engagement
S02 Blom et al. 2015 The Netherlands	RCT Netherlands wide recruitment Data collection: Baseline 3 months 6 months	- Informal caregiver of PLWD who has some symptoms of depression or care burden Sample size=175 IG=90, CG=85 Mean age = 61.2 Female=69.4%	Mastery over dementia internet-based lessons	E- bulletins sent by email every 3 weeks	**Primary outcomes** - Depression (CES-D 20 [score 0-60, ↓=better]) **Secondary outcome** - Anxiety (HAD [score 0-21, ↓=better] **Additional measures for imputation** - Self-perceived stress (SPPIC [score 0-9] - Caregiver's stresses relate to PLWD behaviour (RMBPC [score 0-16] - Caregiver competency (SSCQ [score 0-7]; PMS [score 0-20])	-Caregivers' anxiety and depression significantly decreased in IG - High dropout rate
S03 Boots et al. 2018 The Netherlands	A single-masked RCT 2 clinics in the South of the Netherlands Data collection: Baseline 8 weeks	- Informal caregivers of PLWD - have access to the internet at home - have basic computer skills Sample =68 IG=31, CG=37 Mean age = 67.8 Female=65%	Partner in Balance (PiB): 4 self-paced web-based modules Email or telephone feedback from the coach over 8 weeks	Usual care waiting list group - non-frequent counselling	**Primary outcomes** - Self-Efficacy (CSES: management self-efficacy [score 4-40, ↑=better], service use self-efficacy [score 5-50, ↑=better]) - Depression (CES-D20 [score 0-60, ↓=better]) **Secondary outcomes** - Anxiety (HADS-Anxiety [score 0-21, ↓=better]) - Competency (PMS [score 7-35, ↑=better] - QOL (ICECAP-O) [score 0-1, ↑=better] - Stress (PSS [↓=better])	- Improvement in self-efficacy, service use self-efficacy, mastery and QOL - No differences in caregiver depression, anxiety, and stress.

Author Year Country	Study design settings data collection time	Participants	Intervention	Comparison	Outcome measure (instrument)	Main findings
S04 Brennan et al. 1995 USA	RCT Alzheimer's disease research registry and local support group Data collection: Baseline 12 months	- Informal caregivers of PLWD - have a telephone connection - can read and write English Sample size 96 IG=47, CG=49 Mean age= 64 Female=67%	ComputerLink Monthly phone call Over 12 months	Usual care received placebo training for local service and care provider	**Primary outcome** (not specified) - Decision-making confidence (Modified decision confidence scale [↑=better]) - Decision-making skill (self-report instrument) - Perceived social support (The instrumental and Expressive Social Support Scale [↑=better]) **Additional measures** - Caregiver burden (Impact of caregiving scale [↓=better]) - Depression (CES-D20 [score 0-60, ↓=better])	- Increase in caregivers' decision-making confidence - No effect on decision-making skills and caregivers' social isolation. - Average program access was 2 days a week - using discussion forums more than email
S05 Cristancho-Lacroix et al. 2015 France	Non-blinded RCT A daycare centre geriatric unit in Paris Data collection: Baseline 3 Months 6 Months	- Informal caregiver of PLWD - French-speaking - PSS>12 - have an internet access Sample size=49 IG=25, CG=24 Mean age =64.2 Female=64%	The Diapason program	Usual care provided with information about the illness during semi-annual follow-ups with their geriatrician	**Primary outcome** - Stress (PSS-14 [score 0-56, ↓=better]) **Secondary outcomes** - Depression (BDI-II [score 0-63, ↓=better]) - Caregiver burden (ZBI [score 0-88, ↓=better]) - Self-efficacy (RSCS [score 0-100, ↑=better]) - Caregivers' stress related to memory and behaviour problems (RMBPC- reaction [2 subscales, frequency and caregiver strain, score 0-4, ↓=better]) - Self-perceived health (NHP [score 0-100, ↑=better]) - Self-rating visual analogue scale (1) knowledge about - Alzheimer's disease, 2) overall stress, 3) self-efficacy for coping and 4) quality of relationship [score 0-100, ↑=better])	- There is no significant difference in stress, coping, and self-perceived health. - A significant change in dementia knowledge. - Average use of website 19.72 times - Most visited within 3 months was the forum, after 3 months the connection times were near zero
S06 Duggleby et al. 2018 Canada	Pragmatic RCT Local Alzheimer's Society and carer support groups in Ontario and Alberta Data collection:	- Informal caregiver of PLWD - >18 years old - caring for a person aged 65 years or older - living with PLWD and MCI in the community, - valid email address and access to a computer	My Tools 4 Care (MT4C)	The educational control group received a copy of 'The Progression of Alzheimer's Disease' booklet (Alzheimer's Society)	**Primary outcome** - Health related QOL (SF-12 v2: mental health component [score 0-100, ↑=better]) **Secondary outcomes** - Health related QOL (SF-12 v2: physical health component [score 0-100, ↑=better]) - Self-efficacy (GSES [score 10-40, ↑=better]) - Hope (HHI [score 12-48, ↑=better]) - Cost analysis (HSSUI)	- No significant group differences were observed in the primary or secondary outcome measures. - 73% of participants used the website once over 3 months.

Author Year Country	Study design settings data collection time	Participants	Intervention	Comparison	Outcome measure (instrument)	Main findings
	baseline, 1 month, 3 months, and 6 months	Sample size=199 IG=101, CG=98 Age (Mean)=63.6 SD= 11.6 Female= 80.9%				
S07 Gustafson et al 2019 USA	RCT The Wisconsin Alzheimer's Disease Research Center Data collection: baseline 2, 4 and 6 months	Informal caregiver of PLWD who lives with the care recipient, can read English. Sample size=25 IG=14, CG=11 Age=55-75 Female= 61%	The Dementia Comprehensive Health Enhancement Support System (D-CHESS) Website	A caregiving handbook	**Primary outcome** (not specified) - Caregiver burden (A caregiver load scale [score 0-10, ↓=better]) - Depression (Patient Health Questionnaire [↓=better]) - Family conflict (family conflict on a 4-point Likert scale [average score ↓=better]) - Care decision (the Satisfaction with Decision Scale [↑=better]) - Social support (MOS Social Support Survey [↑=more support]) - Loneliness (UCLA Loneliness Scale [↑= more loneliness) - Anxiety (The Generalized Anxiety Disorder scale [score 0-10, ↓=better]) - Coping competence (Caregiver appraisal scale [↑=better])	- IG showed better results in social support, anxiety, loneliness, and coping competence, with no difference in caregiver burden, decision satisfaction and depression. - IG showed worse results in family conflict.
S08 Hattink et al. 2015 The Netherlands & UK	RCT The Netherlands: meeting centres and Alzheimer's organisations' regional branches; UK: Caregivers' cafes and groups in the community. Data collection: baseline	- Informal caregivers, volunteers and formal carers Sample size=142 Netherlands=85 (informal carer=59) UK=57 (Informal carer=22) Informal carers: IG= 27, CG=32 Informal caregivers' mean age =52.93 Female=74%	STAR training portal	Usual care	**Primary outcomes** - Knowledge of dementia (ADKS) [score 1-30, ↑=better] - Attitudes toward dementia (the Alzheimer's disease survey [Hope scale score 8-40; person scale score 10-50, ↑=better]; the Approaches to Dementia Questionnaire (ADQ) [score 18-90, ↑=better]) **Secondary outcomes** - Empathy (the Interpersonal Reactivity Index) [4 sub-scale, score 0-28, Distress: ↓=better, empathy: ↑=better, Fantasy: ↑=better, Perspective: ↑=better] - Competence (SSCQ) [score 0-7, dichotomising by only counting the value of 4 or 5, ↓=better] - QOL (2 questions rate 1-10) [score 1-10, not clear] - Burden (1 question) [score 1-5, not clear]	- For informal caregivers, there is a significant improvement in attitude towards dementia - IG reported less distress and decreased self-reported competence.

Author Year Country	Study design settings data collection time	Participants	Intervention	Comparison	Outcome measure (instrument)	Main findings
	2-4 months post-intervention					
S09 Hicken et al. 2017 USA	RCT Multisite in the community Data collection: Baseline 4 months, 6 months	- Informal caregivers of PLWD Sample size= 155 IG=77, CG=78 Mean age =71.6 Female=90%	Electronic intervention	The telephone support group received printed educational material adapted from prior caregiver interventions and a DVD that included content identical to the electronic formats	**Primary outcome** (not specified) - Caregiver burden (ZBI Scale [score 0-48, ↓=better]) Caregiver grief (Caregiver Grief Inventory-Short Form [↓=better]) - Depression (PHQ [↓=better])) - Family conflict and hardship (2 questions [↓=better]) - Nursing home placement (The Desire to Institutionalize Scale [↓=better])	No significant outcome difference
S10 Kajiyama et al. 2013 USA	RCT Family service agencies in the community Data collection: 3 months post-intervention	- Informal caregivers of PLWD - >21 years old - have access to the internet - CES-D<30 - engage in care >8 hours a week Sample size=103 IG=46, CG=57 Mean age =56.12 Female=87%	The iCare program Available for purchase	The educational website contains similar information about dementia but without the skills to deal with the stress of caregiving.	**Primary outcome** (not specified) - Stress (PSS-10 [↓=better]) - Level of bother due to behaviour issue (RMBPC-reaction [↓=better]) - Depression (CES-D [score 0-60, ↓=better]) - QOL (Perceived quality of life-19 items [↑=better])	- A significant change in perceived stress for the IG. No changes in other outcomes. - IG's average time spent on a website = 6.42 times/month; 78% of IG applied new knowledge in their caregiving situation.
S11 Metcalfe et al., 2019 UK, France & Germany	Unblinded RCT Memory clinics in Germany and France, not-	- Informal caregivers of PLWD, - >18 years old, - PLWD has an onset of symptoms before 65 yrs	RHAPSODY project in English, French,	Waiting list control group	**Primary outcome** (not specified) - Self-efficacy (Revised Scale for Caregiving Self-Efficacy [score 0-100, ↑=better]) - Stress (PSS-10 [↓=better]) - Burden (BSFC [↓=better]); RMBC-reaction [↓=better]) - Health (EQ-5D-5L) [score 0-100, ↑=better]	- A significant change in IG in stress and caregiver reaction to disturbing behaviour. - There are no significant differences in caregiving self-

Author Year Country	Study design settings data collection time	Participants	Intervention	Comparison	Outcome measure (instrument)	Main findings
	for-profit organisations in the UK Data collection: Baseline, week 6, week 12	- have basic computer skills and literacy Sample size=70 IG=39, CG=31 Mean age = 57.6 Female=60%	German, and Portuguese			efficacy, caregiver burden or health-related quality of life.
S12 Nunez-Naveira et al. 2016 Denmark, Poland & Spain	RCT Local Alzheimer's associations of adult daycare centres Data collection: Baseline 3 months	- Informal caregivers of PLWD who live in Denmark, Poland or Spain, - literate - suffering burden according to ZBI - provided care for at least 6 weeks without remuneration Sample size=61 IG=30, CG=31 Age: NI Female=63.9%	UnderstAID application accessed via internet-connected mobile phone, tablet or PC	Usual care	**Primary outcome** (not specified) - Care burden (ZBI [score 0-88, ↓=better])) - Depression (CES-D [score 0-60, ↓=better]) - Competence (the Caregiver Competence Scale [score 0-16, ↑=better]) - Caregiver satisfaction (the Revised Caregiving Satisfaction Scale [score 0-30, ↑=better])	- There is a significant decrease in depressive symptoms in IG - No change in other outcomes
S13 Torkamani et al. 2014 UK Spain & Greece	RCT Hospital outpatient clinics Data collection: baseline, 3 months, and 6 months	- Informal caregiver of PLWD and care recipients with moderate to mild cognitive impairment Sample size=37 IG=17, CG=20 Mean age = 60.69 Female=45%	A technology platform for the Assisted living of Dementia elDerly INdividuals and their carers' (ALADDIN)	Usual care	**Primary outcome** (not specified) - Caregiver burden (ZBI [score 0-88, ↓=better]) - Neuropsychiatric Inventory (NPI) [score 0-100, ↓=better] - Depression - BDI [score 0-63, =↓better] - Zung Depression Self-Rating Scale [score 20-80, ↓=better]) - QOL (EuroQOL[score 0-100, ↑=better]; Quality of Life Scale [score 16-112, ↑=better])	- IG showed decreased burden and improvement in QOL. - No statistically significant difference in depression symptoms. - IG participants reported fewer depressive symptoms compared to CG.
S14 Gaugler et al. 2015	Pre and post-intervention test	- Informal caregivers of PLWD (living at home or in an assisted facility)	The CARES for Families	N/A	**Primary outcome** (not specified) - Knowledge of dementia (Dementia Care Knowledge- 20 items)	- 81.5% (n = 33) indicated a gain in dementia knowledge

Author Year Country	Study design settings data collection time	Participants	Intervention	Comparison	Outcome measure (instrument)	Main findings
USA	Multiple sites in the community Data collection: NI	- have access to the internet Sample size= 41 Mean age =58.2 Female =90.2%				
S15 Marziali et al. 2011 Canada	Quasi-experimental study Clinics and community service agencies Data collection: Baseline 6 months	- Informal caregivers of PLWD Sample size=91 IG=40; CG=51 Age (mean)=65.51	Caring for Me (CFO) password-protected website and training manuals Education video x 6 Internet-based chat group intervention Available in English and French	Access to all website features except educational videos Weekly internet-based meeting for 1 hour for 20 weeks	**Primary outcome** (not specified) - Neuroticism (The Eysenck Personality Questionnaire-Revised) - Self-efficacy (RSCS [score 0-100, ↑=better]) - Social support (MSPSS [↑=better]) - Health (the Health Status Questionnaire [score 0-100, ↑=better]) - Depression (CES-D [score 0-60, ↓=better]) - Stress relates to PLWD (SMAF [↓=better])	- Both groups showed significant improvement in self-efficacy. - The IG showed more significant improvement in mental health, lower distress scores associated with managing the care recipient's deterioration in cognitive function and improved social support
S16 Mollaei et al. 2021 Iran	Pre and post-test Memory clinic of Taleghani Hospital in Tehran Data collection: baseline Post-intervention	- Informal caregivers living with PLWD for over 1 year - literate - can use messenger network - wellbeing score <52 Sample size=86 IG=43, CG=43 Mean age =51.95 Female=75%	Education message via telegram channel	Usual care	**Primary outcome** (not specified) - Wellbeing (The World Health Organization's 5-question wellbeing questionnaire [↑=better])	- IG showed significant improvement in wellbeing

Author Year Country	Study design settings data collection time	Participants	Intervention	Comparison	Outcome measure (instrument)	Main findings
S17 Pleasant et al. 2017 USA	Pre and post-test Existing consumers of CARES® in Oregon and Oregon Health Care Association Data collection: Baseline, 30 days post-intervention	- Informal and formal caregivers Sample size=51 Mean age =51 Female=88%	CARES® Dementia Basics internet-based program	N/A	**Primary outcome** (not specified) Knowledge (The 16-item dementia-based knowledge questionnaire) Competency (The Sense of Competence in Dementia Care Staff Scale)	- Significant but modest improvement in dementia-specific knowledge at both post-test and 30-day follow-up test
S18 van der Roest et al. 2010 The Netherlands	Pre and post-test Meeting centres, daycare facilities, memory clinics and a support organisation in Amsterdam Data collection: Baseline 2 months	- Informal caregivers of PLWD in the community - familiar with computers and the internet Sample size=28 IG=14, CG=14 Mean age = 60.2 Female=78%	DEMentia-specific Digital Interactive Social Chart (DEM-DISC)	Usual care	**Primary outcome** - Need (The Camberwell Assessment of Needs for the Elderly) - Competency (SSCQ. PMS [score 7-35, ↑=better]) **Secondary outcome** - QOL (Quality of Life Alzheimer's Disease scale)	- IG reported more met needs at post-test, a higher feeling of competence, - no difference was found for QOL and Carer's knowledge. - On average, participants accessed 5.14 times; the mean duration is 14:36 min. - The most consulted questions were about the consequences of dementia and support for practical problems

Author Year Country	Study design settings data collection time	Participants	Intervention	Comparison	Outcome measure (instrument)	Main findings
S19 Wijma et al. 2018 The Netherlands	Pre and post-test, 4 different care institutes in the central and southern regions of The Netherlands. Data collection 1 week prior and 3 weeks after	- Informal caregivers of PLWD at home - Dutch-speaking - no visual or hearing impairment - familiar with computers Completed pre-test= 42 Watched movie=42 Completed post-test=35 Mean age =55.1 Female=40%	Through the D'mentia Lens (TDL)- 360^o simulation movie e-course	N/A	**Primary outcome** - Attitude towards dementia (ADQ' perspective-taking' (PT) subscale of the Interpersonal Reactivity Index) **Secondary outcomes** - Self-perceived pressure (SPPIC) - Self-efficacy (the 'Trust in Own Abilities') - Relationship (the Dyadic Relationship Scale)	- Significantly improved empathy, confidence and positive interactions with the PLWD

Note. IG=intervention group; CG=control group; EQ-5D-5L= A standardised measure of health status in five dimensions (mobility, self-care, usual activities, pain/ discomfort, and anxiety/depression) used in health-economic analyses to indicate the health-related quality of life and calculate quality-adjusted life years (QALYs); N/A= not applicable; NI=not indicated; PLWD=People living with dementia; MCI=mild cognitive impairment; RCT=randomised control trial

Table 2-4 Systematic review and meta-analysis-content of psychoeducation programs

Program/Study	Duration	Content	Theoretical training	Psychological training	Behaviour training	Facilitator	Peer support	Theoretical framework
iSupport (Baruah et al. 2021)	3 months, unlimited access	Total 23 lessons, recommend completing 5 self-directed lessons, relaxation exercise at the end of each lesson. Focus on skill training	yes	yes	yes	no	no	no
Mastery over dementia (Blom et al. 2015)	6 months Unlimited access	8 internet lesson covers: problem-solving; relaxation; arranging help from others; cognitive restructuring; and assertiveness training	yes	yes	yes	yes	no	no
Partner in Balance (Boots et al., 2018)	8 weeks	4 self-paced web-based modules Email or telephone feedback from the coach over 8 weeks	yes	yes	yes	yes	no	no

Program/Study	Duration	Content	Theoretical training	Psychological training	Behaviour training	Facilitator	Peer support	Theoretical framework
ComputerLink (Brennan et al., 1995)	12 months	Content covers information, decision support and communication Over 12 months	yes	unclear	unclear	yes	yes	Multi-attribute utility theory
The Diapason program (Cristancho-Lacroix et al., 2015)	3 months	A free password-protected website, 12 thematic sessions, each session 15-30 min. covers dementia care knowledge	yes	yes	yes	no	yes	cognitive theories of stress; Bandura's self-efficacy model
My Tool 4 Care (Duggleby et al., 2018)	3 months	Each web page contains frequently asked questions, resources, and a calendar. An electronic copy of the Alzheimer Society's The Alzheimer's Disease booklet	yes	yes	yes	no	no	Meleis' theory of transition
D-CHESS (Gustafson et al., 2019)	6 months	a website for use on computers or tablets; Covers information, resources, support, decision guide, and external sensors	yes	yes	yes	no	yes	no
STAR training portal (Hattink et al., 2015)	2 months	8 modules on dementia care; A Learning Path Advisor through an internet-based tool integrated into STAR that assesses baseline knowledge; Facebook and LinkedIn communities to promote peer support In English and Dutch, Swedish, Italian, Romanian Available for a nominal fee	yes	yes	yes	yes	yes	1) the medical model of dementia, (2) the adaption-coping model of Dröes et al.,
The electronic intervention (Hicken et al., 2017)	4-6 months	the electronic intervention (home internet or telehealth) 1) video, once per week, portraying dementia progression and caregiving skills; (2) written information about health topics and caregiving skills; and (3) brief assessments of caregiver health and	yes	unclear	unclear	yes	no	no
The iCare program (Kajiyama et al., 2013)	3 months	6 modules cover dementia care information, delivered in embedded video clips and a workbook. Available for purchase	yes	yes	yes	no	no	no
RHAPSODY (Metcalfe et al., 2019)	6 weeks, unlimited access	7 modules covering the young onset dementia, information, problems and solutions, care and support, and self-care Written and video content, case studies, presentations from professionals, and downloadable materials. Available in English, French, German, and Portuguese	yes	yes	yes	no	no	no
UnderstAID (Núñez-Naveira et al., 2016)	3 months	5 modules with information about 15 different topics, cover information about the care of a PLWD and caring for oneself as a caregiver	yes	yes	yes	no	yes	no
ALADDIN (Torkamani et al., 2014)	6 months	1) Dementia information and educational material 2) Social network-discussion forum 3) My tasks- distance monitoring feature	yes	unclear	unclear	no	yes	no

Program/Study	Duration	Content	Theoretical training	Psychological training	Behaviour training	Facilitator	Peer support	Theoretical framework
		4) Contact us						
The CARES for Families (Gaugler et al., 2015)	NI	CARES for Families modules included three 1-hour modules covering the following topics: (a) Understanding Memory Loss: seven screens, 17 videos(b) Living with Dementia 18 screens, four videos, and (c) Using the CARES Approach 11 screens,18 videos	yes	yes	yes	no	no	no
Caring for Me (Marziali et al., 2011)	6 months	(a) an internet-based Dementia Caregiver Information Handbook, (b) an e-mail link for peer group members, (c) a text-based chat forum, (d) a video conferencing link for group meetings, and (e) a library of educational videos.	yes	yes	yes	yes	yes	Stress and coping theory
Education message via telegram channel (Mollaei et al., 2021)	4 weeks	6 educational messages per week and weekly group meetings with the researcher	yes	yes	yes	yes	yes	no
CARES Dementia Basics internet-based program (Pleasant et al., 2017)	2 weeks	4 modules: (1) Meet Clara Jones, an introduction to person-centred care; (2) introduction to dementia; (3), understanding behaviour as communication; and (4) the CARES® approach to Connect, Assess, Respond, Evaluate, and Share with other team members when providing care	yes	yes	yes	no	no	person-centred care
DEM-DISC (van der Roest et al., 2010)	2 months	Internet sources contain information on diagnosing dementia, practical support, coping, and finding a company and service provider in the region.	yes	yes	yes	no	no	no
Through the D'mentia Lens (Wijma et al., 2018)	3 weeks	13 minutes using a VR device includes scenes of the person with dementia alone, interaction with the informal carer, and interaction with a group of people (face-to-face). Internet-based e-course: 20 min lessons x 3, including problems associated with dementia, communication with PLWD, and dementia in social life. at home, reflecting on what had been experienced in the simulation movie	unclear	yes	yes	no	no	no

Note. Theoretical training: clear scientific and multidisciplinary information about dementia disease; Psychological training: improve the caregiver's feelings and reactions of care recipients; Behaviour training: supports to manage behavioural issues (Dumont, Barvaux, & Cornil, 2016).

2.2.4.4 Characteristics of internet-based psychoeducation programs

Among the 19 internet-based psychoeducational programs included in the review, six fully or partially utilised a theoretical framework to develop content (Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Duggleby et al., 2018; Hattink et al., 2015; Pleasant et al., 2017)(see Table 2-4). ComputerLink (USA), reported in 1995, was the earliest identified internet-based psychoeducation program for informal caregivers (Brennan et al., 1995). Of the 19 studies we reviewed, three are psychoeducation-a programs that had no psychological and behavioural training (Brennan et al., 1995; Hicken et al., 2017; Torkamani et al., 2014). The other 16 psychoeducational programs remain relatively similar, with all setting out to cover theoretical, psychological and behavioural training relevant to dementia care with unlimited access to the website or information and a variable duration of three weeks to 12 months. Basic text-based internet functions such as information, discussion boards and email functions were used ubiquitously across all studies.

All programs had self-directed learning components, with eight programs using basic functions (e.g., text-based information) (Baruah et al., 2021; Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Duggleby et al., 2018; Marziali & Garcia, 2011; van der Roest et al., 2010), and 10 programs adding more complex components such as videos (Blom et al., 2015; Gaugler et al., 2015; Gustafson et al., 2019; Hattink et al., 2015; Hicken et al., 2017; Kajiyama et al., 2013; Metcalfe et al., 2019; Nunez-Naveira et al., 2016; Pleasant et al., 2017; Torkamani et al., 2014). A more recent program utilised virtual reality (n=1) in addition to a website (Wijma et al., 2018). One program was delivered entirely through a telegram chat group by posting text-based messages (Mollaei et al., 2021).

Some programs (n=9) had functionality to facilitate interactive learning between caregivers and facilitators, and caregiver to caregiver (peer support). Interactive learning was incorporated in 7 programs (e.g., the iSupport program incorporated the interactive function of immediate feedback) (Baruah et al., 2021), while others offered recommendations to assist in service-related decision-making (e.g., ComputerLink, Dementia–Comprehensive Health Enhancement Support System [D-CHESS), STAR training portal and DEMentia-specific Digital Interactive Social Chart [DEM-DISC)) (Brennan et al., 1995; Gustafson et al., 2019; Hattink et al., 2015; van der Roest et al., 2010). Two programs offered an opportunity for reflection through the 'homework' function on the website (Kajiyama et al., 2013; Nunez-Naveira et al., 2016). An interaction function via a health questionnaire facilitated the detection and monitoring of health changes in informal caregivers and their care recipients (Torkamani et al., 2014).

Furthermore, seven programs offered interactions with facilitators or health professionals (Blom et al., 2015; Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Hicken et al., 2017; Mollaei et al., 2021) via the application (Blom et al., 2015), email (Boots et al., 2018), messaging (Gustafson et al., 2019), telephone (Hicken et al., 2017) or telegram group chat (Mollaei et al., 2021) utilising variations of two-way contact to provide information, guide discussions, provide feedback or deliver education content. Other programs were facilitated through passive techniques only, such as monitoring or moderating discussion forums (Brennan et al., 1995; Cristancho-Lacroix et al., 2015) or only answering questions if asked (Gustafson et al., 2019).

Peer support was facilitated in 8 programs. While one program did not explain the type of social network used to support peer interaction (Nunez-Naveira et al., 2016), all other programs facilitated peer support through videoconferencing (n=1) (Marziali & Garcia, 2011) or discussion forums (n=5) (Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Marziali & Garcia, 2011; Torkamani et al., 2014). Private email was used in two programs to enable informal caregivers to contact each other (Brennan et al., 1995; Marziali & Garcia, 2011). The arrival of social media has changed people's communication and interactions significantly, yet only two programs utilised social networks, such as Facebook and LinkedIn, in addition to discussion forums to facilitate peer support (Hattink et al., 2015; Torkamani et al., 2014). One study reported using a telegram chat group for peer support meetings (Mollaei et al., 2021).

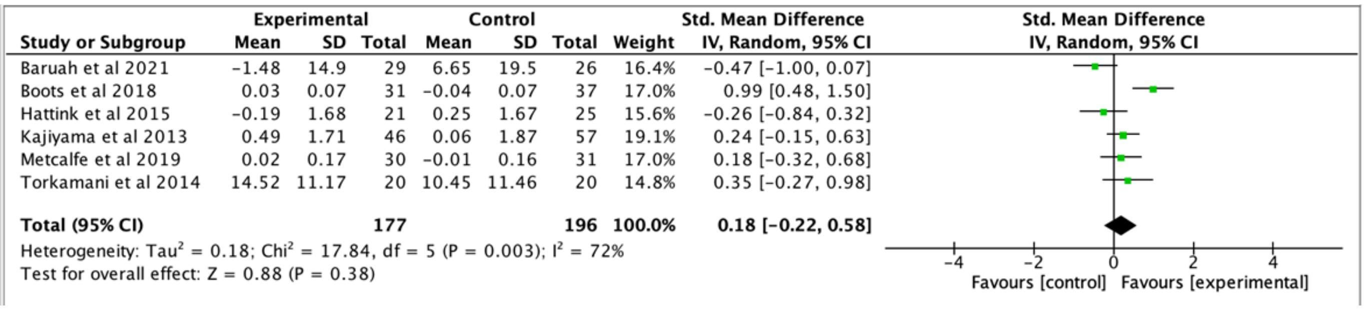
2.2.4.5 Characteristics of comparison groups

Various comparisons were used in the 13 RCTs as detailed in the following. Five studies reported usual care as the comparison group (Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Metcalfe et al., 2019; Nunez-Naveira et al., 2016; Torkamani et al., 2014). Two studies reported usual care plus additional support (i.e., non-frequent counselling or local service training) as the comparison group (Boots et al., 2018; Brennan et al., 1995). Alternative educational information was provided to the comparison group in 4 studies through a booklet (Baruah et al., 2021; Duggleby et al., 2018; Gustafson et al., 2019; Hicken et al., 2017), in one study via a website (Kajiyama et al., 2013) and in one study via email bulletins (Blom et al., 2015).

2.2.5 Meta-analysis

2.2.5.1 Caregiver's QOL

Six RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducation programs on caregiver's QOL (Baruah et al., 2021; Boots et al., 2018; Hattink et al., 2015; Kajiyama et al., 2013; Metcalfe et al., 2019; Torkamani et al., 2014). Compared to the control groups, internet-based psychoeducation programs had no significant effect but favoured the intervention group on the caregiver's QOL [effect size = 0.18; confidence interval (-0.22, 0.58), p= 0.38] (Figure 2-4).



	Experimental			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
Baruah et al 2021	−1.48	14.9	29	6.65	19.5	26	16.4%	−0.47 [−1.00, 0.07]
Boots et al 2018	0.03	0.07	31	−0.04	0.07	37	17.0%	0.99 [0.48, 1.50]
Hattink et al 2015	−0.19	1.68	21	0.25	1.67	25	15.6%	−0.26 [−0.84, 0.32]
Kajiyama et al 2013	0.49	1.71	46	0.06	1.87	57	19.1%	0.24 [−0.15, 0.63]
Metcalfe et al 2019	0.02	0.17	30	−0.01	0.16	31	17.0%	0.18 [−0.32, 0.68]
Torkamani et al 2014	14.52	11.17	20	10.45	11.46	20	14.8%	0.35 [−0.27, 0.98]
Total (95% CI)			**177**			**196**	**100.0%**	**0.18 [−0.22, 0.58]**

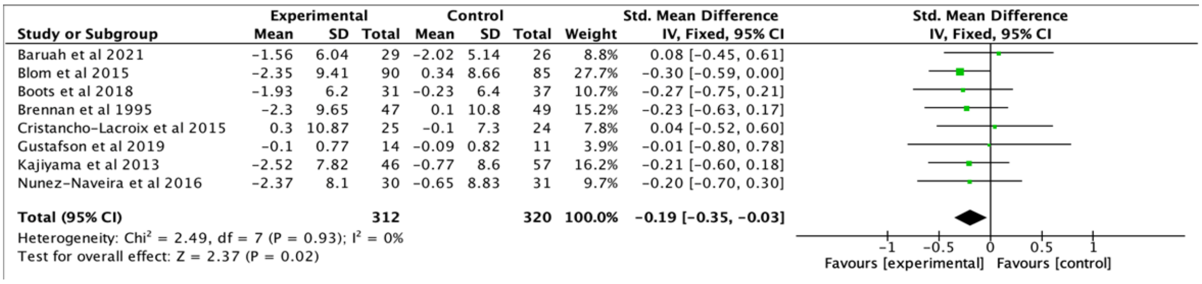
Heterogeneity: $\mathrm{Tau}^2 = 0.18$; $\mathrm{Chi}^2 = 17.84$, df = 5 (P = 0.003); $I^2 = 72\%$

Test for overall effect: Z = 0.88 (P = 0.38)

Figure 2-4 Systematic review and meta-analysis effect on QOL

2.2.5.2 Caregiver's depressive symptoms

Eight RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducation programs on caregivers' depressive symptoms (Baruah et al., 2021; Blom et al., 2015; Boots et al., 2018; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Kajiyama et al., 2013; Nunez-Naveira et al., 2016). Compared to the control groups, internet-based psychoeducation programs had a significant effect on carers' depressive symptoms [effect size =-0.19; confidence interval (- 0.35, -0.03), p= 0.02] (Figure 2-5).



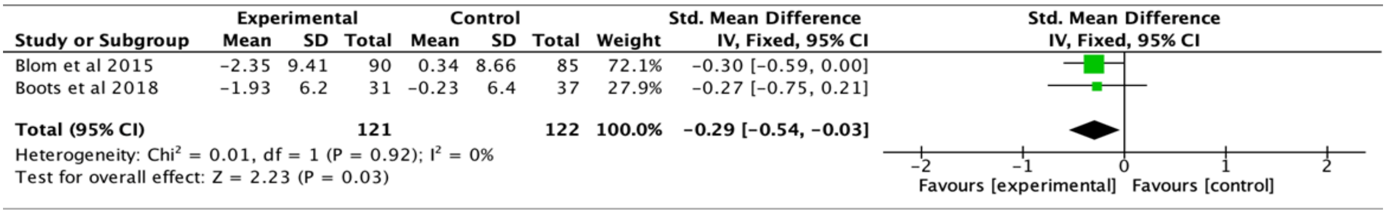
	Experimental			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Fixed, 95% CI**
Baruah et al 2021	−1.56	6.04	29	−2.02	5.14	26	8.8%	0.08 [−0.45, 0.61]
Blom et al 2015	−2.35	9.41	90	0.34	8.66	85	27.7%	−0.30 [−0.59, 0.00]
Boots et al 2018	−1.93	6.2	31	−0.23	6.4	37	10.7%	−0.27 [−0.75, 0.21]
Brennan et al 1995	−2.3	9.65	47	0.1	10.8	49	15.2%	−0.23 [−0.63, 0.17]
Cristancho-Lacroix et al 2015	0.3	10.87	25	−0.1	7.3	24	7.8%	0.04 [−0.52, 0.60]
Gustafson et al 2019	−0.1	0.77	14	−0.09	0.82	11	3.9%	−0.01 [−0.80, 0.78]
Kajiyama et al 2013	−2.52	7.82	46	−0.77	8.6	57	16.2%	−0.21 [−0.60, 0.18]
Nunez-Naveira et al 2016	−2.37	8.1	30	−0.65	8.83	31	9.7%	−0.20 [−0.70, 0.30]
Total (95% CI)			**312**			**320**	**100.0%**	**−0.19 [−0.35, −0.03]**

Heterogeneity: $\mathrm{Chi}^2 = 2.49$, df = 7 (P = 0.93); $I^2 = 0\%$

Test for overall effect: Z = 2.37 (P = 0.02)

Figure 2-5 Systematic review and meta-analysis effect on depressive symptoms

Two RCTs had program facilitators, and these studies were included in the sub-group analysis to evaluate the effectiveness of internet-based psychoeducation programs with a facilitator on caregiver's depressive symptoms (Blom et al., 2015; Boots et al., 2018). Compared to the control groups, internet-based psychoeducation programs with a facilitator had a significant effect on the carer's depressive symptoms [effect size = - 0.29; confidence interval (-0.54, - 0.03), p=0.03] (Figure 2-6).

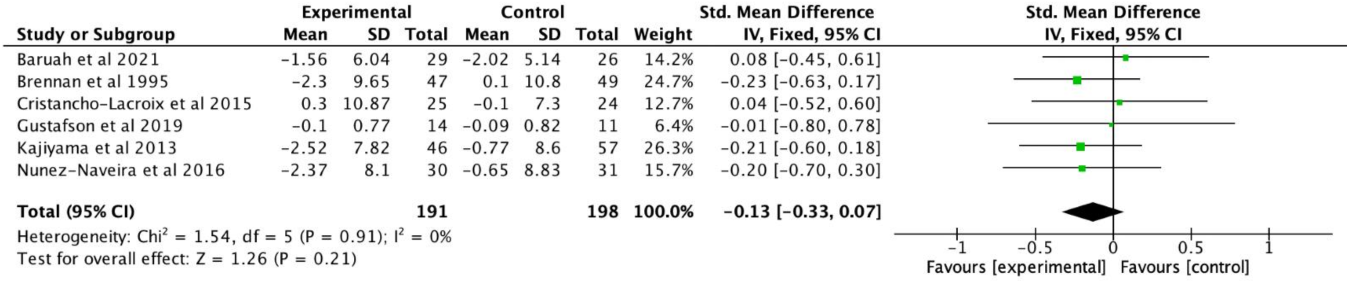


Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Blom et al 2015	−2.35	9.41	90	0.34	8.66	85	72.1%	−0.30 [−0.59, 0.00]
Boots et al 2018	−1.93	6.2	31	−0.23	6.4	37	27.9%	−0.27 [−0.75, 0.21]
Total (95% CI)			**121**			**122**	**100.0%**	**−0.29 [−0.54, −0.03]**

Heterogeneity: Chi² = 0.01, df = 1 (P = 0.92); I² = 0%
Test for overall effect: Z = 2.23 (P = 0.03)

Figure 2-6 Systematic review and meta-analysis-Sub-group analysis effect on depressive symptoms with a facilitator

Six RCTs without a facilitator were included in a sub-group analysis (Baruah et al., 2021; Brennan et al., 1995; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Kajiyama et al., 2013; Nunez-Naveira et al., 2016). The result revealed that internet-based psychoeducational programs without a facilitator had no effect on the caregiver's depressive symptoms [effect size = - 0.13; confidence interval (-0.33- 0.07), p = 0.21] (Figure 2-7).



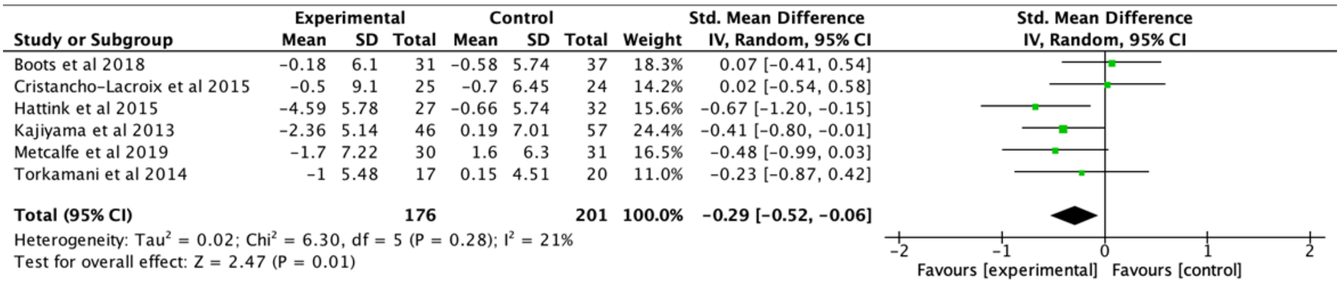
Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Baruah et al 2021	−1.56	6.04	29	−2.02	5.14	26	14.2%	0.08 [−0.45, 0.61]
Brennan et al 1995	−2.3	9.65	47	0.1	10.8	49	24.7%	−0.23 [−0.63, 0.17]
Cristancho−Lacroix et al 2015	0.3	10.87	25	−0.1	7.3	24	12.7%	0.04 [−0.52, 0.60]
Gustafson et al 2019	−0.1	0.77	14	−0.09	0.82	11	6.4%	−0.01 [−0.80, 0.78]
Kajiyama et al 2013	−2.52	7.82	46	−0.77	8.6	57	26.3%	−0.21 [−0.60, 0.18]
Nunez−Naveira et al 2016	−2.37	8.1	30	−0.65	8.83	31	15.7%	−0.20 [−0.70, 0.30]
Total (95% CI)			**191**			**198**	**100.0%**	**−0.13 [−0.33, 0.07]**

Heterogeneity: Chi² = 1.54, df = 5 (P = 0.91); I² = 0%
Test for overall effect: Z = 1.26 (P = 0.21)

Figure 2-7 Systematic review and meta-analysis-Sub-group analysis effect on depressive symptoms without a facilitator

2.2.5.3 *Caregiver's stress*

Six RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducation programs on caregiver stress (Boots et al., 2018; Cristancho-Lacroix et al., 2015; Hattink et al., 2015; Kajiyama et al., 2013; Metcalfe et al., 2019; Torkamani et al., 2014). Compared to the control groups, internet-based psychoeducation programs showed a significant reduction in carer's stress [effect size =- 0.29; confidence interval (-0.52, -0.06), p= 0.01] (Figure 2-8).



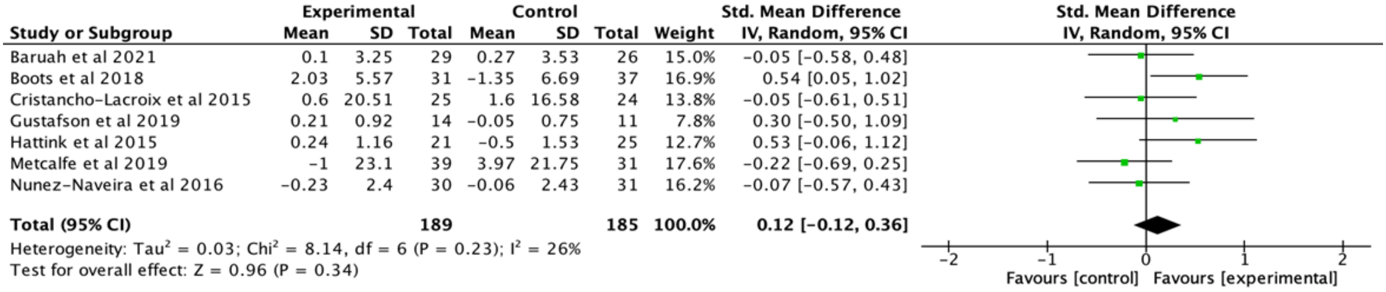
Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
Boots et al 2018	−0.18	6.1	31	−0.58	5.74	37	18.3%	0.07 [−0.41, 0.54]
Cristancho−Lacroix et al 2015	−0.5	9.1	25	−0.7	6.45	24	14.2%	0.02 [−0.54, 0.58]
Hattink et al 2015	−4.59	5.78	27	−0.66	5.74	32	15.6%	−0.67 [−1.20, −0.15]
Kajiyama et al 2013	−2.36	5.14	46	0.19	7.01	57	24.4%	−0.41 [−0.80, −0.01]
Metcalfe et al 2019	−1.7	7.22	30	1.6	6.3	31	16.5%	−0.48 [−0.99, 0.03]
Torkamani et al 2014	−1	5.48	17	0.15	4.51	20	11.0%	−0.23 [−0.87, 0.42]
Total (95% CI)			**176**			**201**	**100.0%**	**−0.29 [−0.52, −0.06]**

Heterogeneity: Tau² = 0.02; Chi² = 6.30, df = 5 (P = 0.28); I² = 21%
Test for overall effect: Z = 2.47 (P = 0.01)

Figure 2-8 Systematic review and meta-analysis effect on caregiver's stress

2.2.5.4 *Caregiver's self-efficacy*

Seven RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducation programs on carer's self-efficacy (Baruah et al., 2021; Boots et al., 2018; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Hattink et al., 2015; Metcalfe et al., 2019; Nunez-Naveira et al., 2016). Compared to control groups, internet-based psychoeducational programs had no significant effect on caregiver's self-efficacy [effect size = 0.12; confidence interval (-0.12, 0.36), p= 0.34] (Figure 2-9).



	Experimental			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
Baruah et al 2021	0.1	3.25	29	0.27	3.53	26	15.0%	−0.05 [−0.58, 0.48]
Boots et al 2018	2.03	5.57	31	−1.35	6.69	37	16.9%	0.54 [0.05, 1.02]
Cristancho−Lacroix et al 2015	0.6	20.51	25	1.6	16.58	24	13.8%	−0.05 [−0.61, 0.51]
Gustafson et al 2019	0.21	0.92	14	−0.05	0.75	11	7.8%	0.30 [−0.50, 1.09]
Hattink et al 2015	0.24	1.16	21	−0.5	1.53	25	12.7%	0.53 [−0.06, 1.12]
Metcalfe et al 2019	−1	23.1	39	3.97	21.75	31	17.6%	−0.22 [−0.69, 0.25]
Nunez−Naveira et al 2016	−0.23	2.4	30	−0.06	2.43	31	16.2%	−0.07 [−0.57, 0.43]
Total (95% CI)			**189**			**185**	**100.0%**	**0.12 [−0.12, 0.36]**

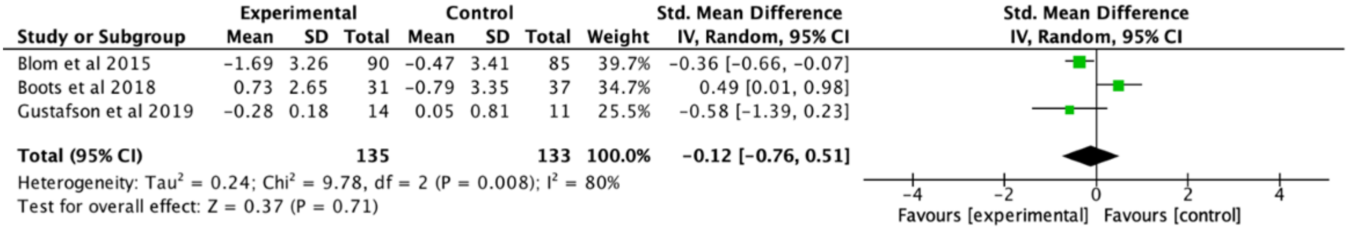
Heterogeneity: $Tau^2 = 0.03$; $Chi^2 = 8.14$, df = 6 (P = 0.23); $I^2 = 26\%$

Test for overall effect: Z = 0.96 (P = 0.34)

Figure 2-9 Systematic review and meta-analysis effect on caregiver's self-efficacy

2.2.5.5 *Caregiver's anxiety*

Three RCTs were included in the meta-analysis of the effectiveness of internet-based psychoeducational programs on caregiver's anxiety (Blom et al., 2015; Boots et al., 2018; Gustafson et al., 2019). Compared to control groups, internet-based psychoeducational programs showed no significant effect on caregiver's anxiety [effect size =-0.12; confidence interval (-0.76, 0.51), p=0.71] (Figure 2-9).



	Experimental			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Random, 95% CI**
Blom et al 2015	−1.69	3.26	90	−0.47	3.41	85	39.7%	−0.36 [−0.66, −0.07]
Boots et al 2018	0.73	2.65	31	−0.79	3.35	37	34.7%	0.49 [0.01, 0.98]
Gustafson et al 2019	−0.28	0.18	14	0.05	0.81	11	25.5%	−0.58 [−1.39, 0.23]
Total (95% CI)			**135**			**133**	**100.0%**	**−0.12 [−0.76, 0.51]**

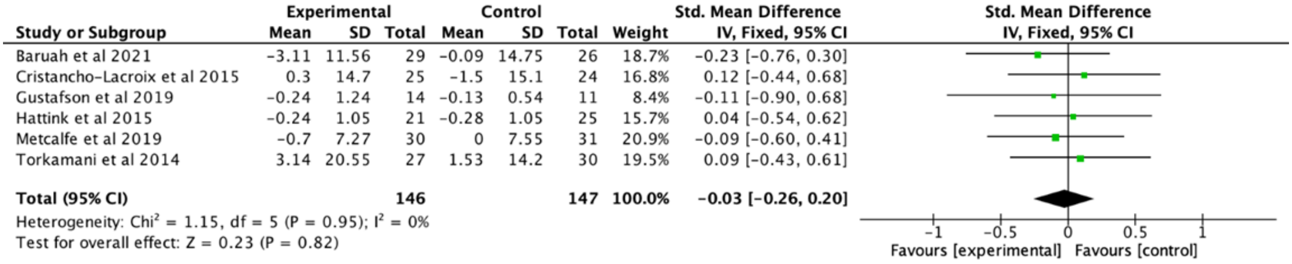
Heterogeneity: $Tau^2 = 0.24$; $Chi^2 = 9.78$, df = 2 (P = 0.008); $I^2 = 80\%$

Test for overall effect: Z = 0.37 (P = 0.71)

Figure 2-10 Systematic review and meta-analysis effect on caregiver's anxiety

2.2.5.6 *Caregiver's burden*

Six RCTs were included in meta-analysis of the effectiveness of internet-based psychoeducational programs on caregiver's burden (Baruah et al., 2021; Cristancho-Lacroix et al., 2015; Gustafson et al., 2019; Hattink et al., 2015; Metcalfe et al., 2019; Torkamani et al., 2014). Compared to control groups, internet-based psychoeducational programs showed no significant effect on caregiver burden [effect size =-0.03; confidence interval (-0.26, 0.20), p= 0.82] (Figure 2-11). A summary of meta-analysis findings is provided in Appendix 3.



	Experimental			Control				Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Fixed, 95% CI**
Baruah et al 2021	−3.11	11.56	29	−0.09	14.75	26	18.7%	−0.23 [−0.76, 0.30]
Cristancho-Lacroix et al 2015	0.3	14.7	25	−1.5	15.1	24	16.8%	0.12 [−0.44, 0.68]
Gustafson et al 2019	−0.24	1.24	14	−0.13	0.54	11	8.4%	−0.11 [−0.90, 0.68]
Hattink et al 2015	−0.24	1.05	21	−0.28	1.05	25	15.7%	0.04 [−0.54, 0.62]
Metcalfe et al 2019	−0.7	7.27	30	0	7.55	31	20.9%	−0.09 [−0.60, 0.41]
Torkamani et al 2014	3.14	20.55	27	1.53	14.2	30	19.5%	0.09 [−0.43, 0.61]
Total (95% CI)			**146**			**147**	**100.0%**	**−0.03 [−0.26, 0.20]**

Heterogeneity: $\text{Chi}^2 = 1.15$, df = 5 (P = 0.95); $I^2 = 0\%$

Test for overall effect: Z = 0.23 (P = 0.82)

Figure 2-11 Systematic review and meta-analysis effect on caregiver's burden

2.2.5.7 *Description of studies not included in the meta-analysis*

Two RCTs did not have sufficient available data to be included in the meta-analysis despite contacting authors (Duggleby et al., 2018; Hicken et al., 2017). Data from 6six pre-and post-test studies were not suitable for inclusion in the meta-analysis but study results showed these psychoeducation programs to improve participants' mental health significantly (Marziali & Garcia, 2011), wellbeing (Mollaei et al., 2021), knowledge of dementia (Gaugler et al., 2015; Pleasant et al., 2017) and competence (Pleasant et al., 2017; van der Roest et al., 2010; Wijma et al., 2018). Within these studies, there was no change in caregiver burden, QOL or self-efficacy (Duggleby et al., 2018; Hicken et al., 2017; van der Roest et al., 2010).

2.2.6 Discussion

This systematic review and meta-analyses showed that internet-based psychoeducation programs have a significant effect on caregiver's depressive symptoms and stress but have no statistically significant effect on caregivers' QOL, burden and self-efficacy. The authors developed a clear definition of internet-based psychoeducational programs and used it in the selection of studies, which allows future studies or reviews to compare the outcomes. Furthermore, using the 'stress and health process' model informed program analysis and outcome measures of internet-based psychoeducation interventions (Conde-Sala et al., 2010). These measures were based on the theoretical assumption that psychoeducation programs address multifaceted factors, including caregiver contextual factors (caregiver factors), primary stressors (care recipient factors) and secondary stressors (other factors) by which they have a positive effect on the health, wellbeing and QOL of caregivers (Conde-Sala et al., 2010). Previous systematic reviews on the impact of psychoeducation interventions rarely detailed relations between the program content and the multifaced factors the content addressed (Egan et al., 2018; Gonzalez-Fraile et al., 2021).

We carefully analysed the content of each psychoeducation program included in the review and clarified the relations between the program content and the aforementioned multifaced factors (see Table 2). Program content that addressed caregiver factors included positive thoughts towards the relationship with PLWD due to dementia (Blom et al., 2015; Boots et al., 2018) and how to be a caregiver (either as an adult-child caregiver or a spouse caregiver) (Baruah et al., 2021). Moreover, content that helped caregivers to cope with care recipient factors comprised how to prevent and manage changed behaviours (Hattink et al., 2015; Metcalfe et al., 2019) and how to provide activities of daily living to address the functional deficits of PLWD (Cristancho-Lacroix et al., 2015; Nunez-Naveira et al., 2016). In addition, content that enabled caregivers to deal with other factors included how to seek help within and outside the family (i.e., peer support and support from facilitators (Gustafson et al., 2019; Kajiyama et al., 2013). This theory-informed analysis may enhance stakeholders' confidence in translating findings into practice.

The meta-analyses showed that internet-based psychoeducational programs had a significant effect on the reduction of depressive symptoms. The depression reduction identified in our review showed the same effect size (-0.19) to psychoeducation-a programs, but a smaller effect size compared to psychoeducation-b programs (effect size = - 0.37), as reported by Cheng et al. (2020) in their review. It should be noted that of the 8 studies included in the present meta-analysis of depressive symptoms, only 1 study was a psychoeducation-a program according to the definition by Cheng et al. (2020). Therefore, the result may indicate that internet-based psychoeducation programs are less effective in depression reduction compared to psychoeducation-b programs (Cheng et al. 2020). It also should be mentioned that the systematic review and meta-analysis by Cheng et al. (2020) included an additional 46 psychoeducation programs excluded from our review according to our definition of psychoeducation programs. Excluded programs had a broader range of program delivery methods than our focus here, such as face-to-face and telephone-based programs and other information technology formats (i.e., video conferencing, web platforms or DVD-based self-learning programs) and may or may not have facilitators (Cheng et al., 2020). Therefore, reported differences in the effectiveness of psychoeducation programs between our review and the review by Cheng et al. (2020) may be due to program delivery methods. Future studies need to explore the impact of program delivery on the program's effectiveness.

Our sub-group analysis indicated that programs with a facilitator had a significant effect on reducing depressive symptoms (Figure 2-6), while programs without a facilitator showed no significant effect (Figure 2-7). Of the 19 programs reviewed, nine had program facilitators, and two of these studies were included in this sub-analysis. The role of facilitators in these two programs was similar and included a trained psychologist who provided feedback to caregivers (Blom et al., 2015; Boots et al., 2018). Our review supports a previous review that increased professional support in a dementia care education program was associated with a better effect on caregiver depressive symptoms (Zhao et al., 2019). The mechanism underlying the better effect might be due to the facilitator's role as a mediator in addressing caregiver contextual factors and care recipients' factors (Huang, 2022). However, as we only included two studies in the meta-analysis, the result needs to be interpreted with caution and future studies need to further explore the relationships.

Our meta-analysis also revealed that internet-based psychoeducational programs had a significant effect on improving caregivers' emotional wellbeing, as evidenced by stress reduction. The effect size of internet-based psychoeducational programs (-0.29 on stress) is like that reported by Cheng et al. (2020) (effect size=-0.23 on stress and burden). This is evidence that internet-based psychoeducational programs show a similar reduction of stress compared to psychoeducation programs delivered by various other methods as aforementioned.

Our findings suggested that internet-based psychoeducation programs did not have a significant effect on reducing anxiety symptoms. This may be due to the risk factors underlying anxiety differing from depression. Watson et al. (2019) suggested that anxiety symptoms were associated with female gender, spousal caregivers, care recipients' condition, low levels of self-efficacy and other existing underlying anxiety problems. In our systematic review, most participants in the three studies that measured anxiety included in the meta-analysis were female spouse carers living with PLWD in the same household. These characteristics relate to caregiver contextual factors based on the 'stress and health process' model (Conde-Sala et al., 2010). Addressing these factors may require instrumental support such as social care services (i.e., respite care and home care services for PLWD) (Brodaty & Donkin, 2009). Our review suggested that an internet-based psychoeducation program alone may not be sufficient to achieve anxiety reduction. Future studies need to explore interventions that include multiple approaches such as emotional and instrumental support, counselling and peer support groups for reducing anxiety among caregivers.

The present review suggests that internet-based psychoeducation programs have no statistically significant effect on caregiver burden. Research showed that caregiver burdens were associated with PLWD's high level of dependence (primary stressors) and less social support for caregivers (Connors et al., 2020a). In this review, we could not clarify the correlation between caregiver burden and primary stressors and between caregiver burden and social support they received due to limited data available. However, a systematic review and meta-analysis by Williams et al. (2019) revealed that only multiple approaches, for example, respite care, home care for PLWD, peer support groups and psychoeducation, showed significant burden reduction.

Our review showed that internet-based psychoeducational programs did not have a significant effect on caregiver self-efficacy. Our finding differs from a systematic review that showed a significant effect on self-efficacy in group-based face-to-face psychoeducational programs (Frias, Garcia-Pascual, et al., 2020). The differences may be due to the learning environment for caregivers. In group-based face-to-face programs, caregivers had opportunities to interact with peers to share experiences in dementia care, learn from and be motivated by role models, gain emotional and social support, and gain information to cope with challenges (Frias, Garcia-Pascual, et al., 2020). This environment reflects Bandura's self-efficacy development theory that emphasises a person's ability to learn a particular task and the environmental factors influencing the learner through cognitive, motivational, affective and behavioural processes (Bandura, 1993).

Our review also revealed that internet-based psychoeducational programs did not have a statistically significant effect on QOL. The finding is in line with a systematic review by Frias, Garcia-Pascual, et al. (2020) who reported that technology-based intervention (i.e., website and telephone-assisted interventions) had no significant effect on QOL. However, findings from Fria et al. (2020) were based on a narrative summary rather than a meta-analysis, and our review did not include telephone-assisted interventions. Moreover, Fria et al. (2020) stated that face-to-face group interventions showed significant improvement in QOL. This result may be due to multiple approaches to interventions being included in group-based face-to-face psychoeducational programs than internet-based programs; for example, offering additional individualised supports such as providing resources, information, follow-up phone calls and help with navigating the health and social care system (Frias, Garcia-Pascual, et al., 2020). However, among 6 studies that measured QOL in our review, 5 programs were self-directed learning, which means no additional support to caregivers in the internet-based psychoeducation programs (Baruah et al., 2021; Hattink et al., 2015; Kajiyama et al., 2013; Metcalfe et al., 2019; Torkamani et al., 2014). Moreover, the comparison groups in the 6 studies on QOL in our review received usual care (n=3) (Hattink et al., 2015; Metcalfe et al., 2019; Torkamani et al., 2014), additional information support (n=2) (Baruah et al., 2021; Kajiyama et al., 2013) and infrequent counselling (Boots et al., 2018), which were similar to the comparison groups in the review of face-to-face programs (n= 5) by Frias et al. (2020) which included usual care (n=4) and additional information support (n=1). Therefore, the differences in QOL might not be associated with the comparison groups but with the multiple approaches to interventions used in the face-to-face programs aforementioned. Future interventional programs need to consider multiple approaches to interventions to improve QOL for caregivers.

Crellin et al. (2014) in their systematic review identified that dementia caregiving-related self-efficacy was a main factor contributing to caregivers' QOL. In addition, Farina et al. (2017) in their systematic review confirmed at least 10 factors associated with caregivers' QOL, for example care recipient factors, didactic relationship factors, caregivers' self-efficacy, health and emotional wellbeing, and support received. These findings suggest that future internet-based psychoeducational programs should be designed to target as many QOL factors as possible to achieve a positive effect for caregivers.

2.2.7 Strengths and limitations

This review had several strengths. First, the literature search covered both English and Chinese language databases which reduced bias. Second, we performed a meta-analysis to calculate the effect size of the changed mean score, which is crucial for comparisons between internet-based and non-internet-based psychoeducational programs. In addition, we included pre- and post-test studies in addition to RCTs to analyse the educational designs. There were also several limitations of this review. First, while this review searched English and Chinese language literature, it could have expanded to other languages if other multilingual researchers had been included in the study team. Second, variations in program design, intervention duration, dose and socio-cultural contexts prevented us from undertaking sub-group analysis to calculate precise intervention effect size.

2.2.8 Conclusion

Internet-based psychoeducation programs showed increased importance during the COVID-19 pandemic due to restrictions on social contact and the interruption of face-to-face education programs for caregivers. Our review indicated that internet-based psychoeducational programs show a significant effect on depressive symptoms and stress reduction. However, our findings also indicate that internet-based psychoeducational programs have no effect on reducing anxiety, burden, and improving self-efficacy or QOL for caregivers. Future studies need to explore how to improve internet-based psychoeducational programs to maximise effectiveness and the impact of program facilitators on the health and wellbeing of caregivers.

This is the end of the publication.

2.3 FEASIBILITY AND FIDELITY OF INCLUDED RANDOMISED CONTROLLED TRIALS

Among 13 RCTs included in this systematic review, only one study used 12 months of intervention, with data collected only at baseline and 12 months (Brennan et al., 1995), while some studies of shorter duration (<6 months) collected data twice at baseline and two or three months (Baruah et al., 2021; Boots et al., 2018; Hattink et al., 2015; Kajiyama et al., 2013; Nunez-Naveira et al., 2016). There was one 3-month study (Metcalfe et al., 2019) and all six 6-month studies (Blom et al., 2015; Cristancho-Lacroix et al., 2015; Duggleby et al., 2018; Hicken et al., 2017; Torkamani et al., 2014) collected data three times.

It is worth noting that for exploring feasibility, some authors did not report their recruitment, retention, attrition, and program completion rates. Among all reported RCTs, the recruitment period was between seven and 24 months, and the recruitment rate was between 38% and 94%, indicating the challenges the current study might face in recruitment.

Among those studies that did report attrition rates and reasons, the lowest attrition rate was the study conducted by Brennan et al. (1995), which only had six (0.06%) participants drop out during the 12-month study. The highest attrition rate was 63% in a 3-month study by Baruah et al. (2021), followed by a multi-centred, cross-national 4-month study conducted by Hattink et al. (2015). The top reason for attrition includes lack of time; PLWD passed away (Blom et al., 2015; Boots et al., 2018; Duggleby et al., 2018; Gustafson et al., 2019; Kajiyama et al., 2013) and unable to contact (Blom et al., 2015; Boots et al., 2018; Brennan et al., 1995; Duggleby et al., 2018; Hattink et al., 2015). Followed by less suitable (Blom et al., 2015; Boots et al., 2018; Nunez-Naveira et al., 2016), illness (Brennan et al., 1995; Cristancho-Lacroix et al., 2015), PLWD deteriorated (Boots et al., 2018; Cristancho-Lacroix et al., 2015; Duggleby et al., 2018) and PLWD admitted to nursing home (Blom et al., 2015; Duggleby et al., 2018; Gustafson et al., 2019). The least reported attrition reason was unable to install a computer (Brennan et al., 1995; Hattink et al., 2015), using other services (Blom et al., 2015), carer passing away (Brennan et al., 1995) and no new information (Boots et al., 2018).

Limited information was reported regarding fidelity. Baruah et al. (2021) reported that 45% of participants in their study did not finish any lesson. Similarly, 27% of participants in the intervention group did not use their program, but 73% used it at least once in the study conducted by Duggleby et al. (2018). In comparison, Gustafson et al. (2019) reported that 100% of their participants accessed their multicomponent intervention in the first month, and 64% logged on during month six. Similarly, Metcalfe et al. (2019) reported that 60% of their participants logged on to the program at least once.

2.4 SUMMARY

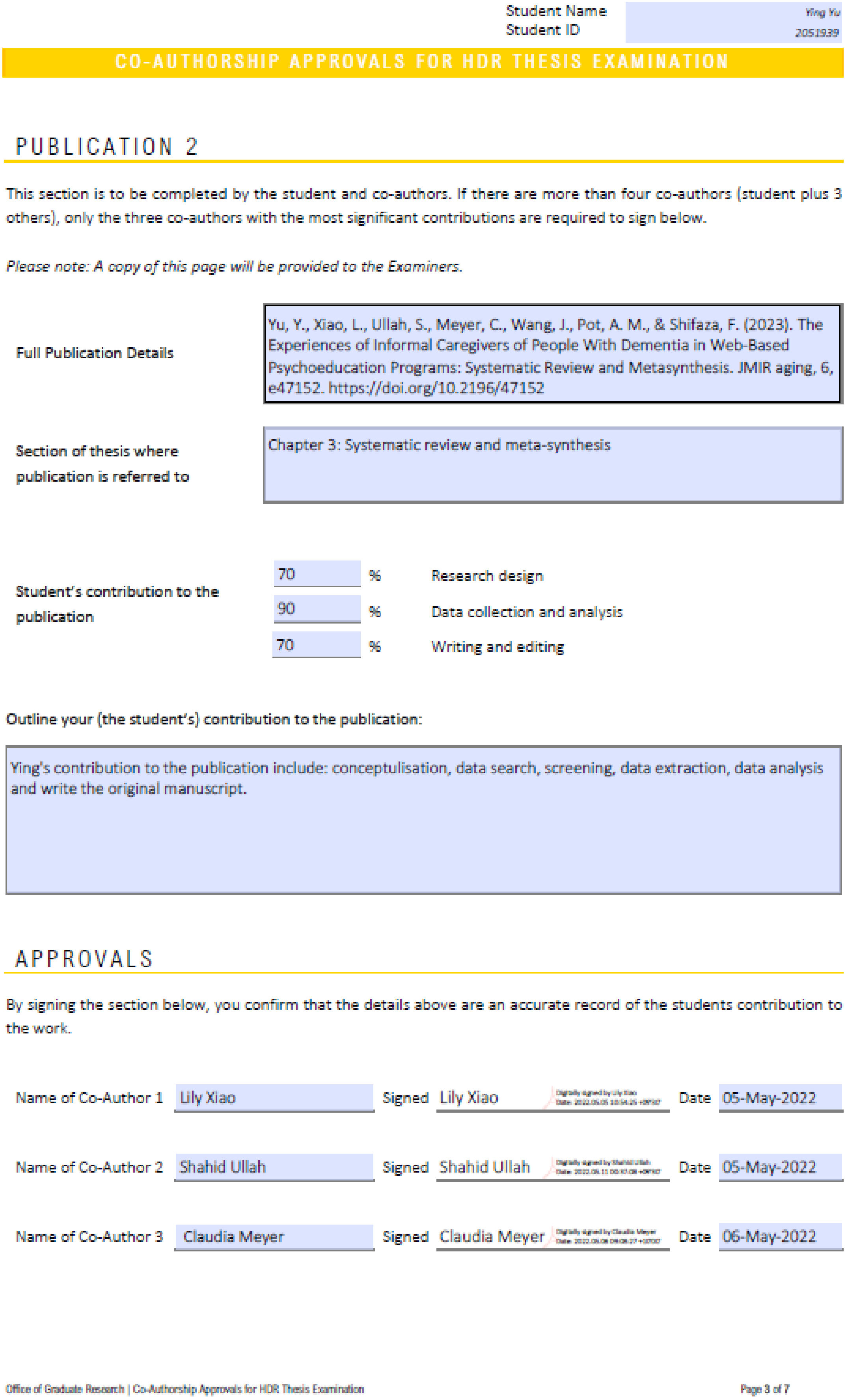
This chapter presented a systematic review and meta-analysis of quantitative studies. The systematic review aimed to identify existing knowledge about the effectiveness of internet-based psychoeducation programs. The review identified that longitudinal research related to facilitator-enabled internet-based psychoeducation programs is scarce and that no study has been conducted in the Australian context. The review only identified seven psychoeducation programs that had facilitator support. Findings from the review indicated that internet-based psychoeducation programs can significantly reduce carers' depression and stress symptoms. Findings also showed that facilitator-enabled internet-based psychoeducation programs had better depressive symptom reduction compared to non-facilitator-enabled internet-based psychoeducational programs. However, the effectiveness of such programs on carers' anxiety, burden, self-efficacy, and QOL remains inconclusive due to limited available studies. The systematic review supported the need for 12-month facilitator-enabled iSupport program, as shown in phase 2 of the study. Carers' experiences in these internet-based psychoeducation programs, however, were uncertain, given the nature of quantitative study design. Therefore, a systematic review was needed to synthesise qualitative evidence of internet-based psychoeducation programs

3 Systematic review and meta-synthesis

3.1 INTRODUCTION

The previous chapter presented a systematic review and meta-analysis of the quantitative studies of internet-based psychoeducation programs. Due to the limitation of quantitative designs, it was difficult to determine the family carers of PLWDs' experiences in those programs. This chapter presents the systematic review synthesising carers' experiences in internet-based psychoeducation programs conducted between July 2021 to January 2022. This review aims to understand the experience of informal caregivers of PLWD when participating in internet-based dementia psychoeducation programs. In this chapter, section 3.2 presents a publication from this thesis published in JMIR Aging as an open-access article. Some words in this publication are changed to enhance the flow of the thesis. For example, 'web-based and online' are changed to 'internet-based'. References are also updated using the present thesis's APA style; therefore, the format might differ slightly from the published article. Section 3.3 provides a chapter summary.

This section presents a publication from this thesis published in JMIR Aging. The first author's contribution to this paper was leading and coordinating the systematic review, 70% to research design, 90% to data collection and analysis and 70% to writing and editing. Citation: *Yu, Y., Xiao, L., Ullah, S., Meyer, C., Wang, J., Pot, A. M., & Shifaza, F. (2023). The Experiences of Informal Caregivers of People With Dementia in Web-based Psychoeducation Programs: Systematic Review and Meta Synthesis. JMIR Aging. https://doi.org/10.2196/47152. .*



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CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

PUBLICATION 2

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

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Full Publication Details	Yu, Y., Xiao, L., Ullah, S., Meyer, C., Wang, J., Pot, A. M., & Shifaza, F. (2023). The Experiences of Informal Caregivers of People With Dementia in Web-Based Psychoeducation Programs: Systematic Review and Metasynthesis. JMIR aging, 6, e47152. https://doi.org/10.2196/47152
Section of thesis where publication is referred to	Chapter 3: Systematic review and meta-synthesis

Student's contribution to the publication

70	%	Research design
90	%	Data collection and analysis
70	%	Writing and editing

Outline your (the student's) contribution to the publication:

Ying's contribution to the publication include: conceptulisation, data search, screening, data extraction, data analysis and write the original manuscript.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

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3.2 THE EXPERIENCES OF INFORMAL CAREGIVERS OF PEOPLE WITH DEMENTIA IN INTERNET-BASED PSYCHOEDUCATION PROGRAMS: SYSTEMATIC REVIEW AND META SYNTHESIS.

3.2.1 Abstract

Background: Informal caregivers of people living with dementia experience a higher level of physical and mental stress compared with other types of caregivers. Psychoeducation programs are beneficial for building caregivers’ knowledge and skills and decreasing caregiver stress.

Objective: This review synthesised the experiences and perceptions of informal caregivers of people with dementia when participating in internet-based psychoeducation programs and the factors that enable and impede informal caregivers' engagement in internet-based psychoeducation programs.

Methods: This review followed the Joanna Briggs Institute protocol of systematic review and meta-aggregation of qualitative studies. The authors searched 4 English, 4 Chinese, and 1 Arabic database in July 2021.

Results: A total of 9 studies written in English were included in this review. From these studies, 87 findings were extracted and grouped into 20 categories. These categories were synthesised into themes: internet-based learning as an empowering experience, peer support, satisfactory and unsatisfactory program content, satisfactory and unsatisfactory technical design, and challenges encountered in internet-based learning.

Conclusions: High-quality and carefully designed internet-based psychoeducation programs offered positive experiences for informal caregivers of people living with dementia. To meet broader caregiver education and support needs, program developers should consider information quality and relevancy, the support offered, individual needs, flexibility in delivery, and connectedness between peers and program facilitators.

Keywords: informal caregivers; dementia; psychoeducation; internet-based; internet-based; qualitative research; systematic review; meta-synthesis; internet-based

3.2.2 Introduction

Dementia is one of the major causes of disability among older adults worldwide (WHO, 2021a). People living with dementia have complex care needs and are often highly dependent on others to care for them (WHO, 2021b). Most people living with dementia are cared for by unpaid informal caregivers who are their family members or friends. Worldwide, in 2019, informal caregivers spent approximately five hours per day per person with dementia assisting in daily living activities (WHO, 2021b). They experienced a higher level of physical and mental stress compared to other types of caregivers, showed increased caregiver burden, anxiety and depression, and showed decreased quality of life (QOL) (Chang et al., 2021; A. Feast et al., 2016; Teahan et al., 2021). Such caregiving situations directly impact the caregiver's ability to provide quality care.

Early educational intervention to prepare informal caregivers for their caregiver role is crucial (Fazio et al., 2018; WHO, 2021b). However, the educational interventions offered do not always meet their needs. Informal caregivers often feel that they lack knowledge of dementia progression and symptom management and the skills for providing daily care (Alves et al., 2019; Bressan et al., 2020). They also expressed the need for more support at home from trained health professionals (Fitzgerald et al., 2019) that could foster knowledge sharing, build skills such as symptom management and physical care, and provide emotional support (Aoun et al., 2018; Brodaty & Donkin, 2009).

Psychoeducation programs are viewed as beneficial for meeting caregivers' expectations and learning needs through knowledge and skill-building while encouraging positive thoughts, decreasing caregiver stress, and improving caregivers' psychological wellbeing and QOL (Cheng et al., 2020). According to Cheng et al. (2020), psychoeducation programs usually incorporate theoretical, psychological and behavioural training components relevant to dementia care to achieve these benefits. Traditionally, psychoeducation programs are delivered face-to-face in small groups (Cheng et al., 2020). Internet-based psychoeducation programs have been widely used in recent years to offer convenience and flexibility to increase caregivers' participation and retention (Egan et al., 2018; Parker Oliver et al., 2017; Pot et al., 2015). However, many informal caregivers reported a lack of time or flexibility to commit to these programs due to care responsibilities (S. Teles et al., 2020).

Despite the known advantages of internet-based psychoeducation, underutilisation and a lack of program trustworthiness have been identified (WHO, 2021b). Furthermore, studies revealed a high dropout rate among caregivers in internet-based psychoeducation programs (Gonzalez-Fraile et al., 2021). The reasons for the high dropout varied across studies and programs. For example, the low recruitment and retention rates reported in a study by Baruah et al. (2021) indicated a need for further adaptations to the program to improve acceptability and accessibility. Whereas other studies have suggested that gender (Cristancho-Lacroix et al., 2015), program length (Christensen et al., 2009) and uncertain factors (Blom et al., 2015) contributed to the dropout rate. There is a need to synthesise studies on caregivers' experiences using internet-based psychoeducation programs to gain further insights into their experiences and facilitators affecting participation in a global context. This review is to address this gap in the literature.

This review synthesises 1) the experiences and perceptions of informal caregivers of people with dementia when participating in internet-based psychoeducation programs and 2) the factors that enable and impede informal caregivers" engagement in internet-based psychoeducation programs.

3.2.3 Method

3.2.3.1 Inclusion and exclusion criteria

This review included studies that reported components of the experiences of informal caregivers of people living with dementia when using internet-based psychoeducation programs in a home care setting. The review included qualitative studies and mixed methods studies that included qualitative components. The following studies were excluded from the review: (1) quantitative design; (2) internet-based programs without an educational component, such as social support groups (i.e., singing group) and telehealth; (3) non–internet-based programs, such as a DVD or booklet; (4) the population of interest in the study were people with dementia in residential care or hospital settings, rather than home care settings; and (5) not written in English, Chinese, or Arabic (because of team members’ backgrounds).

3.2.3.2 Search strategy and screening method

Keywords were identified according to the study's population (informal caregivers of people living with dementia), interest (internet-based psychoeducation program), and context (home care setting), interest, and context around internet-based psychoeducation for informal caregivers of people living with dementia (see Table 3-1). A Boolean search was conducted by combining the keywords. The following English databases were searched in July 2021, including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, Medical Literature Analysis and Retrieval System Internet-based (MEDLINE), and Scopus. Keywords were translated into Chinese (by YY) and Arabic (by FS) by the review team. The Chinese database includes China National Knowledge Infrastructure, Wang Fang Data, Weipu Data and Chaoxing Data (see Appendix 4). We also manually searched the Academic Journal of the Middle East for articles written in Arabic. No time limit was applied to the search. All retrieved records were imported to Endnotes 20 (The EndNote Team, 2013) and Covidence (Veritas Health Innovation, 2021) to remove the duplicate studies. Four reviewers (YY, LX, CM and SU) screened the English title and abstract. In addition, two reviewers (YY, JW) screened the Chinese titles and abstracts to identify studies that met the inclusion criteria, and two reviewers (YY and LX) reviewed the full text retrieved. The reference list of each selected article was scanned manually.

Table 3-1 Systematic review and meta-synthesis keywords

Population	Interest	Context	Research type
Informal caregivers of people living with dementia	Internet-based dementia carer education Experience	Homecare settings	Qualitative and Mixed Method
Carer or Caregiver or carer taker or family or friend or spouse or adult children or acquaintance or neighbour or neighbour or home nursing people with dementia or Alzheimer disease or Mild Cognitive Impairment	Internet or internet-based or e-health or telecomputing or tech or health or computers or software or electronic or digital Intervention or program or course or psychoeducation or training or support or cognitive therapy or psychological or platform or e-learning or telemedicine or telehealth or application or interface or APP Views, experiences, opinions, attitudes, perceptions, beliefs, feelings, knowledge, or understanding		

3.2.3.3 *Assessment of Methodology*

The methodology of all selected papers was assessed using Joanna Briggs Institute (JBI) critical appraisal instruments for qualitative research (Lockwood et al., 2020). The review team only included studies that satisfied > 5 appraisal questions. The main findings from each paper were critiqued by two reviewers to evaluate the level of credibility (ranked as unequivocal, credible, and not supported) according to JBI (Lockwood et al., 2020). The final synthesised findings were derived from unequivocal (findings and supporting data are beyond reasonable doubt and therefore not open to challenge) and credible (findings and supporting data are lacking clear association and consequently open to challenge) findings. Throughout the quality assessment process, disagreement between any two reviewers was resolved through comparison and discussion between those reviewers or through a third reviewer.

3.2.3.4 *Data extraction*

Qualitative data were extracted by two reviewers (YY and LX) using the standardised data extraction tool from the JBI Qualitative Assessment and Review Instrument (JBI QARI) (Lockwood et al., 2020). The tool includes 1) the author, publication year and country; 2) participants' characteristics and sample size; 3) internet-based education or training program details including duration, facilitator details and theoretical framework; 4) study setting, design, and methods; and

5) main findings. The main findings from each paper were extracted with an illustration to evaluate the finding's level of credibility (see Appendix 5).

3.2.3.5 Data synthesis and reporting

Data synthesis in this review followed the JBI protocol of meta-aggregation of qualitative studies (Lockwood et al., 2020), with the following three steps: 1) two reviewers reviewed the main findings from each paper to evaluate the level of credibility with unequivocal (U) and credible (C) findings included in the data synthesis and meta-aggregation; 2) similar findings were grouped into categories; and 3) categories were synthesised into final findings. Final findings were reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 (Page et al., 2021).

3.2.4 Results

3.2.4.1 Study inclusion

A total of 6168 articles were identified from the databases and uploaded to Covidence (Veritas Health Innovation, 2021) (English database n=5163; Chinese database n=1005; Arabic database n=0). Covidence automatically removed duplicates (n=2422). Duplicates were manually removed from the Chinese database (n= 350). After a title and abstract screening (English, n= 2721; Chinese, n= 655; Arabic, n= 0), 128 (English, n= 117 and Chinese, n= 11) full-text articles were retrieved. An additional 12 articles were identified from the search of the reference list of the included articles. After assessing the eligibility of full-text articles, nine English studies met the inclusion criteria and were included for methodology assessment. No article written in Chinese or Arabic met the inclusion criteria. The study selection process is displayed in Figure 3-1.

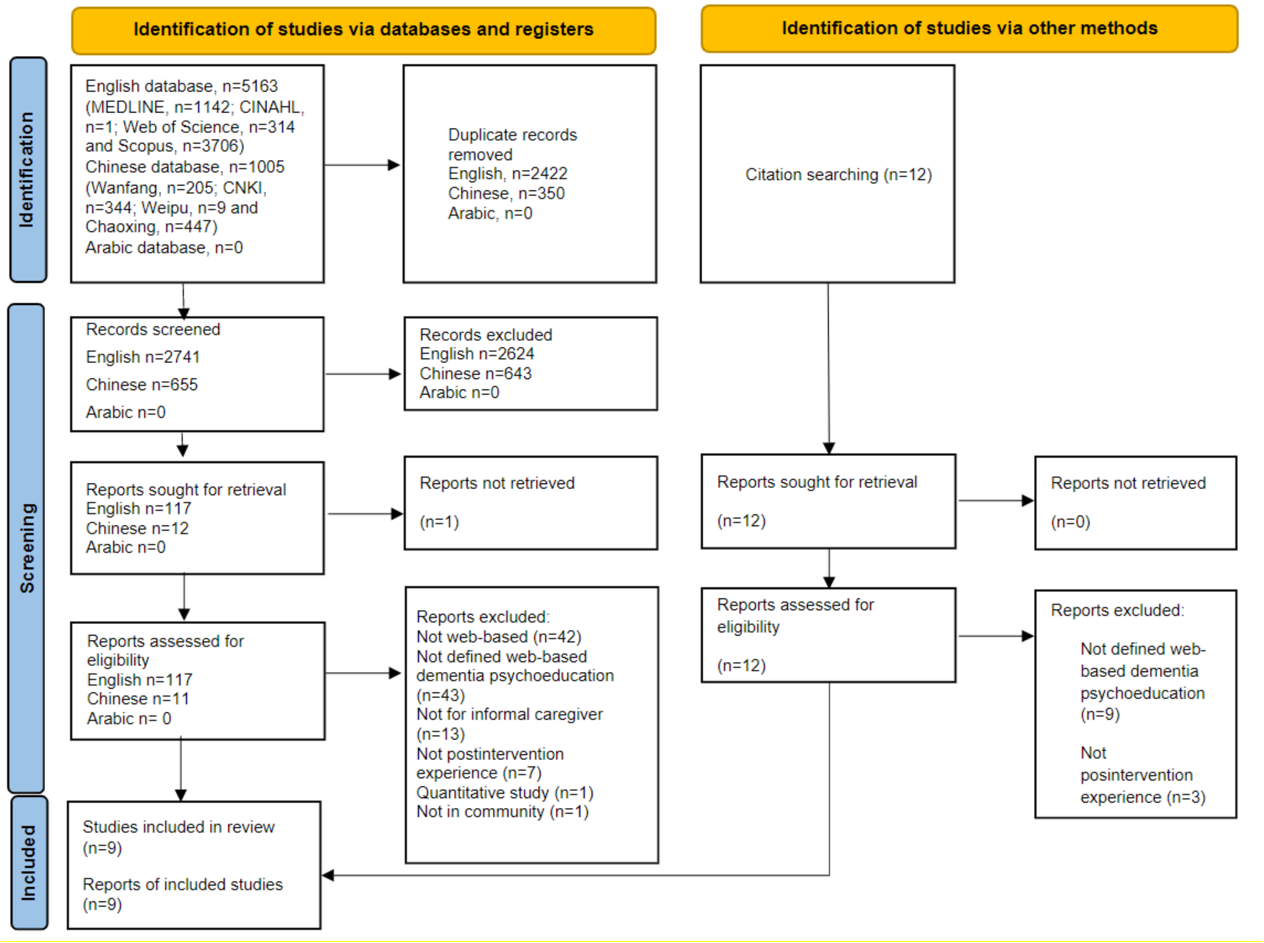


Figure 3-1 Systematic review and meta-synthesis article searching PRISMA flow chart (Page et al., 2021)

3.2.4.2 *Methodology Quality*

The methodological quality of nine selected studies was assessed and displayed in Tables 3-2. Of the nine studies reviewed, five (56%) were mixed-method studies, and four (44%) were qualitative studies. Only one study indicated philosophical perspectives underpinning methodology (Ploeg et al., 2018). In total, three studies were not explicit about the cultural and theoretical orientation of the researcher (Gaugler et al., 2015; Halbach et al., 2018; Hattink et al., 2016), and five studies did not address researchers' influence on the study (Brennan et al., 1991; Fowler et al., 2016; Gaugler et al., 2015; Halbach et al., 2018; Kovaleva et al., 2019). Moreover, one study only selected two cases to represent the qualitative data collected (Fowler et al., 2016). Therefore, the adequate representation of the participants in that study is questionable. All studies except one indicated ethics review (Halbach et al., 2018). No studies were excluded from this review based on the methodological quality assessment.

Table 3-2 Systematic review and meta-synthesis-Quality appraisal for qualitative studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Brennan et al. (1991).	U	Y	Y	Y	Y	Y	U	Y	Y	Y
Duggleby et al. (2019).	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Fowler et al. 2016	U	Y	Y	Y	Y	Y	U	U	Y	U
Gaugler et al. 2015	U	Y	Y	Y	Y	U	U	Y	Y	Y
Halbach et al. 2018	U	Y	Y	Y	Y	U	U	Y	U	Y
Hattink et al. 2016	U	Y	Y	Y	Y	U	Y	Y	y	Y
Kovaleva et al. 2019	U	Y	Y	Y	Y	Y	U	Y	Y	Y
Lewis et al. 2010	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ploeg et al. 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. Q1= Is there congruity between the stated philosophical perspective and the research methodology? Q2= Is there congruity between the research methodology and the research question or objectives? Q3= Is there congruity between the research methodology and the methods used to collect data? Q4= Is there congruity between the research methodology and the representation and analysis of data? Q5= Is there congruity between the research methodology and the interpretation of results? Q6= Is there a statement locating the researcher culturally or theoretically? Q7= Is the influence of the researcher on the research, and vice- versa, addressed? Q8= Are participants, and their voices, adequately represented? Q9= Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? Q10 = Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data? Y=yes, N=NO, U=unclear, N/A=not applicable

3.2.4.3 *Characteristics of the Included Study*

The included studies were published between 1991 and 2019 and were conducted in the United States (n=5), Canada (n=2), the Netherlands (n=1) and Norway (n=1) (see Table 2). A total of 367 people participated in the qualitative component of these studies. Among the included studies, five used a mixed methods design, and four applied a qualitative study design. Methodologies used in those studies included case studies (Fowler et al., 2016; Halbach et al., 2018), qualitative descriptions (Kovaleva et al., 2019; Ploeg et al., 2018), content analysis of open-ended questions in the survey (Brennan et al., 1991; Gaugler et al., 2015; Kovaleva et al., 2019; Lewis et al., 2010) and secondary analysis of telephone interviews (Duggleby et al., 2019). The data collection methods used in these studies included focus group interviews (Halbach et al., 2018) and semi-structured interviews either via telephone or face-to-face (Fowler et al., 2016; Kovaleva et al., 2019; Ploeg et al., 2018) or surveys with open-ended questions (Brennan et al., 1991; Gaugler et al., 2015; Kovaleva et al., 2019; Lewis et al., 2010).

3.2.4.4 Content of the psychoeducation program

Nine studies reported eight programs (see Table 3-4). Two studies reported the same program from different perspectives (Duggleby et al., 2019; Ploeg et al., 2018). For example, Duggleby et al. (2019) only reported the reasons for non-users in the internet-based MT4C program, whereas Ploeg et al. (2018) reported users' experiences in the same program. All programs were asynchronised internet-based psychoeducation programs and had a clear indication of the education component (Brennan et al., 1991; Duggleby et al., 2019; Fowler et al., 2016; Gaugler et al., 2015; Halbach et al., 2018; Hattink et al., 2016; Kovaleva et al., 2019; Lewis et al., 2010; Ploeg et al., 2018). A total of four programs offered peer support functions (Brennan et al., 1991; Fowler et al., 2016; Hattink et al., 2016; Kovaleva et al., 2019); of these four programs, three used asynchronised discussion forums or blogging (Brennan et al., 1991; Fowler et al., 2016; Hattink et al., 2016); and synchronised method such as video conferencing (Kovaleva et al., 2019). Health professionals' involvement in the programs was reported in four studies(Brennan et al., 1991; Fowler et al., 2016; Hattink et al., 2016; Kovaleva et al., 2019). Moreover, one study reported a program in a mobile app format with limited details of psychoeducation content (Halbach et al., 2018). The duration of the psychoeducation programs ranged from seven weeks (Kovaleva et al., 2019), two months (Hattink et al., 2016), three months (Duggleby et al., 2019; Fowler et al., 2016; Ploeg et al., 2018) to 12 months (Brennan et al., 1991). Overall, three studies did not have a specific time frame for participants to view or test the program (Gaugler et al., 2015; Halbach et al., 2018; Lewis et al., 2010).

Table 3-3 Systematic review and meta-synthesis- Characteristics of the included studies

Author Year Country	Study design	Program	Participants in the qualitative study	Method	Findings
Brennan et al. (1991). USA	Mixed methods	ComputerLink	Family caregivers of people with dementia (PLWD) (n=22)	Data collection: - messages posted on the discussion forum were collected. Data analysis: - Qualitative content analysis of collected messages	Pros: - The forum and Q&A section served as emotional support and social interaction opportunities for caregivers of PwD. - The public communication section allows participants to control the discussion focus and address the issue in a timely manner. - Self-paced learning provided more flexible learning for caregivers without time and space restraints. Cons: - Findings do not represent a diverse population (i.e., different age groups and cultural backgrounds).
Duggleby et al. (2019). Canada	Secondary analysis of a mixed method study	My Tools 4 Care (MT4C)	Family caregivers of PLWD (n=92)	Data collection: - Telephone interviews Data analysis: - Qualitative content analysis	Pros: - Improved PLWD's self-efficacy Cons: - Poor internet connectivity and low computer literacy were the barriers to accessing MT4C. - Reasons for not using the program included caregiver demands and preference for a paper or a face-to-face interaction.
Fowler et al. 2016 USA	Case study	Virtual Healthcare Neighborhood Technology	Family caregivers of PLWD used the program (n=28)	Data collection: - Interviews Data analysis: - Qualitative descriptive	Pros: - Provided social support and information sharing using the blog section. The blogs included safety, sleep issues, memory, social engagement, enjoyment, and suggestions. - Participants have opportunities to interact with health professionals from different disciplines. Cons: - Only reported two cases
Gaugler et al. (2015). USA	Mixed methods	CARES® Dementia Care for Families	Family caregivers of PLWD (n=41)	Data collection: - Survey Data analysis - Qualitative content analysis of open-ended questions in the survey	Pros: - Comprehensive content - Use of real individuals with dementia in videos - The video shows the stages/progression of dementia. - The flexibility of internet-based delivery Cons: - The video segment was too small. - Some audio segments were incomplete.
Halbach et al. 2018 Norway	Qualitative case report	Mobile app mYouTime,	Relatives and staff of PLWD (n=17)	Data collection: - Focus group interviews. Data analysis: - Qualitative descriptive	Pros: - Well-structured learning units. - Large font size. - Contains videos. - Contains basic and in-depth information. Cons: - The quiz section was the least attractive. - Need more local information rather than be redirected to another webpage.

Table 3-3 Systematic review and meta-synthesis- Characteristics of the included studies

Author Year Country	Study design	Program	Participants in the qualitative study	Method	Findings
Hattink et al. 2016 The Netherlands	Mixed methods	The Digital Alzheimer Center (DAC)	Family caregivers of PLWD (n=6), PwD (n=6), professional staff (n=6)	Data collection: - observations - internet-based survey - semi-structured interviews Data analysis: - Thematic analysis	Pros: - Clear layout, calm background, large font and contrasting colour. - Comprehensive and well-written information. - Helped caregivers of PwD understand and deal with dementia. - Information can be accessed anytime and anywhere (flexibility in delivery). Cons: - Posting a message on the forum, finding information on driving and watching videos appeared difficult to some participants. - Small sample size
Kovaleva et al. 2019 USA	Qualitative description	Tele-Savvy	Family caregivers of PwD (n=36)	Data collection: - Interviews, Data analysis: - Qualitative content analysis	Pros: - Provided opportunity for caregivers to connect with others via video conferences (peer support, learning from others). - The internet-based program promoted access for those who need to travel. - A health professional facilitated video conferencing. - Contains pre-recorded expert-delivered lessons. - Provided caregiver manual. Cons: - Information needs to be more relevant to stage-specific caregiving. - More videos are needed to cover more complex situations and represent more diverse cultural backgrounds. - The program needs to be longer. - Videoconferences need to be longer. - Video conferencing needs to be more engaging. - Technical issues (poor internet connection) - Insufficient instructions on how to join videoconferences. - Need more detailed written and illustrated instructions for video viewing. - The internet-based program may not be suitable for some people. The study only included people who have internet access.

Table 3-3 Systematic review and meta-synthesis- Characteristics of the included studies

Author Year Country	Study design	Program	Participants in the qualitative study	Method	Findings
Lewis et al. 2010 USA	Mixed methods	The Internet-Based Savvy Caregiver program	Family caregivers of PwD (n=47)	Data collection: - Survey with open-ended questions Data analysis: - Constant comparative analysis	Pros: - Information and caregiving strategies were relevant and interesting to participants. - Videoclips of professionals, caregivers, and PwD. - The convenience of the internet program. - presentation of the program. Cons: - Spelling errors - Technical difficulties (difficulty in navigating the website). - Repetition of information. - Length of the program. - Did not provide an opportunity for participants to interact with other people. - Need a hardcopy workbook.
Ploeg et al. 2018 Canada	Qualitative	My Tools 4 Care (MT4C)	Family caregivers of PwD (n=56)	Data collection: - Semi-structured, open-ended telephone interviews Data analysis: - Qualitative content analysis	Pros: - Easy to navigate. - Provided the opportunity to reflect on and share their caregiving experiences. - Information was relevant and applicable to the individual caregiver's situation. - Provided and affirmed their caregiving experiences through the website's content and linked videos. Cons: - MT4C did not apply to the caregiver's current situation or suit their current needs because of their stage in the caregiving journey. - Technical issues and security concerns. (3) writing or sharing their thoughts and experiences in MT4C. - Need a directory of services searchable by postal code. - Not having a person available to answer caregivers" questions. - Not having a navigator to help the caregiver identify and access resources that meet their needs.

Table 3-4 Systematic review and meta-synthesis-details of psychoeducation programs

Author	Program and duration	Delivery format	Program content
Brennan et al.1991	ComputerLink 12months	Asynchronised internet-based	- Content: dementia care information, decision support and communication. - Theoretical framework: multi-attribute utility theory - Theoretical training: yes - Psychological training: unclear - Behaviour training: unclear - Peer support: using private email and discussion forum. - Facilitator: Discussion forums were facilitated by health professionals.
Duggleby et al.2019 **Ploeg et al. 2018**	My Tool 4 Care Three months	Asynchronised internet-based	- Content: Each web page contains frequently asked questions, resources, and a calendar. An electronic copy of the Alzheimer's Society's Disease booklet was available. - Theoretical framework: Meleis' theory of transition - Theoretical training: yes - Psychological training: yes - Behaviour training: yes - Peer support: not offered. - Facilitator: not offered.
Fowler et al. 2016	Virtual Health Care Neighbourhood 3 months	Asynchronised internet-based	- Content: information relevant to caring for a PwD at home. - Theoretical framework: not indicated. - Theoretical training: yes - Psychological training: yes - Behaviour training: yes - Peer support: using Question and Answer and Social Support forums. - Facilitator: The blogging section was supported by health professionals.
Gaugler et al. 2015	The CARES for Families The duration was not indicated.	Asynchronised internet-based	- Content: information on understanding memory loss, living with dementia and using the CARES Approach. - Theoretical framework: not indicated - Theoretical training: yes - Psychological training: yes - Behaviour training: yes - Peer support: not offered. - Facilitator: not offered
Halbach et al. 2018	mYouTime mobile application The duration was not indicated.	Asynchronised internet-based	- Content: lectures, videos and hyperlinks about dementia care. Details were not discussed in the paper. - Theoretical framework: not indicated. - Theoretical training: unclear - Psychological training: unclear - Behaviour training: unclear. - Peer support: not offered. - Facilitator: not offered.

Table 3-4 Systematic review and meta-synthesis-details of psychoeducation programs

Author	Program and duration	Delivery format	Program content
Hattink et al. 2016	Digital Alzheimer centre The duration was not indicated.	Asynchronised internet-based	- Content: information about dementia, an overview of appointments, community sections, news and upcoming events. - Theoretical framework: not indicated. - Theoretical training: yes - Psychological training: yes - Behaviour training: yes - Peer support: using the forum. - Facilitator: Participants can privately email health professionals or make an appointment.
Kovaleva et al. 2019	Tele-Savvy 7 weeks	Hybrid Asynchronised internet-based information with synchronised video conferencing for peer support.	- Content: pre-recorded expert-delivered lessons about dementia care. - Theoretical framework: Social cognitive theory and stress and coping theory. - Theoretical training: yes - Psychological training: yes - Behaviour training: yes - Peer support: weekly instructor-facilitated video conferences. - Facilitator: health professionals
Lewis et al. 2010	Internet-Based Savvy Caregiver program The duration was not indicated.	Asynchronised internet-based	- Content: information on 1) the effects of dementia on thinking; 2) taking charge and letting go; 3) providing practical help; and 4) managing daily care and difficult behaviour. - Theoretical framework: stress and coping theory. - Theoretical training: yes - Psychological training: yes - Behaviour training: yes - Peer support: not offered. - Facilitator: not offered

3.2.4.5 *Synthesised findings*

Overview

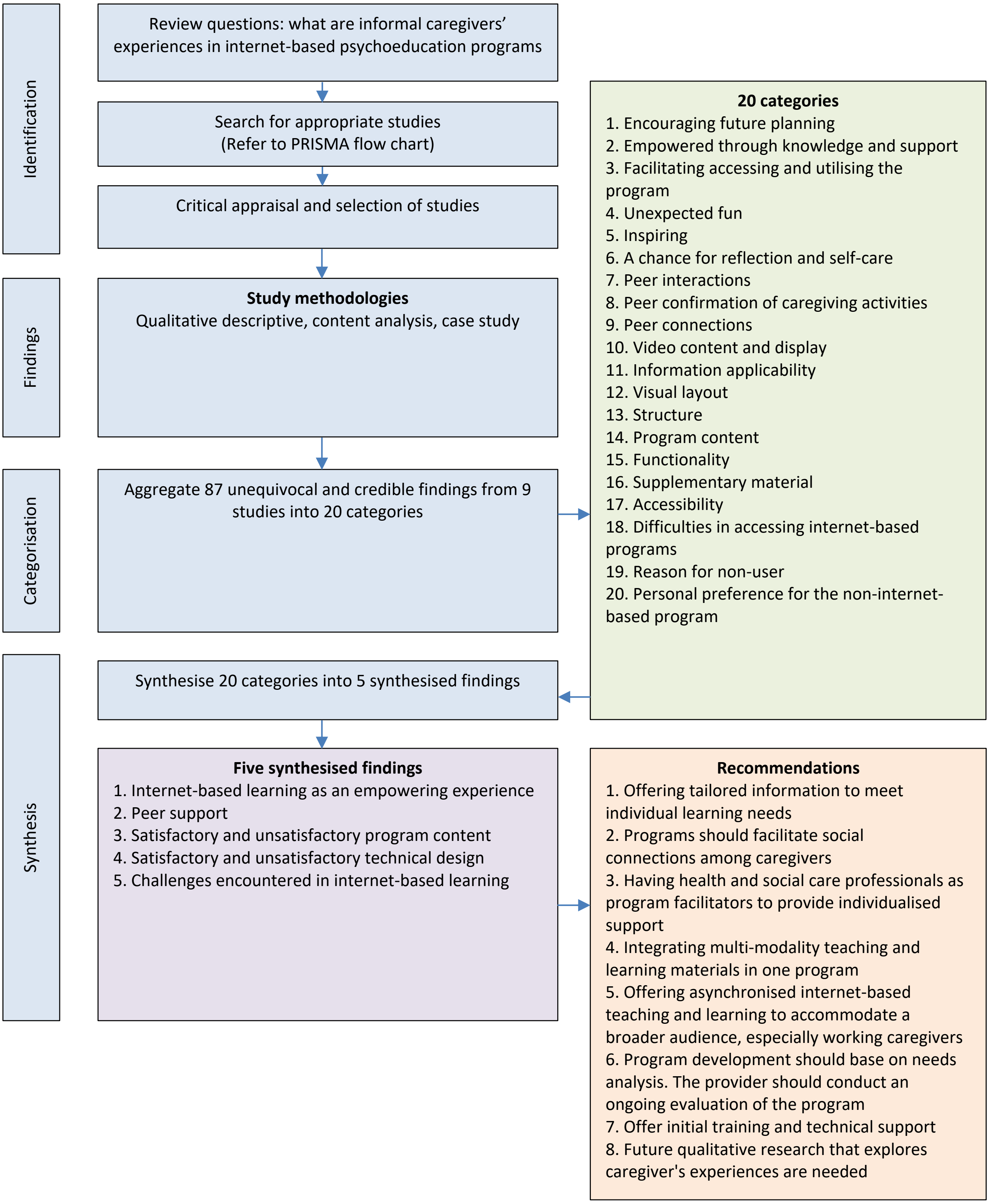
A total of 87 findings were extracted and grouped into 20 categories based on similarities and differences. These were further synthesised into five findings: 1) internet-based learning as an empowering experience; 2) peer support; 3) satisfactory and unsatisfactory program content; 4) satisfactory and unsatisfactory technical design; and 5) challenges encountered in internet-based learning. These synthesised findings are built on evidence rated as moderate to high confidence, outlined in the ConQual summary of findings in Table 3-5. The meta-aggregation flow chart is presented in Figure 3-2. More information relate to results of meta-synthesis is displayed in Appendix 6.

Table 3-5 Systematic review and meta-synthesis -the ConQual summary of findings

Systematic review title: The experience of informal caregivers of people with dementia in internet-based psychoeducation programs: a systematic review and meta-synthesis of qualitative studies
Population: Informal caregivers of people with dementia
Phenomena of interest: Internet-based psychoeducation

Synthesised findings	Type of Research	Dependability	Credibility	ConQual Score
Synthesised Finding 1: Internet-based learning as an empowering experience	Qualitative and qualitative components in mixed-method research	High	High	High
Synthesised Finding 2: Peer support	Qualitative and qualitative components in mixed-method research	High	High	High
Synthesised Finding 3: Satisfactory and unsatisfactory program content	Qualitative and qualitative components in mixed-method research	High	Downgrade 1 level	Moderate
Synthesised Finding 4: Satisfactory and unsatisfactory technical design	Qualitative and qualitative components in mixed-method research	High	Downgrade 1 level	Moderate
Synthesised Finding 5: Challenges encountered in Internet-based learning	Qualitative and qualitative components in mixed-method research	High	High	High

Note: Dependability: high= 4-5 responses to critical appraisal questions; Credibility: high=Unequivocal: all findings accompanied by an illustration (no change); Downgrade one level due to a mix of unequivocal and credible findings



Review questions: what are informal caregivers' experiences in internet-based psychoeducation programs

Search for appropriate studies (Refer to PRISMA flow chart)

Critical appraisal and selection of studies

Study methodologies
Qualitative descriptive, content analysis, case study

Aggregate 87 unequivocal and credible findings from 9 studies into 20 categories

20 categories
1. Encouraging future planning
2. Empowered through knowledge and support
3. Facilitating accessing and utilising the program
4. Unexpected fun
5. Inspiring
6. A chance for reflection and self-care
7. Peer interactions
8. Peer confirmation of caregiving activities
9. Peer connections
10. Video content and display
11. Information applicability
12. Visual layout
13. Structure
14. Program content
15. Functionality
16. Supplementary material
17. Accessibility
18. Difficulties in accessing internet-based programs
19. Reason for non-user
20. Personal preference for the non-internet-based program

Synthesise 20 categories into 5 synthesised findings

Five synthesised findings
1. Internet-based learning as an empowering experience
2. Peer support
3. Satisfactory and unsatisfactory program content
4. Satisfactory and unsatisfactory technical design
5. Challenges encountered in internet-based learning

Recommendations
1. Offering tailored information to meet individual learning needs
2. Programs should facilitate social connections among caregivers
3. Having health and social care professionals as program facilitators to provide individualised support
4. Integrating multi-modality teaching and learning materials in one program
5. Offering asynchronised internet-based teaching and learning to accommodate a broader audience, especially working caregivers
6. Program development should base on needs analysis. The provider should conduct an ongoing evaluation of the program
7. Offer initial training and technical support
8. Future qualitative research that explores caregiver's experiences are needed

Figure 3-2 Systematic review and meta-synthesis-Meta-Aggregation flow chart

3.2.4.6 Synthesised finding 1: Internet-based learning as an empowering experience.

This synthesised finding is based on nine findings from seven studies (Brennan et al., 1991; Fowler et al., 2016; Gaugler et al., 2015; Halbach et al., 2018; Hattink et al., 2016; Kovaleva et al., 2019; Lewis et al., 2010). Caregivers who used internet-based psychoeducation programs felt empowered through the knowledge they gained and activities undertaken (Brennan et al., 1991; Fowler et al., 2016; Hattink et al., 2016). For example, one participant stated the following: *'Being a part of the study at that time in my life really helped me cope with difficult family issues and decisions'* (Fowler et al., 2016).

Caregivers welcomed topics on caregiver coping skills, which help them gain strategies to deal with everyday challenges (Brennan et al., 1991; Lewis et al., 2010). One participant stated the following:

> *'It is a gentle reference vehicle for understanding Alzheimer's changes. It won't smack you in the face with the fear of what is coming but will prepare you for techniques to cope' (Lewis et al., 2010).*

Caregivers perceived that the knowledge they learned through real-life stories enabled them to understand the disease which improved their self-efficacy (Gaugler et al., 2015; Halbach et al., 2018; Hattink et al., 2016). One participant stated the following:

> *'The examples and the stories of families who live with Alzheimer's were very informative and gave me comfort that I, too, can do this' (Gaugler et al., 2015).*

Some programs encouraged participants to complete behaviour appraisal and develop a long-term plan:

> *'It [MT4C] made me even realise somebody else needs a list of doctors and [chuckles], you know, things like that ... It made me think about personal care in the future because that is long-term care' (Ploeg et al., 2018).*

Some caregivers were initially intimidated by internet-based learning, but their experience in a well-run internet-based classroom encouraged them to engage with the program. For example:

> *'At first, I was ... this is not going to work; I am 60 years old. It really worked; I loved going to school online, and I thought I was in a real class--I am talking in a real classroom' (Kovaleva et al., 2019).*

Similarly, another participant indicated the following:

> *'I was a little intimidated by it at first, but then I got on, and it worked very smoothly, you know, the way it was supposed to, and it made the experience kind of fun' (Fowler et al., 2016).*

Participants expressed that having a program facilitator to answer their questions may further enhance their experience (Ploeg et al., 2018). For example, one participant commented the following:

> *'Having a person available to answer caregivers' questions by telephone and having a*

> *navigator to "be that bridge" to help the caregiver identify and access resources that meet their specific need' (Ploeg et al., 2018).*

Overall, internet-based psychoeducation programs empowered participants by enhancing their self-efficacy, skill building, knowledge sharing and self-reflection, contributing to a positive learning experience.

3.2.4.7 Synthesised finding 2: Peer support.

This synthesised finding was based on nine findings identified from six studies (Brennan et al., 1991; Fowler et al., 2016; Hattink et al., 2016; Kovaleva et al., 2019; Lewis et al., 2010; Ploeg et al., 2018). Peer interactions were essential factors influencing caregivers' experience in the internet-based psychoeducation program. Asynchronised peer support included internet-based forums for participants to exchange information and was perceived positively by participants (Brennan et al., 1991; Fowler et al., 2016; Hattink et al., 2016). One author stated:

> *'There are frequent statements of encouragement and support among caregivers, for example, "My husband is in the middle stages of the disease, and I would like some suggestions on how to occupy his time…" ''Dorothy, I also have a problem with my wife who likes to walk and gets bored…" '' Hi this is Sue. I noticed a reply to idle Time…"' (Brennan et al., 1991).*

Reading fellow caregivers' stories provided an opportunity for caregivers to share, reflect on, and have a better understanding of dementia care. For example, one participant wrote the following:

> *'Oh, I'm not out here alone, kind of thing but just to be able to see what other people's stories were like, how others were handling things and seeing how people interacted with each other. That medium was really valuable' (Fowler et al., 2016).*

Encouragement and support from synchronised internet-based peer support groups were also considered helpful (Kovaleva et al., 2019). However, not all peer support was positive. Issues identified in synchronised internet-based peer support groups were more apparent. Poor group interactions were reported in one study which used video conferences and negatively influenced caregivers' experience. Group members were not focused on the topic, and a lack of equal opportunity to contribute to the group meeting and a desire to have more interactions were reported (Kovaleva et al., 2019).

When the program did not offer a peer support function, participants specifically commented on the value of connecting and sharing experiences with others (Lewis et al., 2010; Ploeg et al., 2018). For example, one participant commented the following:

> *'I do not have the option of sharing or interacting with others. The opportunity for questions*

> *related to my situation are not possible' (Lewis et al., 2010).*

Caregivers also suggested the following:

> *'Adding a feature to MT4C to enable caregivers to connect with one another to share information, experiences, and caregiving strategies would be helpful' (Ploeg et al., 2018).*

Caregivers perceived that a facilitator played a crucial role in motivating them and clarifying issues discussed in peer support groups:

> *'One of the very helpful parts of the chats was to have positive feedback from the teachers. I don't think caregivers get very many "good job on that"... comments. It is easy to know when we mess up ... hard to know that we did it well' (Kovaleva et al., 2019).*

Peer support during the program reduced caregivers' feelings of isolation, and many participants expressed a desire to stay connected after the program ended:

> *'For me, it was a lifesaver ... seeing all those people from all around the country ... they are not really handling it any better than I am. I don't feel so alone in spirit' (Kovaleva et al., 2019).*

3.2.4.8 Synthesised finding 3: Satisfactory and unsatisfactory program content.

This synthesised finding was based on a total of 17 findings identified from seven studies (Brennan et al., 1991; Gaugler et al., 2015; Halbach et al., 2018; Hattink et al., 2016; Kovaleva et al., 2019; Lewis et al., 2010; Ploeg et al., 2018). The program content aspects considered in this finding include program components such as video, the information presented in the video or text format such as different topics covering dementia caregiving strategies. No content was delivered in a synchronised format in the included studies.

A video component was welcomed by most participants, especially when a real person with dementia and their caregivers were featured in the video (Lewis et al., 2010). Videos enhanced caregivers' understanding of dementia progression and care needs at different stages (Gaugler et al., 2015; Halbach et al., 2018; Kovaleva et al., 2019). One caregiver stated (Gaugler et al., 2015):

> *'I really liked the videos that showed the progression of the disease in the early, middle, and late stages of the disease—for example, making coffee and taking a bath example. I also liked the driving example, too, about the different parts of the brain and how they are affected' (Gaugler et al., 2015).*

Other caregivers echoed similar comments:

> *'Person with dementia was very interesting and I felt like I could connect with them' (Lewis et al., 2010).*

The video structure and content also contributed to caregivers' experiences. Although some programs' videos were well structured (Halbach et al., 2018), in other programs, the video display was too small (Gaugler et al., 2015), had poor audio quality (Halbach et al., 2018), and the content lacked cultural diversity (Kovaleva et al., 2019). Additional videos to highlight more challenging situations were requested by participants in one study (Kovaleva et al., 2019); for example:

> *'The Caucasian daughter (age 61) suggested the vignettes did not portray the "messiness of life"—times when a care recipient may not follow caregiver's guidance, multiple family members involved in caregiving, and families with limited resources: I would have liked to see a daughter or son single caregiver with just a parent, try to make it more identifiable and inclusive'(Kovaleva et al., 2019) .*

Caregivers perceived that the information provided in the internet-based psychoeducation program was important. They welcomed information that accommodated their individual learning needs (Halbach et al., 2018; Hattink et al., 2016; Kovaleva et al., 2019). One caregiver stated: '*Good information, I found myself surprised at being able to relate to a lot of it'* (Lewis et al., 2010). Participants also perceived that the information provided should be relevant to individual caregivers' needs and their caregiving journeys (Gaugler et al., 2015) and detail practical solutions (Ploeg et al., 2018). One participant stated the following: '*I feel like I am not there yet; Mom's still early, so some things are more advanced…*' (Ploeg., 2018).

They particularly liked the information presented by both caregivers and experts (Lewis et al., 2010). The participants also noted that some programs missed important topics (Halbach et al., 2018; Kovaleva et al., 2019; Ploeg et al., 2018). One participant stated:

> *'It was a known issue that the 23 lectures were not covering the entire area, and this was also remarked on with several participants mentioning missing topics and in-depth information' (Halbach et al., 2018).*

Most participants in this review were satisfied with the video content and written information included in internet-based psychoeducation programs.

3.2.4.9 Synthesised finding 4: Satisfactory and unsatisfactory technical design.

This synthesised finding came from a total of 23 findings identified from six studies (Gaugler et al., 2015; Halbach et al., 2018; Hattink et al., 2016; Kovaleva et al., 2019; Lewis et al., 2010; Ploeg et al., 2018). The program design aspects considered in this finding include structure, language, functionality, accessibility, and supplementary material.

Participants liked a clear page layout with a large font size for the content (Halbach et al., 2018; Hattink et al., 2016; Lewis et al., 2010). The lack of a systematic layout was reported in one study:

> *'Participants suggested that the [printed] manual be laid out more clearly (e.g., include a table of contents and a glossary) and be more precisely coordinated with the videos,*

> *videoconference "lecture", and "homework" assignment' (Kovaleva et al., 2019).*

Participants identified grammar and spelling errors in two programs (Halbach et al., 2018; Lewis et al., 2010). There were also concerns about the literacy level of one program:

> *'It is a lot of text and the literacy level. Oh, the other thing is it's only in English ... you need to make the language a bit simpler' (Ploeg et al.,2018).*

One caregiver suggested that the case scenario presented needed to be positive to provide a better learning experience:

> *'I found it very sad to be left with the vision of the dear man peeling bananas. You could have chosen something a bit more uplifting' (Gaugler et al., 2015).*

Caregivers in one program considered quizzes to be the least helpful component (Halbach et al., 2018). Participants in another program experienced information overload and were frustrated by lengthy, repetitive and missing content (Lewis et al., 2010). Caregivers especially welcomed the flexibility, convenience and easy navigation of psychoeducation programs delivered on the web: *'You can check this information anytime, even in the middle of the night'* (Hattink et al., 2016). These features were extremely helpful for caregivers who lived far from the place where a face-to-face program might be delivered:

> *'I live forty miles from everywhere; it was wonderful…It was good to be able to do it internet-based rather than trying to get in the car, considering the traffic situation here' (Kovaleva et al., 2019).*

The caregivers expressed that the program website should have a bookmark function (Lewis et al., 2010). Supplementary materials, such as instruction manuals, were also suggested by participants when not provided (Kovaleva et al., 2019; Lewis et al., 2010). Caregivers would also like ongoing access to the program after completion for various reasons (Fowler et al., 2016; Gaugler et al., 2015; Kovaleva et al., 2019). One caregiver stated:

> *'Caregivers could not access the videos after Tele-Savvy conclusion; however, many stated that they would be willing to rewatch videos, share them with family members, and rewatch them when their care recipient is in a later dementia stage' (Kovaleva et al., 2019).*

3.2.4.10 Synthesised Finding 5: Challenges encountered in Internet-based learning

This synthesised finding was based on a total of seven findings identified from four studies (Duggleby et al., 2019; Hattink et al., 2016; Kovaleva et al., 2019; Ploeg et al., 2018). Technical issues, such as problems with accessing and poor internet connection, were a great challenge in using two internet-based programs (Duggleby et al., 2019; Kovaleva et al., 2019), which did not differentiate between synchronised programs (information accessing) or synchronised internet-based peer support. One participant commented the following: '*My internet connection at home is poor—I live in a rural area*' (Duggleby et al., 2019). Others experienced problems during synchronised video conferencing. For example:

> *'Problems during videoconferences (e.g., poor Internet connection, slow sound and video transmission, and insufficient instructions on joining videoconferences) affected connectedness' (Kovaleva et al., 2019).*

A low level of computer literacy among the participants also contributed to access difficulties (Duggleby et al., 2019; Kovaleva et al., 2019). One participant commented the following:

> *'Some caregivers noted that others struggled to follow some directions…and needed to be better aligned relative to their webcam and sit in a position with good lighting' (Kovaleva et al., 2019).*

Caregivers who struggled with the technology seem to prefer hardcopy information:

> *'Sometimes, you actually have to have something printed in front of you, uh, and I am better off with paper'(Duggleby et al., 2019).*

Time was another challenge in this regard. Caregiving demands prevented some from participating in internet-based psychoeducation programs (Duggleby et al., 2019; Hattink et al., 2016; Ploeg et al., 2018). One participant commented the following:

> *'[I] work full-time early morning to late evening ... and at the end of the day, I don't have the energy or time to go on the computer'(Duggleby et al., 2019).*

Similarly, another carer stated:

> *'The more time I spend on the computer, the more [name of spouse] approaches me and saying "What are you doing? Why aren't you sitting with me?"' (Ploeg et al., 2018).*

Other caregivers preferred learning through actual social contact:

> *'It would have been better to absorb the content in a group setting, person to person ... very difficult to have a personal connection with a computer screen' (Kovaleva et al., 2019).*

3.2.5 Discussion

3.2.5.1 Principle findings

This review revealed that the empowerment caregivers experienced from participating in an internet-based psychoeducation program was built on knowledge sharing, individualised support from the program facilitator and skill-building to foster positive thoughts. This empowerment enables active management of care activities. Our findings support previous studies that define empowerment for caregivers as a learning process that enables them to improve coping capabilities by enhancing self-efficacy and self-determination, thereby creating more constructive relationships with the people surrounding them (Sakanashi & Fujita, 2017; Sakanashi et al., 2021; Yoon & Kim, 2020). Self-efficacy is the belief that a person can complete tasks effectively when faced with stressors (Bandura, 1993). A positive outcome of self-efficacy is associated with cultivating positive thoughts and self-control (Crellin et al., 2014). According to the self-determination theory introduced by Ryan and Deci (2000), people are motivated to learn to achieve their goals when they have a sense of self-control and self-efficacy and feel connected to other people. The carefully designed programs identified in our review reflect the development of these capabilities that empower caregivers in their caregiving role. Our finding on empowering learning is also in line with the study by Sakanashi and Fujita (2017), in which empowering education programs for caregivers of people living with dementia included coping strategies, understanding the caregiver role, self-reflection and quality information to enable the person to find autonomy and capacity in taking on the role.

We found that peer support through psychoeducation programs positively impacts caregivers" experiences. Caring for people living with dementia is associated with social isolation because of demands from caregiving and dementia stigma (Alzheimer's Disease International, 2019). Peer support provides caregivers with opportunities to communicate with others and share their experiences, which can potentially help them acquire new knowledge, build skills, develop resilience and reduce caregiver burden (Bernabéu-Álvarez et al., 2021; Daughtrey & Board, 2021; Küçükgüçlü et al., 2018; Wilkerson et al., 2018). The caregivers in this review valued peer support experiences, reflecting on the benefits they received. Research also shows that knowledge exchange through peer interactions can improve caregivers' sense of self-efficacy (Kamalpour et al., 2021) and reduce depressive symptoms (Gallagher et al., 2022). In contrast, the absence of group learning and support may be associated with a low level of self-efficacy (Queiroz et al., 2020).

Our review revealed caregivers' preferences regarding internet-based psychoeducation program content. From our review, video components were preferred by caregivers to facilitate a better understanding of the information presented. We found that caregivers were particularly touched by videos that portray real-life stories. The findings of our review also indicated that the relevance of information presented in pictures and text influenced caregivers' experiences. This finding could be explained in the context of human cognitive function in processing information, in which visual stimuli, such as pictures, text and videos, during focused attention are useful for learners to attain new knowledge (Taylor, 2021; Vu et al., 2021). However, the cognitive learning process is based on the condition that the information, or learning content, is relevant to learners

(Taylor, 2021). A study that explored caregivers' information needs and information-seeking behaviours indicated that the most frequently requested information is general information on dementia, care provision, self-care and how to use available services (Soong et al., 2020). A caregiver's decision to access information depends on the quality and trustworthiness of the source (Allen et al., 2020). Caregivers in this review valued learning content that facilitated reflection on their role and promoted self-care. In addition, our review found that caregivers' learning needs were influenced by the stages of the dementia journey. Caregivers requested that information should accommodate these differences to enhance their learning experience while avoiding mismatching of information and learning content. The information included in internet-based programs should be tailored to the individual situation and address the individual's needs while simultaneously preventing information overload.

In the review, we identified that the technical design of an internet-based psychoeducation program is another factor that influences caregivers' learning experiences. The visual layout, structure, language used, functionality and accessibility of the internet-based program were important to caregivers. Caregiver expectations in these aspects of program design within this review can be explained by how people sense and perceive displayed information in an internet-based program. The first step in human cognitive functioning for information processing occurs via the sensory system (i.e., visual and audio), which filters out irrelevant information, notes the information that is of interest and relevance via short-term memory, and then lays down long-term memories (Atkinson & Shiffrin, 2016). According to Vu et al. (2021), website design must consider the user's cognitive and physical capabilities. For example, older people will see contents on the screen more easily when the program design avoids using blue or green colours from the short-wavelength end of the visual spectrum and increases the resolution of screen contents (Vu et al., 2021, p. 1017). Caregivers' feedback on the internet-based psychoeducation program design noted in our review reflects these recommendations.

This review also identified various challenges for caregivers when using internet-based psychoeducation programs and learning internet-based. These challenges included but were not limited to, caregiving demands, especially for those in the workforce, technical issues, and program design. In contrast to previous studies, our review did not identify caregivers' concerns about the privacy and confidentiality of information (Spann et al., 2022; White et al., 2020). Although caregivers, especially those living in remote areas, perceived internet-based psychoeducation programs as flexible, caregiving demands precluded many working caregivers from participating.

Previous studies found that internet-based programs can support working caregivers to achieve a balance between work and caregiver demands, supporting them through internet-based peer interactions, which save both time and money (Han et al., 2020; Spann et al., 2022), but this does require an individual's resolution. According to West and Hogan (2020), regular support group attendance was associated with members' perception of support from the group, subjective wellbeing, compromises they made and care responsibilities. Moreover, according to our review, utilising an internet-based program depends on an individual's perception of how useful it is to address their needs. Research has identified that working caregivers report lower carer confidence than non-working caregivers, indicating the need for additional support to build their skills and confidence (Clarke et al., 2021). However, education support programs reviewed here do not necessarily reflect this. A flaw noted in this review was that most programs were not available after the completion of the study, despite participants wanting to revisit some of the information. A previous study suggested that program usefulness depended on whether the function and cost met individual needs (Spann & Stewart, 2018). These factors potentially influence caregivers' feelings about internet-based program usefulness in the long term.

It is important to consider group dynamics if peer interactions are included in a program. Previous studies have focused more on the positive aspects of support groups, with negative experiences rarely directly discussed. A forum was convened in one study to ascertain barriers to successful internet-based group meetings and made recommendations, for example, that groups be arranged according to the similarity of caregiver's experience, have clear meeting agendas and consider participants' diversity (Armstrong & Alliance, 2019). Other studies showed that the positive impact of support groups depended on peer interactions and how well groups were organised (Lauritzen et al., 2022; West & Hogan, 2020). The caregivers in our review expressed concerns about poor peer interaction, lack of discussion topics and equal opportunities to contribute during the group meeting. This highlights the importance of a trained facilitator leading a caregiver support group.

As identified in multiple studies (Armstrong & Alliance, 2019; Spann et al., 2022), technical difficulties accessing a program, such as a poor internet connection, challenge the use of internet-based programs, as does an individual's confidence and computer skills (Bai et al., 2020; Schulz et al., 2015). In our review, most participants felt positive about internet-based psychoeducation programs, but to meet a broader audience, programs must consider the caregiver population that may not be technically savvy.

3.2.6 Recommendation

High-quality and carefully designed internet-based psychoeducation programs offer positive experiences to informal caregivers of people living with dementia. To meet broader caregiver education and support needs, program designers should consider the following recommendations (See Appendix 7). First, the learning content and information must be tailored to caregivers' learning needs. This can be achieved by encouraging caregivers to self-diagnose their learning needs and select relevant sections. Second, internet-based psychoeducation programs must include components to facilitate social connectedness among caregivers so they can share their experiences and help each other. Third, having program facilitators who are trained health or social care professionals is imperative to engage caregivers in the program and provide individualised support. Fourth, programs should integrate multi-modality teaching materials, such as text, videos, discussion boards, and supporting group meetings, to attract learners at the cognitive information processing level. Fifth, asynchronised internet-based learning and teaching are recommended to accommodate a broader audience, especially working caregivers. Sixth, program content should be developed based on an education needs analysis of caregivers. Program providers should conduct ongoing evaluations of the quality and relevancy of the information presented to ensure caregivers' confidence in the program, hence enhancing utilisation. Seventh, initial training and ongoing technical support for caregivers are required when implementing internet-based psychoeducation programs. A program should be accompanied by hardcopy instructions to support caregivers when there are any technical issues. Finally, most psychoeducation research is focused on program effectiveness. Future research should also focus on informal caregivers' experiences using internet-based psychoeducation programs to increase utilisation.

3.2.7 Limitations

The main strength of this review is the rigorous following of the JBI systematic review and meta-aggregation protocol to minimise bias during the process. However, there were a few limitations of this review. First, only nine articles were included, indicating that research evidence from qualitative studies is limited. Second, this review was based on database searches in English, Chinese and Arabic. Therefore, a bias exists in selecting studies. Despite the primary effort to review studies in Chinese and Arabic, the lack of diverse evidence from different contexts in non-English studies is apparent. The caregivers' experiences identified in this review may not be represent a wider culturally and linguistically diverse population. Transferability to similar contexts in qualitative research needs to be confirmed by the reader.

3.2.8 Conclusions

This is the first comprehensive systematic review to synthesise qualitative studies on dementia caregivers' experiences in internet-based psychoeducation programs in a global context. The findings contribute to new knowledge about caregivers' learning experiences, including interactions with peers, learning content, program technical design and challenges encountered in internet-based programs. The synthesised findings confirmed that multiple factors impacted informal caregivers' experiences. The enabling factors most often mentioned included the program's quality and relevancy, support received, relevance to individual caregivers' needs, flexibility in delivery, and ability to connect to other caregivers and program facilitators without time and space restrictions. The impeding factors included caregiving demands, poor program performance (e.g., internet connection) and the inability to meet individual caregivers' needs (e.g., their caring situation) or preferences (e.g., for a paper-based program).

This is the end of the publication.

3.3 SUMMARY

This chapter presented a systematic review and meta-synthesis of qualitative studies of internet-based psychoeducation programs. The review identified that a quality internet-based psychoeducation program could positively impact the carers' learning experience. Carers in this review valued opportunities for peer interaction, peer support, and support from program facilitators. They also desired high quality and relevant information to be presented to them. Within the review, it was noted that technical issues and caregiver demand can be a challenge for carers. Results indicated that there were limited qualitative studies in Australia and worldwide to explore carers' experiences in internet-based psychoeducation programs. This review lends weight to the need for the facilitator-enabled iSupport program, collecting both quantitative and qualitative data using a mixed methods study design. The detailed methodology and method are discussed in the following chapter.

4 Research Methodology and Method

4.1 INTRODUCTION

Chapters 2 and 3 reported two systematic reviews that revealed the level of effectiveness of, and carers of PLWD's experiences in, internet-based psychoeducation programs. The systematic reviews identified gaps in the research related to reporting the feasibility, effectiveness and participants' experiences of internet-based multicomponent interventions such as facilitator-enabled virtual iSupport programs in the Australian context. The aims and objectives of the facilitator-enabled virtual iSupport study were introduced in Chapter 1. The two study aims are 1) phase 1: engage with stakeholders to reach a consensus on activities to be delivered by iSupport facilitators for carers of PLWD in a planned iSupport for Dementia program and 2) phase 2: to assess the feasibility, fidelity and preliminary effectiveness of a facilitator-enabled virtual iSupport for Dementia program for informal carers of PLWD. The seven study objectives are to 1) reach a consensus on the activities to be delivered by iSupport facilitators to strengthen support for carers of PLWD in the planned iSupport program in hospital and community aged care settings, 2) reach a consensus on the iSupport facilitator's roles and responsibilities when embedding the Australian iSupport for Dementia program in care services in hospital and community aged care settings, 3) determine the feasibility of the participant recruitment and factors affecting the recruitment, 4) determine the attrition rate and factors contributing to the attrition, 5) monitor intervention fidelity and factors affecting the fidelity, 6) explore strategies to embed and sustain the facilitator-enabled iSupport program after the trial and 7) determine the intervention effectiveness with the given sample size at six months. Chapter 4 presents the research methodology and methods applied to the facilitator-enabled virtual iSupport study to achieve the aims stated in Chapter 1. This chapter starts by presenting the overview of the research paradigm, the rationale of the mixed-methods study design and the philosophical background that underpins the mixed-methods research design in section 4.2.

Section 4.3 discusses the methodology used in the study's phases 1 and 2. Section 4.4 details the method employed in the study phase 1 and 2. Section 4.5 presents the theoretical framework that underpins the present study. Finally, the summary of the chapter is presented in section 4.6.

4.2 OVERVIEW OF RESEARCH PARADIGM

A research paradigm is a philosophical view of the world, first introduced by American philosopher Thomas Kuhn (1967). The four commonly mentioned research paradigms in the literature are positivist/post-positivist, constructivist, transformative and pragmatist (Abdul Rehman & Alharthi, 2016; Creswell & Plano Clark, 2018; Liamputtong, 2017). Each research paradigm consists of ontology, epistemology, methodology, methods and axiology (Creswell & Plano Clark, 2018; Polit & Beck, 2017). Ontology refers to the assumptions of the nature of reality, epistemology means what can be known about this reality, the methodology is the approach taken by the researcher to guide the conduct of the research, and methods is the process used to conduct research (Creswell & Poth, 2018; Morgan, 2014). In addition, axiology is another critical component of a research paradigm, which considers the ethical behaviours, decisions or values researchers use to guide the study (Khatri, 2020).

Positivists or post-positivists believe there is a single reality, and the truth can be measured objectively through experimental research using a quantitative technique, for example, RCTs using surveys to collect data for outcome measures (Liamputtong, 2017). In contrast, constructivists, also called interpretivism, believe there is more than one reality, and it needs to be interpreted subjectively through qualitative research, for example, qualitative descriptive studies using group or individual interviews to collect data (Liamputtong, 2017). The transformative paradigm was introduced by Mertens (1999), who believes reality is based on different social and cultural positions, especially those whose voices have not been heard, and requires the researcher to collaborate with participants at all stages of the study, with results enhancing social justice. Meanwhile, pragmatist researchers believe that reality is constantly interpreted in light of its usefulness in a new situation, with the best method being the most appropriate to address the research question (Kaushik & Walsh, 2019). Pragmatism was first introduced in the United States around 1870 by Charles Sanders Peirce (1839–1914), further developed by William James (1842–1910), and explicitly applied to politics, education and social improvement by John Dewey (1859–1952) and Jane Addams (1860–1935) (Burke, 2013; Wills & Lake, 2020). A pragmatist researcher usually applies multiple ontological positions to justify being objective or subjective, using a combination of qualitative and quantitative research methodologies or mixed methods research to address research questions (Liamputtong, 2017; Maarouf, 2019). The present study used a pragmatic approach, applying mixed methods research to address the two aims described above. The details of mixed method research, including its definition, philosophical underpinning, and commonly used research designs, are discussed in the following section.

4.2.1 Mixed Methods Research Definition

Researchers define mixed method research according to its method, methodology, and philosophical stance. Some definitions focused on the research methods without emphasising the research paradigm; for example, they emphasise how qualitative and quantitative data were collected within one study (Greene et al., 1989; Hesse-Biber, 2015; Tashakkori & Creswell, 2007). In contrast, Johnson et al. (2007) defined mixed methods research from the viewpoint of philosophy, method, and purpose of the study. A comprehensive definition was proposed by Creswell and Plano Clark (2018) that incorporates elements of philosophy, methodology and method. All definitions and the viewpoint of the definition are described in Table 4-1.

Table 4-1 Mixed methods definition and focus of the definition

Author and year	The viewpoint of the definition	Definition
Greene et al. (1989)	Methods	'A mixed method design includes at least one quantitative method (designed to collect numbers) and one qualitative method (designed to collect words), where neither type of method is inherently linked to any particular inquiry paradigm' (p. 256).
Tashakkori and Creswell (2007)	Methodology, method	'Mixed methods [research] is research in which the investigator collects and analyses data, integrates the findings, and draws inferences using qualitative and quantitative approaches or methods in a single study or a program of inquiry '(p. 4).

Author and year	The viewpoint of the definition	Definition
Johnson et al. (2007)	Philosophy, methods, and research purpose	'Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, and inference techniques) for the broad purposes of breadth and depth of understanding and corroboration' (p. 123).
Hesse-Biber (2015)	Methods	'Mixed methods have at least one qualitative and one quantitative method in the same research project or set of related projects' (p. xxxix).
Creswell and Plano Clark (2018)	Philosophy, methodology and methods	'In mixed methods, the researcher 1) collects and analyses both qualitative and quantitative data rigorously in response to research questions and hypothesis; 2) integrates (or mix or combines) the two forms of data and their results; 3) organise these procedures into specific research designs that provide the logic and procedures for conducting the study; and 4) frames these procedures within theory and philosophy' (p. 5).

4.2.2 The Mixed Methods Research Paradigm

The four paradigms discussed above are all relevant to the general philosophical orientation of mixed methods research (Creswell & Plano Clark, 2018). However, many researchers argue that mixed methods research sits within the pragmatism paradigm (Creamer, 2018; Maarouf, 2019). They argue that pragmatism 'accommodates positivism, constructivism, and qualitative and quantitative methods' (Hammond, 2020, p. 155). Another paradigm that sits well with mixed methods is the transformative paradigm, which bridges philosophy and social justice research (Creswell & Plano Clark, 2018). Others argue that various paradigms may serve as the philosophy underpinning mixed methods research, also called paradigm pluralism (Ghiara, 2019; Jennifer, 2006; Teddlie & Tashakkori, 2012). Debates are ongoing as to which research paradigm informs mixed methods research. Creswell and Plano Clark (2018) suggested that mixed methods researchers can use multiple paradigms in one research that best fit the study context, supporting paradigm pluralism. Therefore, the present study applied pragmatism as the overarching paradigm shifting between the post-positivism paradigm for the quantitative component and the constructivism paradigm for the qualitative component.

4.3 METHODOLOGY

As discussed, the mixed methods approach enables researchers to collect and analyse quantitative and qualitative data within one study (Shorten & Joanna Smith, 2017). The epistemological belief of mixed-methods research is viewed as reality being measured using quantitative and qualitative data depending on the research question (Biesta, 2010). For this study, a mixed methods experimental design was applied, as described by Creswell and Plano Clark (2018), with the rationale discussed in the following section.

4.3.1 Mixed Methods Experimental Research Design

Creswell and Plano Clark (2018) introduced three core mixed methods designs: the convergent design, explanatory sequential design, and exploratory sequential design, which can be variably applied according to the complexity of the study design (see Table 4-3). These designs vary based on three considerations: integration of data, timing or sequence of data collection and priority of the method (Creswell & Plano Clark, 2018). The study reported in this thesis used a mixed methods experimental design, a complex application of the core mixed methods design.

Table 4-2 Core mixed method research design

Design type	Integration type	Timing of data collection
Convergent designs	Merged or embedded	Concurrent qualitative and quantitative data collection
Explanatory sequential	Embedded or connected	Quantitative data collection before qualitative data collection
Exploratory sequential	Embedded or connected	Qualitative data collection before quantitative data collection

Phase 1 of this PhD study design is a modified explanatory sequential mixed method design, using a modified Nominal Group Technique (NGT) with a survey (quantitative) first followed by group discussions/interviews (qualitative) and then a survey (quantitative) again to reach a consensus. In phase 2, a convergent mixed method design is applied in which an internal pilot RCT and a qualitative approach are conducted concurrently. The advantage of mixed methods design is that the researcher can address different research questions, collect both qualitative and quantitative data, and offer opportunities to compare, combine, or validate one set of data with another (Creswell & Plano Clark, 2018). The design also allows researchers to use qualitative findings to enhance the understanding of the quantitative findings and to answer questions that quantitative studies cannot answer. Another advantage is that this design allows researchers to collect data from different sources at different times and sites, so-called data triangulation (Denzin, 2009). The limitations of mixed method design include time-consuming and can be costly.

4.3.2 Phase 1. Modified Nominal Group Technique

The explanatory sequential mixed methods experimental study design was used in phase 1 using modified NGT to engage with stakeholders (Table 4-3).

Table 4-3 Visual model for phase 1 study design

Steps	Procedure	Product
Quantitative data collection ↓	Pre-developed survey with area for comments sent to participants	Numeric data (pre-workshop survey ranking) Text data (survey comments, new activities added)
Data analysis ↓	Descriptive analysis of pre-workshop survey ranking Survey modification based on participants' feedback	Modified survey based on feedback
Qualitative data collection ↓	Modified NGT Group discussion or interview	Text data (interview transcripts)
Quantitative data collection ↓	Post-workshop survey	Numeric data (post-workshop survey ranking) Text data (survey comments)
Data analysis ↓	Descriptive statistics Coding and thematic analysis	Ranking of the activities Cross-reference theme and surveys
Integration of quantitative and qualitative results	Interpretation of quantitative and qualitative results	Feasibility, relevance, and acceptance of the proposed activities.

	Facilitators’ role and responsibilities in Phase 2. (Study objectives 1 and 2)

The NGT was developed by Delbecq and Van de Ven in 1968. it is a collaborative process designed to generate ideas and prioritise solutions to a question posed to a group of participants to reach a consensus (Manera et al., 2019). Traditional NGT is conducted face-to-face in small groups, facilitated by the researcher and includes four stages: 1) idea generation, 2) round-robin, 3) group discussion and 4) voting (McMillan et al., 2016). The NGT is highly adaptable and can be used in qualitative, quantitative, and mixed methods study design (Manera et al., 2019).

Phase 1 of the iSupport study design used qualitative and quantitative design. The study included three related stages (pre-workshop survey, workshop (or interview), and post-workshop survey) to reach a consensus on activities to be delivered and the roles and responsibilities of iSupport program facilitators. First, a draft list of activities to be delivered by the iSupport facilitator was developed based on a literature review and consultations with the project reference group. Second, the list of activities was sent to participants to add, revise, and rank them based on their perceptions of the relevance, feasibility, and acceptability of these services for carers of PLWD. Third, participants were invited to workshops or interviews either online or face to face to elaborate and re-rate the revised activities after the workshop or interviews.

4.3.2.1 Methodology Justification for phase 1

Using quantitative and qualitative methods is resource-efficient for idea generation from a wide range of stakeholder groups in a limited period (Manera et al., 2019). It also allows the researcher to clarify and explore the reasons for disagreement in a group discussion. Combined survey and group discussions allowed the interactions between the researcher and participants. They provided opportunities for participants to elaborate on their perspectives based on their lived experiences and enabled interpretation of the findings close to participants' viewpoints (Doyle et al., 2020). The study also sends out a list of activities first and allows participants to add to the list before the group discussion, generating new ideas through this three-stage approach.

The disadvantages of the NGT include only addressing one question at a time, less stimulation in a structured format, and face-to-face meetings can be burdensome (Manera et al., 2019; McMillan et al., 2016). The modified NGT in this study used face-to-face and online conferences or individual interviews to accommodate participants' preferences and covid 19 restrictions in different states in Australia.

4.3.3 Phase 2. Internal Pilot RCT and qualitative descriptive design

A convergent mixed methods experimental study design was used in phase 2(Figure 4-1). Data for the internal pilot RCT and the qualitative component were collected concurrently, followed by a semi-structured interview at six months.

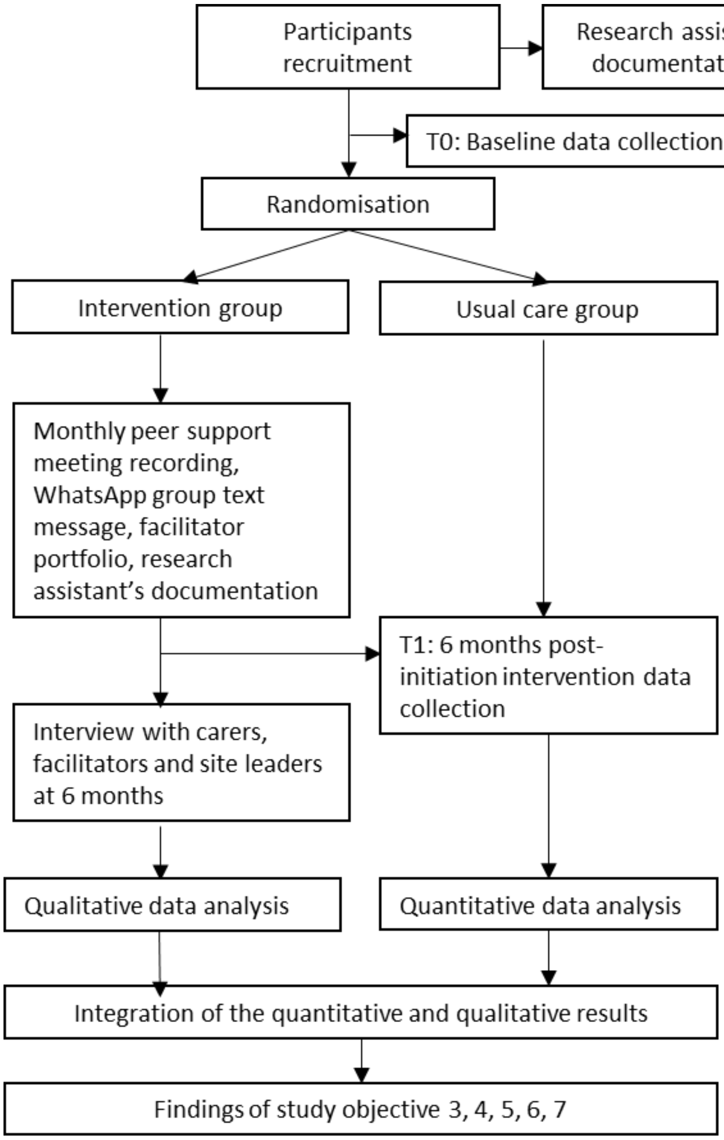


Figure 4-1 Visual model for phase 2 study design

4.3.3.1 Randomised controlled trial

RCT is a quantitative study design used to test an intervention's effectiveness by randomly allocating participants to intervention and comparison groups (Bhide et al., 2018). The earliest RCT studies appeared in the 18th and 19th centuries (Bothwell & Podolsky, 2016), and they are still considered the most rigorous approach to evaluating the effectiveness of an intervention (Polit & Beck, 2016). The critical components of RCT design are a pre-determined study population, intervention/control groups, sample size calculation, participant randomisation and an outcome of interest (Boruch et al., 2009). A version of RCTs is an internal pilot RCT, the method of which is discussed in section 4.4. For this PhD thesis, the internal pilot RCT was conducted as part of a larger funded RCT, especially to evaluate the feasibility of the full RCT protocol (Appendix 8).

4.3.3.1.1 Internal pilot randomised controlled trial

An internal pilot RCT is defined as a smaller scale version of the main RCT, not only testing the main RCT feasibility but also using the same methodology and method to collect data, from which generated outcome data can still contribute to the final analysis (Bond et al., 2023; Kerry et al., 2017). The internal pilot RCT reported in this thesis was conducted within the main trial, over a shorter time and with a small, targeted sample size to evaluate the study protocol and ensure the success of the full-scale RCT.

4.3.3.2 A Qualitative descriptive study design in addition to RCT

A qualitative descriptive study was conducted concurrently with the internal pilot RCT as part of phase 2. This qualitative component used multiple data sources to enhance the understanding of carers' experiences in the study. Semi-structured interviews were conducted with carers in the intervention groups, site leaders and facilitators to explore their experiences in the iSupport program. A qualitative thematic analysis approach was also applied to analyse phase 2 carer support group meeting records, facilitator's portfolios, and group messages. Qualitative descriptive study is commonly used in mixed methods research to provide a broad understanding of the research questions (Doyle et al., 2019). Purposeful sampling strategies, content analysis of meeting records and thematic analysis of interviews, in addition to quantitative data collected during the RCT, are employed in this study (Kim et al., 2017; Sandelowski, 2000b, 2010). This approach can explore participants' experiences and ensure the findings are more meaningful and transparent for questions that quantitative study cannot answer (Doyle et al., 2019). Detailed data analysis was described in section 4.5.3.7.

4.3.3.3 Intervention feasibility, fidelity, and strategies to embed and sustain the intervention

Feasibility measures in this study have twofold meanings. First, the feasibility of the RCT means testing if the RCT has the best chance of success, considering recruitment, retention, and attrition rates (Bond et al., 2023). This type of feasibility is explored by quantitative content analysis of recruitment documentation. The intervention's feasibility also means how well the iSupport program can be embedded in routine care services considering the individual organisation's situation and economic impact (Evans, 2003). This is evaluated by qualitative descriptive study design using interviews. Furthermore, intervention fidelity in RCT is the degree to which the program is delivered or modified as intended and differentiated from the usual care group as planned (Nelson et al., 2012). This is explored by quantitative and qualitative descriptive study design using thematic analysis of research assistants' and facilitators' documentation. The detailed method is discussed in the method section.

4.3.3.4 Methodology Justification for phase 2

The primary advantage of an RCT is that it compares intervention and control groups, producing unbiased estimates of the effect of the intervention (Boruch et al., 2009). Although RCTs are considered the gold standard for testing intervention effectiveness and establishing cause-effect relationships (Hariton & Locascio, 2018), the limitations of RCTs cannot be overlooked. These include the inability to answer broader research questions (i.e., experiences), potential randomisation bias (i.e., imbalanced distribution of characteristics of participants), and challenges to implementation fidelity (Krauss, 2018). Therefore, qualitative research designs such as qualitative descriptive studies can complement understanding the outcomes and explain 'why' the outcome is effective or not effective. Thus, a convergent mixed methods experimental study design is deemed suitable to address the aims and objectives of phase 2, to interpret outcome results using quantitative and qualitative data that collected at the same time point A pilot RCT also allows flexibility in modification to find the best solution to meet care needs in real clinical settings, enhancing the main RCT's success.

Furthermore, researchers undertaking RCTs usually experience challenges associated with recruitment, retention, and a sense of perceived burden on participants (Naidoo et al., 2020; Rodríguez-Torres et al., 2021). Thus, an internal pilot RCT is considered appropriate as it can identify uncertainties that may occur when implementing a complex multi-centre trial and improve the chance of success of the main trial (Kathryn et al., 2021; National Institute for Health and Care Research, 2021). Furthermore, demonstrating trial fidelity can also challenge researchers in RCTs. In addition, there are increasing expectations from the funding bodies and stakeholders for researchers to translate the research evidence generated from RCTs into real-world settings after the trial. Therefore, exploring strategies to embed and sustain the intervention from the beginning of the grant proposal throughout the trial is critical. Studies discussed the need to identify the degree to which the intervention is delivered as planned and changes that need to be made to the original design to fit real-world practice (Pérez et al., 2016; Von Thiele Schwarz et al., 2019). Hence, an internal pilot study can explore strategies based on participants' experiences that could inform the modification of the intervention to fit clinical practice and end-users best. In other words, the literature suggests that including a study objective in an RCT to explore strategies to embed and sustain the intervention is advantageous (Loudon et al., 2015). An internal pilot study design potentially reduces the timeline of the main trial (recruitment period), allowing for ongoing resolution of issues raised as the main trial proceeds and minimising the main trial's participant recruitment/retention pressures (Eldridge, Lancaster, et al., 2016).

4.3.4 Ethics consideration

The study was conducted in full conformance with the principles of the "Declaration of Helsinki", Good Clinical Practice, the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council et al., 2007), the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council et al., 2018) and within the laws and regulations Australia. Ethical approval was obtained from the Southern Adelaide Human Research Ethics Committee and Bolton Clarke Human Research Ethics

Committee (see Appendix 9). By the *SA Health Research Governance Policy Directive,* Site Specific Assessment Approval was sought from individual public health sites, including Canberra Health Services and Southern Adelaide Local Health Network, where the study was conducted (see Appendix 10).

4.3.4.1 Consent

The site-specific research assistant and I thoroughly explained the study aims and process to ensure participants fully understood the study. When a face-to-face meeting was unachievable, the researcher met potential participants online or over the phone. After the initial consent, before each survey, a statement was made to inform carer participants that they consent to participate by submitting the survey. Carers were also notified about each survey by email and text message. Carers can reply 'stop' to indicate the termination of the reminder and withdrawal from the study. In the intervention group, the program facilitator gained verbal consent from participants to participate in each carer support group meeting. Participants could confirm their participation or withdrawal from the study at any point.

4.3.4.2 Confidentiality

All data was collected in a re-identified form, and study-related data was only accessible to my supervisors and me. Data collected by each participating site was stored in site specific secured computer and password-protected electronic files. Each participant was assigned a site and personal codes before the data collection in phases 1 and 2. Therefore, their identity can only be re-identified upon request. In phase 1, a transcription company transcribed the voice-recorded meeting, and a confidentiality agreement was signed between the research team and the company. In phase 2, the confidentiality of the Zoom meetings was ensured by iSupport program facilitators verbally reminding carers in each carer group meeting to maintain the confidentiality of the information discussed. Meeting recordings in phase 2 were transcribed by me and checked by supervisors. Transcripts from phase 1 group meetings, phase 2 peer support meetings, downloaded WhatsApp messages, and facilitators' portfolios were de-identified before the data analyses.

4.4 METHOD

4.4.1 Settings

This study was conducted in two tertiary hospitals and two community aged care organisations across multiple states in Australia. Figure 4-3 presents the structure of the research team for this project. Facilitators in site 4 shared responsibility of a research assistant. I am responsible for ethics application, recruitment and data collection for study sites 1 and 2 and data analysis for all 4 sites. Phase 1 of the study was conducted between September 2021 and March 2022, and phase 2 commenced in March 2022. The first participant for RCT was enrolled in June 2022. The internal pilot study reports that the participants enrolled between June 2022 and April 2023 and completed 6 months of intervention in Oct 2023.

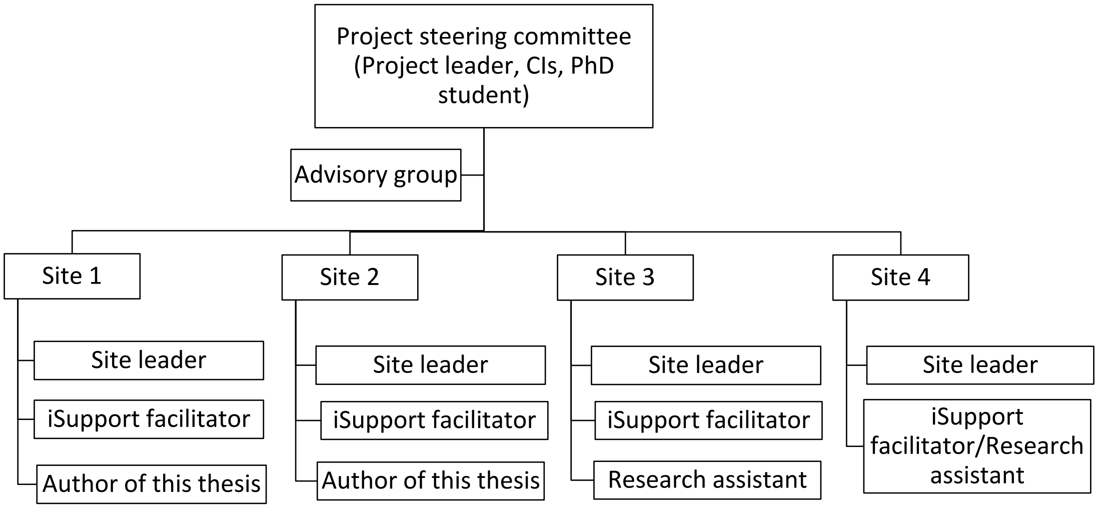


Figure 4-2 Research team structure

4.4.2 Phase 1: Engage with stakeholders using a modified Nominal Group Technique

4.4.2.1 Participants

Participants in phase 1 included two cohorts: (1) carers of PLWD who were clients of the participating organisations and (2) health and social care professionals of the participating organisations. The inclusion and exclusion criteria are displayed in Table 4-4.

Table 4-4 Phase 1 Participants' inclusion and exclusion criteria

Participants	Inclusion criteria	Exclusion criteria
Family carers of PLWD	1) ≥18 years old 2) Provide care activities at least three times a week. 3) Cared for a PLWD for at least six months.	
Health and social care professionals	1) From various disciplines 2) At least one year of experience in dementia care	Casual staff

Note: PLWD= person living with dementia

Participants were recruited using convenience and snowball sampling strategies. Potential carer participants were identified by clinicians or expressed interest after seeing an advertising flyer in the participating organisations. Potential staff participants were informed of the study through information sessions presented by the researchers during various staff meetings, via flyers through emails, or displayed in staff rooms. Site-specific researchers or research assistants contacted potential participants based on their expressions of interest, assessed their eligibility, and obtained their written consent.

Carer participants were offered a gift card to compensate for the time they spent on the study. One study site offered a one-day respite service for carer recipients and transportation for their carers to attend the meeting. Most health and social care professional staff participated in the study during their paid working hours. A gift card compensated for their time when they needed to participate in the meetings outside working hours.

4.4.2.2 Sample size

The literature did not provide formal recommendations or criteria for ideal sample sizes for studies to reach a consensus using NGT. However, it was recommended that the ideal group size when utilising a nominal group technique be 6 to 9 panel members (Potter et al., 2004). Therefore, we estimated a minimum sample size of 6 panel members in each carer and staff group per study site, or 48 participants in total.

<u>The following section contains part of a publication from this thesis published in the Journal of Clinical Nursing as an open-access article. The first author's contribution to this</u>

paper was leading and coordinating the participants' recruitment, 50% to research design, 70% to data collection and analysis, and 70% to writing and editing.

This is part of the peer-reviewed version of the following article: [Yu, Y., Hunter, S. C., Xiao, L., Meyer, C., Chapman, M., Tan, K. P., Chen, L., McKechnie, S., Ratcliffe, J., Ullah, S., Kitson, A., Andrade, A. Q., & Whitehead, C. (2023). Exploring the role of a facilitator in supporting family carers when embedding the iSupport for Dementia programme in care activities: A qualitative study. Journal of Clinical Nursing. https://doi.org/10.1111/jocn.16836], published in final form at [https://doi.org/10.1111/jocn.16836]. This article may be used for non-commercial purposes by Wiley Terms and Conditions for Use of Self-Archived Versions. This article may not be enhanced, enriched or otherwise transformed into a derivative work without express permission from Wiley or by statutory rights under applicable legislation. Copyright notices must not be removed, obscured or modified. The article must be linked to Wiley's version of the record on Wiley Online Library, and any embedding, framing, or otherwise making available the article or pages thereof by third parties from platforms, activities and websites other than Wiley Online Library must be prohibited."

4.4.2.3 Data collection

In phase 1, the modified co-design principle described by Goeman et al. (2019) and a modified NGT described by Manera et al. (2019) was applied. The first step of the engagement included iterative consultations with stakeholders to ensure that the critical aspects of activities to support family carers and the iSupport facilitator's role would be adequately delineated, acceptable to stakeholders and implementable in actual care settings. Firstly, the project team developed a draft activities to be delivered by the iSupport program facilitators in engaging participants in discussions (Table 4-5) based on previous studies of stakeholders' expectations of iSupport implementation in Australia (Xiao et al., 2021) and a systematic review on the effectiveness of the support worker role for carers of PLWD (Goeman et al., 2016). Secondly, the team invited 10 associate investigators from the project, who were experts in various disciplines (aged care and dementia care nursing, geriatrics, geropsychiatry, gerontology, psychology and pharmacology, a past carer and a consumer representative) and 12 project advisory groups, members (5 carers, 2 PLWD at early stages and 5 professional care staff) to review and revise the listed activities before inviting participants to rank the list.

Table 4-5 Phase 1 Draft list of activities to be delivered in the iSupport program

Relationship to the theoretical framework	Description of services: iSupport facilitators support carers to (or by) …
Carer recipient factors	1. Prevent and manage dementia-related symptoms and changed behaviours.
	2. Manage chronic conditions the person with dementia has (i.e., hypertension, diabetics and other chronic diseases and conditions)
	3. Identify risks, causes, and triggers that will contribute to presentation at the emergency department.
	4. Identify risks, causes, and triggers contributing to hospital admission.
	5. Identify risks, causes, and triggers contributing to premature permanent admission to residential aged care homes.
	6. Identify early signs of deterioration in the person with dementia.
Carer factors	7. Use self-care strategies to care for themselves and reduce stress and distress.
	8. Assess carers' learning needs and choose relevant learning units from the online iSupport for Dementia program to help them look after themselves and the person with dementia.
	9. Participate in virtual carer support groups to gain social support and to exchange their dementia care knowledge, skills, and experiences.
	10. Coordinating the virtual carer support groups
System factors	11. Navigate, access, and utilise dementia care resources and multidisciplinary care services to meet the care needs of the person with dementia and their carers.
	12. Manage transitions between care settings (i.e., hospital-to-home) and care types (i.e., receiving palliative care at home).
	13. Work with professional staff to develop or revise care plans for home care packages or care plans in hospital clinics to meet the needs of the person with dementia.
	14. Provide feedback to service providers regarding the strengths of the care services and the areas that need to be improved.
	15. Providing a personal touch and a single point of contact with a live person rather than a computer or telephone-activated voice.

The second step of the engagement with participants was through modified NGT. Data were collected through three related stages: a pre-workshop survey, workshops or interviews, and a post-workshop survey, as detailed in the following. For the pre-workshop survey, the project team developed a survey containing 15 proposed activities (see Table 4-5). Participants were invited to rate the activities to be delivered by the iSupport facilitators on a 5-point Likert scale regarding their relevance, feasibility, and acceptability. The team defined the relevance of the activities delivered by the iSupport facilitators as how relevant the activities are in the context of dementia care in community care settings. The feasibility of the activities refers to how practical the activities is in the context of dementia care in community care settings. Meanwhile, the acceptability of the activities refers to how well the health professionals and carers of PLWD receive the activities. The survey was sent to carers and staff via email or postal mail based on their preferences. Participants were encouraged to comment and revise the activities or list new activities they would like to see.

In the workshops or interviews stage, participants were invited to one of the scheduled workshops to elaborate their thoughts on revising activities to be delivered by the iSupport facilitators. Those unable to attend the workshops were offered a one-on-one phone interview. Each workshop lasted approximately 90 minutes, while each interview lasted around 40-45 minutes. Two researchers at each study site facilitated workshops, while phone interviews were undertaken by a single researcher at each study site. During the workshop or interview, the researcher introduced the collated preworkshop survey results to participants and facilitated their discussions of the listed iSupport facilitator's roles and any activities added by participants. The workshop discussions and the interviews were audio-recorded and transcribed verbatim for data analysis. Face-to-face workshops were conducted in site 1 and site 2, where COVID-19 restrictions were not in place, and participants were not required to wear masks. Online workshops were conducted in site 3 and site 4 due to COVID-19 restrictions. Data saturation was achieved, as evidenced by the presentation of repeated information. The revised survey questionnaire was rated by participants after the workshops or interviews to reach a consensus.

This is the end of the publication.

4.4.2.4 Data analysis

Quantitative data analysis, including demographic information and surveys, used descriptive statistics. Findings displayed as the total number and corresponding percentage of responses rated ‘strongly agree’ and ‘agree’ for each service on relevance, feasibility, and acceptability. Survey data were entered into IBM SPSS version 28.0 for data analysis (IBM Corp., 2021). A 75% for the *relevance of the activities* was used to determine which activities reached consensus (Diamond et al., 2014). The rationale of using ‘relevance’ to decide on which services were retained was that the feasibility and acceptability of these activities would be explored in phase 2 of the project to determine whether the iSupport facilitator and the leadership and management in the organisation could create an enabling environment to deliver these activities.

Qualitative data collected from workshops, interviews and comments on the survey were analysed using thematic analysis. Audio-recorded data was transcribed verbatim for data analysis. The six-step thematic analysis introduced by Nowell et al. (2017) was used for the thematic analysis. The author led the data analysis by (1) familiarising themself with the transcripts, (2) generating initial codes and grouping those codes based on similarities and differences, (3) searching for potential themes by analysing the concepts arising from the grouped codes, the relationships among these concepts, and how the codes related to the study's aim and conceptual framework; (4) reviewing themes with the team; (5) naming themes; and (6) producing the report. Two authors checked codes and themes. A computer-assisted qualitative data analysis programme, NVivo (released in March 2020), was used to manage qualitative data and facilitate analysis (QSR International Pty Ltd, 2020). I completed the first-round of data coding, and the principal supervisor (LX) checked and validated that coding. The project team reviewed the codes, group codes, preliminary themes and subthemes and then refined them to address the team's feedback. The project advisory group members were invited to review and comment on the findings and make changes accordingly. After completing the qualitative data analysis, minor modifications were made to the proposed activities stated in the pre-workshop survey to reflect the workshop and interview findings (see Appendix 11 for examples). Suggested activities by participants that did not share the same meanings as those in the pre-workshop survey were added as new activities to the list.

Findings from quantitative and qualitative studies were further synthesised and presented as integrated findings to communicate with stakeholders on how the agreed activities could potentially reduce care recipient-related stress, carer-related stress and system-related stress in the planned facilitator-enabled iSupport program. Qualitative and quantitative finding were compared for the similarities and differences. During the comparison, quantitative data were transformed into qualitative descriptive data based on Sandelowski's (2000a) data transformation strategies. I created a table to display the transformed quantitative and qualitative findings to show a clear link between the quantitative and qualitative findings and the integrated findings related to the intended study aims and the theoretical framework that informed this study.

4.4.2.5 Study rigour in phase 1

For the quantitative components in this phase, the reliability and validity of the survey were ensured at the survey design stage. The survey was developed based on the comprehensive literature review by the research team. The survey was undertaken with an internal review to ensure readability, then reviewed by an advisory group, including carers of PLWD, followed by a review by dementia care experts. The credibility and validity of the survey were also enhanced by data triangulation, which used qualitative data to verify survey responses and minimise survey response errors (Denzin, 2009).

For the qualitative components in this phase, best practice principles were followed to achieve the necessary rigour of credibility, confirmability, dependability, and transferability, as detailed below (Liamputtong, 2017). The research team collectively has expertise in qualitative and quantitative study design. The study's credibility was enhanced by transcribing the recorded voice data verbatim for data analysis. Moreover, the transcripts were checked by the researchers who conducted the workshops and interviews to ensure the accuracy of the data. In addition, this data accrual was conducted over a prolonged engagement period with participants, over six months during this phase of the study, which increased the confidence of the findings. The confirmability of the study was strengthened by having team members, as part of the data analysis, crosscheck the codes, subthemes and themes and by presenting quotations from participants, when possible, to ensure participants' views were correctly presented and interpreted. Differences in opinion on findings existed among team members but were resolved through discussion. The study's dependability was ensured by training the researchers involved in the data collection and analysis and by complying with a documented study protocol to minimise disparities in the data collection process between different sites and researchers. Moreover, the same interview questions were used for all participants. The telephone interviews were conducted after the workshops, and a summary of the workshop discussions was provided to the telephone interviewees to prompt their responses and ensure their views were fully captured. All researchers met regularly during the data collection and analysis to ensure the defined method was used. The transferability of the study was demonstrated by a detailed discussion of the findings and the context and findings of the study.

4.4.3 Phase 2: Internal pilot randomised controlled trial

The RCTs s protocol was registered with the Australia New Zealand Clinical Trials Registry (Registration No. ACTRN12622000199718). The published main trial protocol for the main trial is listed as follows:

Xiao, L., Yu, Y., Ratcliffe, J., Milte, R., Meyer, C., Chapman, M., Chen, L., Ullah, S., Kitson, A., De Andrade, A. Q., Beattie, E., Brodaty, H., McKechnie, S., Low, L. F., Nguyen, T. A., Whitehead, C., Brijnath, B., Sinclair, R., & Voss, D. (2022). Creating 'Partnership in iSupport program' to optimise family carers' impact on dementia care: a randomised controlled trial protocol. BMC Health Serv Res, 22(1), 762. https://doi.org/10.1186/s12913-022-08148-2.

PUBLICATION 3

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	Xiao, L., Yu, Y., Ratcliffe, J., Milte, R., Meyer, C., Chapman, M., Chen, L., Ullah, S., Kitson, A., De Andrade, A. Q., Beattie, E., Brodaty, H., McKechnie, S., Low, L. F., Nguyen, T. A., Whitehead, C., Brijnath, B., Sinclair, R., & Voss, D. (2022). Creating 'Partnership in iSupport program' to optimise family carers' impact on dementia
Section of thesis where publication is referred to	Chapter 4: Research design and Method, method section

Student's contribution to the publication	10	%	Research design
	40	%	Data collection and analysis
	40	%	Writing and editing

Outline your (the student's) contribution to the publication:

Ying's contribution to the publication include: obtaining ethics approval, obtaining trial registration, obtaining license agreement for outcome measurer instrument and drafted original manuscript.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1	Lily Xiao	Signed	Lily Xiao Digitally signed by Lily Xiao Date: 2022.05.05 10:55:37 +09'30'	Date	*05-May-2022*
Name of Co-Author 2	Shahid Ullah	Signed	Shahid Ullah Digitally signed by Shahid Ullah Date: 2022.05.11 00:37:46 +09'30'	Date	05-May-202
Name of Co-Author 3	Claudia Meyer	Signed	Claudia Meyer Digitally signed by Claudia Meyer Date: 2022.05.06 09:12:52 +10'00'	Date	06-May-202

During the pilot study period, several changes were made to the study protocol, and the changes were published in the Australia New Zealand Clinical Trial Registry to foster transparency of the main RCT. These changes, as informed by the findings of this pilot study, were mainly focused on participant recruitment, specifically recruitment feasibility and attrition rates. These changes are detailed in Chapter 6.

4.4.3.1 Participants

There were two cohorts of participants in phase 2: 1) participants for the full-scale RCT and 2) participants for the interview. The inclusion and exclusion criteria are displayed in Table 4-6.

Table 4-6 Phase 2 Participants' inclusion and exclusion criteria

Participants		Inclusion criteria	Exclusion criteria
RCT	Family carers of PLWD	1) ≥18 years old 2) Provide care support for PLWD at least twice a week 3) if the care recipient has no formal dementia diagnosis, based on the carer's observation, the care recipient presents the following symptoms: a) cognitive impairment, b) declined self-care ability and c) behaviour change.	Involved in similar studies
Interview	Site leaders, iSupport facilitators	Convenience sampling, all site leaders, current and previous employed iSupport facilitators	
	Family carers of PLWD	1) Carers in the intervention group. 2) Six months of intervention and survey were completed.	1) Carers who have not completed 6-month of intervention or 6-month of survey 2) Carers who were in the usual care group

Note: PLWD= person living with dementia

4.4.3.1.1 Person living with dementia Assessment

Care recipients living with dementia who were willing to be involved were assessed for their ability to make a decision using the Evaluation to Sign a Consent form (ESC) (Resnick et al., 2007) (see Table 4-7). The care recipient's cognitive impairment stage was assessed using one of the following assessment tools: Standardised Mini-Mental State Examination (SMMSE) (Molloy et al., 1991), Global Deterioration Stages between Normal Ageing and Alzheimer's Disease (GDS) (Reisberg et al., 1998) or Rowland Universal Dementia Assessment Scale (RUDAS) (Storey et al., 2004). Where the PLWD was unwilling to be involved, the cognitive stage of the PLWD was based on the carer's observation using the GDS. Where care recipients had not been formally diagnosed with dementia, the following assessment was conducted based on their family carers' observation to determine their eligibility: 1) cognitive impairment using GDS; 2) self-care decline and changed behaviours assessment using Blessed Dementia Dependence Score (Blessed et al., 1968) (see table 4-7).

Table 4-7 Phase 2 Person living with dementia assessment

Measures	Items	Score range	Score direction
SMMSE	11	0-30	25 or higher = normal 21-24=mild cognitive impairment 10-20= moderate cognitive impairment 0-9 = severe cognitive impairment
GDS	7	Stage 1-7	Stage 4-stage 5 = Mild to moderate AD (Lower = better)
RUDAS	6	0-30	10-22 = Mild to moderate dementia (Higher = better)
ESC	6	N/A	Need to be all correct
BDS	22	0-27	Lower=better

Note: SMMSE= Standardised Mini-Mental State Examination; GDS= Global Deterioration Stages between Normal Ageing and Alzheimer's Disease; RUDAS= The Rowland Universal Dementia Assessment Scale; ESC= Evaluation to Sign the Consent; BDS= Blessed dementia score

4.4.3.1.2 iSupport facilitator employment and training

Each of the four industry partner sites employed a facilitator. The essential criteria for an iSupport facilitator are 1) currently employed as a health or social care professional and 2) experience in dementia care or aged care. iSupport facilitators were recruited from internal job advertisements within each participation organisation. Four facilitators were employed at the beginning of the project; two facilitators from hospitals were registered nurses, and two facilitators from community aged care services were social care professionals. Two facilitators were employed at 0.2 full-time equivalent (FTE) as the project planned; one facilitator was employed at 0.4 FTE, and another was employed as a project officer full-time because the organisation has multiple projects but only allocated to the iSupport project three days a week. All facilitators were required to familiarise themselves with the Australian iSupport for Dementia manual, undertake two days of online training with the research team, and received an iSupport implementation manual (Appendix 13). The implementation manual contains dementia care-related case scenarios and research procedures for facilitators to do self-directed learning before the commencement of the recruitment. The facilitators were also required to attend bi-weekly online facilitator meetings to share their experiences in supporting carers according to the required intervention as described in the study protocol, the difficulties they encountered in delivering the required intervention, and the strategies they used to address the difficulties. The project leader chaired the regular meetings as part of strategies to monitor the fidelity of the intervention. iSupport facilitators were requested to submit a monthly portfolio reflecting their project activities and experiences (Appendix 14).

4.4.3.1.3 Participant Recruitment

Recruitment for RCT: The recruitment flyer was distributed to partner organisations, and the social media campaign via the Flinders University media team started in June 2022 to improve recruitment. At the same time, in sites 1 and 2, I supported 2 iSupport facilitators who screened organisations' historical data to identify potential participants, where I could not access the organisation's data. In sites 3 and 4, site leaders employed site-specific research assistants to recruit carers for the study. However, the screening on site 4 was conducted by clinical professionals instead of the research team due to the local policy. Potential participants were sent a text message, an email or a phone call by me or the site-employed research assistant to obtain their expression of interest. I contacted potential participants who expressed interest (sites 1 and 2) or a site-employed research assistant (sites 3 and 4) to complete eligibility assessments and the PLWD's cognitive impairment stage assessment before the consent. All participants received a paper-based or electronic information pack according to their preference and had opportunities to discuss the study with the research assistant. Potential participants were assured that participating in the trial was voluntary and that they could refuse or withdraw without affecting the services they received. Participants who opted to receive paper-based information and consent forms were provided with a pre-paid, pre-addressed envelope. The consent pack included consent to participate in the RCT and a release of Medicare Benefit Schedules (MBS) and Pharmaceutical Benefits Scheme (PBS) information relevant to the cost analysis after the RCT (not part of this thesis). The research assistant documented the recruitment process for data analysis. All participants in the RCT study received a $50 gift card per month for the period of the study.

Recruitment for interview at six months: I sent an invitation letter to site leaders and iSupport facilitators for the interview. Site leaders and iSupport facilitators who expressed interest in the interview were then provided with a Participants' information pack and a consent form. They were offered opportunities to ask questions regarding the interview. Signed consent was returned, and an interview was scheduled via Microsoft Team or Zoom based on their preferences. Carers in the intervention group who completed six months of intervention and six months of survey were approached by the iSupport facilitator to gain their expression of interest. Once carers agreed to be contacted, I contacted individual carers and explained the interview and consent process. The meeting was scheduled via Microsoft Team or phone call. Signed consent was returned before the interview. All interview participants received $50 gift cards to compensate for their time.

4.4.3.2 Sample size

The sample size of the main trial was 184 cares with a 40% attrition rate; at 90% power, the recruitment period was anticipated 12 months from the first participant enrolment (June 2022), and the follow-up was six months and 12 months after the intervention, make the total study period 24 months (Xiao et al., 2022). For the pilot study, there was no consensus on the minimum sample size, and the recommendation in the literature is for a minimum sample size of 12-30 per group (Eldridge, Chan, et al., 2016). The sample size for the present pilot study was calculated based on the length of the pilot study compared to the main trial (Herbert et al., 2019). The present internal pilot study was 16 months from the first participant enrolment (10 months recruitment and six months follow-up). Therefore, this internal pilot study took up 67% of the length of the main trial and aimed to recruit 30-35% of the targeted sample size for the main trial (approx. 55-64), similar to other internal pilot studies in the literature (Herbert et al., 2019). The targeted sample size for the present internal pilot study was 30 carers per arm, a total of 60 carers and the sample size was sufficient. Because it is an internal trial, the recruitment for the main trial was continued while we reported the preliminary result from the pilot study.

The interview data were monitored for data saturation. Data saturation was reached as repeated information was presented during the interview, indicating that the sample size for the interview was sufficient.

4.4.3.3 Intervention

According to the main RCT protocol published by Xiao et al. (2022), carers were randomised into the intervention or usual care groups. Carers in the usual care group continued with the support they were already receiving, plus a monthly reminder email from the facilitator to encourage them to seek information and support from the Dementia Australia website.

Carers in the intervention group were supported by the iSupport facilitator and given the Australia iSupport for Dementia manual in a hardcopy book, electronic book or web-based book access based on their preference. Carers were encouraged to choose 20 out of 30 units (70%) relevant to them from the iSupport for Dementia manual to learn at their own pace. Carers were encouraged to contact the facilitator for the support they might need about managing transition, dementia progression-related questions, or feedback to service providers. iSupport facilitators also created one or two private WhatsApp groups and peer support meetings for carers to exchange information. The planned peer support group size was 12 carers per group per site. Monthly online peer support meetings that lasted 30 minutes were facilitated by iSupport facilitators to allow carers to interact with each other. The meeting was video recorded for carers in the same group to assess. Carers participated in the main RCT for 12 months, continuing their intervention, while the internal pilot study data was analysed at six months.

4.4.3.4 Randomisation

Each participant was assigned a site and personal code for the study. A biostatistician conducted randomisation, the second supervisor, who had not been involved in recruitment nor knew the participants. The personal code, the participant's relationship with the PLWD and the PLWD’s stage of cognitive impairment were sent to the biostatistician. The randomisation result was then communicated to me, the facilitator and the site-employed research assistant for follow-up. A randomly generated block size of four was used to allocate carers to one of the two groups for each recruitment site to ensure the two groups were of equivalent size. The randomisation ensured an equivalent distribution of spouse versus non-spouse carers and PLWD with mild versus moderate cognitive impairment in each intervention group.

4.4.3.5 Outcome evaluation in the internal pilot study

This internal pilot study evaluated these outcomes as listed in Table 4-8. Each outcome was evaluated against the study objectives in phase 2 of the study using qualitative and quantitative data.

Table 4-8 Phase 2 Outcome evaluation against study objectives

Study objectives	Outcome evaluation	Details
Objective 3 To determine the feasibility of participant recruitment and factors affecting the recruitment	Estimate recruitment rate and factors affecting the recruitment	Number of data screened, number of potential participants who met the selection criteria, number of eligibility assessments, number of participants who consented and randomised
		Individual interviews with facilitator and site leaders
		Facilitator portfolio that documents recruitment-related reflections
Objective 4 To determine the attrition rate and factors contributing to the attrition.	Monitor retention and attrition.	Number of participants who withdrew or left the program earlier, reasons for withdrawal if available
Objective 5: Monitor intervention fidelity and factors affecting the fidelity	Completion of required iSupport for Dementia manual	Number of units completed by carers in the intervention group
		Facilitator portfolio that documents activities related to psychoeducation program delivery using iSupport for dementia manual.
		WhatsApp group message that related to iSupport for Dementia manual
	Completion of Facilitator-enabled iSupport for dementia program intervention	Number of participants who completed six months of intervention, number of participants were supported by a facilitator.
		Peer support meeting recording, number of participants who attended the meeting
		WhatsApp group activities
		Facilitator portfolio related to support requested by carers and support offered by facilitators.
	Carer satisfaction with the program	Using a carer satisfaction survey at six months
		Individual interviews with carers
	Data collection method	Estimating the survey return rate, survey completeness, and participant feedback to the research assistants while completing the survey.
Objective 6: To explore strategies to embed and sustain the facilitator-enabled iSupport program after the trial	Obtain feedback from participants	Feedback on iSupport for Dementia manual Feedback on facilitator-enabled iSupport program
Objective 7: Determine the intervention effectiveness with the given sample size at six months	Carer's QOL, PLWD's QOL, carer's self-efficacy, and carer's perceived QOS	Survey using: SF-12; QOL-AD; caregiver self-efficacy; QOS; RMBPC
		Peer support meeting recording that relates to the effectiveness of the program
		WhatsApp group activities that relate to the effectiveness of the program
		Facilitator portfolio that relates to the effectiveness of the program

Study objectives	Outcome evaluation	Details
		Individual interviews with carers, facilitators, and site leaders

Note: SF-12= QOL: 12-item Short-Form Health Survey; QOL-AD= QOL in Alzheimer's Disease- Family version; QOS=The Carers of Older People in Europe Index-Quality of Social Support; RMBPC= Revised Memory and Behaviour Problem Checklist

4.4.3.5.1 Estimate recruitment rate and factors affecting the recruitment, retention and attrition

The feasibility of the study was evaluated by estimated recruitment rate, retention and attrition. The anticipated recruitment rate was 185 carers over 12 months over four sites (4 carers/site/month or 16 carers/months) for the main RCT. Successful recruitment in this pilot study was defined as participants consenting to RCT and being randomised. Participants who expressed interest then changed their minds after learning more about the trial or were ineligible after assessment were considered as not recruited.

4.4.3.5.2 Monitor the RCT fidelity

The RCT fidelity was measured by documented online peer support group attendance, carer's support request and delivery, and completion rate of the facilitator-enabled iSupport program and iSupport for Dementia manual. Protocol adherence was evaluated by analysing the documented facilitators' portfolios. The carers' satisfactory survey included 10 questions and was used with carers in the intervention group. In this survey, carers were asked whether they were satisfied with the support provided by the facilitator and the program. The answer was rated between 1= strongly disagree to 5 strongly agree. The survey is presented in Appendix 15. Data collection methods were evaluated by estimating the survey return rate, survey completeness, and participant feedback to the research assistants while completing the survey.

4.4.3.5.3 Strategies to embed and sustain the facilitator-enabled iSupport program after the trial

The strategies to embed and sustain the intervention were explored via participant feedback. Comments that relate to the iSupport for Dementia manual, the overall program and the long-term sustainability of the program were extracted from interviews or survey comments for data analysis.

4.4.3.5.4 Intervention effectiveness at six months.

The effectiveness outcome measures displayed in Table 4-9 were designed for the main RCT (Xiao et al., 2022). These measures were used in this internal pilot RCT to evaluate the intervention's effectiveness at six months in a pilot study sample.

Table 4-9 Phase 2 Intervention effectiveness outcome measure

Survey	Item	Survey details		Scoring	Score direction	Validity	Reliability	Theoretical framework
QOL: 12-item Short-Form Health Survey version 2 (SF-12 Health Survey v2) (Ware et al., 1996).	12	Physical health-related domains Mental health-related domains:	carer's general health, physical function, and pain Vitality, social functioning, role emotional and mental health.	0-100	Higher=better	0.91-0.92	0.76-0.89	Care factor Higher=Less stressor
QoL in Alzheimer's Disease (QoL-AD)-Proxy-Family Version (Logsdon et al., 1999)	13	Physical condition, changed behaviours, memory, mood, relationship, financial situation, ability to participate in meaningful activity and the overall QOL		13-52	Higher=better	0.84-0.86	0.76-0.92	Carer recipient factor Higher=Less stressor
Caregiving self-efficacy scale (Steffen et al., 2002)	15	Self-efficacy for obtaining respite (seeking help from family and friends responding to atypical patient behaviours controlling upsetting thoughts about caregiving		0-100	Higher=better	0.80	0.70	Care factor Higher=Less stressor
The Carers of Older People in Europe Index-Quality of Social Support (QOS) (McKee et al., 2003)	5	quality of social support (from friends, neighbours, family, service providers)		0-20	Higher=better	0.76	0.80	System factor Higher=Less stressor
Revised Memory and Behaviour Problem Checklist (RMBPC) (Teri et al., 1992)	24	Frequency of the behaviour Carer's reaction		0-96	Lower=better	good	0.84-0.90	Carer recipient factor Lower=Less stressor

4.4.3.6 Phase 2 data collection

Data was collected on the number of people screened via historical datasets, the number of people who met the selection criteria, the number of people who were assessed for eligibility, and the proportion of eligible people who agreed to participate. Site-employed research assistants and I documented participants who withdrew or left the study earlier. The research team also pre-determined that data collection ceased if PLWD was admitted to a long-term aged care facility or passed away. Carers who withdrew from the study were encouraged to disclose their reasons for withdrawing, but respecting their privacy was not mandatory.

Participants' demographic data were collected at the baseline. Data used to evaluate intervention effectiveness was collected at baseline and six months post-intervention. Phase 2 of the data collection process, which aligns with study objectives, is displayed in Table 4-10. Participants were offered different formats of survey data collection, including paper-based, online, or via phone, with the research assistant based on their preferences. The paper-based survey was posted to the carer's nominated address with a pre-paid, pre-addressed envelope and the research assistant's phone number. The online survey was built in Qualtrics (Qualtrics, 2005) via the university server for data security. The iSupport facilitator sent the survey link to the carer's nominated email address. If needed, the research assistants or I conducted a phone survey at the carer's preferred time. Survey data collection was ceased if PLWD was admitted to permanent residential care or passed away. Survey comments, virtual peer support meeting recordings, WhatsApp group text messages, the facilitator's portfolio, and research assistant records were downloaded, transcribed, and reported descriptively. Carers in the intervention group, site leaders and facilitators were invited to an interview after six months of intervention. The semi-structured interview was voluntary, consented to, lasted 40 – 60 minutes, and was audio recorded for data analysis. The semi-structured interview guide is displayed in Appendix 12.

Table 4-10 Phase 2 data collection process

Study objectives	Evaluation method	Explanation	Data type	Data collection Time
Objective 3 To determine the feasibility of participant recruitment	Estimate recruitment rate	Number of data screened, number of potential participants who met the selection criteria, number of eligibility assessments,	Numeric	During recruitment period

Study objectives	Evaluation method	Explanation	Data type	Data collection Time
and factors affecting the recruitment		number of participants who consented and randomised		
		Individual interviews with facilitator and site leaders	Text (interview transcripts)	Six months post-initiation of the intervention
		Facilitator portfolio that documents recruitment-related reflections	Text	Monthly
Objective 4 To determine the attrition rate and factors contributing to the attrition.	Monitor retention and attrition.	Number of participants who withdrew or left the program earlier, reasons for withdrawal if available	Numeric Text (reasons for withdrawal)	Ongoing while intervention is delivered
Objective 5: Monitor intervention fidelity and factors affecting the fidelity	Completion of required iSupport for Dementia manual	Number of units completed by carers in the intervention group	Numeric	Six months post-initiation of the intervention
		Facilitator portfolio that documents activities related to psychoeducation program delivery using iSupport for dementia manual.	Text	Monthly
		WhatsApp group message that related to iSupport for Dementia manual	Text	Ongoing while the intervention was delivered
	Completion of Facilitator-enabled iSupport for dementia program intervention	Number of participants who completed six months of intervention, number of participants were supported by a facilitator.	Numeric	Six months post-initiation of the intervention
		Peer support meeting recording, number of participants who attended the meeting	Numeric	Monthly
		WhatsApp group activities	Text	Ongoing
		Facilitator portfolio related to support requested by carers and support offered by facilitators.		Monthly
	Carer satisfaction in the program	Using a carer satisfaction survey at six months	Numeric	Six months post-initiation of the intervention
		Individual interviews with carers	Text	Six months post-initiation of the intervention
	Data collection method	Estimating the survey return rate, survey completeness, and participant feedback to the research assistants while completing the survey.	Numeric	Six months post-initiation of the intervention
Objective 6: To explore strategies to	Obtain feedback from participants	Feedback on iSupport for Dementia manual	Feasibility of the iSupport program	Obtain feedback from participants

Study objectives	Evaluation method	Explanation	Data type	Data collection Time
embed and sustain the facilitator-enabled iSupport program after the trial				
Objective 7: Determine the intervention effectiveness with the given sample size at six months	Carer's QOL, PLWD's QOL, carer's self-efficacy, and carer's perceived QOS	Survey using: SF-12 QOL-AD Self-efficacy QOS RMBPC	Numeric Text (survey comments)	Baseline and six months post initiation of the intervention
		Peer support meeting recording that relates to the effectiveness of the program	Text	Monthly
		WhatsApp group activities that relate to the effectiveness of the program	Text	Ongoing
		Facilitator portfolio that relates to the effectiveness of the program	Text	Monthly
		Individual interviews with carers, facilitators, and site leaders	Text	Six months post-initiation of the intervention

4.4.3.7 Data analysis

Mixed methods data analysis and interpretation procedures introduced by Creswell et al. (2018) were applied: 1) separate quantitative and qualitative data analysis; 2) compare the two sets of data; 3) transform quantitative data to qualitative data, 4) joint display transformed data and 5) further interpretation and integration through narrative description and synthesis. The first step was separately analysing quantitative data and qualitative data as the following:

Quantitative data analysis: Descriptive statistics was applied to summarise feasibility measures and demographic data and presented as means and standard deviations (SD) for continuous variables and numbers and percentages for categorical variables. The recruitment rate was calculated as the percentage of consented and randomised participants from the total express of interest. Missing value analysis was applied to six months of intervention effectiveness measure surveys to evaluate survey completeness. The accepted missing data percentage was set at 5%.

The intervention effectiveness data was analysed based on the intention to treat based on group assignments. Two-sample Student's t-test for continuous variables with normal distribution, Wilcoxon rank-sum for non-normally distributed continuous variables, and Chi-squared test for categorical variables to explore any differences between the two groups (intervention and usual care groups) were conducted at the baseline and six months. Sub-group analysis was also conducted using the same method to understand whether there were differences between community aged care support and hospital support. Multiple imputation was used for missing data in the outcome survey. A paired sample t-test was performed to compare the differences between the baseline and 6-month surveys.

A multivariate multilevel mixed-effects linear regression model (two-level random slope model) was applied to fit linear mixed models to examine the outcome differences between intervention/usual care groups due to the hierarchical structure of the data (participants nested with age care/hospital groups). The random effects for age care/hospital groups are included to account for the fact that participants within the same age care/hospital groups may be more like each other than to participants in others. The main effects refer to the predictors that are being examined in relation to the outcomes. As the outcome occurs with repeated time points, the models extended to three-level random slope models both fixed effects (iSupport/usual care group, baseline/6 months timeframe, and group by time interaction) and random effects (Age care/hospital support) within the data. Univariate models were first used, and then multivariate modelling was undertaken by adding variables considered clinically meaningful or statistically significant from the univariate model to adjust for confounding effects between variables. The baseline measure of the outcome variable adjusted the model. The maximum likelihood estimate procedure was used to compare significant differences in effectiveness outcomes over time and between groups. A series of models was undertaken by adding and subtracting variables, with changes in model fit assessed by log-likelihood to choose the final multivariate model. The two-sided test was performed for all analyses, a 95% confidence interval (CI) was reported, and the significance level was set at $p < 0.05$. All quantitative data analyses were performed using IBM SPSS Statistics 28 (IBM Corp., 2021).

Qualitative data analysis: Recorded peer support meetings, facilitators' portfolios, survey comments, and WhatsApp messages between October 2022 and October 2023 were downloaded. Audio-recorded data was transcribed verbatim using the online Microsoft Word transcription function for analysis. A deductive qualitative analysis suggested by Love and Corr (2021) was applied. A coding framework was developed based on the outcome evaluation against the study objectives and three carer stressors (care recipient’s factor, care factor and system factor) in the stress and health theoretical framework. The stress and health theoretical framework also informed the data analysis and the presentation of findings. The codes and themes were checked by supervisors and then refined to address the team's feedback.

Mixed methods data analysis, interpretation, and integration: After the first step of quantitative and qualitative data analysis, a joint display table was developed to compare and examine the similarities and differences between both data sets. During the comparison, similarities and differences were identified. Quantitative findings were grouped under the aims and objectives of the study (i.e., feasibility, fidelity, and effectiveness of the program). Findings on the effectiveness of the iSupport program were further grouped under the factors related to the source of stress (i.e., care recipient factors, carer factors, and system factors) to allow comparison and integration with qualitative findings. Then, quantitative data was transformed into qualitative descriptive data based on Sandelowski (2000a) data transformation strategies. After this, another table that displays the transformed quantitative and qualitative findings was produced in the narrative to provide a clear link between the intended study aims, objectives and conclusions. The last step was to integrate further, interpret the findings, and then synthesise them in this thesis's discussion chapter.

4.4.3.8 Study rigour in phase 2

For RCT components in this phase, the reliability and validity of the RCT are ensured by the following strategies. The internal validity of the RCT is enhanced by controlling group differences, selection bias, allocation bias and the use of valid and reliable instruments (Liamputtong, 2017). First, the research team strictly follows inclusion and exclusion criteria to minimise selection bias. Second, the allocation of participants to groups was conducted by the biostatistician who had no contact with the participants; concealed allocation minimised the allocation bias. Third, block randomisation is used to control the confounding variables, such as carers' relationship to PLWD and PLWD's dementia stages. This approach enhances the possibility of detecting the differences between intervention and control groups while minimising the blocking variables effect on the outcomes (Polit & Beck, 2017). Fourth, intention to treat analysis maintains the balance of confounders established by randomisation and provides a real-life estimate of the result (Liamputtong, 2017). Last, regular audits and support enhance the fidelity of the intervention. For example, facilitators meet the research team every two weeks and submit their portfolio monthly to ensure ongoing support from the research team and maintain the RCT's quality. The external validity of the RCT was enhanced by the multi-site study design, thus enhancing the generalisability of the result (Liamputtong, 2017).

For qualitative descriptive study components in this phase, the study's credibility was enhanced by transcribing the recorded data verbatim for data analysis. The confirmability of the study was reinforced by having team members crosscheck the codes, subthemes and themes during the data analysis. When possible, presenting quotations from participants to ensure participants' views were correctly presented and interpreted. Differences in opinion on findings existed among team members but were resolved through discussion. The study's dependability was ensured by using the same interview questions for all participants.

Although the present internal pilot RCT intends to identify and resolve issues as the main trial proceeds, one of the study objectives is to evaluate the intervention effectiveness at six months. Therefore, the study also considered the following strategies to minimise the qualitative data collection introduced bias to RCT, subsequently affecting the effectiveness outcomes at the six months. Firstly, most qualitative data were collected in an unobstructed method (i.e., peer support meeting recordings, WhatsApp group messages), and the author had minimal contact with the participants, therefore minimising the risk of introducing bias that influence the outcome of the RCT. Second, interviews were conducted after six months of the intervention, which could have minimal effect on six months' results. Finally, the interview was semi-structured, and questions were carefully designed not to affect how carers engage with the iSupport program after six months, which will have minimal impact on the main RCT.

4.5 THE THEORETICAL FRAMEWORK

The WHO and Australian iSupport for Dementia program aims to support carers with mild stress (Pot et al., 2019). Hence, a theoretical framework for stress and health was chosen to underpin the facilitator-enabled iSupport program. This section outlines this framework.

4.5.1 Overview of the stress and health theory

Several stress and coping theoretical models explain the sources of stress, caregivers' actions/reactions to it, and the impact of the stress on caregivers and those they care for (Biggs et al., 2017; Walinga, 2010). These models also indicate interventions that positively impact caregivers' health, wellbeing and QOL. Detailed descriptions of these models are presented below.

4.5.1.1 Stress as a stimulus model

This model assumes that an individual is a passive recipient of stress, and stress is a significant life event that demands response, adjustment, or adaptation (Rahe & Arthur, 1978; Walinga, 2010). Stress as a response model was introduced by Hans Selye, who described stress as a non-specific biological response of the body to demand (Fink, 2016; Selye, 1976). This model focuses on the physiological analysis of stress and stress responses such as hormonal response (Fink, 2016). Selye's stress model has been criticised due to its ignorance of cognition and psychological factors of stress (Fink, 2016).

4.5.1.2 Transaction stress and coping model

This model was developed by Lazarus and Folkman (1984), with stress defined as the relationship between a person and their environment based on a cognitive evaluation of what is personally significant and beyond their resources for coping. Coping is a cognitive and physical effort to reduce environmental demand (Biggs et al., 2017; Lazarus & Folkman, 1984). This model emphasises coping processes that either modify the stressor or regulate an individual's response to stressors (Biggs et al., 2017). There are several concepts of coping, such as problem-focused coping (i.e., primary appraisal of whether an individual can cope with the challenge), emotion-focused coping (i.e., wishful thinking, distancing or positive thinking) (Lazarus & Folkman, 1984), and approach and avoidance coping (Roth & Cohen, 1986).

4.5.1.3 Stress Process Model

Pearlin et al. (1990) introduced this model, focusing on the caregiver's needs. Pearlin et al. (1990) conceptualised the stress process into four domains, each with multiple components. The four domains of caregiver stress are 1) background and context (i.e., carer's socio-demographic factors, access to networks and social support), 2) primary stressors (i.e., the PLWD factors: dependence level, changed behaviour and other comorbidities), 3) secondary role strains (i.e., family conflicts, constrictions of social lives, work–caregiving conflicts and financial problems) and 4) intrapsychic strains (i.e., negative thoughts: perceptions of loss of self and role captivity).

4.5.1.4 Stress/Health Process Model

Initially developed by Schulz et al. (2002), this model focuses on dementia caregiving, its health impact, and intervention effects on primary and secondary stressors. Conde-Sala et al. (2010) evolved this model by considering the stress process models introduced by Pearlin et al. (1990), highlighting the intervention effect on contextual, primary and secondary stressors. According to Conde-Sala et al. (2010), variables affecting caregiver health and wellbeing are multifaceted, including caregiver contextual factors (i.e., ability to provide dementia care, family relationships, co-residing status, gender and time spent on care activities), care recipient factors or primary stressors (i.e., changed behaviours, dependence and multimorbidity); and other factors or secondary stressors (i.e., family conflict and financial difficulties). Interventions that can improve caregivers' symptoms of stress, such as anxiety, depression, isolation, burden and physical health, include non-pharmacological interventions (i.e., psychoeducation, social support and social resources) and treatment (i.e., pharmacological treatment)(Conde-Sala et al., 2010).

4.5.2 Concepts related to facilitator-enabled iSupport for Dementia program

Based on a literature review and an analysis of previous conceptual models, the research team, including myself, conceptualised a facilitator-enabled iSupport framework to inform the project design to achieve the project's aims (Figure 4-2). The detailed framework is published by the Journal of Clinical Nursing (Ying Yu et al., 2023). This framework was applied to this two-phase PhD study. In this framework, the primary stressors in Pearlin et al.'s (1990) model were described as 'care recipient factors' to identify suitable support to mitigate these sources of stress. Interventions or activities aimed at this category including educational support carers managing dementia related symptoms and other comorbidities. Education support about dementia can also include wide range of information such as disease progression, symptom management and available services (Whitlatch & Orsulic-Jeras, 2018). In the iSupport program, iSupport facilitator work closely with family carers to support them in dementia education and symptom management.

Moreover, the stressors associated with carers' background and context, secondary role strains and intrapsychic strains are grouped into a single category, 'carer factors', to enable service providers to pay attention to carers and understand the main stressors they face and their relationships. For example, a lack of social support and dementia education may also contribute to unpleasant thoughts during dementia care. Thus, the care support needs to target each source of stress simultaneously when appropriate (Figure 1-2). Interventions aimed at this category focused on carer's psychosocial support including psychoeducation, counselling, peer support, leisure and physical activities (Wiegelmann et al., 2021). In the iSupport program, iSupport facilitators assist carers to learn from iSupport for Dementia psychoeducation program, offering emotional support and facilitate peer support to mitigate this type of stress.

Furthermore, stressors related to service availability were included in background factors by Pearlin et al. (1990). However, Inadequate services, poor communication between service providers was reported as sources of stress for carers have been widely reported as sources of stress for carers (Steiner et al., 2020). Therefore, we synthesised 'System factors' as one of standalone stressors include availability, accessibility, acceptability, and quality of care services. Interventions that aimed reduce system-related stress including case management to support carers in problem solving and accessing available resources (Kiely et al., 2021; Reilly et al., 2015). In the iSupport program, iSupport facilitators employed by service providers to support carers in accessing resources and act as single-point-contact to reduce this type of stress.

This framework also considers the suggestion by Conde-Sala et al. (2010) that interventions need to consider improving the health and wellbeing of carers. Therefore, these three types of interventions that can address carers' stressors were reframed as 1) support from service providers, 2) support from peers, and 3) support from mental health specialists. Support from service providers emphasised their role in engaging carers in dementia care education and peer support and linking them to relevant care services to meet the care needs of PLWD. Support from peers highlighted the carer's need for socialisation with others. At the same time, support from mental health specialists emphasises the need to assess carers' mental health and provide referrals accordingly (See Figure 4-3). All these supports are promoted by iSupport facilitators. This framework guided study phase 1 development of the activities and iSupport facilitator's role and responsibilities to emphasise the support that can address carers' three stressors. Meanwhile, the outcome measures of phase 2 also emphasised the carer's stressors to test the effectiveness of the multicomponent facilitator-enabled virtual iSupport program.

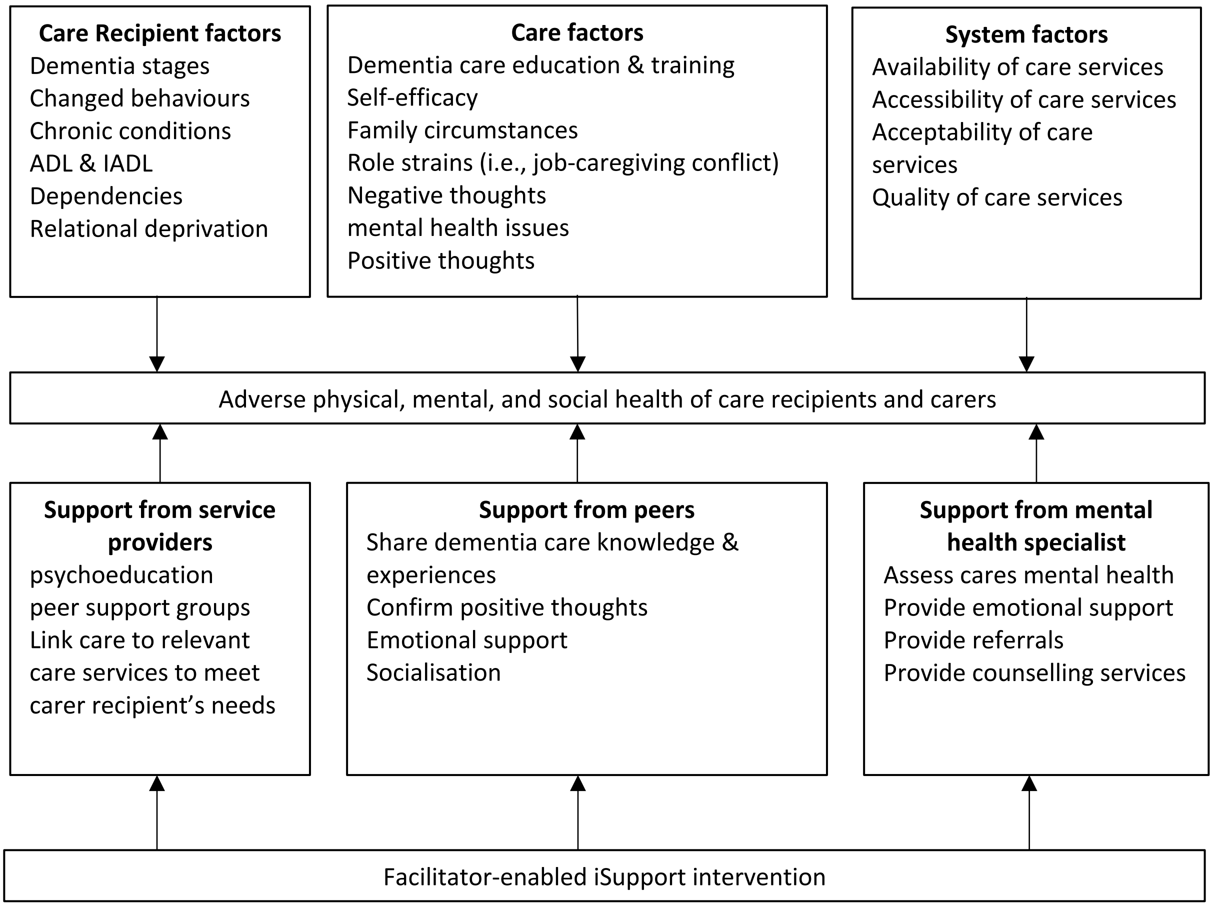


Figure 4-3 Theoretical framework

4.6 SUMMARY

This chapter discussed the research design and method employed for the facilitator-enabled virtual iSupport study. A complex mixed methods experimental research design, underpinned by a pragmatic paradigm or paradigm pluralism, allowed the researcher to use multiple paradigms in one study to answer various research questions. Phase 1 of the present study applied an explanatory sequential mixed methods experimental study design using modified NGT to engage with stakeholders to achieve consensus on activities and roles and responsibilities of the iSupport facilitators. Phase 2 used a convergent mixed methods experimental study design, with an internal pilot RCT and a qualitative descriptive study. The author presented the methodology, justification of the chosen methodology, ethics consideration and approval in this chapter, followed by the methods for phases 1 and 2. This chapter also presented the details of data collection and data analysis.

5 Findings Phase 1: Activities to be delivered and iSupport facilitators’ role and responsibility in the iSupport program

5.1 INTRODUCTION

The systematic review presented in Chapter 2 and 3 identified the need for the facilitator-enabled virtual iSupport for Dementia program to address carers’ unmet needs. This chapter reports the findings from the phase 1 study. The aim of phase 1 was to engage with stakeholders to reach a consensus on the activities to be delivered by iSupport facilitators in a planned iSupport for Dementia program; with objectives of reaching a consensus with stakeholders on 1) the activities to be delivered by iSupport facilitators to strengthen support for carers of PLWD in the planned iSupport program in hospital and community aged care settings and 2) the iSupport facilitator's roles and responsibilities when embedding the Australian iSupport for Dementia program in care services. In this chapter, section 5.1 presents overall findings in phase 1. Characteristics of the participants in phase 1 are presented in section 5.2. Section 5.3 presents the results from quantitative data analysis, and section 5.4 presents the results from qualitative data analysis. Section 5.6 presents the integrated final findings that address objective 1 of the study, while section 5.7 presents final integrated findings that address objective 2. Finally, Section 5.8 presents a chapter summary.

5.2 OVERALL FINDINGS IN PHASE 1

Table 5-1 displays the overall findings of the phase 1 study using quantitative and qualitative data. Quantitative and qualitative data findings are integrated and narratively described in these findings.

Table 5-1 Phase 1 overall findings

Study objectives	Findings	Related quantitative data	Related qualitative data
Objective 1: to reach a consensus with stakeholders on the activities to be delivered by iSupport facilitators to strengthen support for carers of PLWD in the planned iSupport program in hospital and	Finding 1: Support for carers to cope with care recipient-related challenges Finding 2: Support carers to cope with carer-related challenges	Pre-workshop survey: 5 out of 15 activities (33%) were feasible 4 out of 15 (26%) were acceptable 4 new activities were suggested Post-workshop survey:	The agreed activities: Activity 1, 3, 7,8,9,10,11,14 Disagreed activities: Activities 2, 4, 12, 13, The new activity: 5, 6, 15, 16

Study objectives	Findings	Related quantitative data	Related qualitative data
community aged care settings	Finding 3: Support carers to cope with system-related challenges	all revised 16 activities were relevant, 12 out of 16 were feasible and acceptable	
Objective 2: to reach a consensus with stakeholders on the iSupport facilitator's roles and responsibilities when embedding the Australian iSupport for Dementia program in care services	Finding 1 the facilitator’s role at the time of dementia diagnosis, Finding 2. The facilitator’s role throughout the everyday dementia care journey Finding 3 the facilitator’s role during transition moments.	Pre-workshop survey: 5 out of 15 activities (33%) were feasible 4 out of 15 (26%) were acceptable 4 new activities were suggested Post-workshop survey: all revised 16 activities were relevant, 12 out of 16 were feasible and acceptable	Themes: 1) the need to support carers to navigate dementia care services, 2) The need to help carers understand dementia and care services; 3) support carers in managing changed behaviours; 4) support carers in coping with emotional stress; 5) manage medication at home; 6) obtain respite; 7) manage the transition

The following section presents part of a manuscript submitted to the Journal of Advanced Nursing and currently under review. The first author’s contribution to this paper was 50% to research design, 70% to data collection and analysis and 70% to writing and editing.

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

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Student's contribution to the publication	50	%	Research design
	70	%	Data collection and analysis
	70	%	Writing and editing

Outline your (the student's) contribution to the publication:

Ying's contribution to this publication include: leading and coordinating the participants' recruitment and data collection in South Australia, data analysis and draft the original manuscript.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

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5.3 CHARACTERISTICS OF THE PARTICIPANTS

Invitations to the study were sent to 212 potential participants. Seventy-five participants joined the study, equivalent to a 35% recruitment rate, and 57 participants completed the three-stage study. Participant recruitment and retention in the study are outlined in Figure 5-2.

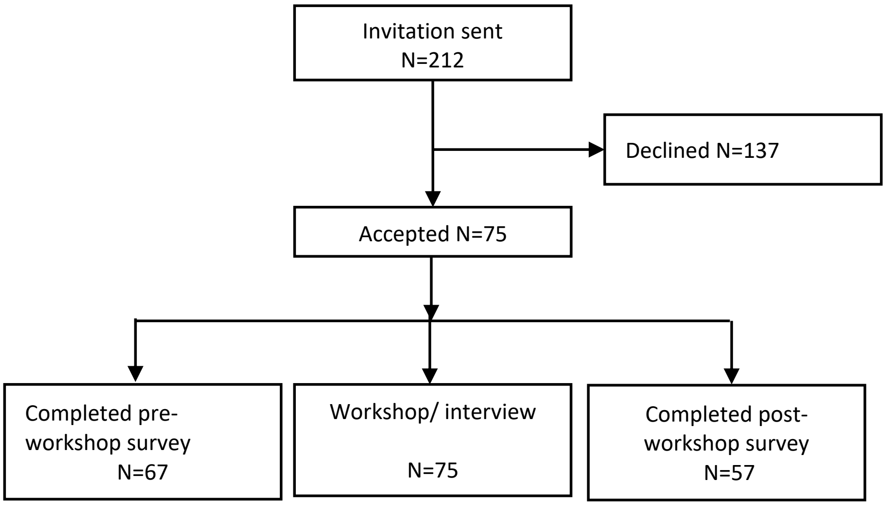

Figure 5-1 Phase 1 Participant recruitment and retention

Among all participants, 45 were health and social care professionals, and 30 were family carers of PLWD. Health and social care professionals include nurses (n = 20), physiotherapists (n = 5), doctors (n = 3), occupational therapists (n = 3), social workers (n = 1) and aged care service coordinators or managers (n = 14). Family carers include spouses (n = 23), adult children (n = 5), siblings (n = 1) and grandchildren (n = 1). Table 2 outlines the demographic characteristics of the participants. Overall, there are more female than male participants in both staff and family carer groups. Staff participants are more than family carer participants and more spouse carers than other types of relationships among family carers.

Table 5-2 Phase 1 demographic characteristics of participants

Participants characteristics		Staff n (%)	Family carers n (%)
Number of participants who provided demographic information: n (%)		36 (65.45)	19 (34.55)
Age: mean (SD)		46 (11.4)	73 (11.55)
Gender: n (%)			
	Male	3 (8.6)	1 (5.3)
	Female	32 (91.4)	14 (73.7)
Years in the service: mean (SD)		15.83 (9.72)	N/A
Years in the carer role: mean (SD)		N/A	5.88 (3.63)
Relationship with the care recipient		N/A	Adult Child = 1 Grandchild = 1 Spouse =13
Occupational categories		Registered Nurse =11 Enrolled nurse=1 Social care professionals=8 Physiotherapist=5 Occupational therapist =3 Geriatrician =1	Employed =1 Unemployed =2 Retired = 15

Medical officer = 1
Social worker=1

Note: 1) Social care professionals, including care advisors, case managers and care coordinators in community aged care. 2) Not all participants provide their demographic information via the online survey.

5.4 FINDINGS FROM QUANTITATIVE DATA

Sixty-seven participants completed the pre-workshop survey, and 57 participants completed the post-workshop survey. The results are outlined in Table 5-3. In general, participants agreed that 13 out of 15 proposed activities (87%) were relevant for the iSupport facilitators to deliver to enhance support for carers of PLWD. However, participants only considered 5 out of 15 activities (33%) feasible and 4 out of 15 (26%) acceptable before the workshops or interviews. They also suggested four new activities to be delivered by the iSupport facilitators to address care recipient factors and system factors in dementia care in the pre-workshop survey (Table 5-3). After the workshops and interviews, activities were revised, and new activities were added; all revised 16 activities achieved a 75% or over agreement rate on relevance, and 12 out of 16 achieved a 75% or over agreement rate on feasibility and acceptability (see Table 5-3).

Table 5-3 Phase 1 The agreement on the activities in the pre-and post-workshop survey

Activity	Time	Relevance		Feasibility		Acceptability	
		N	%	N	%	N	%
Carer recipient factors							
1. Prevent and manage dementia-related symptoms and changed behaviours.	S1	54	81	50	75	51	76
	S2	52	95	45	82	47	87
2. Manage chronic conditions the PLWD has (i.e., hypertension, diabetics and other chronic diseases and conditions)	S1	49	73	42	63	44	66
	S2	45	80	36	65	40	71
3. Identify risks, causes, and triggers of hospitals and ED admission (combined activity).	S1	57	85	52	77	54	81
	S2	51	94	45	83	48	87
4. Identify risks, causes, and triggers of nursing home admission	S1	53	79	49	73	47	70
	S2	49	90	40	74	39	71
5. Engage PLWD in meaningful activities (new activity)	S1	N/A					
	S2	47	98	41	89	39	85
6. Initiate a regular review of medications (new activity).	S1	N/A					
	S2	31	80	27	69	30	75
Carer factors							
7. Maintain mental health through self-care, education and counselling.	S1	59	88	52	78	53	79
	S2	47	96	44	92	40	85
8. Assess carers' learning needs and choose relevant learning units from the online iSupport for Dementia program to help them look after themselves as well as the person with dementia	S1	52	78	47	70	47	70
	S2	47	87	41	75	37	65
9. Coordinating virtual peer support groups	S1	42	62	35	52	36	53

Activity	Time	Relevance		Feasibility		Acceptability	
		N	%	N	%	N	%
	S2	49	90	42	78	43	81
System factors							
10. Navigate, access, and utilise dementia care resources and multidisciplinary care services to meet the care needs of the person with dementia and their carers	S1	63	94	57	85	57	85
	S2	56	100	48	85	54	98
11. Manage transitions between care settings (i.e., hospital-to-home) and care types (i.e., receiving palliative care at home)	S1	53	79	44	66	45	67
	S2	51	92	41	75	47	87
12. Work with professional staff to develop or revise care plans for home care packages or care plans in hospital clinics to meet the needs of the person with dementia	S1	53	79	43	64	45	67
	S2	49	89	39	70	42	76
13. Provide feedback to service providers regarding the strengths of the care services and the areas that need to be improved.	S1	50	75	44	66	41	61
	S2	48	86	38	69	36	66
14. Providing a personal touch and a single point of contact with a live person rather than a computer or telephone-activated voice.	S1	50	75	46	69	46	69
	S2	53	96	48	87	47	87
15. Consider cultural influence in dementia care and direct carers to relevant groups (new activity).	S1	N/A					
	S2	7	100	6	86	6	86
16. Having actions to prevent elder abuse (new activity).	S1	N/A					
	S2	6	86	7	100	6	86

Note: S1=pre-workshop survey, S2=post-workshop survey

5.5 FINDINGS FROM QUALITATIVE DATA

Seventy-five participants participated in workshop discussions (n=69) or phone interviews (n=6), which generated rich information about their perspectives on activities to be delivered by iSupport facilitators. In addition, we received 274 comments from the pre-workshop survey and 193 comments from the post-workshop survey. We identified three themes related to proposed activities to be delivered by facilitators and described these themes as 1) the agreed activities, 2) disagreed activities, and 3) newly suggested activities as detailed in the following (See Table 5-4, section 5.5.1 to 5.5.4). Six themes related to facilitators' roles and responsibilities were also identified from qualitative data analysis and described as 1) the need to support carers in navigating dementia care services, 2) the need to help carers understand dementia and care services; 3) support carers in managing changed behaviours; 4) support carers in coping with emotional stress; 5) manage medication at home; 6) supporting carers in obtaining respite and 7) supporting carers in managing the transition. Detailed findings are presented in section 5.6.

In this chapter, ‘IN’ was used to indicate quotations from interview data, ‘G' to indicate data from group discussions in workshops and ‘S’ to indicate data from survey comments.

Each quote was labelled 'staff' or 'carer' as an indication of the participant cohort, except for some comments from the post-workshop survey.

Table 5-4 Phase 1 findings from qualitative data analysis related to activities

Themes	Activity	Example
1. Agreed activities	1. Prevent and manage dementia-related symptoms and changed behaviours.	'I think change of strategies needs to be taught to the carer, especially about not taking things personally' [G11_staff].
		You need to be prepared for that [changed behaviours], I think, mentally prepared. [G1_carer]
	3. Identify risks, causes, and triggers of hospitals and ED admission (combined activity).	'We need to be mindful that the carer is not deterred from taking the PLWD to the hospital when it is needed. Risk of creating feelings of guilt and/or failure if a hospital admission is required. However, it remains important – of course, keeping the PLWD at home is (the majority of the time) the overall goal' [S2_staff]
		'Like advanced care planning and then likes/dislikes. I know that often, well from residential, there is always a care plan sent through based on likes and dislikes' [G6_carer]
	7. Maintain mental health through self-care, education and counselling.	'I am just wondering whether anyone finds the acceptability challenge for the carer. We see it as relevant, but how well do they accept it? It is something that they need to put energy into' [G11_staff]
		'I am stressed, but there are other people out there. But then I have to wait however long I can' [G1_carer]
	8. Assess carers' learning needs and choose relevant learning units from the online iSupport for Dementia program.	'So, carers need help to work out what parts of the program they need. This would vary over time and as different situations arise' [S1_staff]
		'I prefer to be given the ones that are most relevant to what I need; otherwise, I just have information overload' [G2_carer]
	9. Coordinating virtual peer support groups	'So, I think it is absolutely relevant, but it has to be that double-edged sword that supports the person who does not have computer access' [G3_staff].
		'It does not appeal to me because I have a choice of driving somewhere'[G1_carer].
	10. Navigate, access, and utilise dementia care resources	'So, it is nearly a full-time job for me to navigate the system, let alone try to teach a carer' [G11_staff]
		'Linking people into services to meet their care needs, and I think that is really crucial, like the different time points, the different needs and having, being linked into the right places, and it might not be at that point, obviously a care service, but a legal service, all that sort of information' [G1_carer]
	11. Manage transitions between care settings (i.e., hospital-to-home) and care types (i.e., receiving palliative care at home)	'So, the education of the staff would be fundamental in going forward and providing the care that we need to provide' [G3_staff]
		'It is not only in the transition, it is people in hospitals knowing what to do when they are transitioning people out of hospitals to places like this' [G4_carer]
	14. Providing a personal touch and a single point of contact with a live person rather than a computer or telephone-activated voice.	'Having that one person to advocate on behalf of that family. You want to be the main communicating person just to help with clearing the information I think that would be helpful, but in terms of how to manage that, I think it could be a bit of a barrier' [G13_staff]
		'I really did not know what to do, and I got really annoyed and abusive at the reception because I was frustrated, so if someone were there to help, that would be good' [G14_carer]
2. Disagreed activities	2. Manage chronic conditions	'This is difficult for Geriatricians at times as there is no clear way to manage the conditions of older people. Depends on symptoms, cognition, goals of care, etc. I think this is beyond the scope' [S2_staff]
		'For some people, that's really important, and for others, it's not …' [G2_carer]
	4. Identify risks, causes, and triggers of nursing home admission	'We need to be careful with this one to ensure carers do not feel bad if their person ends up in care earlier than expected' [S1_staff]
		'I want information on that because, at some point, he is not going to be able to stay with us, so I need to know…you need to put him on a put the name down waiting list cos

Themes	Activity	Example
		it can take 2 or 3 years to get a spot in aged care or, I do not know how to do it, I need to plan for it. And my partner and I have to work 5 days a week' [G14_carer]
	12. Work with professional staff to develop or revise care plans	'Professionals already complete this… not sure if time is required on this' [S2 Survey 19].
		'I am very interested in this subject. I would love some assistance to review the current home care package care plan and revise it if there are better ideas' [S1_carer]
	13. Provide feedback to service providers regarding the strengths of the care services and the areas that need improvement.	'Feedback is valuable. Just because we think we provide a good service does not mean we do' [S1_staff]
		'You need someone who you can ring and advocate for or something, and they fight for you because you just do not have the energy' [G1_carer]
3. New activities	5. Engage PLWD in meaningful activities (new activity)	'I think with conversations around, you know, what – you know, just because they have dementia, does not mean they want to do different activities' [G12_staff]
		'When the person with dementia has been a high-functioning, multi-talented person, and now his and my world are different, I struggle with finding activities to use the abilities he still has' [S1_carer].
	6. Initiate a regular review of medications (new activity).	'I actually think pharmacists in geriatric-specific wards have a greater tendency to do that…' [G3_staff]
		'The pharmacy is going to be more important if you have got those- … conditions. And then, obviously, the facilitator will be linking you with different types of specialists' [G1_carer]
	15. Consider cultural influence in dementia care and direct carers to relevant groups (new activity).	'I would imagine the acceptability is really high because they are going to get the support from others…the feasibility may be related to who is in their support group as to if they can get that support' [G11_staff].
		'Linking people into activities to meet the care needs is really crucial…obviously a care service, but a legal service, all that sort of information also needed' [G1_carer].
	16. Having actions to prevent elder abuse (new activity).	'Maybe the role of the Facilitator may be actually more about awareness of the issue and mechanisms and strategies to deal with their own moral distress rather than necessarily feeling like they have got an active role and trying to manage that challenge' [IN2_staff]
		'Putting actions in place to assist the safeguard of elder abuse' [S1_carer]

5.5.1 Theme 1: The agreed activities

Participants elaborated and agreed with these activities: Managing changed behaviours (activity 1), providing mental health support (activity 7), assessing carer learning needs (activity 8), coordinating virtual peer support groups (activity 9), supporting in navigating the system (activity 10), managing transition (activity 11), providing feedback to service providers (activity 13). and act as a single point contact (activity 14). For example, staff described the need to strengthen mental health support: '*Extremely important given that you know the high statistics for people who present with mental health issues and then the comorbidity of mental health and physical health as well. I mean, it is hugely important.* [G8_staff]. Carer participants echoed a similar view: '*We did not want to go and speak to a psychologist or anything either because that does not help'* [G4_carer]. These statements indicated facilitators may need to establish trusting relationships with carers before offering emotional and mental health support.

5.5.2 Theme 2: The less agreed activities

Participants did not reach an agreement on activities on managing chronic conditions (activity 2), Identifying risks of nursing home admission (activity 4), and updating care plans (activity 12). Staff participants disagreed on activity 2 (managing chronic conditions) because they believe it is too complex to be managed by one facilitator; instead, a multi-disciplinary team approach is needed. One staff member stated: *'This is difficult for Geriatricians at times as there is no clear way to manage the conditions of older people. Depends on symptoms, cognition, goals of care, etc. I think this is beyond the scope [S2_staff]*. The finding indicates the need for the facilitator to partner with other health professionals in the iSupport program.

Similarly, staff and family carers had different views on activity 4 (identify risks of nursing home admission). Staff were concerned that emphasis on avoiding nursing home admission might put pressure on the family carers who need to send their loved ones to the facility. For example, *'Need to be careful with this one, to ensure carers do not feel bad if their person ends up in care earlier than expected' [S1_staff].* However, family carers welcomed this activity because they needed support. One care stated:

> *I want information on that… you know, at some point, he is not going to be able to stay with us, so I need to know these things…put the name down on a waiting list because it can take 2 or 3 years to get a spot in aged care or, I don't know anything about how to do it, how to go about it, I need to plan for it. And my partner and I have to work 5 days a week. [G14_carer]*

Moreover, staff participants viewed activity 12 (update care plan) as duplicating existing activities in the current services: '*This is already completed by professionals… not sure if time is required on this'* [S2 Survey 19] and concern about the reaction from service providers: *'Not sure how providers would respond'* [S2 Survey 45]'. Staff were also concerned about time constraints: *'Time constraints in hospital clinics with staff specialists'* [S1_staff]. In contrast, carers would like some support in this area: *'I am very interested in this subject. I would love some assistance in reviewing the current home care package care plan and revising it if there are better ideas*' [S1_carer].

5.5.3 Theme 3: The new activities suggested by participants

Participants also suggested and agreed upon four new activities, including engaging PLWD in meaningful activities (activity 5), initiating a regular review of medications (activity 6), considering cultural influence (activity 15), and taking action to prevent elder abuse (activity

16). For example, participants agreed that facilitators need to be educated and build therapeutic relationships with carers before they can identify older abusive behaviour. One staff stated:

> *I think you have to support and educate the facilitator about how to pick up on this and what to do when they pick up on it. And they may pick up on this if they have continuity with someone and develop a relationship. They may, after a while, realise or have suspicions that there is elder abuse going on and what they do with that knowledge. [IN2_staff]*

5.5.4 Final findings after Integrations of quantitative data and qualitative data

Quantitative and qualitative data were further integrated to address study objectives. Three final findings were identified to address study objective 1, stakeholder's consensus on activities to be delivered by iSupport facilitators are activities that 1) Support carers to cope with care recipient-related challenges, 2) Support carers to cope with carer-related challenges and 3) Support for carers to cope with system-related challenges. Furthermore, three final findings were identified to address study objective 2: stakeholders agreed on iSupport facilitators' roles and responsibilities 1) at the time of dementia diagnosis, 2) throughout the everyday dementia care journey and 3) during transition moments.

5.6 FINAL FINDINGS ON OBJECTIVE 1: ACTIVITIES TO BE DELIVERED BY ISUPPORT FACILITATORS TO STRENGTHEN SUPPORT FOR CARERS OF PLWD IN THE PLANNED ISUPPORT PROGRAM

5.6.1 Finding 1: Support for carers to cope with care recipient-related challenges

This finding is based on six proposed activities (See Table 5-2, Activity 1-6) and two new activities (engage PLWD in activities and medication management) suggested by participants. Based on participants' suggestions, the proposed activities of identifying risk factors for emergency department admission, identifying risks of hospital admission, and identifying early signs of deterioration in the PLWD were combined as a single activity 3 for the iSupport facilitator to enact. Participants agreed that activities 1 (manage dementia-related symptoms) and 3 (identify risks of hospital admission) are relevant, feasible and acceptable. Health professionals and family carers shared similar views on these activities related to care recipients. For example, one carer stated: '*You need to be prepared for that [changed behaviours], I think, mentally prepared*' [G1_carer]. Staff participants also expressed the importance of carer support in managing changed behaviours: *'I think the change of strategies* *needs to be taught to the carer, especially about not taking things personally'* [G11_staff]. Participants suggested engaging PLWDs in meaningful activities (activity 5). Both staff and family carers agreed that delivering this activity is necessary. One staff member said, '*Just because they have dementia, it does not mean they want to do any different activities'* [G12_staff]. Family carers also expressed the support they need around this area. One carer stated: *'When the person with dementia has been a high-functioning, multi-talented person, and now his and my world are different, I struggle with finding activities to use the abilities he still has'* [S1_carer].

Although activity 6 (medication review) achieved consensus on relevance and acceptability, staff participants expressed uncertainty regarding who should take the responsibility to review the medication: '*It is always good to have that initial review of medications, maybe with a facilitator or a pharmacist*' [G5_staff]. Family carers preferred that the pharmacist do a medication review. For example: *'The pharmacy is going to be more important if you've got those conditions. And then, obviously, the facilitator will be linking you with different types of specialists' [G1_carer].* It appeared that clearly defining the iSupport facilitator's roles and responsibilities was much needed to address the feasibility and acceptability of this activity.

5.6.2 Finding 2: Support for carers to cope with carer-related challenges

This finding concerns three activities (Table 5-2, Activity 7-9). Health professionals and carers shared similar views on these activities. They agreed that carers need mental health, education, and peer support. Carers often make PLWD's health a priority. One carer stated: '*To me, my wife's welfare is more important than mine; I can look after myself, she cannot'* [G2_carer]. ISupport facilitators might need to work with staff to deliver activities to increase carers' awareness of self-care because staff are often very focused on their patients or clients (PLWD) instead of carers. One staff member added, '*You can only think about the condition of the patient you care for because you have many thoughts'* [G9_staff]. Participants welcomed activity 9 to be delivered by iSupport facilitators (coordinate virtual peer support groups). Staff participants think this activity could offer opportunities for interaction between carers. One staff member said, '*Virtual is great for someone who is computer-oriented, and some people do not like people in their home. Maybe they could be educated on using a virtual system and may feel comfortable with that'* [G3_staff]. However, finding time to attend peer support groups can be challenging for some carers. One carer stated: '*I can tell you it is really very difficult for the carer to try and find time'* [G14_carer]. Another carer echoed this: '*I mean, in my situation, because I am not terribly elderly, I find the biggest problem with something like that is the time'* [IN1_carer]. It appeared that the iSupport facilitators would need to be flexible in offering support to suit carers' situations.

Qualitative data analysis suggested that participants agreed on activity 8 (access carer learning needs and identify learning units from the iSupport manual). However, this was not reflected in the survey results as it did not achieve consensus on acceptance. Carers welcomed the idea of the facilitator providing tailored information to prevent information overload. One carer stated: '*I prefer to be given the ones most relevant to what I need; otherwise, I just have information overload'* [G2_carer]. Another participant supported this and explained: '*Need to consider individual needs and learning styles with alternatives offered. If some carers cannot participate in one method, another approach should be provided'* [S2 Survey 20].

5.6.3 Finding 3: Support for carers to cope with system-related challenges

These findings are around five activities (See Table 5-2, Activity 10-14) and two newly stated activities, 15 (cultural considerations) and 16 (preventing elder abuse). Participants agreed that having a facilitator to assist carers navigating care services in the system (activity 10) is very important. Participants commented on the reasons for delivering this activity: '*I certainly found it hard to work out how to access services to start with…Help is certainly needed'* [S1 Survey 5]. Carers and staff also expressed the importance of activity 11, managing the transition. One carer stated: *'It is not only in the transition but also people in hospitals knowing what to do when they transition people out of hospitals to places like this'* [G4_ carer]. Staff welcomed this activity to be delivered by the facilitator because this can help PLWD to settle in more quickly in the new environment. One staff member stated, '*The earlier we know, the better – the more about our patients, the better off, especially if they are coming into us already confused'* [G7_staff]. Participants welcomed activity 14 (providing single-point contact). Staff consider it necessary to support carers during difficult situations. One staff said: '*Having that one person to advocate on behalf of that family…be the main communicating person just to help clear the information, I think that would be helpful'* [G13_staff].

Activity 13 (provide feedback to service providers) did not achieve agreement on feasibility and acceptance in survey results. However, qualitative data suggested that staff and carer participants agreed upon this activity. Staff supported the idea of facilitators providing feedback: '*Feedback is valuable. Just because we think we provide a good service does not mean we do*' [S1_staff]. Carers also welcomed the activity: *'I think that would be a great idea if I did not have to spend 45 minutes on the phone with my dad… We spoke to somebody to get the authority for me to speak on his behalf'* [G14_carer]. Some carers still preferred to provide feedback to service providers: *'As family members of the person, I do not see why we cannot speak to the facility'* [G4_carer]. This finding suggested that activities to support carers in coping with system-related challenges could focus on navigating the health system, managing the transition and providing single-point contact. At the same time, consider cultural differences and prevent possible elder abuse.

This is the end of the submitted manuscript.

This section presents a part of publication from this thesis published in the Journal of Clinical Nursing as an open-access article. The first author's contribution to this paper was leading and coordinating the participants' recruitment, 50% to research design, 70% to data collection and analysis, and 70% to writing and editing.

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This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

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	70	%	Writing and editing

Outline your (the student's) contribution to the publication:

Ying's contribution to this publication include: leading and coordinating the participants' recruitment and data collection in South Australia, data analysis and draft the original manuscript.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

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5.7 FINAL FINDINGS ON OBJECTIVE 2: THE ISUPPORT FACILITATOR'S ROLES AND RESPONSIBILITIES WHEN EMBEDDING THE AUSTRALIAN ISUPPORT FOR DEMENTIA PROGRAM IN CARE SERVICES

5.7.1 Finding 1: The facilitator’s role at the time of dementia diagnosis

Carer participants perceived that dementia care activities and resources were not organised to be easy for them to navigate and access. They also perceived that they had been unaware of where or whom to approach for help at the time of dementia diagnosis. Staff participants perceived having limited time to assist carers in navigating information and activities. Both carers and staff perceived that a designated iSupport facilitator should address the unmet needs of carers at the time of dementia diagnosis, as detailed under the following subthemes.

5.7.1.1 Sub-finding 1: The need to support carers in navigating dementia care activities and resources

At the time of dementia diagnosis, carers were not provided with the breadth of support they needed. For example: ‘*Well, day one, when they tell you that you have got terminal Alzheimer’s, does not tell you all the legal, all the basics. Power of attorney is critical because if you do it later, you get into trouble* [G1_carer]. Another carer stated: ‘*It can be very daunting in the beginning … As far as all the things available to you … accessing them and finding out about all the help you can get*’ [IN1_carer]. Carers expected the facilitator to help them at the point of diagnosis: ‘*I think that person needs to be there when the diagnosis is made … because it is then that you need the information, not six months later*’ [G4_carer].

Carers also encountered difficulties in understanding terms: one carer stated: ‘*It takes a while for you to work out what an ACAT [aged care assessment team] is and whom you need to see*’ [G4_carer]. Working carers perceived role strain from finding the information they needed: ‘*I have got to work, I have got to spend time with the kids, I have got to spend time with the family … I just do not know what the resources are and how to access them*’ [G14_carer]. Another working carer echoed this: ‘*To have somebody to talk to or guide me or say—just advise me on how, not to be shocked and taken aback every time and think, what is going on? … So that is very much needed*’ [G1_carer].

5.7.1.2 *Sub-finding 2: The need to help carers understand dementia and care activities*

Staff reported that time constraints limited how much they could support carers: '*We have very little time to sit with people, and we really need to explain to them what dementia is, what is delirium*' [G7_staff]. Staff also acknowledged that the system is complex for carers to navigate: '*We end up referring many carers to social workers to assist with even really minor things like getting people set up with Dementia Support Australia*' [IN 2_staff]. The complexity of the dementia and aged care system was also challenging for staff to navigate: '*It is nearly a full-time job for me to navigate the system, let alone trying to teach a carer*' [G11_staff].

Information overload was another concern: '*It is overwhelming being presented with that information just once as well. So, people need time to think about it … you gave them all this paperwork, and they are like, oh, it is too hard* [IN2_staff]. Staff perceived that an iSupport facilitator could be in an ideal position to address the unmet information needs and ongoing support: '*They need some support as well from someone*' [IN2_staff].

Findings categorised under this theme revealed that the sources of stress carers encountered at the time of diagnosis were attributed to carer factors (inability to access information and social support), role strains for carers in paid employment, and service provider factors (limited time to provide emotional and information support for carers, or lack of support for carers). Participants perceived that a designated iSupport facilitator could mitigate these sources of stress by helping carers access support networks and trustworthy information, helping them plan their care journeys and providing timely emotional support.

5.7.2 Finding 2: The facilitator's role throughout the everyday dementia care journey

Participants described that managing changed behaviour and daily medication for PLWD were the primary sources of stress for carers. Moreover, carers often experienced emotional and psychological stress and even reached crises, but they rarely sought help from others. They believed a designated iSupport facilitator could be crucial in supporting carers to cope with stress and stabilise home care, as detailed under the following subthemes.

5.7.2.1 *Sub-finding 1: The need to support carers in managing care recipients' changed behaviour*

Carers in this study learned how to identify causes and triggers of changed behaviour, mainly through a trial-and-error approach: '*There were a few triggers with Dad that we* *worked out later. We did not understand why he was getting so aggressive*' [G4_carer]. Another carer echoed a similar experience: '*[I] gauge whether it is okay in this situation when I am dealing with dementia? … it has taken me a while to hopefully get some confidence that I can read the situations now*' [IN1_carer].

Carers would like tailored dementia care education to help them effectively prevent or manage changed behaviour: '*That is important at the right time because you have to know what can happen and what alternatives you have before it happens*' [G2_carer]. Carers recommended that a facilitator, as a real person who could provide ongoing support to help them deal with changed behaviour, would be beneficial: '*I would prefer to access to a person or a workshop, rather than reading a bunch of papers online*' [G14_carer]. Carers perceived that acquiring knowledge and skills in dementia care was a slow process and involved trial and error over time. For example, one carer stated: '*I have learnt to make my husband as happy as I can, as he wants. Communicate with him so that it does not frustrate him*' [G14_carer].

Staff perceived that carers' behaviour usually triggered the changed behaviour of PLWD:

> *Because the husband or wife wants them to do the things they did prior and they have lost enough capacity that they cannot do those things, they want to try and encourage them, and that is great, but then the person with dementia is getting really agitated. [G3_staff]*

Therefore, staff underscored carers' participation in dementia education:

> *Education and how to manage the best to their ability. You cannot really change the behaviour of the client … the carer can change their behaviour or their look into their parent by obviously understanding that they do have dementia. [G12_staff]*

Staff suggested that a '*support worker could help them [carers] to identify the fact that they are starting to … You can tell when someone is not coping well even with a phone call*' [G3_ staff]. The suggestion indicates that iSupport facilitators need skilled health or social care professionals who usually provide direct care to PLWD.

5.7.2.2 Sub-finding 2: The need to support carers to manage medication at home

People with dementia usually depend on their carers to manage their daily medications. Staff strongly suggested the need to provide carers with medication education so that they could advocate for their care recipients: '*You often see one change in medication, a huge* *change in them [PLWD] going to the toilet, their behaviour, their sleeping patterns. So, I think there needs to be more advocacy for them*' [G5_staff]. Furthermore, staff recognised that organising medication review for PLWD in the community could be challenging: '*The problem is, if you are out in the community, and you rock up at a pharmacist for a medication review. They cannot do much unless you go via the GP [general practitioner)*' [G7_staff]. Therefore, the staff suggested '*a facilitator could smooth the review process'* [G5_staff].

Carers perceived that information about medication management provided by health professionals was inconsistent: '*There is a conflict between when I am told by someone when I am told by someone else*' [G2_carer]. Therefore, they had to ask for help from a trusted community pharmacist: '*I go to the pharmacist … and they know what you have got and what you have not got … actually I take the pharmacist's advice more than I take some doctor's advice*' [G2_carer]. Staff also echoed similar concerns about inconsistent information about medication provided to the carers: '*If you go to one specialist, a heart specialist, it says you do not take this tablet … you go to the kidney specialist, and they say oh, you need it now. They are getting mixed messages*' [G13_staff].

The PLWD usually experiences constant medication changes due to complex health conditions. This situation was a source of stress for carers: '*The numbers of medication changes, not just doses, but the medication itself, and that was expensive, difficult*' [G4_carer]. Staff suggested that a facilitator could be crucial in supporting carers to reduce the stress associated with medication changes: 'If there is actual support there, *then the likelihood is that their medications are being well-managed*' [G8_staff]. Moreover, the facilitator could enable carers to use various methods such as Webster packs to prevent them from spilling or mixing up the medicines as '*some carers do not know there was Webster pack*' [G5_ staff]. However, carers questioned the possibility of facilitators having a role in medication management: '*I do not know whether a facilitator would help … a facilitator would not know more than the prescribing doctor, I am sure*' [G4_carer]. The findings indicate that the facilitator needs to be a skilled health professional or play a coordinator's role in assisting carers in communicating with pharmacists, GPs and registered nurses regarding medication management when needed.

5.7.2.3 Sub-finding 3: The need to support carers to cope with emotional stress

Carers often experience emotional stress: '*As a carer, I know I have run the full gamut of all those emotions … that you are in a hopeless cruel situation in so many ways. So, getting that support is vital*' [IN1_carer]. However, they rarely shared their stress with health and social care professionals or asked for help from them: '*Just somebody else sticking their nose in our business when they offered us mental health support because we just did not want to have to keep telling different people the same story over and over again*' [G4_carer]. Staff participants suggested that to modify such a situation; it was important that relationships with carers involved trust: '*You will need to find some ways to build up trust relationship for us to be able to understand each other and ready to find that to help them*' [IN2_staff]. Carers further described the reason for not seeking help during stressful times: '*I do not think anyone else understands, especially if they are not going through our journeys. You can sit here and talk to me for as long as you want, but you do not understand*' [G4_carer]. This case emphasised the need for staff and facilitators to demonstrate empathy.

Staff were involved in referring carers to mental health activities when they found that carers were in a crisis:

> *There have been a few cases where I have had to get the aged care mental health service involved, to do an urgent assessment and hospitalisation of some of my clients because they have just had such huge dementia crises. [G12_staff]*

In such cases, mental health support came too late and was insufficient. Staff were aware that their ability to provide counselling support for carers was limited: '*I think we could provide mental health support to a point. Moreover, I think it needs to be specialised*' [G7_staff]. Carers and staff agreed that a facilitator could '*offer timely personalised support in person*' [G14_carer], '*enhance the relationship building*' [IN2_staff], '*better understand carers' needs*' [IN2_staff] and '*[link] carers to mental health support activities*' [G3_staff].

Overall, finding 2 revealed the sources of stress related to the changed behaviour of PLWD (care recipient factors), difficulties managing dementia and medication (carer factors) and lack of timely emotional support for carers (service provider factors). Participants perceived that a facilitator could play crucial roles as an educator, resource person and coordinator who could support carers in managing changed behaviour and reviewing medication and as a trusted professional who could check carers' mental health status and provide timely interventions and referrals.

5.7.3 Finding 3: The facilitator's role during transition moments

Carers often experience significantly stressful situations during transition moments, for example, being unable to care for their care recipients when they experience health issues or when their care recipients experience changes or transitions between home and hospital. The sub-findings detailed in the following subsections indicate the role a designated iSupport facilitator could play during transition moments.

5.7.3.1 Sub-finding 1: The need to help carers obtain timely respite care activities

Carers usually experienced difficulties in obtaining respite care for PLWD, especially when PLWD presented with changed behaviour: '*I was on the phone trying to organise a respite before I went for my surgery, but no one would take him [due to changed behaviours]. We were both in the hospital at the end*' [IN4_carer]. This case indicated that a provider factor was those with changed behaviour being excluded from respite care. Staff who worked in the hospital settings also observed a lack of suitable respite care for PLWD: '*It is always a known fact that just before Christmas you get a lot more dementia patients so families can go on holiday*' [G3_staff]. Such situations revealed that avoidable hospitalisations for PLWD were due to difficulties in accessing respite care when carers needed it. Some carers reported a lack of competence among staff caring for PLWD in respite care: '*Kathy [pseudonym] got expelled from the nursing home after a day because they just could not do anything with her*' [G4_carer]. Long waiting times were also a stressor for carers:

> *Because Veterans Affairs told me you are entitled to so many hours, I thought, okay, I am going to put her in somewhere for a couple of days so I can reboot … But then I have got to wait however long. [G1_carer]*

Carers often needed to fill out multiple forms and contact multiple agencies: '*It is overwhelming, and there are some things that I have got sitting here that I am supposed to do*' [G10_carer]. They often tirelessly tried to access activities: '*You need a lot of time and effort to access precisely what the service provider provides, and it can be multiple service providers*' [IN2_staff].

Staff were also concerned that respite care was not accessible for some PLWD: '*In-home respite is quite more expensive … you would only really be able to have that if you have Level*

4 [Home Care Package]’ [G5_staff]. Staff also noticed some carers' reluctance to utilise respite care due to their guilt: ‘*They feel if they are not there to provide care. At least they could be physically there with the patient … it is hard, especially when the patient is elderly and the carer is also an elderly person*’ [IN2_staff]. Meanwhile, underutilised respite care was also observed by staff: ‘*So we do see patients where they are underutilising their Home Care Package, not because it is not available but just because they did not know they could ask for more help*’ [IN2_staff]. Carer and staff welcomed the idea of a designated facilitator who could ‘*link them to available activities*’ [G3_staff] to alleviate stress because ‘*they often do not know where to start*’ [G14_carer].

5.7.3.2 Sub-finding 2: The need to support carers during the hospitalisation of their care recipients

Hospital admission was a significant source of stress for carers. Carers rarely understood the information provided by healthcare staff during hospitalisation: ‘*It has been a nightmare of just, once you are in the system, you just get random phone calls from people that tell you things, and you cannot internalise it and understand what they are telling you*’ [G14_carer]. Carers also experienced stress when they observed a lack of dementia care strategies in the hospital settings:

> *She was in a room by herself. She had the railings up. However, for her to get the railings down to go to the loo on the floor, which she would not understand … she would have fallen. Moreover, the staff could not be there 24/7 because they were so busy. [G9_carer].*

Carers’ stress increased when they were unable to be the voice of PLWD because they were denied hospital visitation: ‘*We had two incidents during the [COVID-19] lockdown where mum falls—by taking her to hospital by ambulance. One hospital would not allow me to go in at all*’ [G9_carer].

Staff recognised that a lack of information regarding PLWD affected their care performance: ‘*It becomes challenging to understand what is happening. Moreover, it may take a couple of days to understand how to manage that thing*’ [G10_staff]. Staff identified the need to partner with carers in all aspects of care, for example: ‘*PLWD’s usual behaviour*’ [G7_staff], ‘*communication style*’ [G3_staff], ‘*discharge planning*’ [G11_staff], ‘*medication list*’ [G13_staff] and ‘*advance directives*’ [G3_ staff]. Moreover, staff described a lack of continuity of care in the current health and social care systems: ‘*You have got to start from* *scratch with rapport and everything like that*' [IN 2_staff]. They embraced the idea of a facilitator to enhance care continuity: '*So having some continuity for those transitions with a support worker who follows you through all of those changes from home to hospital, back home, to placement, palliative care*' [IN 2_staff].

Overall, finding 3 revealed that there are three types of factors contributing to carer stress, as described in the conceptual framework: care recipient factors (i.e., hospitalisations), carer factors (i.e., lack of knowledge of respite care or lack of self-efficacy needed to obtain it) and service provider factors (i.e., exclusion of PLWD with changed behaviour from respite care, and lack of support for and partnership with carers during hospitalisation). Participants perceived that a designated iSupport facilitator could mitigate these stressors and advocate on behalf of PLWD for inclusive respite care activities.

This is the end of the publication.

5.8 SUMMARY

Chapter 5 presented the findings from phase 1, as part of publication 4 and 5, which explored activities to be delivered by iSupport facilitators to better support carers and the roles and responsibilities of iSupport facilitators to address the aim of the present study. Stakeholders agreed on 16 relevant activities to be delivered by iSupport facilitators in the program. These 16 activities aimed to support carers to cope with 1) care recipient-related challenges; 2) carer-related stress, and 3) system-related stress. Stakeholders also agreed that iSupport facilitator support should occur at the time of dementia diagnosis, throughout the everyday dementia care journey, and during transition moments. The engagement with stakeholders informed the project team of the facilitators' role and relevant activities to support carers of PLWD in the program. The knowledge generated from phase 1 provided the groundwork for facilitator training requirements to prepare for phase 2 of the study.

6 Findings Phase 2: Feasibility, fidelity and strategies to embed and sustain iSupport program

6.1 INTRODUCTION

Chapter 5 reported findings from phase 1 of the study. The relevant activities and the roles and responsibilities for iSupport facilitators identified in phase 1 informed the training program development for iSupport facilitators and the implementation manual. This allowed for standardisation of the intervention in the RCT of the planned iSupport program in phase 2. This chapter reports the phase 2 findings related to study objective 3) to determine the feasibility of the participant recruitment and factors affecting the recruitment; 4) to determine the attrition rate and factors contributing to the attrition; 5) To monitor intervention fidelity and factors affecting the fidelity; and 6) to explore strategies to embed and sustain the facilitator-enabled iSupport program after the trial. Findings related to study objective 7, determining the intervention effectiveness with the given sample size at six months, are presented in the next chapter. This chapter starts with the overall findings in phase 2 using qualitative and quantitative data according to the methodology and method discussed in Chapter 4. Section 6.3 presents the characteristics of participants in phase 2 related to the study objectives 3-6. Section 6.4 presents other data analysed for phase 2. Section 6.5 presents finding 1, the feasibility of participant recruitment, followed by section 6.6, which discusses finding 2, participant retention and attrition in the study, and finding 3, intervention fidelity. Section 6.6 presents finding 4, strategies to embed and sustain the facilitator-enabled iSupport program after the trial. Finally, a summary of chapter 6 is presented in section 6.7.

6.2 OVERALL FINDINGS IN THE INTERNAL PILOT STUDY

Table 6-1 displays the overall findings of the internal pilot study using quantitative and qualitative data.

Table 6-1 Phase 2 overall findings

Study objectives	Findings	Related quantitative data	Related qualitative data
Objective 3: To determine the feasibility of the participant recruitment and factors affecting the recruitment.	Finding one: feasibility of participants recruitment to the study Sub-finding 1: recruitment rate Sub-finding 2: Factors related to difficulties in recruitment Sub-finding 3: Inclusion Criteria modification to address the recruitment difficulties	Recruitment rate: 10%	**Reasons for declining** participation: 1) group preference. 2) too busy; 3) wanted the research team to contact their children; 4) already well supported; 5) not interested in Zoom meeting; overwhelmed by paperwork and survey **Factors related to difficulty in recruitment:** 1) The recruitment process was time-consuming 2) carers factors 3) need to modify inclusion criteria
Objective 4: To determine the attrition rate and factors contributing to the attrition	Finding two: Study retention and attrition and associated factors	Retention rate: 80% Attrition rate: 20% The attrition rate in the intervention group: 30% Attrition rate in usual care group: 11%	**Reason for attrition:** 1)PLWD passed away; 2) PLWD being admitted to permanent residential care; 3) being unable to contact; 4) withdrawing without disclosing the reason
Objective 5: Monitor intervention fidelity and factors affecting the fidelity.	Finding three: intervention fidelity Sub-finding 1: Intervention modification Sub-finding 2: Carers' completion of iSupport manual Sub-finding 3: Facilitator support Sub-finding 4: Online peer support meetings Sub-finding 5: WhatsApp group Sub-finding 6: Carers' satisfaction with the program Sub-finding 7: Compliance with data collection methods	**iSupport manual completion:** Completed some of the book: 92% Completed entire book: 29% Completed half of the book: 28% Completed 20% of the book: 20% Not complete any: 7% **iSupport facilitator support** - facilitator motivated carers to learn: 96% - Individual support request: at least 2/month -Time spent on support: 20-60 min/each support **Online peer support meetings** -most participants attended 80% of the peer support meetings **WhatsApp group** 5 private groups	- Need to modify intervention - most cares engaged with the iSupport manual - iSupport facilitators regularly posted dementia knowledge in a peer support group - Facilitator support to carers was welcomed by carers and considered extremely helpful -peer support meeting was last more than 30 min -some carers are active, others are not
Objective 6: To explore strategies to embed and sustain the facilitator-enabled iSupport program after the trial.	Finding four: Strategies to embed and sustain the facilitator-enabled iSupport program after the trial. Sub-finding 1: Enablers and challenges of embedding		-Organisation-supported site leaders and iSupport facilitators well -difficulty in facilitator employment

	and sustaining the iSupport program Sub-finding 2: Engaging carers in the program using ISupport for Dementia manual and diverse carer needs for learning resources Sub-finding 3: Introducing the facilitator-enabled iSupport program to carers through the dementia care journey. Sub-finding 4: Strategies to improve carers' experience in support groups Sub-finding 5: The need to identify a funding source to sustain the iSupport program Sub-finding 6: The need to demonstrate the innovation of the iSupport program		- Carer feedback on iSupport for Dementia manual -carers feedback on facilitator-enabled iSupport program
Objective 7: Determine the intervention effectiveness with the given sample size at six months.		QOL-PCS↑	51.98 to 52.62
		QOL-MCS↑	43.57 to 45.88
		SE-OR ↑	46.69 to 52.77
		SE-RB↑	69.82 to 76.01
		SE-CT↑	57.65 to 57.93
		RMBPC-R↑	1.99 to 1.77

Notes: QoL-AD= QoL in Alzheimer's Disease- Family version; RMBPC-F= Revised Memory and Behaviour Problem Checklist-Frequency; RMBPC-R= Revised Memory and Behaviour Problem Checklist-carer reaction; SF12-MCS= QoL: 12-item Short-Form Health Survey mental health component score; SF12-PCS= QoL: 12-item Short-Form Health Survey physical health component score; QOS= The Carers of Older People in Europe Index-Quality of Social Support; SE-OR=Self-efficacy-obtaining respite; SE-RB= Self-efficacy-respond to behaviour; SE-CT=Self-efficacy-control unpleasant thoughts.

6.3 CHARACTERISTICS OF PARTICIPANTS

Eighty-four carers were randomised for the internal pilot RCT (Figure 6-1). Of these, 40 were allocated to the intervention group and 44 to the usual care group. The carer participants' demographics are displayed in Table 6-2. The average age of the family carers was 66 years (SD=14). Most carers were female (n=57, 68%), spousal (n = 45, 54%), retired (n=49, 60%), and lived in the same household as the PLWD (n=59, 70%). Family carers spent 10 hours (SD=11) a day and nearly six days (SD=2) a week on care activities.

Table 6-2 Phase 2 Carers' socio-demographic characteristics

Demographics	Total (N=84)
Age, mean (SD)	66 (14)
Gender, n (%)	
Male	27 (32)
Female	57 (68)
Relationship, n (%)	
Spouse	45 (54)
Non-spouse	39 (46)
Marital status, n (%)	

Demographics	Total (N=84)
Married/partner/de-facto	69 (79)
Single/divorced/widow	17 (20)
Employment status, n (%)	
Employed	29 (35)
Unemployed	4 (5)
Retired	49 (60)
Live in the same household as PLWD, n (%)	
yes	59 (70)
No	25 (30)
Years living in the same household as PLWD, mean (SD)	40 (22)
Average hours per day on carer activities, mean (SD)	10 (11)
Average days per week on carer activities, mean (SD)	6 (2)
Years of being in a carer's role mean (SD)	4 (4)
Do other family members support you in your caring role, n (%)	
Yes	67 (82)
No	15 (18)

Note: PLWD=person living with dementia

The PLWD's social demographics are displayed in Table 6-3. The average age of PLWD is 80 years (SD=11), and they are almost equally present as males and females. 65% PLWD (n=55) presented with mild cognitive impairment, and most of them (n=49, 58%) had more than one chronic condition other than dementia or cognitive impairment.

Table 6-3 Phase 2 Person living with dementia's socio-demographic characteristics

Demographics	Total (N=84)
Age, mean (SD)	80 (11)
Gender, n (%)	
Male	41 (49)
Female	42 (50)
Cognitive stage, n (%)	
Mild	55 (65)
Moderate	29 (35)
Chronic condition, n (%)	
no	12 (18)
1-4	49 (58)
≥ 5	7 (10)
Length of diagnosis or show symptoms, mean (SD)	4 (4)

A total of 19 individual interviews were conducted with 13 carers, three facilitators and three site leaders. The characteristics of the participants who attended the interview were displayed in Table 6-4.

Table 6-4 Phase 2 characteristics of participants in the interview

	Staff	Carers
	Site leaders n=3 Facilitators n=3	Spouse n=7 Children n=6
Age		
20-40	1	1
41-65	4	5
>65	1	7
Gender		
Male	1	2
Female	5	11
Education level	Diploma n=1 Bachelor n=1 Masters n=1 PhD n=3	N/A
Units completed in the iSupport manual	N/A	All n=5 80% n=3 70% n=2 <50% n=3
Role in the organisation	Project officer n=2 iSupport lead n=1 Director n=1 Unit manager n=1 Senior research fellow n=1	N/A
working status	N/A	Full-time worker n=2 Part-time worker n=1 Casual worker n=1 Retired with casual work n=1 Retired n=7 Unemployed due to caring role n=1
Length in the current role		
1 month -11 months	2	N/A
1 year – 4 years	1	
5 years -9 years	3	
>10 years	1	
Length in the carer role		
1 year – 4 years	N/A	9
5 years -9 years		3
>10 years		1
Length of employment in the organisation		
1 month -11 months	1	N/A
1 year – 4 years	2	
5 years -9 years	2	

6.4 OTHER DATA ANALYSED FOR STUDY PHASE 2

Other data analysed for phase 2 were 24 recorded peer support meetings, 32 facilitators' portfolios, 97 comments in the survey, WhatsApp messages between October 2022 and October 2023, and research assistants' documentation from March 2022 to April 2023. A letter from one carer that summarised his experiences was also included in this analysis with permission. Selected quotes were given a code based on the data source. The list of legends is displayed in Table 6-5.

Table 6-5 Phase 2 Code legend

G_P	Peer support meeting recording	C_L	Carer's letter to the researcher
G_T	WhatsApp messages	FP	Facilitator portfolio
I_C	Carer in the iSupport group interview	SC	Survey comments
I_F	Facilitator interview	RA	Research assistants' documentation
I_SL	Site leader interview		

6.5 FINIDNG 1: FEASIBILITY OF PARTICIPANT RECRUITMENT TO THE STUDY

6.5.1 Sub-finding 1: Recruitment rate

The recruitment process is displayed in Figure 6-1. Four historical data sets were screened, with 7000 potential recruits. However, only 815 identified carers meeting the selection criteria were contacted. Of those, 411 (50%) declined to participate. A further 493 potential participants were assessed for eligibility, including 404 carers identified via data screening across four sites and 89 carers expressing interest from social media. Further, 306 carers were ineligible or declined to participate after the initial assessment. Another 101 potential participants met the eligibility criteria and agreed to participate but did not return consent forms or withdraw prior to randomisation. One participant did not return consent because the care recipient moved to an aged care facility (approximately 3 months). Eighty-four carers (an average of 7 participants/month) consented to participate and were randomised to intervention or control groups, equivalent to a 10% recruitment rate.

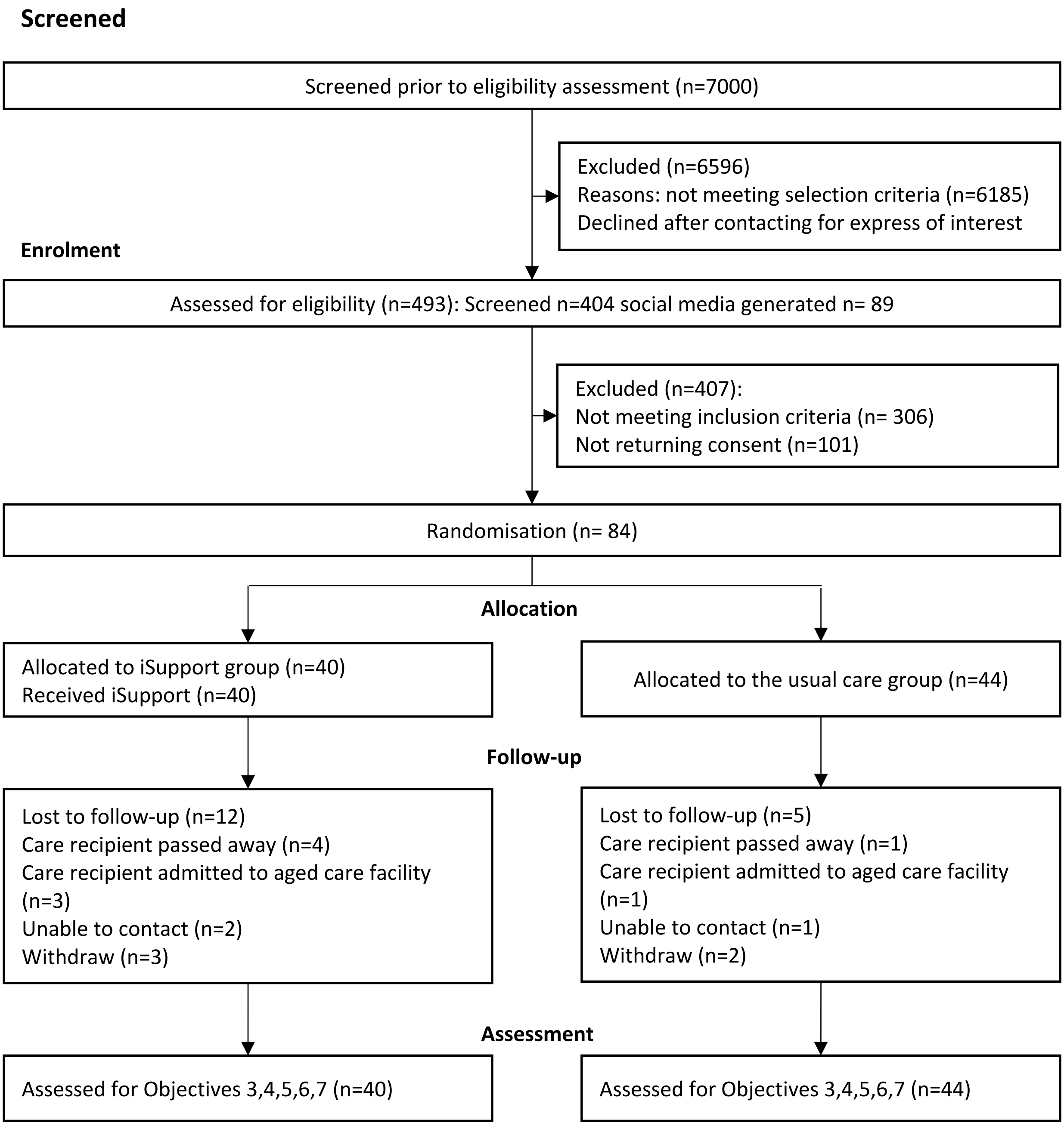


Figure 6-1 Phase 2 Flowchart of recruitment and retention

The reasons for carers declining the study include ‘*uncertainty of which group they may be allocated to (i.e., a preference for intervention or usual care group)*’ [RA]; ‘*the iSupport program did not meet their needs (e.g., the carer needed a financial advisor at the time)*’[RA]; *‘too busy to participate’* [RA]; ‘*wanted research team to contact their children (Children were not contactable)*’ [RA], ‘*already well supported*’ [FP3_2], ‘*not interested in Zoom meeting*’ [FP3_2], or ‘*overwhelmed by the paperwork for consent and monthly surveys*’ [RA]. One interviewee also expressed concern about the paperwork involved in the consent process: ‘*The very onerous process of getting people through the consent process through all of that baseline data collection, it has put many people off*’ [I_S2]. Other reasons, such as difficulty in reading or accessing the internet, were also documented by one facilitator who was helping with the recruitment:

> *We have had feedback relating to older carers not having access to schooling, and they can only read and write basics, so participating where there is reading matter is of no interest to them. Some admitted to being too old to read books or go online. [FP3_2]*

6.5.2 Sub-finding 2 Factors related to difficulties in recruitment

6.5.2.1 The recruitment process was time-consuming.

The screening process was identified as taking longer than anticipated as '*care recipients had no easily identifiable diagnosis of dementia*' [RA]. Case notes needed to be read in detail to identify the medical history or symptoms of PLWD, which prolonged the screening process. The assessment of eligibility and the consent process took longer than anticipated. It often took multiple phone calls to book or reschedule appointments. '*Each phone call could take 10 to 60 minutes for the research assistant to explain the study*' [RA]. The return of consent forms was slow and often took several weeks, up to 3 months, with '*some carers requiring 3 to 7 reminder phone calls/emails/text messages from the research assistant or facilitator*' [RA, FP3_2]. Having carers accept calls from unknown numbers presented difficulty in contacting potential participants. One interviewee said: *'The older generation and I also class myself in this. When somebody phones and you do not know the number. They do not answer'* [I_F3].

There was a limitation in obtaining PLWD data as *'many did not want to be involved'* [RA] or *'were not available when carers were undergoing assessment (e.g., attending day respite services)*' [RA]. Many potential participants were daunted by the lengthy participants' information and consent form, with the MBS/PBS release of data being of most concern. '*Given that this form releases extensive personal information with risk of security breaches, many participants opted out of consent for this component*' [RA].

6.5.2.2 Clinician-related factors in the recruitment process

Relying on clinical staff to refer potential participants was difficult because clinical staff already had a heavy workload. Clinical staff can also have different priorities, for example:

> *The recruitment was not easy and also relying on staff within the organisation to support the recruitment…where it is easy to be let down in that space, just because this projects at the forefront of your mind does not mean it is at the forefront of everyone else's. [I_F1]*

Staff turnover also challenges recruitment: '*We have had a huge turnover staff, so a lot of the coordinators were not here when the project started'* [I_F2]. Competing with other projects within one organisation to recruit was also identified as a challenge: '*The difficulty for us was, at the same time, other research projects were also going on. So even when we identify [them] if they were included in other dementia studies, we would not recruit them'* [I_S3].

6.5.2.3 Carer-related factors in recruitment

The recruitment challenges also prompt questions about the needs of participants with generational differences and differences during their care journey. One interviewee said:

> *There is a misalignment to the [project] requirements of the population [younger, internet user], [we are] trying to sell that [iSupport program] to a person who is of the different population [most service users are older, majority of them are not an internet user] is difficult…Carers need more assistance earlier in their journey. [I_F2]*

A site leader from the hospital also raised this. For example:

> *Maybe it is not just a recruitment challenge in terms of getting people to do consent processes and other things within a difficult time, but maybe actually that is not the right moment in a carer's journey to be wanting to do a whole bunch of extra self-care, education and psychoeducation work. [I_S3]*

Expressing interest through social media was considered a feasible approach and resource-saving strategy, welcomed by site leaders. For example, one site leader stated:

> *Trying to utilise EOI approaches rather than the point of care approaches, I think, has been hugely beneficial for the feasibility of the project… focusing much more explicitly on those kinds of methods would have probably saved much time and probably not cost as much in terms of recruitment challenges. [I_S1]*

6.5.3 Sub-finding 3: Inclusion criteria modification to address recruitment difficulties

The study was initially intended to recruit carers of people with a formal diagnosis of mild or moderate dementia; PLWD were assessed by the research assistant to determine the carer's eligibility. In addition, the family carer needed to be a computer user and have internet access. In the first two months of unsuccessful recruitment on receiving feedback from research assistants and site leaders, the inclusion criteria were expanded to include carers of people with any level of cognitive impairment. The assessment of PLWD's level of impairment was altered to accommodate the carer's observation. A further modification was that carers in the intervention group no longer needed to be computer users and could opt to receive phone call support instead.

The modified selection criteria were beneficial for the recruitment process. One site leader stated in the 6-month interview: '*I think it was beneficial to change the criteria a little bit to improve the recruitment…we also know that in the community there are many people who are not necessarily formally diagnosed*' [I_S3]. Another site leader echoed this: *'The softening of inclusion criteria requirements… was beneficial'* [I_S1]. These comments from team members and recruitment improvement indicated that the modification was necessary.

6.6 FINDING 2: STUDY RETENTION AND ATTRITION AND ASSOCIATED FACTORS

Of the 84 participants, 17 were lost at the 6-month follow-up, making up to a 20% attrition rate or 80% retention rate. However, more participants dropped out from the intervention group (n=12, 30%) compared to usual care group (n=5). Of the 12 participants who dropped out from the intervention group, more were from community aged care services (n=8) than hospitals (n=4). The reasons for the 17 participants dropping out included 1) PLWD passing away (n=5), 2) PLWD being admitted to a permanent residential care facility (n=4), 3) being unable to contact (n=3), and 4) withdrawing from the study without disclosing reason (n=5).

6.7 FINDING 3: INTERVENTION FIDELITY

6.7.1 Sub-finding 1: Intervention modification

The planned facilitator-enabled iSupport program was to use an internet-based iSupport program, and carers were required to be computer users to attend monthly Zoom meetings to receive virtual support. The modification of the inclusion criteria results in the modification of the intervention. Furthermore, the internet-based iSupport program was delayed in development and was only available six months after we started the project. Therefore, the intervention was modified from solely virtual intervention and support to enable carers to receive hard copies of books and support from facilitators via phone calls to accommodate carers without internet access.

6.7.2 Sub-finding 2: Carers' completion of iSupport manual

All intervention group carers received a hard copy or an electronic book. In addition, some participants requested website access after it opened for use. Of the 28 participants in the intervention group at 6-month follow-up, 25 carers documented their book completion, and 23 (92%) carers completed some part of the book. Eight carers (29%) completed the entire book, seven carers (28%) completed over 50% of the book and eight carers (29%) completed around 20% of the book. Only two (7%) carers did not read any part of the book; one carer due to a busy family lifestyle, and the other because the electronic book link was broken; however, this carer did not contact the facilitator for an updated link. The book completion rate was much lower than planned in the protocol, in which all carers in the intervention group completed 70% of the book in six months.

Qualitative data analysis indicated that most carers engaged with the iSupport hardcopy manual with facilitators' support. For example, one carer stated in the peer support meeting: *'I read module four because you [facilitator] asked us to, which was helpful. It confirmed many things I had picked up along the way* [G4_P]'. ISupport facilitators tried different methods to engage carers in using the iSupport manual via WhatsApp groups and monthly peer support meetings [G4_P]. One facilitator posted regular small pieces of dementia knowledge in the WhatsApp group, for example: '*Another bite-sized iSupport module today on tips for helping with toileting…*' [G4_T].

Facilitator posted the link to the iSupport manual on WhatsApp as a reminder. One facilitator posted:

> *I mentioned in the meeting that the iSupport program is developed by the WHO, which aims to support the carers for people living with dementia…All the contents are trustworthy and evidence-based…This month's topic is " changed behaviour and what is the better way to deal with it". The relevant pages are 263…[G2_T]*

This finding indicated that although some carers may not have completed the required proportion of the manual, the information in the manual was delivered by facilitators in different formats and potentially affected their understanding of dementia.

6.7.3 Sub-finding 3: Facilitator support

Most carers (n=15, 68%) in the intervention group were satisfied with support from their facilitators, and another six (27%) carers did not request support from the facilitator (Table 6-6). Facilitators offered support in different ways. For example, one facilitator encouraged her group to document their loved one's favourite things on '*Capturing Memories*' [FP3_2]. The carer also requested one-on-one support from the facilitator for various reasons. All facilitators received requests from carers for one-on-one support at least twice a month, and some facilitators can receive phone calls or emails up to eight per month.

The time spent by the facilitator for each support varied *'from 20 minutes to 60 minutes'* [FP1_2, FP2_2, FP3_2, FP4]. One carer requested support because she *'wanted to decide to see a psychologist for loneliness'* [FP3_2]. Carers found one-on-one support from the facilitator was extremely helpful, for example:

> *I have had my father die (not with dementia) a few weeks ago, and I have had to manage my mother's emotions (she is the one with dementia). It was distressing and stressful. I felt the overall support I got from iSupport on an individual basis was great - from mostly an emotional level. [SC27]*

Site leaders also acknowledged facilitators' contributions, for example:

> *I think the facilitator role is critical. The carers appreciate that consistency, that same person they can come to; no question is too small. So, helping people navigate services and the journey helps them understand that many things are. [I_S2]*

Facilitators also enjoyed the emotional support and practical professional advice they could offer carers. One facilitator stated: *'I think that the facilitator role was more than just a listening ear and listening to the problems because they relied on having that professional Point of view'* [I_F1].

However, improved training may better support facilitators. Facilitators often need to draw on their own experiences to provide support. One facilitator said:

> *iSupport Facilitator is giving support through experience. No education and training were given before this task. As I have more than ten years experience as a registered nurse caring for people with dementia, I have given participants psychological support. [FP2_2]*

The site leader also raised this. For example:

> *[Facilitator] training could be strengthened by using the scenario-based that we can discuss in different situations. Because you had the previous iSupport project, we could learn from what they have encountered…I think it would perhaps make the approach a little bit more consistent. [I_S3]*

6.7.4 Sub-finding 4: Online peer support meetings

Online peer support meetings were designed to run 30 minutes monthly and organised by iSupport facilitators. The attendance of online peer support meetings varied at each site. One site runs '*two peer support meetings on two days'* [FP1_2], while another runs '*two on the same day to accommodate carers' needs*' [FP3_2]. Two other sites run '*one peer support meeting'* [FP2_1, FP4]. Each meeting had 4-8 carers attending. When more carers attended meetings, facilitators reported that some meetings needed to run over 30 minutes, and most needed one hour due to '*many carers having difficulty logging in at the beginning or wanting to chat more after the 30 minutes*' [FP1_2, FP2_2]. Compared to the planned peer support meeting length (12 carers/30 min/session = 2.5 min/carer), a much longer peer support meeting was delivered (8 carers/60 min/session or four carers/30 min/session =7.5 min/carer).

Many participants commented on the length of peer support meetings. One participant in the WhatsApp group suggested that '*the meeting should be 45 to 60 minutes instead of 30 minutes*' [G1_T]. This was echoed by other carers in the interview*: 'Need longer meeting. 30 minutes is insufficient for everyone to talk'* [I_C4, I_C7, I_C8, I_C10, I_C11, I_C13, I_C16, I_C17, I_C19]. It was also because new carers joined the group every month since the recruitment continued, and new participants were added to the existing group. One carer expressed: *'Because we are also getting new people in, we would always have to return to introduce ourselves again'*[I_C17]. However, the time was sometimes insufficient because carers had difficulties logging in to the Zoom meeting. For example: '*It was sort of a bit awkward because a lot of the time was wasted as people were trying to get on and you know, they are not understanding the system*' [I_C10].

According to the facilitator portfolio, most participants attended 80% of the peer support meetings. Not everyone in the study was willing to participate in the monthly Zoom peer support meetings. For example, one site has '*four participants opt out of Zoom meetings but are happy for the facilitator to contact them via phone monthly*' [FP1_2]. One participant withdrew from the peer support meeting because '*she was the only one who cared for persons with earlier onset dementia in the group; all other people were interested in aged care services, whereas her focus was on disability services*' [FP1_2]. One participant attended a peer support meeting with her daughter as her technical support [G2_P].

6.7.5 Sub-finding 5: values of WhatsApp group

iSupport facilitators created five private WhatsApp groups for carers in the intervention group. Site one created two WhatsApp groups to limit the numbers in each group. Carers' interactions on WhatsApp varied between groups. Most groups have carers who regularly interact while others remain in the group but do not interact. One carer stated:

> *And I guess it was good to be able to chat and ask questions, but it is also hard, I think, to get different people to become involved because I noticed that I might ask a*

> *question, someone else might say something, but there would only be a couple of us that actually would use it, and I do not know would you encourage people to have more of a conversation? [I_C17].*

Relationships need to be built before carers can interact with each other via WhatsApp. One carer stated:

> *It [text each other] has not happened. We do not know each other well enough. Theoretically, we were supposed to talk to each other, but the group changes, and there is no way that sort of thing has been able to happen [I_C8].*

Facilitators often posted information to encourage group interaction. Carers often use WhatsApp messages to exchange information and support each other. The information exchanged includes ‘*how to access services’* [G2_T], ‘*nutrition*’ [G2_T], ‘*how to respond to changed behaviours’* [G1_T] and ‘*ensure other carers were doing ok’* [G3_T]. On one occasion, the facilitator was on leave, and carers in the group also texted to ‘*make sure the facilitator was okay* ‘[G4_T]. Facilitators also posted the website or support services link through WhatsApp groups. For example: ‘

> *I wanted to make sure you knew about Aged Care Alternatives. There is a FREE information service located…They can provide information regarding a wide range of services offered by aged care organisations…They offer info on a range of services such as Advance Care Directives, Wills, Financial Advice… [G1_T]*

Facilitators and site leaders observed the increased WhatsApp group interactions over time. One site leader stated: ‘*Now I see a lot of the interaction between them [carers] automatically, and they did share a lot of their photos and the place they have visited*’[I_S3]. Others also suggested that having regular face-to-face catchups in the same city may be helpful, for example: ‘*I would like to build these relationships if the people in Adelaide can perhaps go for a coffee together and meet somewhere’* [I_C12]. These findings indicate that the use of WhatsApp among carers of PLWD is varied and may take longer time before carers are comfortable interacting with each other.

6.7.6 Sub-finding 6: Carers’ satisfaction with the program

Carers in the intervention group are satisfied with the program, indicated by most attritions were due to PLWD passing away or being admitted to a permanent residential care facility. Many carers stated that ‘*they would like to stay in contact with the group after the completion of the program’* [FP1-2]. Carers were also satisfied with the individual components of the program as presented above. Furthermore, the carers' satisfaction survey result (Table

6-6) showed that the majority (n=23, 96%) of carers in the intervention group considered the iSupport facilitator motivated them to learn from the program. ISupport facilitators helped most carers (n=18, 75%) identify their learning needs. Most carers were satisfied with the peer support meetings (n=15, 71%) and interaction on the WhatsApp (n=14, p=67). Eight (47%) carers considered the facilitator responded to their request promptly, whereas another eight (47%) indicated it did not apply to them. Two participants expressed that their facilitator did not help them identify learning needs, and three reported that the facilitator did not motivate them to join peer support groups or encourage them to interact with others. None of them elaborated on their concerns in the comments area.

Table 6-6 Phase 2 carer's satisfaction survey

	Agree/strongly agree		N/A	
	N	%	N	%
1.My facilitator motivates me to learn from the iSupport program.	23	96	0	0
2.My facilitator helped me identify learning units of the iSupport that are relevant to my situation.	18	75	4	17
3.My facilitator helped me identify healthcare/social care services my care recipient and/or myself need.	15	68	6	27
4.My facilitator motivates me to participate in the care support group meeting.	13	62	7	25
5.I am satisfied with the carer support group meeting.	15	71	5	24
6.My facilitator motivates me to interact with other carers on a weekly basis.	14	67	5	24
7.I am satisfied with the weekly carer interactions via chat and text messages.	14	67	6	29
8.My facilitator responds to my request for support on a timely manner.	8	47	8	47
9.I am satisfied with the individualised support my facilitator provided to me.	11	58	7	37
10.Overall, I am satisfied with the support my facilitator provided to me	15	68	6	27

Note: N/A=not applicable or not requested

6.7.7 Sub-finding 7: Compliance with data collection methods

At six months, 28 participants completed their survey, with a further three lost to follow-up. Among participants lost at six-month follow-ups, three could not be contacted and did not return their six-month survey. Missing data analysis showed that data was missing completely at random (p=0.005) (See Table 6-7). Univariate statistics show missing data in survey SF12 Health Survey v2, QOL-AD, RMBPC, QOS, and SE-CT were acceptable (<5%). In the carers' self-efficacy survey, self-efficacy for obtaining respite and responding to disturbing behaviours have missing data values of over 5%. Research assistants' records showed that participants often questioned this survey due to how the question was asked. Many participants filled in the information that was not applicable to the entire survey. Some carers '*have no family'* [SC29] and '*no friends to ask for help'* [SC 52], or they '*go everywhere together [instead of asking for help]'* [SC98]. Many carers were concerned that the survey they completed could not fully capture their experience. For example, one carer said: *'It [survey] was targeted more at people who were working, and I think I said before I do not work, but I do a lot of volunteer work, but that was not assessed in any way' [I_C10].* Another carer also expressed this:

> *I think maybe just the survey [is a difficulty]. My situation was a bit different, and my mum went into full-time, but respite care was quite extended, so I think maybe I should have reached out to get some clarity, but it was just around filling out some of the hours and times. Because she was getting full-time care in a facility but was not signed up as a full-time resident yet. [I_C11]*

Table 6-7 Phase 2 missing value analysis

Surveys	N	Mean	Std. Deviation	Missing		EM means
				N	%	
SF12 PCS	66	52.02	10.78	1	1.5	52.02
SF12 MCS	66	44.21	11.49	1	1.5	44.21
QOL-AD	66	60.30	14.56	1	1.5	27.03
RMBPC-F	66	44.56	13.39	1	1.5	60.30
RMBPC-R	66	27.03	5.97	1	1.5	44.56
QOS	66	12.55	3.84	1	1.5	12.55
SE-OR	59	243.22	135.17	8	11.9	241.58
SE-RB	63	312.29	124.22	4	6.0	308.71
SE-CT	64	288.84	144.33	3	4.5	291.71

Little's MCAR test: Chi-Square = 64.485, DF = 38, Sig. = .005

Notes: EM= expectation-maximization; MCAR= missing completely at random; QoL-AD = QoL in Alzheimer's Disease- Family version; QoS= The Carers of Older People in Europe Index-Quality of Social Support; RMBPC-F= Revised Memory and Behaviour Problem Checklist-Frequency; RMBPC-R= Revised Memory and Behaviour Problem Checklist-carer reaction; SF12-MCS= QoL: 12-item Short-Form Health Survey mental health component score; SF12-PCS= QoL: 12-item Short-Form Health Survey physical health component score; SE-OR=Self-efficacy-obtaining respite; SE-RB= Self-efficacy-respond to behaviour; SE-CT=Self-efficacy-control upsetting thoughts.

6.8 FINDING 4: STRATEGIES TO EMBED AND SUSTAIN THE FACILITATOR-ENABLED ISUPPORT PROGRAM AFTER THE TRIAL

6.8.1 Sub-finding 1: Enablers and challenges for site specific staff of embedding and sustaining the iSupport program

All site leaders and facilitators believed that their organisation supported them well. One side leader from the hospital said: *'[we are not an aged care team in the hospital], we have got close links to those services [outside our team], and we have had to build increasingly close links to those groups'*[I_S1]. Communication was a key element during the pilot study. Another site leader stated: '*I have good support at higher level management…I struggle with the support at the [management] next level down because they struggle to see how it could work in practice, so I am trying to be that person in between'*[I_S2]. Their organisation and site leaders are well-supported facilitators. For example: *'Just an amazing amount of support from people here wanting to know information and spending time with me to make sure I understand components of aged care'* [I_F2].

However, employing iSupport facilitators was a challenge for site leaders. One site leader who had three iSupport facilitators in a short time said: '*Not many nurses understand research, and they may feel anxious about what they are going into and whether it will affect their substantive role. So there were many concerns in our workplace'* [I_S3].

The facilitator's job was not easy. One carer stated: '*She [facilitator] tried to help everybody, but that gets quite hard'*[I_C17]. The facilitator's workload concerns site leaders. One site leader stated:

> *I do not know the FTE given to the facilitators on other sites, but if you look at the number of people screened and also the number of participants in hand for them to liaise with, the facilitator here on our site had more participants, hence their workload is higher compared to others. [I_S2]*

Another site leader acknowledged that the facilitator's involvement was beyond what was planned. For example: '*The facilitator here at least has this vast amount of work they cannot get to for the facilitator role because they are doing all this other stuff [recruitment]*' [I_S3].

During this study, three partner organisations had to re-employ iSupport facilitators (2 at 0.2FTE and one at full-time). One organisation had three facilitators during a short period. Site leaders completed new facilitators' training. The facilitator turnover did not interrupt the intervention. iSupport facilitators ensured the peer support meetings were organised and delivered before they left the job. Whereas there was no iSupport facilitator, one of the researchers facilitated the peer support meeting. These findings indicated that conducting the study was built on extensive collaboration and communication within the organisation. Our facilitators were also well supported by site leaders and their organisations.

6.8.2 Sub-finding 2: Engaging carers in the program and supporting carers' diverse needs

Carers in this study engaged in the iSupport for Dementia manual and provided valuable feedback. Many carers in the study loved the iSupport for Dementia manual. One care said: '*It [iSupport for Dementia manual] is an absolute bonus to me when I have a bit of a hiccup. It is easy to find the article. Yeah, and sometimes it jogs my memory'* [I_C7].

iSupport for Dementia manual also serves as a reminder and helps them to prepare ahead; for example, one carer stated:

> *I found the book to be a great read. I used a highlighter on many of the pages to highlight things I thought would be a good resource for me in the future as well…It is wonderful to have resources to learn skills to be best prepared for what we are all faced with. [G2_T]*

However, the book could be improved by increasing the font size. For example: '*The font size is too small. It could be difficult for anyone with vision issues to read, which would be a consistent issue with the target demographic'*[FP1_2].

The delayed iSupport website made evaluating the carer's user experience difficult. Among all the carers who were interviewed, none of them engaged in the online version. Two carers from one group requested a hardcopy book after receiving website access, according to the facilitator:

> *Two carers requested hard copies of the book this month and were very grateful to have received them. They commented about never going back to the online system because they cannot even remember how to access it and do not want another password to remember [FP1_2].*

Many carers have been in the caring role for a long time and considered the information provided by the iSupport manual less relevant. For example:

> *I could suggest maybe more detailed, diverse advice on how to cope with various situations. The iSupport training manual was very comprehensive, but because I have [accessed] Dementia Australia and I was given advice from dementia advisors over the last ten years. It reminded me of all those strategies, but the manual did not offer me more. They are not quite suitable or applicable to my case [I_C13].*

To some carers, the information did not apply to their situation. For example:

> *The writings in the book do not apply to my situation. Xx is blind due to dementia. Many of your suggestions in the book, like changing the colour of things or putting notices on doors that would not apply because she cannot see them anyway [I_C19].*

Some carers consider the information in the manual was not in-depth enough for their knowledge level. One care was a retired medical doctor who read the entire book and stated:

> *I have read it all…It uses very simple language, and the answers are rather obvious to me - they could almost all be summarised by saying "Be kind". It would be helpful for someone starting the care journey if they did not know much about dementia [G1_T].*

These findings highlight the differences in care journeys that influence their learning needs. Thus, one type of recourses may not always be relevant to everyone. The diversity of the learning material is very important.

6.8.3 Sub-finding 3: Supporting carers through dementia care journey

Many carers in the study believe the program was imperative for those who started their dementia care journey. One carer stated: '*I would say I lacked this type of support early on…I definitely would have got some value because I would have known where to start asking these questions around Mum's diagnosis*' [I_C11]. Carers welcomed ongoing facilitator support. One carer stated: '*I know she [facilitator] is there. I can contact her anytime, and she will get back to me reasonably quickly, which is good to have someone to rely on like that*' [IC_19]. Carers valued the information shared by the facilitator. One carer stated: '*The Information provided [by the facilitator] was really helpful*' [IC_11]. Many carers enjoyed peer support meetings when they could exchange ideas and get practical advice from fellow carers regardless of their care journey. One carer stated: '*The times that you can talk in the meetings help you to see that people are doing the same sorts of things that you are doing*'[I_C3]. This finding suggested that different components of the facilitator-enabled iSupport program benefit different carers of PLWD who are on different care journeys. Therefore, tailored to individual needs is essential for embedding and sustaining such a program.

6.8.4 Sub-finding 4: Strategies to improve carers' experience of peer support

Carers' experiences in the peer support group are varied. The meeting time during working hours has potentially prevented working carers from participating. Some carers expressed that if the peer support meetings can run after hours, it may accommodate more working carers. For example:

> *I have a suspicion that [not attending peer support meeting] might have something to do with the times that people were available because we had to be during work hours…Having a group outside working hours might help some people feel like they could attend [I_C17].*

Group dynamics also cause some concerns. One carer stated that her negative experience was because of another fellow carer in the peer support meetings. She stated: *'[My negative experience was] at the beginning of the program, someone took over the peer support meeting and talked for over 30 min'* [I_C8]. Others consider the peer support group better suited for them if they are in a similar age group. For example, one carer stated: '*I think for myself, being a lot younger than most people who are carers, I have found. That was probably my barrier, but not so much that I think it would be very beneficial'* [I_C11].

Carers welcomed the WhatsApp group because they could ask questions anytime via WhatsApp. One carer said: *'There is always someone to ask [on WhatsApp]'* [IC_5]. Carers considered the extra information posted in the WhatsApp group helped them with affirmation. One carer stated:

> *I think you often think you know things, but there is a lot more you need to know. So having that extra Information and perhaps for me, I am going to say in particular knowing the possible pathways ahead have been important [I_C3].*

These findings suggested that carers welcomed peer support in the facilitator-enabled iSupport program. However, there is room to improve to accommodate more carers' needs.

6.8.5 Sub-finding 5: funding source for iSupport program sustainability

Site leaders and facilitators were concerned about the program's long-term sustainability after the main trial. The main concern was the funding to sustain this type of program. One facilitator suggested to embed in existing services:

> *The best way to implement it into the organisation is by using what we currently have, such as the Commonwealth Home Support Program or the Home Care Package program. So, embed the program in a financial model within the organisation [I_F1].*

However, multiple projects run in one organisation, and the outcome of each project will also affect the uptake of the iSupport program in the long term. One facilitator from aged care service providers stated:

> *It is still a big question, and one of the reasons for that is that we have got several ongoing projects. Now, and until we understand the outputs of those projects and how they intend to be delivered, I am still questioning how this would fit into the business as usual because I do not know what the impacts of these other projects were, which are quite significantly crossover with this [I_F2].*

6.8.6 Sub-finding 6: Demonstrating innovation of the iSupport program

Differentiating the iSupport program from the existing available government-funded program is also a concern for long-term feasibility. One site leader stated: '*I feel like in the Australian context, there is some appreciation or feeling amongst stakeholders that ISupport is valuable, but not completely discrete from other resources that might be available and out there'* [I_S1]. Another site leader echoed this: *'I do not know how similar they are [iSupport program] to those material provided by Dementia Australia because they [discharge nurses] already provided those [to carers]*' [I_S3]. The facilitator also suggested identifying the gaps in the existing system and incorporating them into the program, which will allow one point of help for carers. For example:

> To assess what Dementia Australia is currently offering as an education package compared to the iSupport package and whether or not there is a benefit in recommending to the government any gaps that currently exist…Just from having that one entry point if they are [carers] in crisis, it is like muscle memory, and they return to what they know to look for an answer rather than everyone doing little bits of it *[I_F2].*

Carers suggested a more flexible approach when asked about further program implementation. For example: '*It might be good to think about how people have easy access, and I am going to say if we are talking about 12 months programs and even something that's just a drop-in and drop-out session'* [I_C3]. Carers also suggested letting people try the program before signing up: '*Maybe get carers to join in one session to see if they like it; often they found it helpful, and they will stay'* [I_C19].

These findings indicate that embedding and sustaining the iSupport program need to be innovative. A faciliatory-enabled iSupport program can complement existing care support resources to address the current gap in the system.

6.9 SUMMARY

This chapter presented phase 2 findings that address the study objectives 3, 4, 5 and 6. Findings indicated that the present study had a 10% recruitment rate and a 70% retention rate in the intervention group at the six months. Based on the knowledge generated from the pilot study, modifications were made to the main RCT, including providing carers with hard copy books and phone support and modifying inclusion criteria to include carers of people with cognitive impairment. Findings show that carers in the intervention group were actively engaged in the program. Participants at the end-of-intervention interviews also recommended strategies to embed and sustain such a program after the trial.

7 Findings Phase 2: Exploring program effectiveness

7.1 INTRODUCTION

The previous chapter reported phase 2 findings related to study objectives 3 to 6. This chapter reports the phase 2 findings related to the study objective 7: determine the intervention effectiveness with the given sample size at six months. In this chapter, quantitative and qualitative data were analysed separately and integrated, as discussed in methodology in Chapter 4. In section 7.2, findings from quantitative data were presented. The effectiveness results were measured by carers' QOL, PLWD’s QOL, PLWD's changed behaviours and carers reactions using the Revised Memory and Behaviour Problem Checklist, and the carer perceived Quality of Social Support and Carer's Self-efficacy. Section 7.3 reported findings from qualitative data analysis. Section 7.4 integrated quantitative and qualitative findings and narratively presented three themes according to three types of stressors, intervention, and support received through the iSupport program. Finally, Section 7.5 presents the summary of the chapter.

7.2 FINDINGS FROM QUANTITATIVE DATA

7.2.1 Characteristics of participants in the intervention and usual care group

Eighty-four carers were randomised for the pilot study. Of these, 40 were allocated to the intervention group and 44 to the usual care group. The participants' demographics in the intervention and usual care group are displayed in Table 7-1.

Table 7-1 Phase 2 carers' socio-demographic characteristics between intervention and usual care group

Demographics	**Intervention Group (N=40)**	**Usual care (N=44)**	***P* value**
Age, mean (SD)	66 (14)	66 (13)	.97
Gender, n (%)			.60
Male	14 (35)	13 (30)	
Female	26 (65)	31 (71)	
Relationship, n (%)			.49
Spouse	20 (50)	22 (50)	
Non-spouse	20 (50)	22 (50)	
Marital status, n (%)			.44
Married/partner/de-facto	32 (80)	37 (84)	
Single/divorced/widow	7 (18)	7 (16)	
Employment status, n (%)			.68
Employed	15 (38)	14 (33)	
Unemployed	2 (5)	2 (5)	
Retired	23 (58)	26 (62)	
Live in the same household as PLWD, n (%)			.06

Demographics	Intervention Group (N=40)	Usual care (N=44)	*P* value
yes	32 (80)	27 (61)	
No	8 (20)	17 (39)	
Years living in the same household as PLWD, mean (SD)	38 (23)	42 (21)	.52
Average hours per day on carer activities, mean (SD)	10 (10)	9 (11)	.53
Average days per week on carer activities, mean (SD)	6 (1)	5 (2)	<.05
Years of being in a carer's role mean (SD)	4 (2)	5 (5)	.18
Do other family members support you in your caring role, n (%)			.84
Yes	33 (83)	34 (81)	
No	7 (18)	8 (19)	
Do you feel financially stressed as a result of caring for a PLWD, n (%)			.23
no	20 (51)	29 (67)	
Yes, but I can cope	19 (49)	13 (30)	
Yes, I cannot cope.		1 (3)	

Note: PLWD: a person living with dementia

There were no significant demographic differences between the intervention and usual care groups (p >.05) (See Table 7-1). The average age for carers in the intervention and usual care group is the same as 66 years. More carers in the intervention group lived in the same household than the usual care group. Furthermore, carers in the intervention groups spent more days in care activity compared with the usual care group (p<.05). More carers in the intervention group felt financial stress (n=19, 49%) compared to the usual care group (n=13, 30%), however, the difference was not statistically significant. Only one care stated unable to cope with financial stress because of the quick progression of the PLWD's condition and need to upgrade home care package.

Table 7-2 displayed care recipients' characteristics in the intervention and usual care groups. The two groups had no significant demographic differences (p>.05). The average aged for care recipients in the intervention and usual care group is the same as 80 years. 77% care recipients in the intervention group had some chronic conditions.

Table 7-2 Phase 2 PLWD socio-demographic characteristics between intervention and usual care group

Demographics	Intervention group (N=40)	Usual care groups (n=44)	P value
Age, mean (SD)	80 (8)	80 (13)	.97
Gender, n (%)			.92
Male	20 (50)	21 (49)	
Female	20 (50)	22 (51)	
Cognitive stage, n (%)			.71
Mild	37 (68)	28 (64)	
Moderate	13 (33)	16 (36)	
Chronic condition, n (%)			.77
no	5 (14)	7 (21)	
1-4	27 (77)	22 (67)	
≥ 5	3 (8)	4 (12)	
Length of diagnosis or show symptoms, mean (SD)	5 (3)	4 (4)	.40

Demographics	Intervention group (N=40)	Usual care groups (n=44)	P value

Note: PLWD=person living with dementia; SD= standard deviation

7.2.2 Intervention effectiveness

7.2.2.1 Carer's QOL: 12-item Short-Form Health Survey (SF-12 Health Survey)

Table 7-3 displayed findings from physical health (SF12-PCS) and mental health (SF12-MCS) between the intervention and usual care group.

Table 7-3 Phase 2 carer's QOL: 12-item health survey between intervention and usual care group

Outcome measures	Groups	Baseline T0	6-month T1	Within-group effect 6-month vs baseline			Between group effect Difference at 6-month		
				MD	95%CI	P	MD	95%CI	P
SF-12-PCS	IG	51.98 (8.96)	52.62 (10.66)	-.50	-3.55 to 4.55	.8	1.06	-4.3 to 6.4	.69
	UG	50.83 (10.74)	51.56 (10.84)	-1.08	-6.52 to 4.36	.69			
SF-12-MCS	IG	43.57 (9.68)	45.88 (11.04)	-1.18	-7.03 to 4.67	.68	2.53	-3.2 to 8.2	.38
	UG	44.46 (10.27)	43.36 (11.88)	1.02	-4.02 to 6.06	.68			

Noe: SF12-MCS= QOL: 12-item Short-Form Health Survey mental health component score; SF12-PCS= QOL: 12-item Short-Form Health Survey physical health component score; IG=intervention group; UG=usual care group; Score direction: higher is better.

There were no significant differences in physical health and mental health measures between groups at baseline or six months. It appears that carers in the intervention group had slightly better physical health (SF12-PCS) compared to carers in the usual care group at the baseline and six months, although it was not statistically significant. In contrast, carers in the usual care group showed better mental health (SF12-MCS) than the intervention group at the baseline. However, over six months, carers in the intervention group showed improved mental health (SF12-MCS) scores from 43.57 to 45.88 (MD=-1.18, p=0.68), while carers in the usual care group showed a decline in mental health scores from 44.46 to 43.36 (MD=1.02, p=0.68) but not statistically significant (See Figure 7-1, Table 7-3).

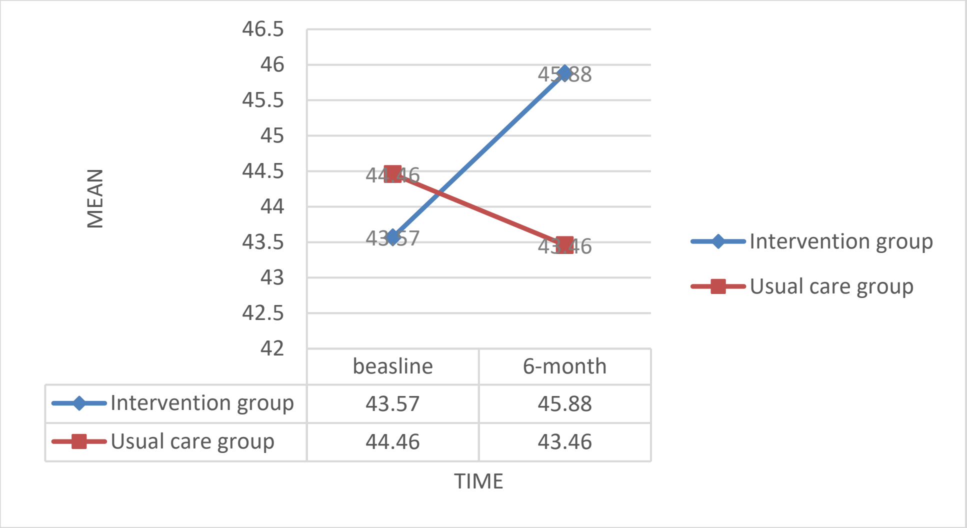


Figure 7-1 Phase 2 Carer’s QOL: 12-item health survey-mental health between baseline and 6-month.

7.2.2.2 PLWD’s QOL: QOL in Alzheimer’s Disease- Family version (QOL-AD)

PLWD’s QOL (QOL-AD) was rated by the family carers. At the baseline, PLWD showed poor energy, memory, and ability to do things around the house and doing things for fun (all rated <2). However, there was no significant difference between the intervention and the usual care group (Table 7-4).

Table 7-4 Phase 2 PLWD’s QOL between intervention and usual care group

Outcome measures	**Groups**	**Baseline T0**	**6-month T1**	**Within-group effect 6-month vs baseline**			**Between group effect 6-month vs baseline**		
				MD	**95%CI**	**P**	**MD**	**95%CI**	**P**
1. Physical health	IG	2.34 (.91)	2.29 (.76)	.06	-.37 to .48	.79	.03	-.39 to .45	.89
	UG	2.19 (.94)	2.26 (.91)	-.07	-.48 to .34	.75			
2. Energy	IG	1.79 (.78)	2.11 (.88)	-.32	-.73 to .09	.12	.36	-.06 to .79	.09
	UG	1.83 (.82)	1.74 (.85)	.09	-.28 to .46	.63			
3.Mood	IG	2.26 (.64)	2.18 (.67)	.08	-.24 to .41	.61	.02	-.30to .34	.88
	UG	2.26(.70)	2.15(.63)	.11	-.19 to .40	.47			
4.Living situation	IG	3.18 (.73)	3.00(.94)	.18	-.23 to .60	.37	-.11	-.51 to .30	.60
	UG	3.12 (.67)	3.11(.69)	.01	-.29 to .32	.93			
5.Memory	IG	1.32 (.57)	1.29 (.46)	.03	-.23 to .29	.82	-.12	-.38 to .13	.33
	UG	1.55 (.67)	1.41 (.55)	.14	-.13 to .41	.32			
6.Family	IG	3.18 (.87)	2.88 (.91)	.30	-.15 to .75	.19	09	-.55 to .37	.70
	UG	2.88 (.83)	2.97 (.90)	-.09	-.48 to .29	.63			
7.Marriage	IG	2.92 (.97)	3.00 (1.00)	-.08	-.65 to .49	.78	.16	-.29 to .60	.49
	UG	3.02 (.85)	3.12(.95)	-.09	-.54 to .36	.69			
8.Friends	IG	2.08 (1.00)	2.07 (.92)	.00	-.48 to .49	.98	.16	-.29 to .60	.49
	UG	2.22(.91)	1.92 (.86)	.30	-.10 to .70	.14			
9.Self as a whole	IG	2.13 (.74)	2.04(.84)	.10	-.29 to .49	.62	.04	-.37 to .44	.86
	UG	2.05 (.70)	2.00(.79)	.05	-.28 to .38	.77			
10.Ability to do chores around the house	IG	1.65 (.68)	1.41 (.69)	.24	-.10 to .59	.17	-.13	-.53 to .27	.51
	UG	1.51 (.71)	1.54 (.85)	-.01	-.36 to .33	.93			
11.Ability to do things for fun	IG	1.63 (.67)	1.43 (.57)	.20	-.11 to .52	.20	-.29	-.71 to .13	.17
	UG	1.62 (.79)	1.71(1.00)	-.10	-.50 to .30	.62			
12.Money	IG	2.13 (.96)	1.81 (1.08)	.32	-.19 to .83	.22	-.63	-1.18 to -.08	.03

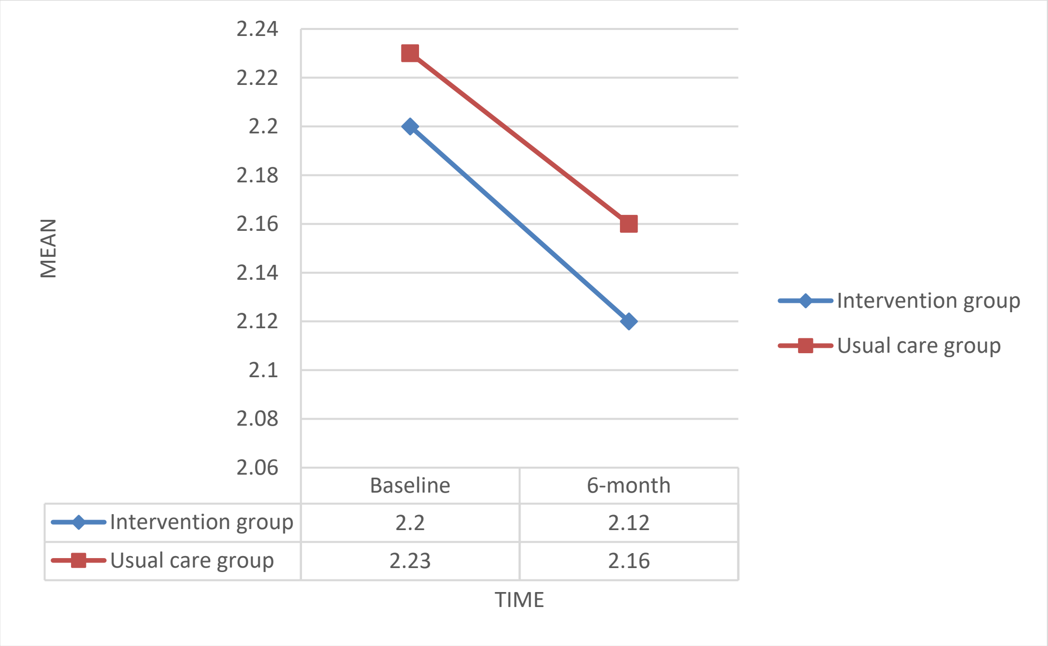
	UG	2.36 (1.10)	2.45 (1.11)	-.09	-.58 to .40	.72			
13.Life as a whole	IG	2.21 (.70)	2.11(.79)	.10	-.26 to .47	.58	-.12	-.51 to .26	.52
	UG	2.31 (.84)	2.23(.78)	.08	-.28 to .44	.66			
Overall QOL-AD	IG	2.20 (.56)	2.12 (.59)	.07	-.05 to .19	.21	-.04	-.5 to .5	.87
	UG	2.23 (.54)	2.16 (.55)	.04	-.03 to .11	.22			

Note: IG=intervention group, UG=usual care group, MD=mean difference, CI=confidence interval, The individual item is rated as 1=poor, 2=fair, 3=good, 4=excellent

Over six months, PLWD's memory, ability to do things around the house, and doing things for fun remained the same. In the intervention group, PLWD demonstrated significant inadequacy in the aspect of 'money' (rated<2, p<.05), while those in the usual care group exhibited insufficiency in the aspect of 'friends'(rated<2) although this disparity did not reach statistically significant (p>.05) (Table 7-4).

Within-group analysis showed that over six months, PLWD in the intervention group had poor, slightly improved energy from 1.79 to 2.11 and poor, declined memory from 1.32 to 1.29. In contrast, the usual care group showed a decline in these items. PLWDs in the intervention group also showed declined, poor ability to do things around the house (from 1.65 to 1.41), doing things for fun (from 1.63 to 1.43) and money aspects (from 2.13 to 1.81). In contrast, the usual care group improved these items (Table 7-4).

Overall, both intervention and the usual care group showed a decline in overall PLWD's QOL over six months but were not statistically significant (Figure 7-2, Table 7-4).



	Baseline	6-month
Intervention group	2.2	2.12
Usual care group	2.23	2.16

Figure 7-2 Phase 2 PLWD's QOL between baseline and 6-month

7.2.2.3 PLWD’s changed behaviours and carer’s reaction: Revised Memory and Behaviour Problem Checklist (RMBPC)

PLWD’s changed behaviours frequency (**RMBPC-F**): There was no significant PLWD’s behaviour frequency difference between the intervention and usual care group at the baseline (Table 7-5). PLWD whose carer were in the intervention group showed more frequent changed behaviours compared to those carers were in the usual care group. After six months of intervention, PLWD of carers who allocated to the intervention group showed significantly less changed behaviour frequencies than those in the usual care group (MD= -0.76, p<.05) (Table 7-5).

Table 7-5 Phase 2 RMBPC-F between intervention and usual care group

Outcome measures	**Groups**	**Baseline T0**	**6-month T1**	**Within-group effect 6-month vs baseline**			**Between group effect Difference at 6-month**		
				MD	**95%CI**	**P**	**MD**	**95%CI**	**P**
RMBPC-F	IG	2.51 (.97)	1.77 (.44)	.01	-.07 to .09	.72	-.76	-1.2 to 3	0.00
	UG	2.41 (.89)	2.53 (.99)	-.12	-.21 to -.02	.02			

Note: RMBPC-F= Revised Memory and Behaviour Problem Checklist frequency, IG=intervention group, UG=usual care group, MD=mean difference, CI=confidence interval; Rated as 0= never occurred, 1=not in the past week, 2=1-2 times in the past week, 3= 3-6 times in the past week, 4=daily or mor often; lower=better

Intra-group analysis showed that over the six months, PLWD whose carers participated in the intervention group experienced an improved changed behaviour frequencies (MD=0.01, p=0.72). Conversely, PLWD whose carers belonged to the usual care group exhibited a statistically significant worsening changed behaviour issues (MD= -.12, p<.05) (Table7-5, Figure 7-3).

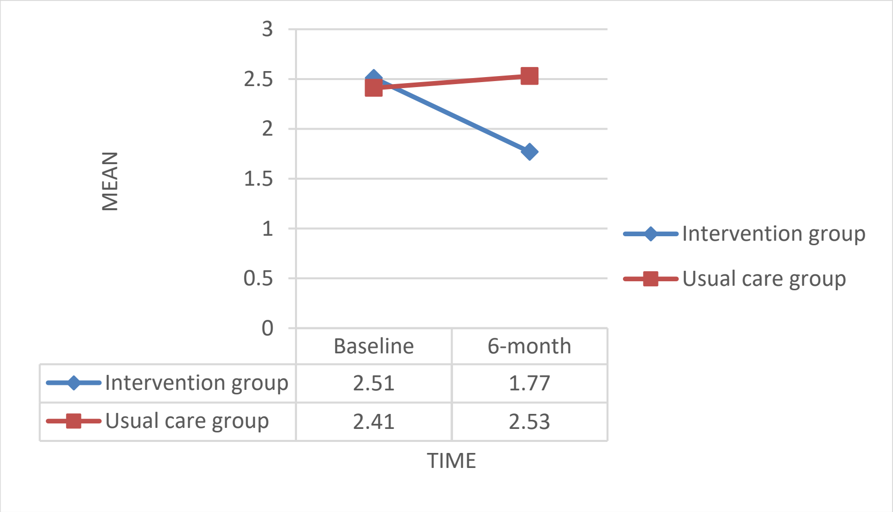


Figure 7-3 Phase 2 RMBPC-F between baseline and 6-month

Carers’ distress reaction to changed behaviours (**RMBPC-R**): There was no significant difference in carers’ distress reaction to the changed behaviours between the intervention and usual care group at the baseline (Table 7-6). Over six months, carers in the intervention group reacted significantly better to PLWD's changed behaviours than the usual care group (MD=-0.16, p<.05) (Table 7-6).

Table 7-6 Phase 2 RMBPC-R between intervention and usual care group

Outcome measures	**Groups**	**Baseline T0**	**6-month T1**	**Within-group effect 6-month vs baseline**			**Between group effect Difference at 6-month**		
				MD	**95%CI**	**P**	**MD**	**95%CI**	**P**
RMBPC-R	IG	1.99 (.45)	1.77(.44)	.22	.14 to .30	<0.001	-.16	-.4 to .1	0.00
	UG	2.05 (.4)	1.93 (.45)	0	-.09 to.1	.91			

Note: RMBPC-R= Revised Memory and Behaviour Problem Checklist reaction; IG=intervention group, UG=usual care group, MD=mean difference, CI=confidence interval; Rated as 0=not upset;1=a little upset; 2=moderate upset; 3=very much upset;4=extremely upset;; score direction: lower=better

The within-group comparison also indicated that carers in the intervention group showed significantly better reaction scores towards PLWD's behaviour at six months than baseline (MD=.22, p<0.001).

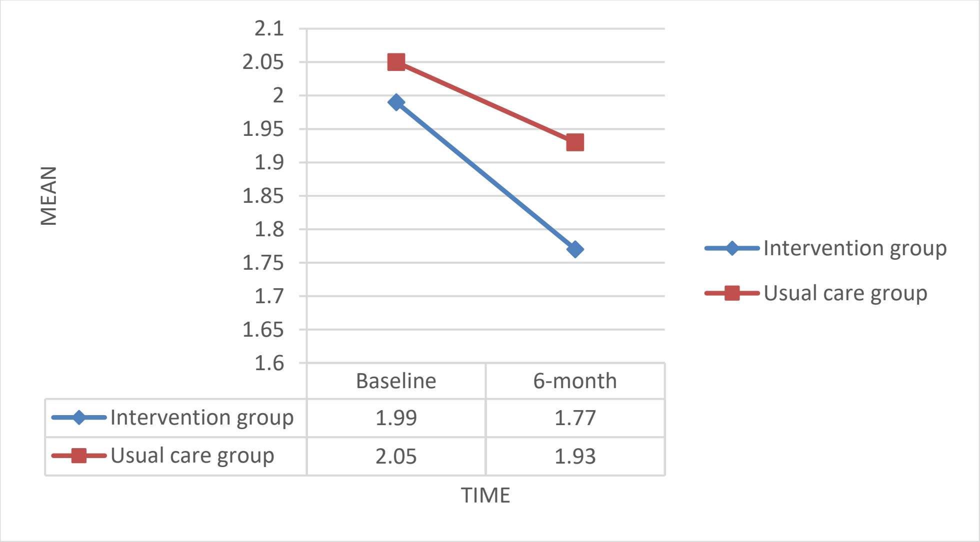


Figure 7-4 Phase 2 RMBPC-R between baseline and 6-month.

Sub-group analysis compared carers facilitated by aged care to hospital groups (See Table 7-7) indicated that carers in the age care group significantly improved (MD=.18, p<0.001) over six months, although the hospital group also had an improved reaction mean score from 1.83 to 1.76. Still, it was not statistically significant (MD=0.07, p=0.06) (See Table 7-7, Figure 7-5)

Table-7-7 Phase 2 Sub-group analysis of RMBPC between the age care group and hospital care group

Outcome measures	**Groups**	**Baseline T0**	**6-month T1**	**Within-group effect 6-month vs baseline**			**Between group effect Difference at 6-month**		
				MD	**95%CI**	**P**	**MD**	**95%CI**	**P**
RMBPC-R	AG	2.16 (.49)	1.99 (.47)	.18	.09 to .27	<.001	.16	-.1 to .4	.24
	HG	1.83 (.43)	1.76 (.44)	0.07 (0.18)	-.004 to .147	.06			

Note: RMBPC-R= Revised Memory and Behaviour Problem Checklist reaction; AG=Aged care group, HG=hospital group; MD=mean difference, CI=confidence interval; Rated as 0=not upset;1=a little upset; 2=moderate upset; 3=very much upset;4=extremely upset; score direction: lower=better

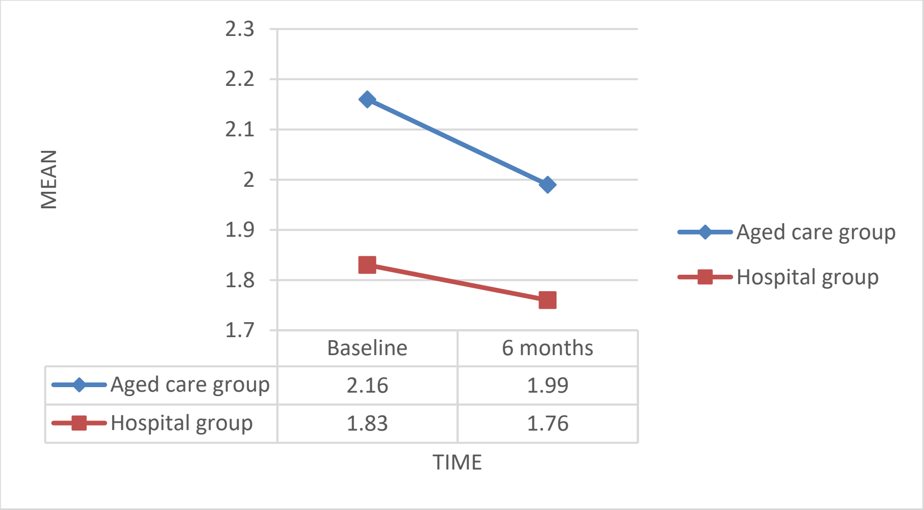


Figure 7-5 Phase 2 Sub-group analysis: RMBPC-R between the aged care and hospital group outcome at 6-month.

7.2.2.4 Carer’s perceived quality of social support: The Carers of Older People in Europe Index-Quality of Social Support (QOS)

At the baseline, carers in both intervention and usual care groups considered the overall support they received was above average, but no significant difference between the intervention and usual care groups. When asked about carer’s feelings about support from health and social services, carers in the intervention group rated 2.45 (MD=.87), which is lower than the usual care group (2.71, MD=.84). However, over the six months, carers in the intervention group improved and rated higher score in ‘support from health and social care services’ than usual care group, but not statistically significant (Table 7-8).

Table 7-8 Phase 2 Quality of social support between the intervention and usual care group.

Outcome measures	**Groups**	**Baseline T0**	**6-month T1**	**Within-group effect 6-month vs baseline**			**Between group effect 6-month vs baseline**		
				MD	**95%CI**	**P**	**MD**	**95%CI**	**P**
1.Feeling supported by friends and neighbours	IG	2.41 (.91)	2.63 (1.04)	-.22	-.74 to .31	.41	.01	-.47 to .50	.96
	UG	2.50 (.86)	2.62 (.85)	-.12	-.52 to .29	.56			
2.Feeling supported by family	IG	2.83 (1.00)	2.81 (1.11)	.01	-.55 to .58	.96	-.11	-.66 to .45	.70
	UG	3.00 (1.01)	2.92 (1.10)	.08	-.40 to .56	.75			
3.Feeling supported by health and social services	IG	2.45 (.87)	2.65 (.89)	-.21	-.68 to .27	.39	.02	-.43 to .47	.92
	UG	2.71 (.84)	2.63 (.88)	.08	-.31 to .47	.69			
4.Feeling appreciated as a caregiver	IG	2.55 (.99)	2.54 (1.10)	.01	-.55 to .58	.96	-.09	-.62 to .44	.73
	UG	2.58 (1.03)	2.63 (1.00)	-.05	-.52 to .41	.82			
5.Overall support in caregiver role	IG	2.48 (.83)	2.52 (.94)	-.04	-.51 to .44	.88	-.01	-.41 to .39	.97
	UG	2.58 (.76)	2.53 (.69)	.05	-.28 to .38	.75			
Overall quality of social support	IG	2.6 (.16)	2.63 (.12)	-.03	-.18 to .11	.55	-.03	-.2 to .2	.75
	UG	2.74 (.19)	2.66 (.15)	.07	-.07 to .21	.21			

Note: IG=intervention group, UG=usual care group, MD=mean difference, CI=confidence interval; Carers rated items related to their feelings of support they received 1=never, 2=sometimes; 3=often and 4=always.

The within-group comparison showed an overall improvement in feeling supported by friends and neighbours in intervention and usual care groups over six months. However, the intervention group improved in feeling supported by health and social care services and overall support in the caregiver role; in contrast, the usual care group showed a decline in these items (Table 7-8).

Overall quality of social support in the six months, carers in the intervention group showed an improved mean score (MD=.03, p=.55). In contrast, carers in the usual carer group showed a decrease in the mean score (MD=.07) (Figure 7-6, Table 7-8).

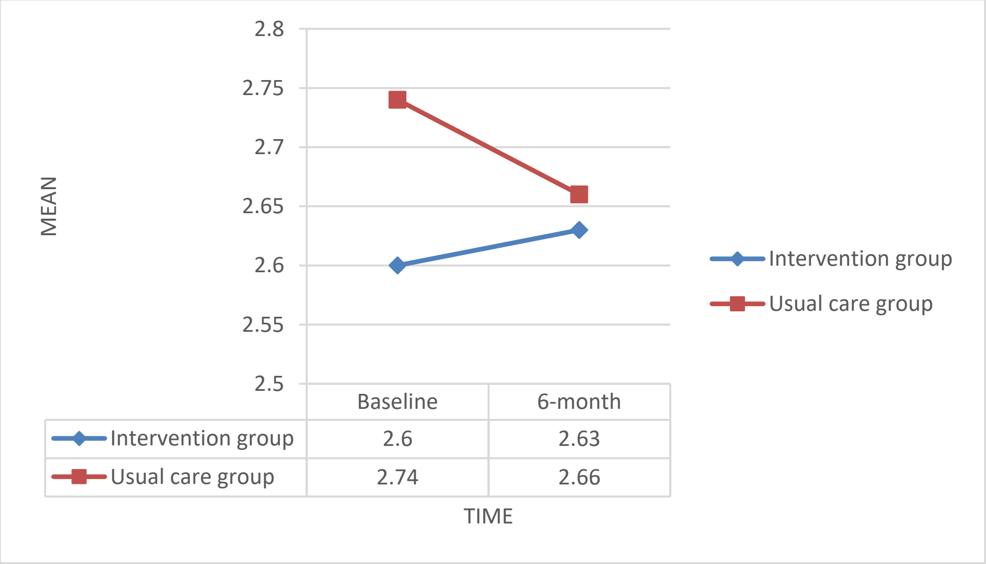


Figure 7-6 Phase 2 Overall quality of social support between baseline and 6-month

7.2.2.5 Carer's perceived self-efficacy: Revised Scale for Caregiving Self-efficacy

The revised scale for caregiving self-efficacy contains three domains, including 1) Self-efficacy for obtaining respite, 2) Self-efficacy for responding to disruptive patient behaviours and 3) Self-efficacy for controlling upsetting thoughts about caregiving.

Self-efficacy for obtaining respite: Table 7-9 displayed the outcome of caregiving self-efficacy for obtaining respite between intervention and the usual care group at the baseline and 6-month. Findings show that all carers have low confidence (<50 confidence) in asking friends or family members to stay with PLWD for a day or a week at the baseline. Over six months, carers in the intervention group increased their confidence to moderate (52.20) in asking friends or family members to stay with PLWD for a day, while the usual care group remained in low confidence. Carers in both groups remained low confidence in asking friends or family members to stay with PLWD for a week.

Table 7-9 Phase 2 self-efficacy for obtaining respite outcome between intervention and usual care group.

Outcome measures	Groups	Baseline T0	6-month T1	Within-group effect 6-month vs baseline			Between group effect 6-month vs baseline		
				MD	95%CI	P	MD	95%CI	P
1.you can ask a friend/family member to stay with care recipient for a day when you need to see your doctor?	IG	62.92 (33.2)	64.38 (35.27)	-1.46	9.9 to -21.39	.88	.24	-18.94 to 19.42	.98
	UG	60.19 (36.95)	64.14 (34.07)	-3.95	-23.15 to 15.26	.68			
2.you can ask a friend/family member to stay with care recipient for a day when you have errands to be done?	IG	58.33 (33.0)	62.92 (33.1)	-4.58	9.55 to -23.81	.63	5.17	-13.05 to 23.40	.57
	UG	55.37 (38.65)	57.74 (33.64)	-2.37	-21.38 to 16.64	.80			
3.you can ask a friend/family member to do errands for you.	IG	55.83 (38.2)	64.58 (34.31)	-8.75	10.45 to -29.79	.41	2.08	-16.15 to 20.31	.82
	UG	63.93 (35.52)	62.5 (34.16)	1.43	-16.33 to 19.18	.87			
4.you can ask a friend/family member to stay with care recipient for a day when you feel the need for a break?	IG	41.46 (34.25)	52.20 (35.48)	-10.74	9.97 to -30.79	.29	11.17	-8.33 to 30.66	.26
	UG	48.21 (40.53)	41.03 (35.69)	7.18	-13.07 to 27.43	.48			
5.you can ask a friend/family member to stay with care recipient for a week when you need time for yourself?	IG	21.25 (31.80)	26.15 (29.78)	-4.9	8.71 to -22.41	.58	3.73	-13.29 to 20.76	.66
	UG	26.15 (31.76)	22.42 (33.64)	3.73	-13.74 to 21.21	.67			
Overall self-efficacy for obtaining respite	IG	46.69 (14.46)	52.77 (16.50)	-6.09	-8.86 to 3.21	<.001	3.74	-21.1 to 28.5	.74
	UG	47.1 (14.16)	49.03 (17.51)	-1.93	-8.08 to 4.21	.43			

Note: IG=intervention group, UG=usual care group, MD=mean difference, CI=confidence interval; Rated:0-100, 0= not confident, 50= moderate confident, 100=very much confident

Within-group analysis showed that carers in the intervention group showed improvement in all items and significant improvement in overall confidence when obtaining respite (MD=-6.09, p<.001) at six months compared to baseline (Figure 7-5, Table 7-9).

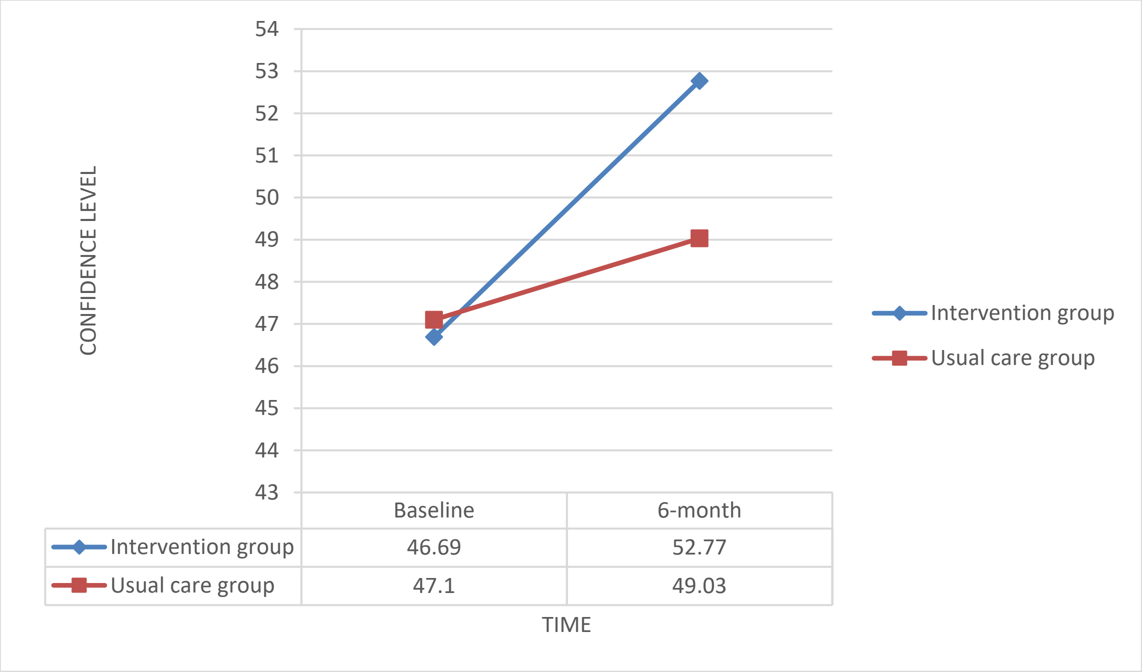


Figure 7-7 Phase 2 Overall self-efficacy for obtaining respite between baseline and 6-month.

Self-efficacy for responding to changed behaviours: Table 7-10 displayed self-efficacy for responding to disruptive behaviours between the intervention and usual care group. Carers in the study showed above moderate confidence in responding to PLWD's behaviours at the baseline (Table 7-10). There was no significant difference in self-efficacy for responding to PLWD's behaviour between the intervention and usual care group at baseline and six months. Within-group analysis showed no significant change in self-efficacy in responding to behaviours over six months.

Table 7-10 Phase 2 self-efficacy for responding to changed behaviours between intervention and usual care group.

Outcome measures	Groups	Baseline T0	6-month T1	Within-group effect 6-month vs baseline			Between group effect 6-month vs baseline		
				MD	95%CI	P	MD	95%CI	P
1.When care recipient forgets your daily routine and asks when lunch is right after you've eaten, how confident are you that you can answer him/her without raising your voice?	IG	76.32 (24.09)	81.55 (16.81)	-5.23	6.42 to -18.21	.42	2.93	-7.24 to 13.11	.57
	UG	79.23 (22.48)	78.61 (19.84)	.62	-10.18 to 11.42	.91			
2.When you get angry because care recipient repeats the same question over and over, how confident are you that you can say things to yourself that calm you down?	IG	66.84 (28.88)	83.10 (22.50)	-16.25	8.14 To -32.74	.05	7.94	-5.78 to 21.66	.25
	UG	72.92 (24.76)	75.15 (25.66)	-2.23	-15.83 to 11.36	.74			
3.When care recipient complains to you about how you're treating him/her, how confident are you that you can respond without arguing back?	IG	71.25 (25.27)	67 (28.77)	4.25	9.71 to -15.61	.66	-5.42	-22.2 to 11.36	.52
	UG	63.70 (29.51)	72.42 (25.33)	-8.72	23.73 to 6.28	.25			

4.When care recipient asks you 4 times in the first 1 h after lunch when lunch is, how confident are you that you can answer him/her without raising your voice?	IG	67.5 (28.63)	73.68 (22.1)	-6.18	8.22 to -22.84	.46	1.03	-12.48 to 15.54	.88
	UG	72.29 (25.19)	72.66 (23.83)	-.36	-13.58 to 12.86	.96			
5.When care recipient interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice?	IG	66.11 (25.7)	81.39 (19.24)	-15.28	7.57 to -30.65	.05	10.26	-2.45 to 22.97	.11
	UG	66.59 (27.58)	71.13 (22.42)	-4.54	-18.35 to 9.27	.51			
Overall self-efficacy for disruptive patient behaviours	IG	69.82 (4.42)	76.01 (5.77)	-6.19	-12.56 to .18	.05	2.84	-3.9 to 9.6	.36
	UG	70.57 (5.65)	73.18 (3.08)	-2.60	-6.33 to 1.12	.12			

Note: IG=intervention group, UG=usual care group, MD=mean difference, CI=confidence interval; Rated:0-100, 0= not confident, 50= moderate confident, 100=very much confident

Table 7-11 displays sub-group analysis of self-efficacy for responding to behaviours between the community aged care and hospital group. Findings showed carers in the hospital group had statistically significantly better scores in self-efficacy responding to PLWD's behaviour (MD=-10.93, Cl=-18.1 to -3.8, p<.05) compared to the aged care group at 6-month. The within-group comparison showed that carers in the hospital group showed significant improvement in response to PLWD's behaviours (MD=-5.49, p<.05) over six months of intervention (Figure 7-8, Table 7-11).

Table 7-11 Phase 2 Sub-group analysis Self-efficacy for responding to behaviours between aged care and hospital group.

Outcome measures	Groups	Baseline T0	6-month T1	Within-group effect 6-month vs baseline			Between group effect Difference at 6-month		
				MD	95%CI	P	MD	95%CI	P
Overall self-efficacy for disruptive patient behaviours	AG	65.81 (5.09)	68.14 (6)	-2.33	-9.16 to 4.51	.39	-10.39	-18.1 to -3.8	.01
	HG	73.57 (6)	79.07 (3.51)	-5.49	-10.36 to .62	.03			

Note: AG=Aged care group, HG=hospital group; MD=mean difference, CI=confidence interval; Rated:0-100, 0= not confident, 50= moderate confident, 100=very much confident

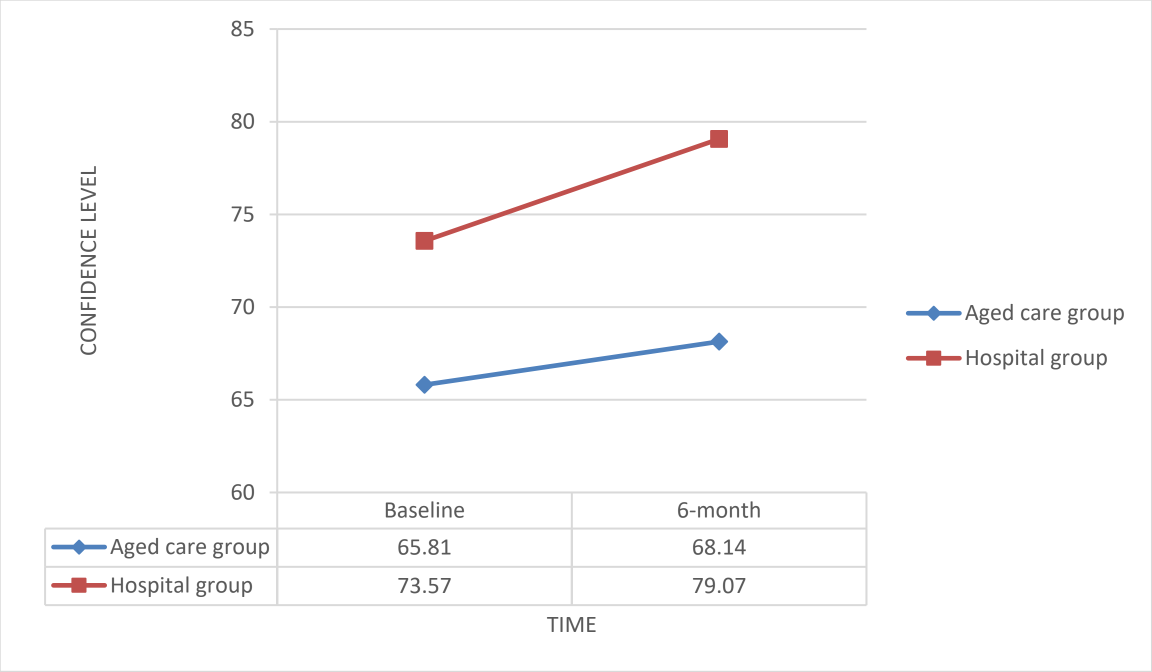


Figure 7-8 Phase 2 Sub-group analysis self-efficacy for responding to behaviours

Self-efficacy for controlling upsetting thoughts about caregiving: Table 7-12 displayed self-efficacy outcomes for controlling upsetting thoughts about caregiving between intervention and usual care group at the baseline. There was no significant difference between the two groups at baseline. Carers in the intervention group showed low confidence in controlling thinking of unpleasant aspects of caring for PLWD (46.58) and what was missing or giving up because of caring role (46.50).

Table 7-12 Phase 2 self-efficacy for controlling upsetting thoughts between intervention and usual care group.

Outcome measures	Groups	Baseline T0	6-month T1	Within-group effect 6-month vs baseline			Between group effect 6-month vs baseline		
				MD	95%CI	P	MD	95%CI	P
1. control thinking about unpleasant aspects of taking care of care recipient?	IG	46.58 (30)	59.81 (32.63)	-13.23	9.53 to -32.44	.17	-6.96	-23.18 to 9.26	.39
	UG	53.33 (27.62)	66.76 (29.90)	-13.43	-27.88 to 1.02	.07			
2.control thinking how unfair it is that you have to put up with this situation?	IG	50 (33.64)	62.19 (36.37)	-12.19	10.62 to 33.60	.26	-3.26	-21.52 to 15	.72
	UG	62.93 (33.58)	65.45 (33.48)	-2.52	-19.59 to 14.55	.77			
3. control thinking about what a good life you had before care recipient's illness and how much you've lost?	IG	58.42 (30.23)	54.23 (40.34)	4.19	11 to -18	.71	-5.46	-24.81 to 13.9	.57
	UG	57.96 (37.58)	59.69 (33.26)	-1.72	-20.19 to 16.74	.85			
4.control thinking about what you are missing or giving up because of care recipient?	IG	46.50 (28.15)	52.31 (34.82)	-5.81	9.55 to -25.06	.55	-7.40	-25.07 to 10.27	.41
	UG	59.83 (33.15)	59.71 (33.17)	.12	-16.64 to 16.88	.99			

5.control worrying about future problems that might come up with care recipient?	IG	69.52 (31.97)	63.52 (32.22)	6.01	9.34 to -12.80	.52	.77	-14.82 to 16.35	.92
	UG	60.17 (30.49)	62.75 (29.37)	-2.58	-17.47 to 12.32	.73			
Overall self-efficacy for controlling upsetting thoughts about caregiving	IG	57.65 (5.04)	57.93 (4.37)	-.29	-7.65 to 7.08	.92	-4.07	-9.5 to 1.3	.12
	UG	60.06 (3.57)	62 (3.06)	-1.95	-.52 to 4.63	.46			

Note: IG=intervention group, UG=usual care group, MD=mean difference, CI=confidence interval; Rated:0-100, 0= not confident, 50= moderate confident, 100=very much confident

Over six months, carers in the intervention group improved self-efficacy in controlling unpleasant thoughts, with all items scaled above 50 in confidence (Table 7-12). Interestingly, carers in the usual care group also improved this aspect. However, the difference between intervention and usual care groups is not significant (p>.05). Within group analysis showed usual care group improved more than intervention group, but not statistically significant over the six-month intervention (Figure 7-9, Table 7-12).

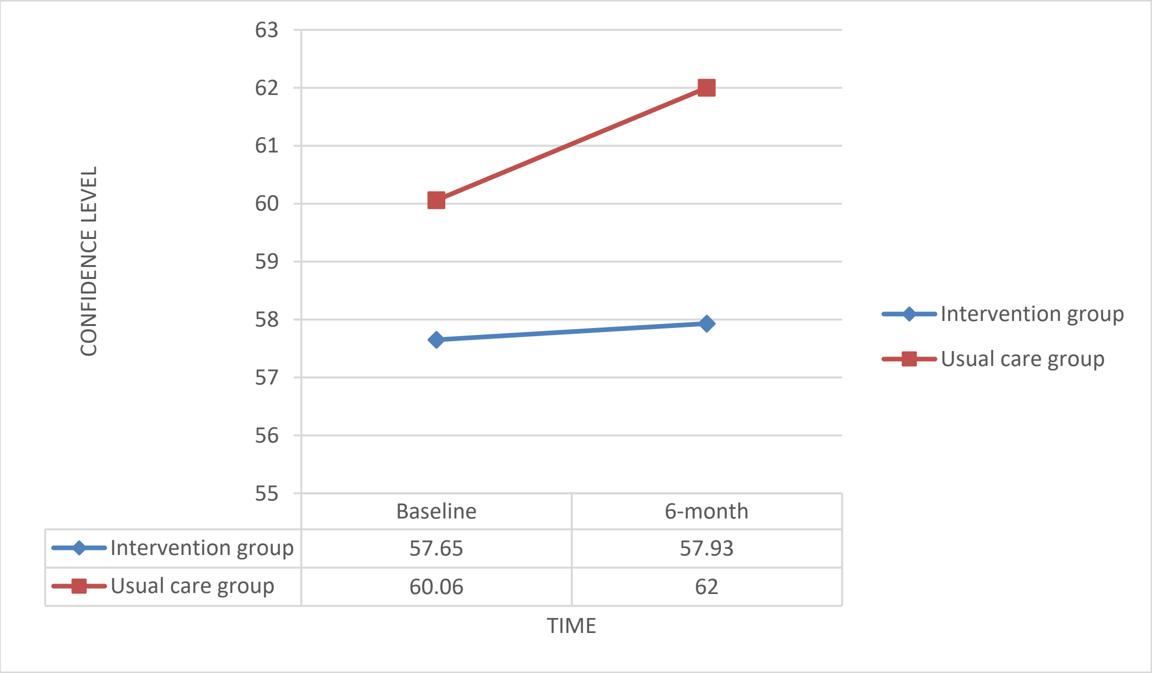


Figure 7-9 Phase 2 Overall self-efficacy for controlling upsetting thoughts at baseline and 6-month

7.3 FINDINGS FROM QUALITATIVE DATA

The characteristics of participants in the interview and analysed qualitative data were introduced in the previous chapter. The findings reported here relate to the effectiveness of the facilitator-enable iSupport program. After qualitative data analysis, seven main themes related to the effectiveness outcome of the iSupport program are described as 1) the PLWD's QOL, 2) engage PLWD in meaningful activities, 3) carer's QOL, 4) carer's self-efficacy, 5) navigate the system, 6) manage transition and 7) facilitator support.

Table 7-13 Phase 2 findings from qualitative data analysis related to intervention effectiveness

Themes	Example
1. PLWD's QOL	'*She just has no short-term memory* [G4_P]'. 'He refuses to acknowledge that he has any problem. He asks me every morning. Can you give me a lift to work? So that's what I have to either find things for him to do to keep him away [G2_P]'.
2. Engage PLWD in meaningful activities	'Get some of your Mum's favourite photos printed and glue 4 or more pieces of a puzzle together (as Dementia gets worse, glue more together). … would be a topic more relatable to your Mum' [G2_T].
3. Carer's QOL	'it's very easy to feel panicky, even though I feel seriously on top of everything. But I can see that if things that really start go down [G1_P]'.
4. Carer's self-efficacy	'My work colleagues probably offer the most support as they help with swapping shifts to facilitate Dad's health appointments, but likewise, I swap with them to help them with their lives such as caring for children and other commitments' [SC 19].
5. Navigate the system	'It's a very long process. It's so many people you have to meet along the way and so many different forms. 18 pages, and I had to do it 3 times because there was something wrong at their end. Oh, ridiculous! [G4_P].'
6. Manage transition	Everybody is talking about keeping them [PLWD] out of residential care and out of hospital…now I don't know if I am doing the right thing' [I_C5].
7. Facilitator support	'She was finding communication was not great between herself and the medical team and she wanted clarification of the plan for her care recipient. I gave her advice about who to contact on the ward to get more information and discuss the communication issues and spoke about changed behaviours and why they may be worse while in hospital' [FP4]'

Note: PLWD=person living with dementia, QOL=quality of life

7.4 FINAL FINDINGS AFTER INTEGRATION OF THE FINDINGS

The following section further integrates all qualitative themes with the quantitative findings described above. The final findings are 1) Intervention and support aimed at reducing stress related to care recipient's factors, 2) Intervention and support aimed at reducing stress related to carers' factors and 3) Intervention and support aimed at reducing stress related to system factors. Selected quotes were given a code based on the data source. For example, G_P means quotes from peer support meeting recordings. The list of legends is displayed in Table 7-14.

Table 7-14 Phase 2 code legend

G_P	Peer support meeting recording	C_L	Carer's letter to the researcher
G_T	WhatsApp messages	FP	Facilitator portfolio
I_C	Carer in the iSupport group interview	SC	Survey comments
I_F	Facilitator interview	RA	Research assistants' documentation

I_SL	Site leader interview		

7.4.1 Finding 1: Intervention and support aimed at reducing stress related to care recipient factors

This finding is related to outcome measure of PLWD's QOL (QOL-AD) and frequency of their changed behaviours (RMBPC-F). Both intervention and the usual care group showed a decline in PLWD's QOL, specifically in memory, ability to do things around the house, doing things for fun and money aspects, as presented in section 7.2.2.2. This may be because many PLWDs in this study have multiple health conditions, as displayed in Table 7-2; almost 50% of PLWDs cared for by participating carers have some chronic conditions that affect their QOL. Qualitative data confirmed that PLWD present with low energy and limited ability to do things around the house or for fun. For example: '*She does not like people. She does not want to go out* [G4_P]'. Others were passive, for example, '*He is very quiet, does not cook, does not do much, but just sits there…*[G2_P]'. Furthermore, PLWD has poor memory, which affects their QOL. One care stated, '*She has no short-term memory* [G4_P]'. Carers were also disappointed that many friends of PLWD disconnected after the diagnosis. One carer said: '*He used to play golf with his friends, but not now… and they lost contact after he cannot play golf anymore…*'[I_C7]. PLWD's QOL was also affected by their physical health, on which the facilitator-enabled iSupport program had less effect. Although carers rated PLWD's physical health as fair, their ability to do things remained poor over a six-month period (Table 7-7). One carer observed: '*Poor physical health is the limiting factor to enjoying a really good life*' [SC39], with pain: *'Pain is mum's main area of concern and distress'* [SC 45] and limited mobility a concern: '*Mum's mobility declined* [G3_T]' and '*her mobility has taken a real hit* [G3_P]'. Poor physical health can lead to falls at home, impacting their ability to do things around the house. For example: '*Mum had a couple of falls and fractured her arm* [G1_P]'. Carers used WhatsApp groups to explore the importance of fall detection and prevention. For example, one facilitator posted in their WhatsApp group: '*Hi everyone, I know we talked a lot about fall prevention, but I found this interesting article which highlights some of the reasons why recovery is more complicated if someone also has Dementia…'*[G1_T].

Changed behaviours of PLWD were another care recipient factor that affected carer stress. Some PLWD have concerns with wayfinding. One carer '*lost her mum in the shopping centre'* [G4_P]. PLWD were sometimes reluctant to accept assistance from others. For example, '*she does not want other people to do many things*' [G4_P]. Or does not want strangers into the house? *'She did not want strangers in her house*[G1_P]'. Positively, after six months of intervention, as shown in section

7.2.2.3, PLWD in the intervention group showed less frequency of changed behaviour, and their carers showed better reactions to the changed behaviours of PLWD. The qualitative data supported these findings, with the iSupport program showing carers and facilitators to be actively engaged in identifying and preventing the changed behaviours. For example, one carer had tradespeople working around the house, with the iSupport facilitator posting a message on WhatsApp to offer some tips to alleviate a potential increase in the frequency of changed behaviours during this time:

> *It may help to remember that you are doing the right thing by keeping as much to the routine as possible while these disruptions happen… In the meantime, being mindful that your mum probably has more questions and will be feeling more unsettled will help you meet her where she is and, as much as possible, deal calmly and clearly with her. Kind reassurance is key because there is a lot of change for her. And that routine you have will help ground her until this is all done. [G4_T]*

The iSupport program also prompted carers to reflect on their reactions to PLWD's changed behaviours. One carer stated:

> *It was beneficial to understand how if I get impatient with mum, it is going to make her worse, whereas it is like, well, OK, how do I control my response to get what we need done or just to step back for a little bit? [I_C17]*

The program was a forum for carers and facilitators to exchange ideas on how to engage PLWDs in meaningful activities, given that some PLWDs '*still like to go out every day*' [G4_P] or want to engage in previous activities, such as going to work; one carer stated:

> *He refuses to acknowledge that he has any problem. He asks me every morning. Can you give me a lift to work? So that is what I have to do: either find things for him to do to keep him away. [G2_P]*

Another carer posted in WhatsApp group: *'Get some of your Mum's favourite photos printed and glue four or more pieces of a puzzle together (as Dementia worsens, glue more together). … would be a topic more relatable to your Mum'* [G2_T].

These quotes lend support to the reduction in changed behaviours of the PLWD and improved carers' reaction score towards their changed behaviours. These findings indicate that stress related to care recipients' factors, such as PLWD's QOL and their changed behaviours, are multifaceted and thus may need multiple interventions to address the different aspects.

7.4.2 Finding 2: Intervention and support aimed at reducing stress related to carer factors

This finding relates to the outcome measure of carer's QOL, carer's self-efficacy and their reactions towards to PLWD's changed behaviours. Over the 6-month intervention period, carers in the intervention group showed improved QOL mental health scores, whereas the usual care group showed a decline in mental health scores.

Carers' mental health and physical health were affected while they cared for their loved ones. One carer stated, '*I am not looking forward to my future* [G2_P]', at the time feeling anxious: '*It is easy to feel panicky, even though I feel seriously on top of everything. However, I can see if things start going down* [G1_P]'. Carers valued the facilitator's emotional support. One carer said: *'The most significant thing was emotional support [from facilitators]…she was caring … she gave me lots of positive thoughts, so emotional support and positive thoughts'* [I_C13].

Peer support through the program was also beneficial to carers' mental health. One carer stated:

> *Because many of them are in similar situations. So, getting practical advice and suggestions from fellow carers was very beneficial. At the same time, having been able to make some suggestions to them in return made me feel like contributing to the group. So it was a mutually beneficial experience having those things. [I_C13]*

It is possible that the iSupport program explains the improvement in mental health scores for carers in the intervention group, while carers in the usual care groups showed a decline in mental health scores.

Carers also experienced physical health strain, but unfortunately it is not within the scope of the facilitator-enabled iSupport program to offer physical support. Some carers sustained an injury when assisting their loved ones at home. For example, one carer said: '*It is so hard transferring them for toileting etc. I pulled my back the other day, so I have been in a lot of pain*[G3_T]'. '*Many carers are still in the workforce*' [G4_P], or '*both parents require support*' [G4_P]. Many carers in our study were not only carers for PLWD, but they were also carers for other family members, which contributing to their physical strain. For example, one carer stated in the interview: '*So essentially, I am a carer, not just for my mum who has dementia, but also my partner who has cerebral palsy and he is deaf, and I did not think of myself as caring for him* [I_C17]'.

Regarding carer's self-efficacy, the domain relating to obtaining respite showed significant improvement for carers in the intervention group (section 7.2.2.5). Carers rated their feeling of support from their family and friends to be above average in the Quality of Social Support survey (section 7.2.2.4). However, many carers expressed that there was no one to help. Many carers expressed that the support from family members cannot be hands-on support; for example, one carer stated: '*Family support is mainly by phone - they do not live locally*' [SC 63]. Another carer made a similar statement with no friends to ask for help: *'No longer have friends, do not speak to* *neighbours. Daughters help in a social role'* [SC 52]. Many carers were reluctant to seek support from their family and friends, for example: '*If I asked for more help, my family and neighbours would help more. I would rather people think we are coping well now and call on others when I may need help in the future*' [SC 17].

Another carer echoed this:

> *To be fair, I do not seek support either; I just do it. My work colleagues probably offer the most support as they help with swapping shifts to facilitate Dad's health appointments, but likewise, I swap with them to help them with their lives, such as caring for children and other commitments [SC 19].*

In contrast, other carers in this study were happy to ask for help from their supported family, and they appreciated it. For example, one carer stated: '*I was lucky that you know husband's daughter took him yesterday [G1_P]*'. Many carers have good support from their friends: '*I have good support from friends in similar situations as me and also from our family'* [SC 12].

For the self-efficacy domain related to responding to PLWD's behaviour, carers in the hospital groups showed significantly better scores than the community aged care group (section 7.2.2.5). Qualitative data supported this finding with the iSupport program prompting carers to think positively about their loved ones' behaviours. One carer in the hospital group stated:

> *On the bright side, after 35 years together, I am only now learning so much about my husband's childhood and military career. He now has ALL the time and details to tell me about things he never told me about. I do love that. [G2_T]*

This was echoed by another carer:

> *I mean, learning patience…patience is number one. If [my wife] does it, it can annoy me sometimes [compared to my two grandchildren] …And then I sort of step back and think...I would not be as upset as I am now, and overall, there is not a lot of difference between three of them [grandchildren and my wife]. [I_C19]*

Facilitators also supported and tried to foster a positive thought environment, as evidenced by WhatsApp group interaction and peer support meetings. For example, one facilitator posted: *'Dementia is not about the past, the successes, the accolades or the accomplishments…Dementia is about the present, the relationships, and the experiences, which are the core of life, the courage to live in the soul'* [G3_T].

Although it was not statistically significant, carers in the intervention group improved their confidence in controlling unpleasant thoughts from low confidence to moderate confidence over six months.

7.4.3 Finding 3: Intervention and support aimed at reducing stress related to system factors

This finding is related to outcome measures of quality of social support, obtaining respite and managing transition. At the baseline, carers in both intervention and usual care groups consider support they received from health and social services to be above average (Section 7.2.2.4), although there was no significant change in the quality of support over six months among all groups. However, carers in the intervention group showed an improved mean score, whereas carers in the usual carer group showed a decrease in the mean score. This finding is also supported by qualitative data. ISupport facilitators offered support to tackle the difficulties related to system factors according to their expertise. One carer stated:

> *The facilitator [aged care service provider] helped me to get a code number to get a respite for my husband; the difficulty was getting a test number when you have already got a package. She [the facilitator] sent me the literature, which showed that I could get just a number because I used up all my packages. That was a practical thing that [facilitator] helped me. [I_C8]*

The facilitator from community aged care services also provided recommendations on the Home Care Package: '*Did anyone tell you that you can extend your package an extra 28 days'* [G1_T]?

There were, however, limitations to what a facilitator can help with at a system level. One facilitator from the community aged care stated: '*Outside the authority of the facilitator to advocate for services as cannot speak on behalf of the PLWD legally'* [FP1_2]. Another facilitator from the hospital also reflected in the portfolio:

> *I have struggled a little with the scope of the facilitator when trying to help participants who were at the limit of their capacity and approaching burnout. I reached out to fellow facilitators and to my principal investigator to gain clarity and support. This was helpful; I was able to come to terms with feeling a bit useless in the face of my participant's burnout and realised that listening could be helpful even if I am not actively referring or providing advice. [FP4]*

Sharing information on how to navigate the health system was part of the facilitator's role. One facilitator posted in the WhatsApp group:

> *The government has developed a website providing online training for people just starting out. It offers information on the different types of devices available and how to access services like online banking, Government websites, and apps. How to be safe online. [G1_T]*

However, some carers expressed that the program could not meet all they needed. For example: *'One thing I guess the program did not cover was how to use My Age Care'* [I_C4].

Carers also found it challenging and frustrating to navigate the healthcare system to access resources, not because they did not know how to access these services but rather somewhat related to how the system operates. One carer stated: *'Are other carers finding it incredibly frustrating emotionally and incredibly time-consuming to connect with carers' resources and support services? I find myself stuck in an awful loop of forms, interviews and obstacles that sometimes seem too high to jump'* [G2_T].

In support of findings related to self-efficacy in obtaining respite, many carers expressed low confidence in asking family and friends to stay with PLWD for a short period of time (section 7.2.2.5), indicating that finding appropriate and acceptable respite care services is important. Many carers only need short-term respite, but most residential care homes have a minimum requirement to access respite care: '*They only offer respite, and care on a minimum of 2 weeks when all we want is a weekend occasionally* [G1_P]'.

Throughout the study, there were numerous reasons for transition of the PLWD -transition from home to hospital, home to a nursing home, or hospital to residential care as documented in the facilitator's portfolio [FP1_1, FP1_2, FP2_3, FP3_2, FP4]. For example: *'One participant's care recipient was admitted to the hospital. I spoke with her to check in and see if she had any issues or needed support'* [FP4]. These transitions were not easy for carers. One carer stated: *'I have to convince myself it is the best place for her'* [G1_P]. Some felt uncertain about their decision as one carer said: *'Everybody is talking about keeping them [PLWD] out of residential care and out of hospital…now I do not know if I am doing the right thing'* [I_C5].

As part of their role, iSupport facilitators actively supported carers dealing with transition. For example:

> *She was finding communication was not great between herself and the medical team, and she wanted clarification of the plan for her care recipient. I gave her advice about who to contact in the ward to get more information and discuss the communication issues. I also spoke about changed behaviours and why they may be worse while in hospital. [FP4]*

Other facilitators also link support for transition to the appropriate iSupport module:

> *One transition noted, the person being cared for is moving into a permanent care facility. The carer has an aged care consultant involved in supporting the transition. I suggested iSupport learning module 6, point 6, 'relinquishing the caring role' (relative module) to the carer to further support the transition. [FP1_1]*

While it is clear from the qualitative data that carers welcomed the facilitator's support, this did not translate into a significant quantitative change in carers' perceived quality of support.

7.5 SUMMARY

This chapter presented findings related to the effectiveness of the facilitator-enabled iSupport program to address study objective 7: Determine the intervention effectiveness with the given sample size at six months. Findings indicated that the facilitator-enabled iSupport program significantly improved PLWD-changed behaviours, carers' reactions towards changed behaviours and self-efficacy in obtaining respite. The hospital group showed significant improvement in self-efficacy for responding to PLWD’s changed behaviour. The program also showed promising tendencies in improving carers' QOL and quality of social support. The effectiveness of PLWD’s QOL and carers’ self-efficacy in controlling upsetting thoughts were inconclusive. In the next chapter, all findings from the study will be further integrated, critically interpreted and presented as a discussion.

8 Discussion

8.1 INTRODUCTION

The aims of the study were to 1) engage with stakeholders to reach consensus on activities to be delivered by iSupport facilitators for carers of PLWD in a planned iSupport for Dementia program in Phase 1 and 2) assess the feasibility, fidelity and preliminary effectiveness of a facilitator-enabled virtual iSupport for Dementia program for informal carers of PLWD in phase 2. The seven study objectives were to 1) reach a consensus on the activities to be delivered by iSupport facilitators to strengthen support for carers of PLWD in the planned iSupport program in hospital and community and aged care settings; 2) reach a consensus on the iSupport facilitator's roles and responsibilities when embedding the Australian iSupport for Dementia program in care services; 3) determine the feasibility of the participant recruitment and factors affecting the recruitment; 4) determine the attrition rate and factors contributing to the attrition; 5) monitor intervention fidelity and factors affecting the fidelity; 6) explore strategies to embed and sustain the facilitator-enabled iSupport program after the trial, and 7) determine the intervention effectiveness with the given sample size at six months. Findings from phase 1 and 2, qualitative and quantitative data, were combined to facilitate the mixed method data analysis. The discussion integrated qualitative and quantitative findings across the thesis and had two parts according to the objectives and stress and health theoretical model. The activities to strengthen support for carers of PLWD in the planned iSupport program was discussed in section 8.2 to address the study's objective 1. Section 8.3 discussed iSupport facilitators' roles and responsibilities to address study objective 2. Section 8.4 focused on study objective 3: determine the feasibility of participant recruitment. Section 8.5 discussed the participant's retention and attrition to address study objective 4. In section 8.6, the discussion focused on study objective 5: the intervention fidelity. Section 8.7 addresses study objective 6, the strategies to embed and sustain the iSupport program after the trial. Section 8.8 discussed the effectiveness of the iSupport program at six months to address study objective 7. Finally, section 8.9 presented a summary of the chapter.

8.2 THE ACTIVITIES TO STRENGTHEN SUPPORT FOR CARERS OF PLWD IN THE PLANNED ISUPPORT PROGRAM

In Phase 1 of this PhD study, the modified Nominal Group Technique process provided opportunities for participants to interact with each other, clarify, elaborate, and exchange ideas. Phase 1 of the study proposed 16 activities to be delivered by iSupport facilitators to strengthen support for carers of PLWD in the Australian context. Although some activities were rated less feasible, they proceeded to phase 2 to see if the facilitator could increase their feasibility during the practice. Findings from phase 1 indicate that activities to strengthen support for carers of PLWD are highly relevant. These 16 activities aimed to reduce carer recipient-related stress, carer-related stress, and system-related stress, as discussed in the following sections.

8.2.1 Activities to reduce care recipient-related stress

Care recipient related stress relates to PLWD's condition such as chronic condition, dementia stage, change behaviours and their dependent level. Stakeholders recommended activities addressing care recipient-related stress including supporting carers to 1) manage dementia-related symptoms, 2) managing chronic conditions, 3) identifying risks of hospital and residential care admission, 4) engaging PLWD in meaningful activities, and 5) medication management. These findings support previous studies that show care recipients' conditions can significantly increase carer burden and affect carers' mental and physical health (Lawlor et al., 2020; Yoshino & Takechi, 2023). Findings from this study support the previous work undertaken on the diversity of PLWD and the need to provide person-centred care, maintain independence and engage them in meaningful activities based on their strengths, preferences, and past experiences (Brummel ‐ Smith et al., 2016). Participants in this study shared their experiences in caring for PLWD in different stages with various care needs. Therefore, ongoing and timely support for carers is necessary to reduce their stress related to care recipient factors.

Some activities related to care recipient factors, however, were rated less feasible in phase 1 and were not requested by carers in phase 2, indicating that they were not likely to be used within the context of participating organisations. For example, chronic condition management was rated less feasible in phase 1, given that it is very broad and often involved in multi-disciplinary care. Common chronic conditions such as diabetes mellitus, cardiac disease and chronic pulmonary disease often require specialised management and complicated treatment regimens, including multiple different medications, doses, and nonpharmacological tasks involving PLWD and carers (Coe et al., 2021; Ibrahim et al., 2017). Similarly, medication management is complex and requires specific knowledge that often involves years of training (Aston et al., 2017). The present study indicates that carers are most likely to ask a community pharmacist medication-related questions to avoid conflicting information from different prescribers. Other studies suggested that GPs, geriatricians, and pharmacists should work collaboratively on PLWD's medication management in the community (Barry & Hughes, 2020; Ibrahim et al., 2017). Furthermore, identifying risk factors for residential care or hospital admission is another complex activity rated less feasible in phase 1. Falls are the most reported reasons for hospital admission in PLWD worldwide (Afonso-Argilés et al., 2020; Australian Institute of Health and Welfare, 2021), while the decision to nursing home admissions is the result of a combination of multiple reasons, such as changed behaviours, dependent level and increased carer burden (Afram et al., 2014). Although there was no direct risk assessment, facilitators delivered activities that potentially prevent hospital and residential care admission, such as fall prevention education and supporting carers in changed behaviour management, indicating this activity is feasible and acceptable in the actual practice. Therefore, managing chronic conditions and medication management maybe better managed by multi-disciplinary team instead of iSupport facilitators.

8.2.2 Activities to reduce carer-related stress

Carer related stress relates to carers' physical and mental ability in providing care for PLWD such as dementia care knowledge, skills, confidence, mental health and family circumstances. Activities aimed at carer-related stress (i.e., training, positive thoughts, social support) include 1) support for carers to develop self-care strategies to maintain their mental health, 2) assess their learning needs, and 3) coordinate a peer support group. Findings from phases 1 and 2 indicate that support for carers to develop self-care strategies to maintain their mental health and coordinate a peer support group are relevant, feasible and acceptable. In alignment with previous studies (Wallace et al., 2021; Wilkerson et al., 2018), the phase 2 results showed that the above activities are promising in improving care's QOL and are welcomed by carers. However, assessing carers' learning needs was rated less acceptable in phase 1. Phase 1 participants explained the reason for the low acceptability of assessing carers' learning needs because they also want the training or support to be inclusive, and information provided need to be tailored and iSupport manual only may not meet carer's needs. For example, alternative methods should be offered when carers cannot use the internet or speak English. ISupport facilitators in phase 2 responded to this feedback by offering multi-modality support using the phone or the internet. They also delivered bite-size pieces of information from the iSupport manual and a variety of trustworthy resources within the peer support meetings and WhatsApp groups, rather than expecting the carers to only read the book.

The individualised and inclusive support offered in phase 2 showed a promising effect, as supported by previous studies that carers need tailored education and support throughout their care journey (Whitlatch & Orsulic-Jeras, 2018).

8.2.3 Activities to reduce system-related stress

System related stress relates to health and social care services such as availability, accessibility, and quality of the services. activities that reduce system-related stress include support for carers to 1) navigate care services, 2) manage the transition, 3) update care plans, 4) provide feedback to service providers, 5) be provided with a single point of contact, 6) consider cultural diversity, and 7) prevent elder abuse. Previous studies report that carers have various support needs after the dementia diagnosis (Bamford et al., 2021; Røsvik & Rokstad, 2020), which the activities of this study align with. There are some activities such as ‘considering cultural influence in dementia care and directing carers to relevant groups’, was not directly applicable for carers in the present study, given that they were from English-speaking mainstream backgrounds in Australia. However, this is an area that must be considered in future studies. Furthermore, participants rated the ‘update care plan’ as low feasibility and ‘provided feedback to service providers’ as low acceptability, given that this is part of routine and ongoing care planning as required by the Aged Care Quality and Safety Commission (2018). Carers, however, welcomed these activities with some facilitators prompting and supporting carers (in phase 2) to update their Home Care Package and providing feedback to service providers to enhance quality of care, while ensuring no duplication of service.

8.3 THE ROLE AND RESPONSIBILITY OF THE ISUPPORT FACILITATORS

The two systematic reviews I undertook in this PhD study indicated that carers of PLWD desired to connect to health professionals when using internet-based psychoeducation programs, and facilitator-enabled psychoeducation programs showed better effects on reducing carers' depressive symptoms. However, the facilitators' role in these programs was limited and diverse, and suggested lack of generalisability due to different social and economic backgrounds in the global context (Goeman et al., 2016). In phase 1 of the study, participants stated that the facilitator role should be present 1) at the time of dementia diagnosis to support carers navigate the system, understand the dementia and care services; 2) throughout the dementia care journey by acting as an educator and a resource person to enable carers to manage changed behaviour, medication and cope with emotional and psychological stress; and 3) during transition to support carers to obtain respite care and during the hospital stays of PLWD. In phase 2, the facilitator focused on five areas: managing transition, managing dementia progression, psychoeducation, facilitating carer support groups and providing feedback on service (Xiao et al., 2022). Findings from this internal pilot study support the idea that facilitators can deliver the planned iSupport programs and their role was welcomed by carers of PLWD in the community. The intervention also generated positive outcomes for carers and PLWD, as discussed in the following sections.

8.3.1 ISupport facilitator's role in addressing stress related to carer recipients' factors

Participants recommended that the facilitator provide ongoing support through the dementia care journey to mitigate care recipient-related stress. Consistent with previous study results (Peeters et al., 2010), the present study also found that lack of timely, ongoing, personalised carer support to manage changed behaviour at home caused significant stress for carers. Carers must be coached to manage dementia-related symptoms and changed behaviours (Chenoweth et al., 2016), indicating that ongoing and timely educational support from iSupport facilitators is necessary. Health and social care professionals in this study also expressed the importance of fostering a partnership with carers to help them understand the causes of changed behaviour in PLWDs. In this study phase 2, iSupport facilitators built therapeutic relationships that strengthened partnerships with carers and offered timely educational support using the iSupport for Dementia manual, indicating their roles are relationship-centred, holistic, and accessible and assisting the carer of PLWD in maintaining their way of living (Renehan et al., 2017). iSupport facilitators actively engaged with carers via peer support meetings and WhatsApp groups to foster a knowledge exchange environment on engaging in PLWD and managing their changed behaviours. This finding suggests that these activities are feasible and accepted by carers.

8.3.2 ISupport facilitator's role in addressing stress related to carer factors

The present study indicated that carers desired that the iSupport facilitator could support them at the time of diagnosis. Previous studies showed that carers’ confidence level, social support and positive thoughts about their carer role were correlated with their mental health and wellbeing (Arenella & Steffen, 2020; Bekhet & Garnier-Villarreal, 2020). In study phase 2, iSupport facilitators promoted psychoeducation using the iSupport manual, offered emotional support and facilitated online peer support groups. Participants from phases 1 and 2 of the study embraced the emotional and educational support from the iSupport facilitators. Unlike existing peer support and education provided by government-funded programs, which usually offer one-on-one peer support by paring carers who want peer support with other carer volunteers, education for carers relies on carers to self-select learning materials online (Dementia Australia, 2022). ISupport facilitators proactively engage with carers to identify their needs, which differs from those supporting mechanisms that rely on carers to initiate requests, which may only support carers who have computer literacy and already know how to access the care services. This type of support mechanism fails to support those who do not know what they do not know in terms of how to access and utilise services.

8.3.3 ISupport facilitator's role in addressing stress related to system factors

Findings from this study indicated that carers of PLWD need a single point of contact, such as an iSupport facilitator, to support them in navigating and accessing relevant care services, provide support during transition, and advocate for carers and PLWD for their best interest. ISupport facilitators in phase 2 provided educational and emotional support in assisting carers in navigating the system and managing the transition. Carers in this study detailed the difficulties they experienced when accessing respite care services. Findings from this study also support those of a previous study that demonstrated that carers lacked knowledge of the available respite services (Phillipson et al., 2019), indicating that an iSupport facilitator is necessary for supporting carers in this area.

8.3.4 The differences between the iSupport Facilitator's Role and the traditional support worker

The iSupport facilitator role differs from the key worker or support worker’s roles in the literature synthesised by Goeman et al. (2016) and Reilly et al. (2015), iSupport facilitators are not necessarily experts in dementia care initially. However, they learn about dementia on the job, draw on their own life experience and utilise the iSupport for Dementia Manual to provide support. In line with the essential competencies for key workers of PLWD and their carers developed by Renehan et al. (2017), empathy and being a good listener are valued more than knowledge and skills that can be learned on the job. Phase 1 findings indicated that carers were reluctant to seek support during emotional stress. Zwingmann et al. (2020) reported carers’ rejection of mental health support. They found that the reasons were related to personal issues (i.e., time constraints), activities issues (i.e., availability) and relational issues (i.e., preference). This study added that a lack of mental health self-care awareness and a lack of trust in health professionals also contributed to carers’ apprehension about mental health support. iSupport facilitators demonstrated empathy and listening skills through the study, which allowed them to build trusting relationships with carers, which is highly valued by participants.

Moreover, iSupport facilitators were selected and trained based on the roles and responsibilities developed in the iSupport program and agreed upon by stakeholders. In addition to their clinical role, they were trained to be interventionists to deliver the planned intervention in the iSupport program. The role of the iSupport facilitator is comprehensive and covers all aspects of caregiving to strengthen support for carers of PLWD across the health and aged care systems. In contrast, the support worker role in the literature only focuses on one or two aspects of support, for example, assisting carers to navigate the system, emotional support, utilise services or education, but not all of them (Kiely et al., 2021; Reilly et al., 2015).

Furthermore, the iSupport facilitators offered were online or via phone, which differs from existing key workers' or support workers' face-to-face roles (Goeman et al., 2016; Reilly et al., 2015). Participants in this study highly valued the online or phone support they received from facilitators. These findings support previous studies that found that carers of PLWD accept online support (Davies et al., 2020; Sitges-Maciá et al., 2021). Online or phone support can alleviate pressures related to travel and space required for the in-person meeting, yet some carers in this study still wished to talk to someone face to face. Therefore, using a mixture of face-to-face and online support may accommodate broader carers' needs.

Findings from this study indicated that such a role as an iSupport facilitator requires a clearly defined scope of practice and adequate initial and ongoing training in dementia care to support individual staff, and iSupport facilitators need to possess the ability to learn problem-solving skills on the job. Similarly, Renehan et al. (2017) also suggested that the key worker role for carers and PLWD need resources and support, such as professional development to maintain and develop dementia knowledge, communication and interpersonal skills, enhance the ability to problem-solve and build relationships.

8.4 FEASIBILITY OF THE PARTICIPANT RECRUITMENT AND FACTORS AFFECTING THE RECRUITMENT

The internal pilot study identified that minor modifications of the recruitment strategies and intervention can reduce recruitment challenges. The modification also allowed the iSupport program to fit the clinical settings better, aligned with the trial design recommendation (Loudon et al., 2015). The modified facilitator-enabled iSupport for Dementia program was feasible with a 20% attrition rate. Participants welcomed the program and showed a higher attendance rate. The survey data collection method was also acceptable, with a higher completion rate for most surveys. The internal pilot RCTs study in dementia care with multi-component interventions is scant in the literature. The present internal pilot study has addressed the gaps in the literature, as discussed in the following sections.

8.4.1 Participant recruitment

This internal pilot study identified that recruiting family carers of PLWD in the community was challenging, as most RCTs reported in the literature (Heward et al., 2022; Walters et al., 2017). Although the recruitment rate for the first year of the study was 1.75 participants per centre per month, which is similar to average multi-centred trials (around 0.95/centre/month) (Walters et al., 2017), the recruitment rate was only 10% which is lower compared to similar trials and feasibility studies (around 20-40%) in the literature (Baker et al., 2023; Baruah et al., 2021). Nonetheless, the present study had a shorter recruitment period, more intervention components, and more frequent data collection than those studies. For example, in the study conducted by Baker et al. (2023), the recruitment period was more than two years, and the study conducted by Baruah et al. (2021) had a 15-month recruitment period. Both studies had three months of intervention, and data were collected at the baseline and three months. These comparisons underscore the need to undertake an internal pilot RCT to assist the project team in adjusting the recruitment plan to achieve the recruitment goal. Based on the monitoring of the carer recruitment, the present internal pilot study informed the project team to extend the recruitment from 12 months to 18 months, and this extension was approved by the MRFF funding body based on the research evidence.

Characteristics of the RCT design can be barriers for participants to enrol, and it was not easy to address (Naidoo et al., 2020; Rodríguez-Torres et al., 2021). The present study identified that the complex consenting process prevented many people from participating in the program. This finding supports the previous studies indicating that the RCT length, the complexity of the information, and follow-ups were all considered burdens to some potential participants and potentially influenced their decision (Baker et al., 2021; Naidoo et al., 2020). Although some components of RCT cannot be modified, broadening eligibility criteria and increasing the flexibility of the intervention was not new in the literature to reduce the participation barriers (Briel et al., 2016; Rodríguez-Torres et al., 2021). One of the strategies that improved the recruitment was to offer more flexibility and autonomy to potential participants by modifying inclusion criteria, providing iSupport for Dementia in hardcopy books, having a choice of not attending online meetings and receiving support from iSupport facilitator via phone call instead. Facilitators also extended the peer support meeting times for carers who would like to stay longer to accommodate individual needs.

Another strategy implemented was to employ more recruiters, extend recruitment sites and broaden study promotion. Similar to the barriers reported in the literature, this study's initial time constraint and burden on the recruiter were apparent and significantly underestimated, potentially impacting recruitment (Briel et al., 2016). The iSupport facilitators' support in recruiting improved recruitment and allowed facilitators to build rapport with participants earlier to offer better support later. This finding supports a previous study that reported that highly engaged organisation-employed staff (i.e., research nurses) or close contact is critical to successful recruitment (Isaksson et al., 2019). The modification during the recruitment also improved the RCT to suit the actual clinical settings better.

8.5 PARTICIPANTS' RETENTION AND ATTRITION

This study had an overall 80%, and the intervention group had 70% retention rate; the usual care group had an 89% retention rate, which is lower than those RCTs that included people with chronic conditions (82-100%) (Harris et al., 2021; Sui et al., 2023) but higher than those similar RCTs that included carers of PLWD (Baruah et al., 2021; Cristancho-Lacroix et al., 2015). Compared to psychosocial interventions for carers of PLWD, regardless of research type, the present study had a similar retention rate (Qiu et al., 2019), which means higher program acceptability among carers. The lower attrition rate in this study could be because of the internal pilot study design that allows the modification of interventions that better fit real-world practice (Loudon et al., 2015). After offering flexibility, the modified iSupport program better met the carer’s needs and was less demanding. The present study's attrition was mainly because PLWD passed away or moved to permanent aged care services, which is similar to the previous RCT study summarised in Chapter 2 (Blom et al., 2015; Boots et al., 2018; Duggleby et al., 2018; Gustafson et al., 2019; Kajiyama et al., 2013). This finding indicated that PLWD’s condition and carer situation can change quickly and committing to a 12-month trial could be challenging.

8.6 INTERVENTION FIDELITY

The findings showed that intervention fidelity was not high meaning further adaptation of the program to the clinical area is needed. The iSupport facilitator’s support reached all carers in the intervention group, the iSupport book completion rate by carers in the intervention group was lower (29% completed 70% of the book) than expected in the protocol (100% completed 70% of the book within 6 months), peer support meetings attendance and WhatsApp groups interaction was varied, more extended peer support zoom meeting was delivered as needed. However, 96% of carers in the present study completed some part of the book, and qualitative data indicated non-measurable regular engagement with the iSupport manual content via peer support meetings and WhatsApp groups. Compared to previous similar dementia psychoeducation RCTs, the present study pre-planned carers to complete 20 out of 30 units (70% over 6 months), which is far more than 5 out of 23 units (22% over 3 months) in the iSupport study conducted by Baruah et al. (2021). Moreover, the carers’ engagement rate (96%) is much higher than the 55% in the study by Baruah et al. (2021) and 73% in the study conducted by Duggleby et al. (2018).

Completion of psychoeducation units was decreased, but engagement was comparatively higher, lending weight to adapting the pilot RCT intervention to be further adapted to meet the carer's needs in different situations, hopefully leading to better program implementation after the RCT (Loudon et al., 2015). It is possible, in the present study that the lower manual completion rate of units is due to carers having been in the role for many years and having some dementia knowledge when they started the program. Although they read less than the required units in the book, they accessed other support offered by the program. One can argue that modified intervention offered more flexibility to end users, which increased the acceptability and appropriateness of the program; although it lowered fidelity, this approach made the RCT better fit in the real world, which is more desirable.

8.7 STRATEGIES TO EMBED AND SUSTAIN THE FACILITATOR-ENABLED ISUPPORT PROGRAM AFTER THE TRIAL

8.7.1 Psychoeducation using iSupport for Dementia Manual

Due to the delay in internet-based program development, carers were provided hardcopy and electronic books of the iSupport for Dementia manual. Carers were also provided access to an internet-based iSupport program later. The monitoring of the internet-based iSupport program is still in progress and will be presented in the main RCT. This pilot study mainly focused on carers’ experience in using hardcopy books. The study identified that carers’ experiences are affected by the information provided in the book, and the visual layout of the hardcopy book is similar to those of carers in the online psychoeducation program (Ying. Yu, Lily. Xiao, et al., 2023). According to Pot et al. (2019), the WHO iSupport for Dementia program suits carers experiencing mild stress and burden. Participants in the present study through phase 1 and phase 2 all identified that they needed information support after the dementia diagnosis, similar to previous studies (Bamford et al., 2021; Hargreaves et al., 2022), indicating that the iSupport program also suits carers who started their dementia carer journey.

Carers who used internet-based programs and hardcopy books expressed in this study that they preferred hardcopy books. Although carers accept internet-based programs in the literature (Ottaviani et al., 2022), they still prefer hardcopy books if there is an option. This finding is not new in the literature; older adults preferred to read text on paper rather than screen due to age-related difficulty in cognitive map formation (Hou et al., 2017). Cognitive maps theory conceptualises that the human brain processes written text not only by gathering visual cues of the text while reading but also by the text's physical location and its spatial relationship to the page as a whole to form a cognitive map, lead to understanding and recall (Hou et al., 2017). The hardcopy book has a fixed layout and is easy for the reader to orientate and form a cognitive map quickly. Reading on the screen involves processing, reading, and operating the website, which increases carers' cognitive load and leads to a more tiring experience than reading printed books (Hou et al., 2017). This can explain why carers in this study, whose average age is 66, preferred hardcopy books. Therefore, iSupport for Dementia manual hardcopy book might need to be a choice for people to meet their individual needs when embedding such a program after the trial.

8.7.2 Support from iSupport facilitators

Carers in this study highly valued iSupport facilitators' support, in line with previous study findings that carers of PLWD would like to have health professional-supported psychoeducation (Ying. Yu, Lily. Xiao, et al., 2023). Carers in the present study valued online or telephone support from the facilitator, again in line with a previous study's findings that suggested that online or telehealth can also positively support carers (Saragih et al., 2022). However, facilitator training and professional development are essential to sustain such a role in everyday clinical practice. The current health workforce shortage in Australia also explains the high turnover of the facilitators in the study (The National Skills Commission, 2022). Future embedding of iSupport program after the trial need to consider balancing between meet carer needs and staff shortage.

8.7.3 Peer support via online Zoom meeting

Most carers welcomed online peer support meetings and opted to attend the meetings. Carers welcomed the exchange of information and support for each other, similar to a previous study, which indicated that knowledge improvement through the experiential knowledge sharing of fellow carers was essential to meeting carers' needs (Carter et al., 2020). Moreover, ongoing technical support was required to ensure carers were confident and competent in using online platforms; this finding is like a previous study conducted by Banbury et al. (2019), which indicated that carers need IT support for videoconference meetings. Unlike existing studies summarising peer support group interventions (Carter et al., 2020), the present study also identified that the length of the peer support meeting affects carers' experiences; it needs to be based on the number of attendants instead of the fixed meeting time as this allows for adequate time for individual carer to actively involved in the conversation. Carers in the present study also suggested having a mixture of online and face-to-face peer support meetings and after-hour peer support meetings to meet diverse carers' needs.

8.7.4 Peer support via WhatsApp group

Some but not all carers in this study used WhatsApp groups to exchange information. Previous studies showed that online chat groups such as WhatsApp have become the leading means of online dementia education platforms in the Chinese American community (Shu & Woo, 2020). Carers also use online platforms or social media to form supporting communities (Johnson et al., 2022). The present study findings indicated that carers in Australia benefited and welcomed facilitator-moderated online chat groups via WhatsApp but were also cautious about the interaction. Carers in the present study who did not use WhatsApp, believed that relationships must be built before exchanging information on social media. This finding is similar to the study conducted by Johnson et al. (2022), who found that carers and PLWD were motivated to use social media to connect to other people; but were also challenged by privacy and publicity concerns. It appears this type of peer support may take longer for carers to build a trusting relationship, before sharing their life experiences. Moreover, carers involved in the group must be informed about social media norms, educated about self-protection on social media, and respect each other's confidentiality, as Johnson et al. (2022) suggested, supporting the need for a facilitator-moderated online chat group.

8.7.5 Strategies to sustain the iSupport program after the RCT

The facilitator-enabled virtual iSupport for Dementia program as a psychoeducation program was welcomed by carers in the study, as discussed above. Findings from this study indicated that the program is suitable for carers at the start of their care journey, and individual components (i.e., psychoeducation, facilitator support and online peer support) can be used to support carers in different situations. A mixture of online and face-to-face support can accommodate a wide range of care needs. Phase 1 of this study and previous studies already identified that carers need support after the diagnosis and everyday dementia care journey (Pavković et al., 2023; Ying Yu et al., 2023). However, according to site leaders and facilitators from partner organisations, to sustain long-term support of the iSupport program, one must consider the existing care models in different organisations and availability of funding. It is important to consider how the element and strategies for embedding the iSupport for Dementia program in community aged care services might differ from hospital settings. This study and Steiner et al. (2020b) strongly suggest using research evidence to inform policymakers, funding bodies and service providers to work together to find a solution, such as shifting community dementia care from PLWD-focused to the dyad (PLWD and the carer) to enable carers to continue providing care for PLWD at home.

Site-specific staff participants in the study identified funding barriers to implementing the iSupport program, as carers of PLWD are not considered clients under the current funding models. As outlined in the report by Low et al. (2023), existing funded post-diagnostic support models, such as short-term support workers, might be more feasible to implement; in contrast, comprehensive support models might be more expensive and challenging to establish and staff for universal availability. A call for more government investment in post-diagnostic support is noted (Pavković et al., 2023). Findings from this study support similar concerns from Steiner et al.'s (2020b) study, which recommended a ‘gold standard' model of care or a one-stop-shop service for PLWD and their carers after a dementia diagnosis. Moreover, findings imply the need to partner with government-funded programs such as Carer Gateway in Australia (a government-funded program to support carers of all types) to further implement such programs after the trial (Department of Social Services, 2023). Long-term sustainability must also consider staff training and retention in the current situation of workforce shortages (The National Skills Commission, 2021, 2022).

8.8 INTERVENTION EFFECTIVENESS AND IMPACT ON CARER STRESSOR

The effectiveness of the facilitator-enabled iSupport program was evaluated based on its effect on the carer stress-related factors, namely carer recipients’ factor, care factor and system factor. The study showed that after six months, the iSupport program impacted the care recipient’s factor by improving PLWD’s changed behaviour frequencies. Regarding carer factors, the study showed improved carers’ mental health scores, significantly improved carer’s reaction to PLWD’s changed behaviours and carers’ self-efficacy in obtaining respite. Furthermore, system factors related to stressors were measured by quality of social support; findings showed that the program improved carers' perception of social support over the six months but was not statistically significant.

8.8.1 Impact on Care Recipient Factor

This study found that the facilitator-enabled iSupport program decreased PLWDs' changed behaviour occurrences at six months. This finding differs from the previous research, indicating that case management, similar to iSupport facilitator support, did not affect PLWD’s changed behaviours at six months but at 12 and 18 months (Saragih et al., 2021). The present study also found that the iSupport program significantly improved carers' reaction towards PLWD’s changed behaviours, which is also different from previous research, indicating that this type of intervention does not affect carers' reactions (Leng et al., 2020). The difference in the results might be because the facilitator-enabled iSupport program included multiple support and education mechanisms in one program compared to the previous study. For example, case management interventions rely on the case manager to build trusting relationships with carers to assist with symptom management (Saragih et al., 2021). Similarly, online interventions synthesised by Leng et al. (2020) do not have facilitator support or regular peer support groups for carers to exchange information. In contrast, facilitator-enabled iSupport programs employed iSupport for Dementia psychoeducation, online Zoom peer support meetings, WhatsApp groups and facilitator support. Changed behaviours in PLWD are multifaceted and require tailored and systemic carer support (Gonçalves-Pereira, 2017). The present multi-component study addresses care recipient factor-related stress from multiple angles like those reported in the literature. For example, iSupport for Dementia psychoeducation program offers carers knowledge and strategies to deal with changed behaviours (Cheng et al., 2020); iSupport facilitators build trusting relationships with carers, provide tips and hints and allow carers to gain insight on behaviour management (Saragih et al., 2021), peer support meetings and WhatsApp groups provided opportunities for carer to exchange strategies of managing changed behaviours and ideas of engaging PLWD in meaningful activities (Dam et al., 2016).

This study also found that PLWD’s QOL declined regardless of their carers' use of the iSupport program. According to a previous study, interventions that support the functional ability of PLWD and cognitive stimulation seem to have a QOL-improving effect on PLWD (Holopainen et al., 2019). This might explain why the iSupport program had minimal impact on PLWD’s QOL, as its focus was on carers, although there are strategies for engaging PLWD in meaningful activities. QOL in PLWD is a multidimensional concept affected by PLWD’s social background, medical condition, and social and caring environment (Holopainen et al., 2019). Carers in the present study indicated that they lost social support from friends after a dementia diagnosis, potentially indicating that PLWD lost their friends, too, which is one of the indicators for the PLWD’s QOL. Dementia is a progressive condition, which was also shown in this study as PLWD’s condition changed quickly during the six months reported by their carers. Findings from this study suggested that the support that positively affected carers may not directly benefit PLWD.

8.8.2 Impact on Carer Factors

Findings indicated that the facilitator-enabled iSupport program improved carers’ QOL mental health after six months compared to carers in the usual care group who declined in their QOL mental health component. This finding supported my systematic review, which indicated that internet-based psychoeducation programs with facilitator support could significantly reduce carer depressive symptoms (Ying. Yu, Lily Xiao, et al., 2023). Phase 1 of the study findings suggested that a lack of mental health self-care awareness and a lack of trust in health professionals contributed to carers' apprehension about mental health support. After six months in the iSupport program, iSupport facilitators and carers established a trusting relationship and played a significant role in emotional support. Findings from this study also suggested that online peer support groups via Zoom meetings and WhatsApp groups played an essential role in improving carers' QOL mental health, similar to a previous study (Carter et al., 2020). Social isolation-related emotional strain was identified in an earlier study (Lee et al., 2022). In the present study, both carers and staff considered emotional support crucial. Online Zoom meetings and WhatsApp groups provided carers with a supportive community to exchange emotional and informational support, which had a positive effect. However, it is not possible within this study to distinguish the specific impact of individual components of the iSupport program.

Furthermore, the present study found that the facilitator-enabled iSupport program improved carers' self-efficacy in obtaining respite care or seeking support from family and friends after six months. This finding differs from a previous study that used the same outcome measures and reported no difference between their groups (Cristancho-Lacroix et al., 2015). The main difference between the present study and Cristancho-Lacroix et al.'s (2015) was that the carers in this study were supported by an iSupport facilitator. The facilitator-enabled iSupport for Dementia program addresses stress related to care factors by offering tailored educational support to enhance the carer's self-efficacy. The program also promoted carer self-reflection, which may impact their ability to recognise problems and confidence in seeking support. Help-seeking behaviour is a cognitive process of problem identification, the decision to act and selecting a source of help (Cornally & McCarthy, 2011). For example, many carers in this study identified that seeking help was difficult, but at the same time, they also recognised there was a problem that they may need help. iSupport facilitator and peer support within the iSupport program can potentially influence the decision to act in the help-seeking process and encourage carers to seek support.

Moreover, the findings indicated that carers in the intervention group significantly improved their reactions towards PLWD's changed behaviours. The facilitator-enabled iSupport program fostered a partnership with carers and the peer support community to help them understand the causes of changed behaviour, thus enhancing their response in this study. The findings aligned with a previous study by Trivedi et al. (2019), who reported in their systematic review that trained professionals could improve carer competence in managing changed behaviours by focusing on problem-solving and coping strategies. Similar findings were reported by Stephan et al. (2018), who also recommended having a single point-of-contact person for carers to optimise support for them in preventing and managing changed behaviours of PLWD. This kind of support would alleviate the negative impact of care recipient factors on carers. Findings also indicated that the hospital group improved significantly in self-efficacy in responding to behaviour but not in reaction to the changed behaviour score. This might suggest that carers may have self-perceived confidence in some perspectives of self-efficacy but may not reflect in their everyday activities.

8.8.3 Impact on System Factors

The Quality of Social Support findings in this study reflected the impact of the iSupport program on stressors related to system factors. Findings showed that the facilitator-enabled virtual iSupport program improved carers' perception of the quality of social support compared to the carers in the usual care group, who had a decreased score of quality of support. iSupport facilitators tried their best to help the carer navigate the system, obtain respite care, and support them during the transition, all related to system factors. The quality of support is affected by individual carers' social networks, service availability, and health professionals' expertise (Donnellan et al., 2017; Morrisby et al., 2018). Many carers in this study expressed a loss of friendship and social networks after a dementia diagnosis, which can potentially affect their perceived quality of support. The iSupport program provided carers opportunities to build new support networks by offering facilitator and peer support. ISupport facilitators also utilise their knowledge and expertise to support carers in navigating the system and managing the transition, contributing to the iSupport program's positive effect.

However, health and social care system issues are challenging to address. Carers in the study phase 1 and 2 continually reported a lack of suitable respite services. This finding aligns with Shea et al. (2017), who highlighted poor respite service availability and accessibility. For example, carers in study phase 1 reported that they had to use hospital beds to care for their loved ones when there were no adequate respite services in the community for carers. This finding reveals that a lack of respite care is associated with potentially avoidable burdens and costs for acute care hospitals. In Australia, in 2021 and 2022, about 40% of people hospitalised for PLWD were discharged home, and 14% were awaiting residential aged care (AIHW, 2023b), suggesting that the burdens of hospital stays (including the costs to the healthcare system) could be diminished by using facilitators. Carers in the study phase 2 continue to experience a shortage of respite, a lengthy and complicated process to access services similar to a previous study (Shea et al., 2017), highlighting systemic issues of poor respite service availability and accessibility.

8.9 SUMMARY

This chapter critically analysed phase 1 and 2 findings and addressed the study's aims and objectives. In particular, the iSupport facilitator’s role and responsibilities were identified, and 16 proposed activities were included. However, in phase 2, iSupport facilitators focused on four areas: psychoeducation, managing transition, managing dementia progression, and providing feedback to service providers. Phase 2 findings confirmed that some activities were less feasible, as suggested in phase 1. For example, managing chronic conditions of PLWD, identifying risks of residential care admission and regular review of the medication. Aim 2 of the study was to assess the feasibility of a facilitator-enabled iSupport for Dementia program for carers of PLWD. Findings indicated that modified recruitment criteria and intervention made RCT feasible with a lower attrition rate. Although low intervention fidelity was identified, the modifications to the RCT make it more likely to be implemented in natural clinical settings. The facilitator-enabled virtual iSupport program showed high acceptability by carers of PLWD and demonstrated the appropriateness of the supporting intervention for long-term implementation after the trial. However, sustaining such a program requires government investment and organisational policy support. The effectiveness of the facilitator-enabled iSupport program at six months showed significant improvement in PLWD’s changed behaviour frequency, carers' reaction to changed behaviours and carers' self-efficacy in obtaining respite. These findings differed from previous studies’ findings, indicating the positive outcome of the innovation of the multicomponent psychoeducation program. Findings also showed promising results of improvement of carers' QOL mental health components, which confirms that previous studies showed that multi-component psychoeducation programs can improve carers' stress and depressive symptoms. Overall, the modified facilitator-enabled virtual iSupport program was feasible, acceptable, and effective in supporting carers of PLWD in the community.

9 Conclusions

9.1 INTRODUCTION

The current study uses the facilitator-enabled virtual iSupport program to address the unmet needs of PLWD's family care in the community. Chapters 5, 6, and 7 present findings from this PhD study to address the study's aims. The aims of the study were to 1) engage with stakeholders to reach a consensus on activities to be delivered by iSupport facilitators for carers of PLWD in a planned iSupport for Dementia program in phase 1 and 2) assess the feasibility, fidelity and preliminary effectiveness of a facilitator-enabled virtual iSupport for Dementia program for informal carers of PLWD in phase 2. Chapter 8 critically discussed the findings of this study. This chapter draws on the findings and discussion and concludes the study. The study summary covers the entire thesis and is presented in section 9.2. The study's strengths and limitations are presented in section 9.3. Section 9.4 discussed the implications of the present study's findings for policy, clinical practice, education, and future research. Finally, a conclusion is presented in section 9.5.

9.2 STUDY SUMMARY

The present study included two systematic reviews: a systematic review and meta-analysis of quantitative studies and a systematic review and meta-synthesis of qualitative studies. Phase 1 used a mixed methods study to identify care activities and iSupport facilitators' roles and responsibilities to strengthen support for carers of PLWD by working with stakeholders. In phase 2, a mixed methods study design used an internal pilot RCT, and a qualitative descriptive study design examined RCT feasibility, fidelity, and strategies to embed and sustain the facilitator-enabled iSupport program after the trial. Phase 2 of the study also evaluated the effectiveness of the facilitator-enabled iSupport program at six months.

Findings from the systematic review and meta-analysis identified 19 internet-based psychoeducation interventions conducted in different countries; only 13 were RCTs, and only seven had a health professional as a facilitator. No such study was conducted in the Australian context. Limited study in the field and differences in socioeconomic background reduced their generalisability. Among these RCTs, the recruitment period was around 7 to 24 months, the average recruitment rate was 57%, and the attrition rate was 29%. The meta-analysis results indicated that the internet-based psychoeducation program has a significant effect on carers of PLWD’s depressive and stress symptoms. This review also confirmed that facilitator-enabled internet-based psychoeducation programs had better depressive symptom reduction compared to non-facilitator-enabled internet-based psychoeducational programs, further supporting the need for a facilitator-enabled iSupport for Dementia program. However, due to the nature of the quantitative study, carers' experiences in these internet-based psychoeducation programs were uncertain. Therefore, a systematic review and meta-synthesise of qualitative studies of internet-based psychoeducation programs was conducted.

The systematic review and meta-synthesis included 9 studies and synthesised the carers’ experiences in internet-based psychoeducation programs and the factors that enable and impede carers’ engagement. The findings confirmed that the enabling factors included the programs’ quality and relevancy, support received, relevance to individual needs, flexibility in delivery, and ability to connect to other carers and program facilitators without time and space restrictions. The impeding factors included caregiving demands, poor program performance (i.e., internet connection), and the inability to meet individual needs (i.e., their caring situation) or preferences (i.e., for a paper-based program). This review also identified that the limited study was conducted globally, and no qualitative or mixed-methods study was conducted in the Australian context. Two systematic reviews confirmed the need for the facilitator-enabled iSupport program to collect quantitative and qualitative data using a mixed methods study design in the Australian context.

Phase 1 of the study addressed aim 1. It explored the supporting activities for carers of PLWD and the role and responsibilities of iSupport facilitators in a planned iSupport for Dementia program by engaging with carers and service providers. All 16 proposed activities facilitators could deliver aimed at mitigating three stressor-related factors (care recipient-related stress, carer-related stress, and system-related stress), and stakeholders reached a consensus that all activities were relevant to dementia care in the Australian community. Results from phase 1 identified that stakeholders welcomed activities and the facilitator role; however, some proposed activities were considered less feasible and acceptable, namely managing chronic conditions of PLWD, identifying risks of nursing home admission, regular review of the medication, revising care plans, assessing carers’ learning needs and providing feedback to service providers. The relevant activities and the roles and responsibilities of iSupport facilitators identified in phase 1 informed the training program development for iSupport facilitators and the implementation manual. This allowed for the standardisation of the intervention in the RCT of the planned iSupport program in phase 2.

Phase 2 of the study considered findings from systematic reviews and phase 1. In this phase, the study aims were to evaluate the feasibility of a facilitator-enabled virtual iSupport for Dementia program for informal carers of PLWD, using an internal pilot RCT and qualitative descriptive study design. Findings indicated that the present study had a 10% recruitment rate and a 70% retention rate in the intervention group at the 6 months. Based on the monitoring of the carer recruitment, the present internal pilot study informed the project team to extend the recruitment from 12 months to 18 months. Moreover, the internal pilot study also informed following modifications to the main RCT: modifying inclusion criteria, providing iSupport for Dementia in hardcopy books in addition to internet-based only, having a choice of not attending online meetings, receiving support from iSupport facilitator via phone calls instead and extending the peer support meetings times to accommodate individual needs. The modification during the internal pilot study improved the recruitment and made the main RCT better suit the clinical settings. Overall, carers of PLWD in the study are highly valued and actively engaged in the program; however, to embed and sustain such a program after the trial needs to be innovative, organisation policy and government funding support.

Phase 2 of the study also indicated that the modified facilitator-enabled virtual iSupport program significantly improved PLWD’s changed behaviour frequencies (care recipient factor) and the carer’s reaction to PLWD’s changed behaviour and self-efficacy in obtaining respite (carer factor). These findings differed from previous studies’ findings, indicating the positive outcome of the innovation of the multicomponent psychoeducation program. The program also showed a promising tendency to improve carers’ mental health scores (carer factor) and their perception of quality of social support (system factor) and self-efficacy for responding to behaviours and controlling upsetting thoughts (carer factor), but it was not statistically significant. Overall, the modified facilitator-enabled virtual iSupport for Dementia program was feasible, acceptable, and effective in supporting carers of PLWD in the community.

9.3 STRENGTHS AND LIMITATIONS

9.3.1 The systematic review

The conducted systematic review and meta-analysis had several strengths. First, the literature search covered English and Chinese databases, reducing bias. Second, a meta-analysis to calculate the effect size of the changed mean score is crucial for comparing internet-based and non-internet-based psychoeducational programs. In addition, the review included pre- and post-test studies in addition to RCTs to analyse the psychoeducational designs. This review also had several limitations.

First, while this review searched English and Chinese literature, it could have expanded to other languages if other multilingual researchers had been included in the study team. Second, variations in program design, intervention duration, dose and socio-cultural contexts prevented us from undertaking sub-group analysis to calculate precise intervention effect size.

The systematic review and meta-synthesis had the strength of rigorous adherence to the JBI systematic review and meta-aggregation protocol to minimise bias during the process. However, this review had a few limitations. First, only 9 articles were included, indicating the limited research evidence from qualitative studies. Second, the review was based on database searches in 3 languages: English, Chinese, and Arabic. Therefore, a bias exists in the selection of studies. Despite the primary effort to review studies in Chinese and Arabic, the lack of diverse evidence from different contexts in non-English studies is apparent. The caregivers' experiences identified in this review may not represent a wider culturally and linguistically diverse population. The reader must confirm transferability to similar contexts in qualitative research.

9.3.2 The phase 1 study

The key strength of the phase 1 study was using a mixed methods study design to reach a consensus on the activities to be delivered and the roles and responsibilities of iSupport facilitators in the planned iSupport for Dementia program. Collecting quantitative and qualitative data from carers and health professionals across multiple study sites over prolonged periods ensures the methodological triangulation to support findings. Moreover, the study design demonstrated authentic partnerships with health professionals, carers of PLWD and partner organisations. Furthermore, face-to-face, online, and phone interviews were combined to accommodate participants' needs and reduce the study burden.

The phase 1 study also had several limitations. First, as the study was conducted during the COVID-19 pandemic, significant recruitment difficulties were experienced. Service providers identified all participants; therefore, selection bias may exist. Second, there were more health professional participants than carer participants and more spouse carers than in other types of care relationships. Therefore, the survey results might represent more towards health professionals and spouse carers. The interpretation of the results needs to be cautious. Third, participants were offered maximum flexibility to complete the survey and participate in a workshop or interview. Therefore, some people only completed 1 round of the survey or workshop, and not everyone provided their demographic information. Fourth, despite the efforts, there were no Aboriginal Australian study participants. Therefore, the result may not represent Australia's diverse community. Fifth, this study was conducted in Australia, which has a comprehensive health and social care system. The findings may not be transferable to other countries with different health and social care systems. Sixth, all participants were fluent in English, and their views may not represent those of people in Australia with limited English proficiency. Seventh, online workshops and telephone interviews may have prevented the researchers from noticing participants' non-verbal cues. Finally, some participants had cared for their loved ones for many years, which could have led to recall bias regarding distant events.

9.3.3 The phase 2 study

The phase 2 study has several strengths. First, to the best of my knowledge, this is the first study to evaluate multicomponent interventions such as facilitator-enabled virtual psychoeducation programs in the Australian context. Second, the findings from systematic reviews and phase 1 of the study provided evidence to prepare for facilitator training and development of the implementation manual, ensuring standardised internal pilot RCT implementation in phase 2, which enhanced the study rigour. Third, a mixed method study design allowed quantitative and qualitative findings to validate and confirm each other to enhance the understanding of the findings. Fourth, an internal pilot RCT design allowed justification of the intervention to ensure the main RCT was more acceptable and suitable for the clinical area and reduced recruitment pressure. Last, qualitative data was collected using unobstructed methods, which minimised bias.

There are limitations to the phase 2 study. First, due to the pilot RCT's sample size, the significance of the effectiveness is difficult to determine. Second, most participants were recruited from partner organisations; they may already have knowledge to access services and navigate the health system, but their stress levels might differ. Third, despite the participants being instructed not to share the iSupport for Dementia Australia version with the usual care group, contamination is possible because the iSupport for Dementia WHO version was freely accessible via the internet. Last, the study aimed to test the facilitator-enabled iSupport psychoeducation program in the Australian context. Therefore, the program is limited in meeting some carer needs such as financial issues or time constraints.

9.4 IMPLICATIONS

9.4.1 Implication for policy

The finding on the need to provide the facilitator-enabled iSupport program for carers and PLWD have implications for the policy development. Federal and state government's dementia care policy needs to fund the program and facilitator role in routine services. For example, federal government could fund home care package to support family carers and PLWD as a dyad instead to support services only based PLWD's assessment. Carers can freely choose a psychoeducation program such as iSupport program and facilitators' support from service providers. An adequate credential and endorsement process for such a role is also necessary. This would involve a formal audit, review, and renewal process to ensure professional standards. Existing organisational models of care to support carers of PLWD could consider upskilling existing staff to incorporate iSupport facilitator role, rather than creating a new role. This form of support offered through service providers could offer more flexibility and choice for carers. Lastly, the policy could also allow combined face-to-face and online format support to accommodate carers’ preferences, alleviate transportation and space restrictions, and potentially reduce costs and better reach people in rural and remote areas.

9.4.2 Implications for clinical practice

Findings from this study can inform the development of iSupport facilitators' role in clinical area, including community aged care services and acute care hospitals. The different requirements of such a role in community aged care services and acute care hospitals need to be acknowledged when establishing such a role. It could be a health or social care professional-enabled dementia care service to meet individual organisation’s needs. First, the facilitator could collaborate with a geriatrician and a GP to ensure the carer is supported at the time of dementia diagnosis. For example, a GP or geriatrician could refer a newly diagnosed PLWD and their carer to the facilitator for dementia care education and for support in accessing resources. The facilitator could also assist PLWD and their carers to understand and navigate care services and identify relevant ones. Second, the facilitator could provide ongoing needs assessment for both carer and PLWD at the different dementia stages. This would allow health care and social care professionals to promptly address carers’ challenges and improve the quality of home-based dementia care.

9.4.3 Implications for education

The Australian version of the iSupport for Dementia program, as a trustworthy psychoeducation program, could be used for carers' education in addition to available government-funded resources to provide diverse educational material to meet individual needs. The program could be further adapted to the individual organisation to be used as education material through their routine services. For example, acute hospitals could use iSupport for Dementia program as patient education material. Acute hospitals also can integrate iSupport facilitator role with existing clinical role to offer discharge planning, education and follow up. While aged care service providers can integrate such a role with care manager or coordinator role to offer ongoing support for carers and PLWD once their support could be funded as dyad. Service providers could use the iSupport for Dementia program Australian version to support carers who are starting their care journey or experience mild stress. Moreover, a systematic and accredited dementia care program could be developed to equip and endorse health and social care professionals to provide better support for carers of PLWD. Trained iSupport facilitators can also be the resource persons to support, mentor and provide ongoing staff training for each organisation.

9.4.4 Recommendations for research

Recruitment of carers for PLWD in the community is challenging, and study promotion should commence as early as possible. It would be beneficial to have a team approach for the recruitment promotion using multiple resources. Researchers must consider the implications of study burden; essential data collection and a simplified consenting process are necessary for recruitment success. Co-designing the RCT with stakeholders, including partner organisations, carers, and PLWD, from the outset will help with the recruitment of the study. Future research also could consider testing intervention such as iSupport program within an existing support group or supporting services, which could target at the people who already show interest in such program.

Future research may consider conducting a cost analysis for an RCT to provide further evidence of the intervention's sustainability. Future research could also focus on testing the effectiveness of the individual components of the iSupport program. For example, the effectiveness of the online support group, phone support and psychoeducation manual. A qualitative study could focus on the iSupport facilitator’s training needs and the short-term effect of facilitator support. Moreover, further co-designing with partner organisations to inform the findings from phase 2 and exploring the opportunities for further implementation of a facilitator-enabled iSupport program is necessary. Furthermore, future studies may also consider exploring the iSupport facilitator’s role in primary health care to enhance post-dementia diagnosis support for PLWD and their carers.

9.5 CONCLUSION

The aims of the study were to 1) engage with stakeholders to reach the consensus on activities to be delivered by iSupport facilitators for carers of PLWD in a planned iSupport for Dementia program in phase 1 and 2) assess the feasibility, fidelity, and preliminary effectiveness of a facilitator-enabled virtual iSupport for Dementia program for informal carers of PLWD in phase 2.

Seven study objectives were to 1) reach consensus on the activities to be delivered by iSupport facilitators to strengthen support for carers of PLWD in the planned iSupport program; 2) reach consensus on the iSupport facilitator's roles and responsibilities when embedding the Australian iSupport for Dementia program in care services; 3) determine the feasibility of the participant recruitment and factors affecting the recruitment; 4) determine the attrition rate and factors contributing to the attrition; 5) monitor intervention fidelity and factors affecting the fidelity; 6) explore strategies to embed and sustain the facilitator-enabled iSupport program after the trial and 7) determine the intervention effectiveness with the given sample size at 6 months. The study achieved all its aims and objectives and contributed new evidence to dementia care research.

Caring for family members with dementia is mentally and physically demanding and stressful for carers. It has a potentially adverse impact on their health and wellbeing throughout their caring journeys. Carers' stress is related to the care recipient, carer, and system factors. The support that can help carers reduce stress includes physical, educational, informational, and social support, which targets care recipients’ related stress, carer-related stress and system-related stress. The iSupport facilitators’ role was welcomed by participants in the study as it reduced their stress. The facilitator-enabled virtual iSupport for Dementia Program effectively improves PLWD-changed behaviours, carers' reaction towards changed behaviours and self-efficacy in obtaining respite. The program also showed a promising tendency to improve carers’ mental health scores, their perception of the quality of social support, and self-efficacy for responding to behaviours and controlling upsetting thoughts. The modified facilitator-enabled iSupport for Dementia program is feasible and effective for future clinical implementation. New knowledge generated from this PhD study can inform policymakers, management, and service providers to establish or improve dementia care services to support carers of PLWD in the Australian community.

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Appendices

APPENDIX 1 SYSTEMATIC REVIEW AND META-ANALYSIS SEARCH STRATEGIES

MEDLINE (in Ovid)

1	(Carer* or caregiver* or "carer taker*"or caretaker* or spouse or "adult children" or acquaintance* or neighbor* or neighbour* or "home nursing").ti,ab.	216854	10.6.2021
2	exp Caregivers/	39963	
3	(dementia*or Alzheimer* or "Mild Cognitive Impairment").ti,ab.	18355	
4	exp Dementia/	175230	
5	exp Alzheimer Disease/	99592	
6	(Internet or online or e-health or e-learning or telecomputing or tech or health or computers or software or electronic or digital).ti,ab.	2654792	
7	exp Computer-Assisted Instruction/	12122	
8	(Intervention* or program* or course* or psychoeducation* or training* or support* or platform* or e-learning or telemedicine or telehealth or application* or interface).ti,ab.	5388185	
9	1 or 2	226717	
10	3 or 4 or 5	184525	
11	6 or 7	2661024	
12	8 and 9 and 10 and 11	2486	

CINAHL

1	Carer* or caregiver* or "carer taker*"or caretaker* or spouse or "adult children" or acquaintance* or neighbor* or neighbour* or "home nursing"	15428	10.6.2021
2	(MH "Mild Cognitive Impairment") OR (MH "Alzheimer's Disease") OR "dementia*or Alzheimer* or "Mild Cognitive Impairment""	33784	
3	"Internet or online or e-health or e-learning or telecomputing or tech or health or computers or software or electronic or digital" OR (MH "Learning Health System") OR (MH "World Wide Web") OR (MH "Online Education") OR (MH "World Wide Web Applications")	82753	
4	(MH "Online Education") OR "Intervention* or program* or course* or psychoeducation* or training* or support* or platform* or e-learning or telemedicine or telehealth or application* or interface" OR (MH "Education, Non-Traditional") OR (MH "Programmed Instruction") OR (MH "Adult Education")	12898	
5	1 AND 2 AND 3 AND 4	59	

Web of Science

1	Carer* or caregiver* or "carer taker*"or caretaker* or spouse or "adult children" or acquaintance* or neighbor* or neighbour* or "home nursing"	560900	10.6.2021

2	dementia*or Alzheimer* or "Mild Cognitive Impairment"	33648
3	Internet or online or e-health or e-learning or telecomputing or tech or health or computers or software or electronic or digital	16,443,596
4	Intervention* or program* or course* or psychoeducation* or training* or support* or platform* or e-learning or telemedicine or telehealth or application* or interface	22,260,880
5	1 AND 2 AND 3 AND 4	812

The Cochrane Library

1	Carer* or caregiver* or "carer taker*" or caretaker* or spouse or "adult children" or acquaintance* or neighbor* or neighbour* or "home nursing"	34633	10.6.2021
2	dementia* or Alzheimer* or "Mild Cognitive Impairment"	29034	
3	Internet or online or e-health or e-learning or telecomputing or tech or health or computers or software or electronic or digital	356168	
4	Intervention* or program* or course* or psychoeducation* or training* or support* or platform* or e-learning or telemedicine or telehealth or application* or interface	866141	
5	1 AND 2 AND 3 AND 4	2066	

Scopus

1	TITLE-ABS-KEY (carer* OR caregiver* OR "carer taker*" OR caretaker* OR spouse OR "adult children" OR acquaintance* OR neighbor* OR neighbour* OR "home nursing")	752288	10.6.2021
2	TITLE-ABS-KEY (dementia* OR alzheimer* OR "Mild Cognitive Impairment")	363114	
3	TITLE-ABS-KEY (internet OR online OR e-health OR e-learning OR telecomputing OR tech OR health OR computers OR software OR electronic OR digital)	13,117,369	
4	TITLE-ABS-KEY (intervention* OR program* OR course* OR psychoeducation* OR training* OR support* OR platform* OR e-learning OR telemedicine OR telehealth OR application* OR interface	18,754,561	
5	1 AND 2 AND 3 AND 4	7924	
6	TITLE-ABS-KEY ((carer* OR caregiver* OR "carer taker*" OR caretaker* OR spouse OR "adult children" OR acquaintance* OR neighbor* OR neighbour* OR "home nursing") AND (dementia* OR alzheimer* OR "Mild Cognitive Impairment") AND (internet OR online OR e-health OR e-learning OR telecomputing OR tech OR health OR computers OR software OR electronic OR digital) AND (intervention* OR program* OR course* OR psychoeducation* OR training* OR support* OR platform* OR e-learning OR telemedicine OR telehealth OR application* OR interface)) AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (LANGUAGE , "English"))	5418	

Clinical Trials.gov

1	dementia or Alzheimer or Mild Cognitive Impairment	344	10.6.2021
2	Online education for informal carers	1	
3	Meet inclusion criteria	0	

Chinese data-base search strategies

Key words

研究对象	照顾者 or 非正式照顾者 or 照护者 or 家属 or 家人 or 配偶 or 妻子 or 朋友 or 儿女 or 儿子 or 女儿 or 子女 or 亲属 or 亲戚 or 邻居 or 照料者 痴呆 or 老年痴呆 or 血管性痴呆 or 额颞叶性痴呆 or 帕金森痴呆 or 失智症 or 认知症 or 认知障碍 or 阿尔茨海默 or 阿尔兹海默 or Alzheimer's or AD or 轻度认知障碍 or MCI

干预	互联网 or 网络 or 网站 or 在线 or 计算机 or 远程 or 手机 or 电脑 or 笔记本 or 电子 or 软件 or APP or 微信 or QQ or 移动设备 or 视频 or 公众号 or 媒体 or 小程序 干预 or 治疗 or 训练 or 疗法 or 项目 or 课程 or 教育 or 心理教育 or 心理 or 培训 or 支持 or 信息平台 or 医疗平台 or 平台 or 移动医疗 or 远程医疗 or 应用 or 界面 or 设备

万方(Wanfang)

	检索式	检索量	检索时间
1	主题:("痴呆"or"老年痴呆"or"血管性痴呆"or"额颞叶性痴呆"or"帕金森痴呆"or"失智症"or"认知症"or"认知障碍"or"阿尔茨海默"or"阿尔兹海默"or"Alzheimer's"or"AD"or"轻度认知障碍"or"MCI")	655979	2021.07.12
2	主题:("照顾者"or"非正式照顾者"or"照护者"or"家属"or"家人"or"配偶"or"妻子"or"朋友"or"儿女"or"儿子"or"女儿"or"子女"or"亲属"or"亲戚"or"邻居"or"照料者")	857757	
3	主题:("互联网"or"网络"or"网站"or"在线"or"计算机"or"远程"or"手机"or"电脑"or"笔记本"or"电子"or"软件"or"APP"or"微信"or"QQ"or"移动设备"or"视频"or"公众号"or"媒体"or"小程序")	10709683	
4	主题:("干预"or"治疗"or"训练"or"疗法"or"项目"or"课程"or"教育"or"心理教育"or"心理"or"培训"or"支持"or"信息化平台"or"医疗平台"or"移动医疗"or"平台"or"远程医疗"or"应用"or"界面"or"设备")	31649708	
5	1 and 2 and 3 and 4	205	

中国知网(CNKI)

	检索式	检索量	检索时间
1	SU %=‘痴呆’+‘老年痴呆’+‘血管性痴呆’+‘额颞性痴呆’+‘帕金森痴呆’+‘失智症’+‘认知症’+‘认知障碍’+‘阿尔茨海默’+‘阿尔兹海默’+‘AD’+‘轻度认知障碍’+‘MCI’+‘Alzheimer’s’	106,316	2021.07.12
2	KY=‘痴呆’+‘老年痴呆’+‘血管性痴呆’+‘额颞性痴呆’+‘帕金森痴呆’+‘失智症’+‘认知症’+‘认知障碍’+‘阿尔茨海默’+‘阿尔兹海默’+‘AD’+‘轻度认知障碍’+‘MCI’+‘Alzheimer’s’	22,901	
3	AB=‘痴呆’+‘老年痴呆’+‘血管性痴呆’+‘额颞性痴呆’+‘帕金森痴呆’+‘失智症’+‘认知症’+‘认知障碍’+‘阿尔茨海默’+‘阿尔兹海默’+‘AD’+‘轻度认知障碍’+‘MCI’+‘Alzheimer’s’	119,418	
4	SU %='照顾者'+'非正式照顾者'+'照护者'+'家属'+'家人'+'配偶'+'妻子'+'朋友'+'儿女'+'儿子'+'女儿'+'子女'+'亲属'+'亲戚'+'邻居'+'照料者'	199,434	
5	KY='照顾者'+'非正式照顾者'+'照护者'+'家属'+'家人'+'配偶'+'妻子'+'朋友'+'儿女'+'儿子'+'女儿'+'子女'+'亲属'+'亲戚'+'邻居'+'照料者'	6,653	

6	AB='照顾者'+'非正式照顾者'+'照护者'+'家属'+'家人'+'配偶'+'妻子'+'朋友'+'儿女'+'儿子'+'女儿'+'子女'+'亲属'+'亲戚'+'邻居'+'照料者'	436,295	
7	SU %=‘互联网’+’网络’+’网站’+’在线’+’计算机’+’远程’+’手机’+’电脑’+’笔记本’+’电子’+’软件’+’APP’+’微信’+’QQ’+’移动设备’+’视频’+’公众号’+’媒体’+’小程序’	3,891,934	
8	KY=‘互联网’+’网络’+’网站’+’在线’+’计算机’+’远程’+’手机’+’电脑’+’笔记本’+’电子’+’软件’+’APP’+’微信’+’QQ’+’移动设备’+’视频’+’公众号’+’媒体’+’小程序’	5,237	
9	AB=‘互联网’+’网络’+’网站’+’在线’+’计算机’+’远程’+’手机’+’电脑’+’笔记本’+’电子’+’软件’+’APP’+’微信’+’QQ’+’移动设备’+’视频’+’公众号’+’媒体’+’小程序’	4,909,096	
10	SU %=‘干预’+’治疗’+’训练’+’疗法’+’项目’+’课程’+’教育’+’心理教育’+’心理’+’培训’+’支持’+’信息化平台’+’医疗平台’+’移动医疗’+’平台’+’远程医疗’+’应用’+’界面’+’设备’	12,631,938	
11	KY=‘干预’+’治疗’+’训练’+’疗法’+’项目’+’课程’+’教育’+’心理教育’+’心理’+’培训’+’支持’+’信息化平台’+’医疗平台’+’移动医疗’+’平台’+’远程医疗’+’应用’+’界面’+’设备’	48	
12	AB=‘干预’+’治疗’+’训练’+’疗法’+’项目’+’课程’+’教育’+’心理教育’+’心理’+’培训’+’支持’+’信息化平台’+’医疗平台’+’移动医疗’+’平台’+’远程医疗’+’应用’+’界面’+’设备’	16,708,134	
13	1 OR 2 OR 3	168,943	
14	4 OR 5 OR 6	522,700	
15	7 OR 8 OR 9	5,983,473	
16	10 OR 11 OR 12	19,939,887	
17	1 AND 2 AND 3 AND 4	344	

超星期刊(Chao xing)

	检索式	**检索量**	**检索时间**
1	Su=痴呆|失智|认知症|认知障碍|阿尔茨海默|阿尔兹海默|Alzheimer’s|AD|轻度认知障碍|MCI	218,390	2021.07.12
2	Su=照顾者|照护者|家属|家人|配偶|朋友|儿女|儿子|女儿|子女|亲属|亲戚|邻居|照料者	1,899,488	
3	Su=互联网|网络|网站|在线|计算机|远程|手机|电脑|笔记本|电子|软件|APP|微信|QQ|移动设备|视频|公众号|媒体|小程序	9,509,204	
4	Su=干预|治疗|训练|疗法|项目|课程|教育|心理教育|心理|培训|支持|信息平台|医疗平台|平台|移动医疗|远程医疗|应用|界面|设备	34,905,180	

5	1 AND 2 AND 3 AND 4	447	

维普（VIP）

	检索式	**检索量**	**检索时间**
1	M=痴呆 or 老年痴呆 or 血管性痴呆 or 额颞叶痴呆 or 帕金森痴呆 or 失智症 or 认知症 or 认知障碍 or 阿尔茨海默 or 阿尔兹海默 or AD or 轻度认知障碍 or MCI or Alzheimer	82,898	2021.07.12
2	M=照顾者 or 非正式照顾者 or 照护者 or 家属 or 家人 or 配偶 or 妻子 or 朋友 or 儿女 or 儿子 or 女儿 or 子女 or 亲属 or 亲戚 or 邻居 or 照料者	265,559	
3	M=互联网 or 网络 or 网站 or 在线 or 计算机 or 远程 or 手机 or 电脑 or 笔记本 or 电子 or 软件 or APP or 微信 or QQ or 移动设备 or 视频 or 公众号 or 媒体 or 小程序	4,112,128	
4	M=干预 or 治疗 or 训练 or 疗法 or 项目 or 课程 or 教育 or 心理教育 or 心理 or 培训 or 支持 or 信息平台 or 医疗平台 or 平台 or 移动医疗 or 远程医疗 or 应用 or 界面 or 设备	14,057,408	
5	1 AND 2 AND 3 AND 4	9	

APPENDIX 2 SYSTEMATIC REVIEW AND META-ANALYSIS GRADE

Certainty assessment							№ of patients		Effect		Certainty	Importance
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	online dementia psychoeducation	control	Relative (95% CI)	Absolute (95% CI)		
Caregiver's QoL												
6	randomised trials	not serious	serious [a]	not serious	not serious	none	175	196	-	SMD **0.18 higher** (0.22 lower to 0.58 higher)	⊕⊕⊕◯ MODERATE	
Caregiver's depressive symptoms												
8	randomised trials	not serious	not serious	not serious	not serious	none	312	320	-	SMD **0.19 lower** (0.35 lower to 0.03 lower)	⊕⊕⊕⊕ HIGH	
Caregiver's depressive symptoms (program with facilitator)												
2	randomised trials	not serious	not serious	not serious	not serious	none	121	122	-	SMD **0.29 lower** (0.54 lower to 0.03 lower)	⊕⊕⊕⊕ HIGH	
Caregiver's stress												
6	randomised trials	not serious	not serious	not serious	not serious	none	176	201	-	SMD **0.29 lower** (0.52 lower to 0.06 lower)	⊕⊕⊕⊕ HIGH	
Caregiver's self-efficacy												
7	randomised trials	not serious	serious [a]	not serious	not serious	none	189	185	-	SMD **0.12 lower** (0.12 lower to 0.36 higher)	⊕⊕⊕◯ MODERATE	
Caregiver's anxiety												
3	randomised trials	not serious	serious [a]	not serious	not serious	none	135	133	-	SMD **0.12 lower** (0.76 lower to 0.51 higher)	⊕⊕⊕◯ MODERATE	
Caregiver's burden												
6	randomised trials	not serious	not serious	not serious	not serious	none	146	147	-	SMD **0.03 lower** (0.26 lower to 0.20 higher)	⊕⊕⊕⊕ HIGH	

CI: confidence interval; **SMD:** standardised mean difference

Explanations a. High heterogeneity

APPENDIX 3 SUMMARY OF META-ANALYSIS FINDINGS

Outcome	Sub-group	Studies	Particip-ants	Statistical method	Effect estimate	P (p<0.05= significant)	I2
Caregiver's QoL	All RCTs	6	371	Std. Mean Difference (IV, Random, 95% CI)	0.18 [-0.22, 0.58]	0.38	72%
Caregiver's depressive symptom	All RCTs	8	632	Std. Mean Difference (IV, Fixed, 95% CI)	-0.19 [-0.35, -0.03]	0.02	0%
	facilitator	2	243	Std. Mean Difference (IV, Fixed, 95% CI)	-0.29 [-0.54, -0.03]	0.03	0%
Caregiver's stress	All RCTs	6	377	Std. Mean Difference (IV, Random, 95% CI)	-0.29 [-0.52, -0.06]	0.01	21%
Caregivers' self-efficacy	All RCTs	7	374	Std. Mean Difference (IV, Random, 95% CI)	0.12 [-0.12, 0.36]	0.34	26%
Caregiver's anxiety	All RCTs	3	268	Std. Mean Difference (IV, Random, 95% CI)	-0.12 [-0.76, 0.51]	0.71	80%
Caregiver burden	All RCTs	6	293	Std. Mean Difference (IV, Fixed, 95% CI)	-0.03 [-0.26, 0.20]	0.82	0%

APPENDIX 4 SYSTEMATIC REVIEW AND META-SYNTHESIS SEARCH STRATEGIES

Medical Literature Analysis and Retrieval System Online (MEDLINE)

1	**carers. mp. or exp Caregivers/**	**49222**	**7.7.2021**
2	(Carer* or caregiver* or carer taker*or caretaker* or spouse or adult children or acquaintance* or neighbor* or neighbour* or home nursing).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	242676	
3	(dementia*or Alzheimer* or "Mild Cognitive Impairment").ti,ab.	18482	
4	exp Dementia/	177047	
5	exp Dementia/ or exp Alzheimer Disease/	177047	
6	(Internet or online or e-health or e-learning or telecomputing or tech or health or computers or software or electronic or digital).ti,ab.	2673306	
7	Computer-Assisted Instruction/	12140	
8	(Intervention* or program* or course* or psychoeducation* or training* or support* or platform* or e-learning or telemedicine or telehealth or application* or interface).ti,ab.	5418314	
9	(View* or experience* or opinion*, attitude* or perception* or belief* or feeling* or knowledge or understanding*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	3470785	
10	1 or 2	242676	
11	3 or 4 or 5	186208	
12	6 or 7	2679543	
13	8 and 9 and 10 and 11 and 12	1207	
14	limit 13 to the English language	1142	

Cumulative Index to Nursing and Allied Health Literature (CINAHL)

1	**TX Carer* or caregiver* or "carer taker*" or caretaker* or spouse or "adult children" or acquaintance* or neighbor* or neighbour* or "home nursing"**	**140,276**	**7.7.2021**
2	TX (MH "Mild Cognitive Impairment") OR (MH "Alzheimer's Disease") OR "dementia*or Alzheimer* or "Mild Cognitive Impairment""	34,046	
3	TX "Internet or online or e-health or e-learning or telecomputing or tech or health or computers or software or electronic	82,975	

	or digital" OR (MH "Learning Health System") OR (MH "World Wide Web") OR (MH "Online Education") OR (MH "World Wide Web Applications")		
4	(MH "Online Education") OR "Intervention* or program* or course* or psychoeducation* or training* or support* or platform* or e-learning or telemedicine or telehealth or application* or interface" OR (MH "Education, Non-Traditional") OR (MH "Programmed Instruction") OR (MH "Adult Education")	13,009	
5	S1 AND S2 AND S3 AND S4	1	

Web of Science

1	**Carer* or caregiver* or "carer taker*”or caretaker* or spouse or "adult children" or acquaintance* or neighbor* or neighbour* or "home nursing" (All Fields)**	**564,621**	**7.7.2021**
2	ALL=(dementia*or Alzheimer* or "Mild Cognitive Impairment")	34,042	
3	ALL=(Internet or online or e-health or e-learning or telecomputing or tech or health or computers or software or electronic or digital)	16,544,485	
4	ALL=(Intervention* or program* or course* or psychoeducation* or training* or support* or platform* or e-learning or telemedicine or telehealth or application* or interface)	13,009	
5	ALL=(View* or experience* or opinion*, attitude* or perception* or belief* or feeling* or knowledge or understanding*)	6,923,690	
6	(((((ALL=(View* or experience* or opinion*, attitude* or perception* or belief* or feeling* or knowledge or understanding*)) AND #5) AND #4) AND #3) AND #2) AND #1	314	

Scopus

1	**TITLE-ABS-KEY (carer* OR caregiver* OR "carer taker*" OR caretaker* OR spouse OR "adult children*" OR acquaintance* OR neighbor* OR neighbour* OR "home nursing")**	**755,407**	**7.7.2021**
2	TITLE-ABS-KEY (dementia* OR alzheimer* OR "mild cognitive impairment")	365,308	
3	TITLE-ABS-KEY (internet OR online OR e-health OR e-learning OR telecomputing OR tech OR health OR computers OR software OR electronic OR digital)	13,187,156	
4	TITLE-ABS-KEY (intervention* OR program* OR course* OR psychoeducation* OR training* OR support* OR platform* OR e-learning OR telemedicine OR telehealth OR application* OR interface)	18,855,762	
5	TITLE-ABS-KEY (view* OR experience* OR opinion* OR attitude* OR perception* OR belief* OR feeling* OR knowledge OR understanding*)	9,529,135	
6	(TITLE-ABS-KEY (internet OR online OR e-health OR e-learning OR telecomputing OR tech OR health OR computers OR software OR electronic OR digital)) AND (TITLE-ABS-KEY (intervention* OR program* OR course* OR psychoeducation* OR training* OR support* OR platform* OR e-learning OR telemedicine OR telehealth OR application* OR interface)) AND (TITLE-ABS-KEY (view* OR experience* OR opinion* OR attitude* OR perception* OR belief* OR feeling* OR knowledge OR understanding*)) AND (TITLE-ABS-KEY (dementia* OR alzheimer* OR "Mild Cognitive Impairment")) AND (TITLE-ABS-KEY (carer* OR caregiver* OR "carer taker*" OR caretaker* OR spouse OR "adult children*" OR acquaintance* OR neighbor* OR neighbour* OR "home nursing"))	3923	
7	LIMITED 6 to English	3706	

APPENDIX 5 SYSTEMATIC REVIEW AND META-SYNTHESIS FINDINGS AND ILLUSTRATIONS

Brennan, P. F., Moore, S. M., & Smyth, K. A. (1991). ComputerLink: electronic support for the home caregiver. ANS Adv Nurs Sci, 13(4), 14-27. https://doi.org/10.1097/00012272-199106000-00004

Findings	Illustration from the study	Evidence
Peer support: opportunity for caregivers to interact with each other	There are frequent statements of encouragement and support among caregivers for example: 'my husband is in the middle stages of the disease and I would like some suggestions on how to occupy his time…' 'Dorothy I also have a problem with my wife who likes to walk and gets bored…' ' Hi this is Sue. I noticed a reply to idle Time,…' (p.21)	Unequivocal
Feeling of being supported by program providers	'I am a new member who wonders how many of you feel abandoned by your friends…' 'Mrs C, you have brought up a question that many people have expressed to me.'(p.21)	Unequivocal
Program designs: practical and relevant	Most used content in the program: research on new medications; obtaining an identification bracelet; choosing a day-care centre; choosing a nursing home; local education programs; Topics relate to behaviour management; Topics on caregiver coping skills include how to manage anger, lack of patience, feeling of rejection by family and friends, loneliness, fatigue, relationship problems with care recipient, change, frustration, working outside the home while caregiving; Q&A section for various concerns caregivers had. (pp.24-25)	Credible

Duggleby, W., Ploeg, J., McAiney, C., Fisher, K., Jovel Ruiz, K., Ghosh, S., Peacock, S., Markle-Reid, M., Williams, A., Triscott, J., & Swindle, J. (2019). A comparison of users and nonusers of a web-based intervention for carers of older persons with Alzheimer disease and related dementias: Mixed methods secondary analysis. J Med Internet Res, 21(10), e14254-e14254. https://doi.org/10.2196/14254

Findings	Illustration from the study	Evidence
Difficulties with site access and navigation	"...my internet connection at home is poor—I live in a rural area." (p.9)	Unequivocal
Low level of computer literacy contributed to access difficulties	"No, it—it's, uh, as far as the computer is concerned, it's the—the operator of it that is at fault."; another said: "Um, well, I get frustrated at myself when, you know, I am working on the website…" (p.9)	Unequivocal

Findings	Illustration from the study	Evidence
Too stressed to take part	“I’m extremely stressed with taking care of my wife, and so I lost the email with login instructions.” “he kept interrupting me. Then, I could not find where I left off to continue...” (p.9)	Unequivocal
Insufficient time for program participation	“...and I got to admit that it was, uh, something that, uh, I did not go onto too much, just strictly because of all the other things that were—were going on this past month.” (p. 9) “Well, um, I just finished reading it, and—and—and then, I had to go off because I had to go help my husband.” (p.9) “...[I] work full-time early morning to late evening...and at the end of the day, I don’t have the energy or time to go on the computer.” (p.9)	Unequivocal
Personal preference for hard copy	“...Sometimes, you actually have to have something printed in front of you, uh, and I am better off—I am better with paper. In some instances, to sit and reflect, I am not really good at what—I’m not really one of those people who can do it all online.” (p.10)	Unequivocal
Personal preference of actual social contact with others	“I think—I think I know—and this is [chuckles]—this is not specific to this Toolkit, but it sort of relates to it: um, I think I am the kind of person who gets a lot more out of, you know, actual social interaction around something (p.10)	Unequivocal

Fowler, C. N., Haney, T., & Lemaster, M. (2016). Helping Dementia Caregivers Through Technology. Home Healthc Now, 34(4), 203-209. https://doi.org/10.1097/NHH.0000000000000372

Findings	Illustration from the study	Evidence
Peer support: opportunity for caregivers to interact with each other	“I think it was beneficial to me to read other people’s stories and interact with them online. (p.208) It was not so much from a perspective of, ‘Oh, I’m not out here alone,’ kind of thing but just to be able to see what other people’s stories were like, how others were handling things and seeing how people interacted with each other. That medium was really valuable.” (p.208)	Unequivocal
Feeling of being supported by program providers	‘The site really helped me through tough times. Having two small children at home and my mom with advanced stage of Alzheimer’s disease was very difficult. I appreciate everything the team	Unequivocal

Findings	Illustration from the study	Evidence
	did to help me through that…Being a part of the study at that time in my life really helped me cope with difficult family issues and decisions.” (p.208)	
Streamlined program provided a positive learning experience	“I was a little intimidated with it at first, but then I got on, and it worked very smoothly, you know, the way it was supposed to, and it made the experience kind of fun.” (p.207)	Unequivocal
Accessibility: enhanced outreach of the program	The idea was exceptional. I wish there were more people who participated in the study. It has great potential for community support (p.207) “Reach a broader audience. I am not a tech person and I am not sure what I could contribute myself, but I felt good about the project. Maybe advertise on community networks/apps such as ‘Next Door.’ There are so many people that stay home with children or elderly folks – those are the people that would benefit from it. I was pleased with the study and was honoured to participate.” (p.208)	Unequivocal

Gaugler, J. E., Hobday, J. V., Robbins, J. C., & Barclay, M. P. (2015). CARES((R)) Dementia Care for Families: Effects of Online, Psychoeducational Training on Knowledge of Person-Centered Care and Satisfaction. J Gerontol Nurs, 41(10), 18-24. https://doi.org/10.3928/00989134-20150804-61

Findings	Illustration from the study	Evidence
Hearing all perspectives empowers caregivers	…the examples and the stories of families who live with Alzheimer’s were very informative and gave me comfort that I, too, can do this (p.22) I would tell them (and already have told several people from my Alzheimer’s [sic] support group) that this program gives real-life instances of issues that arise and suggestions for working through them. The program also gives the perspective of those living with the disease—something I am clueless about. I feel empowered because of the information I have been given. (p.22)	Unequivocal
Videos: related to disease progression	I really liked the videos that showed the progression of the disease in the early, middle, and late stages of the disease. For example, making coffee and taking a bath example. I also liked the driving example, too, in relation to the different parts of the brain and how they are affected. As a 22 caregiver, it really helps me get an idea of how my family member is going to progress (p.21)	Unequivocal
Videos: poor visual display quality	A few technical and display issues. Video segments were displayed smaller than text window…had to go into settings to increase video screen size. Audio was cut short on several of the slides (p.22)	Unequivocal

Findings	Illustration from the study	Evidence
Relevant content: Information for the start of the caregiving journey	’I found all of this training very helpful and well thought out…I have been caring for my grandmother full-time in my home for the past 9 months…this training would have been very helpful if it were available to us at the start of our journey. I did hours of Internet [sic] research to gather the many tips and strategies presented in the training, and they work (p.22).	Unequivocal
Program designs: practical and relevant	I consider myself an even keeled, compassionate person. Yes, sometimes I get frustrated and have to leave the room to keep from saying something I might later regret. This training program showed me ANOTHER WAY, and I didn’t even know there was one (p.22)	Unequivocal
Program design: negative case scenario	I did not like the ending. I found it very sad to be left with the vision of the dear man peeling bananas. You could have chosen something a bit more uplifting…I felt that they had all come to terms and made the best of it—and so can we!!! (p.22)	Unequivocal
Accessibility: enhanced reach of program	I would say that this is a great program for the journey involved in an Alzheimer’s diagnosis, and that this is useful throughout the progression for all stages and for different roles involved in the diagnosis. If this program were available for purchase on DVD, I would consider buying and sharing with family members to educate them and help them to help me care for my mother	Unequivocal

Halbach, T., Solheim, I., Ytrehus, S., & Schulz, T. (2018). A mobile application for supporting dementia relatives: A case study (Vol. 256, pp. 839-846).

Findings	Illustration from the study	Evidence
Inspiring texts	but also the self-reflection prose related to these because the text was inspiring and resulted in a more efficient learning experience. (p.844)	Unequivocal
Video: relevant structure and content	All lectures were rated as being clear and comprehensive… The lectures were judged as being “quite relevant” and “very relevant” (Halbach et al., 2018, p.843) The informants found the structuring of lectures, including basic and extended versions, takeaways, and local information (quite or very) useful and gave the same judgement for the “Getting started” lecture, and the font size. (p.843)	Unequivocal

Findings	Illustration from the study	Evidence
Videos: poor audio quality	An unfamiliar machine voice and a “sharp voice” in videos, which is most likely due to a quite high compression rate for audio in videos. (p.843) A poor pronunciation of medical terms with artificial voices, which is a real problem in many low-level text-to-speech solutions. (p.843) The reading aloud option was generally viewed as less successful. Some said they did not need this option, others found the (computer) voice too monotonous and hard to follow. (p.843)	Credible
Videos: promotes understanding	When it comes to content, the participants (including health workers) liked videos in particular, (p.844). The informants found the videos to be (quite and very) useful and commented on “too few” in their comments. (p.843)	Credible
Relevant content: accommodating caregivers learning needs	It is useful to distinguish between basic and in-depth information. It was convenient for the participants to read the short basic information first and, if needed, to look more closely at in-depth material later on when there was more time. (p.844)	Credible
Relevant content: applicable for other family members	Several persons also commented positively on the information designed for and aimed at children, but also advised that children should have easy access to all other types of information in the app, too. (p.844)	Credible
Program designs: practical and relevant	A more hands-on character of some lectures in form of examples and practical advice was requested. However, also realism was asked for, as one of the patients in the video was “too easy to distract”. (p.843)	Credible
Program designs: need for locally relevant information	The informants recommended more local information, but at the same time they desired this to be easily available in the app rather than to be redirected to the municipality’s web page. (p.844)	Credible
Program design: lack of comprehensiveness	It was a known issue that the 23 lectures were not covering the entire area, and this was also remarked on with several participants mentioning missing topics and in-depth information. (p.843)	Credible

Findings	Illustration from the study	Evidence
Program designs: user friendly text	The limited amount of text per page and short paragraphs worked very well for these participants. (p.844) (Halbach et al., 2018) We had set the font size to values larger than what is usual in apps of this kind, and the participants liked this because it made, as they said, the app more accessible. (p.844)	Credible
Program design: Learning unit structure	In general, the informants were satisfied with the app and found it quite useful. The structure of learning units / lectures worked very well (p.844)	Credible
Program designs: Quality of grammar	Quizzes and “text to speech” got a neutral rating, and one particularly critical person pointed to what she viewed as bad grammar and poor language. (p.843)	Credible
Program design Quizzes not suitable	Most of the participants found the quiz option less attractive. The option might be useful for children, they commented, but advised to remove it from the app. (p.844)	Credible
Content design: relevant and targeted information	For a few participants the content was known from before, which resulted in a lower rating usefulness rating than what was the case in reality. (p.843)	Credible

Hattink, B., Droes, R.-M., Sikkes, S., Oostra, E., & Lemstra, A. W. (2016). Evaluation of the Digital Alzheimer Center: Testing Usability and Usefulness of an Online Portal for Patients with Dementia and Their Carers. *JMIR Res Protoc*, *5*(3), e144-e144. https://doi.org/10.2196/resprot.5040

Findings	Illustration from the study	Evidence
Feeling of being supported by program providers	Interviewed participants specified that it was “very helpful—it really helps me in staying at home by myself” and that it “should certainly be continued in the future.”	Unequivocal
Technical issues precluded engagement	The main reasons they indicated for not using the DAC are: Technical or computer issues, Miscellaneous (eg, “I don’t like the Internet”)	Credible
Insufficient time for program participation	The main reasons they indicated for not using the DAC are: No time	Credible
Program designs: tailored to meet individual needs	“not yet useful enough,” although they later indicated that they expected this would change by “adding more personalization [options].” (p.8)	Unequivocal

Program design: easy to navigate	you can find all the information you might need” and “you can easily show this information to others.” (p.9)	Unequivocal
Program design: flexibility of learning	“you can check this information anytime, even in the middle of the night.” (p.9)	Unequivocal

Kovaleva, M., Blevins, L., Griffiths, P. C., & Hepburn, K. (2019). An Online Program for Caregivers of Persons Living With Dementia: Lessons Learned. J Appl Gerontol, 38(2), 159-182. https://doi.org/10.1177/0733464817705958

Findings	Illustration from the study	Evidence
Peer support: opportunity for caregivers to interact with each other	I felt a connection with every person and believe that I learned something from each participant” (Caucasian daughter, age 66). (p.168) All caregivers stated that they felt listened to and could get answers for their questions: One of the very helpful parts of the chats was to have positive feedback from the teachers. I don’t think caregivers get very many “good job on that” . . . comments. It is easy to know when we mess up . . . hard to know that we did it well. (Caucasian wife, age 57) (p.168) “Wonderful class, we need more . . . You have this group and they bond over 6-7 weeks, there is so much more to learn out there” (Caucasian wife, age 60). (p.170) “[The] group got closer towards the end; people shared some powerful things; we did not have the time to process those powerful things” (Caucasian daughter, age 61). (p.171)	Unequivocal
Peer support: poor group interactions	An African American niece (age 47) commented: “It is a lot harder to connect with people, a lot easier not to stay focused on the topic, you can get distracted, play games on your phone.” This caregiver was in a group with others who were relatively younger (ages 53, 55, 61). (p.168) A Caucasian daughter (age 49) noted, “People that did not appear to be paying attention and you could see them doing other things. That was a little distracting for me.” (p.168)	Unequivocal

Findings	Illustration from the study	Evidence
Peer support: Lack of equal opportunity to contribute	"I don't think I ever was clear on what the purpose of the weekly calls was because I never really walked away from the calls with much practical advice on what to do next." She did not find videoconferences engaging or facilitating for each caregiver to have equal amounts of time to speak. (p.172)	Unequivocal
Peer support: More interaction and discussions required	"More interaction and discussion among the participants to balance out the information that is clinically-based, integrate both perspectives to just get different views on how other people cope." (p.171) "A one-on one session should be offered'. (p.171)	Unequivocal
Peer support: Reduced feelings of isolation	For me it was a lifesaver . . . seeing all those people from all around the country . . . they are not really handling it any better than I . . . I don't feel so alone in spirit. (Caucasian wife, age 69) (p.167)	Unequivocal
Peer support: remaining in contact post-program	Several caregivers expressed willingness to remain in contact with others after Tele-Savvy conclusion. Facilitators asked for participants' permission to have their contact information shared and, when such permission was granted, provided it to other caregivers. (p.168)	Unequivocal
Peer support: Preference for longer duration	"Make it longer, make it longer, make it longer. I cannot say it quite enough . . . Just a few things these professors [said], how they would listen, it was just a gift" (Caucasian daughter-in-law, age 49). Despite apparent novelty of videoconferences (no one indicated their experience with videoconferencing), they were valued: "I just feel like [we had an] amazing time—we could have gone for 3 hours" (Caucasian daughter-in-law, age 49). (p.171)	Unequivocal
Online class: like a real classroom	"At first I was . . . this is not gonna work; I'm 60 years old. It really worked, I loved going to school online, I thought I was in a real class—I'm talking a real classroom" (Caucasian wife, age 60). (p.168)	Unequivocal
Difficulties with site access and navigation	Problems during videoconferences (e.g., poor Internet connection, slow sound and video transmission, and insufficient instructions on joining videoconferences) affected connectedness: "When things went well [with technology], I definitely felt connected" (Caucasian wife, age 57)	Unequivocal
Low level of computer literacy contributed to access difficulties	Some caregivers noted that others struggled to follow some directions (e.g., not muting their microphone when others were speaking to prevent interference with background noise) and	Unequivocal

Findings	Illustration from the study	Evidence
	needed to be better aligned relative to their webcam and sit in a position with good lighting. (p.169)	
Personal preference of actual social contact with others	“It would have been better to absorb the content in a group setting, person to person . . . very difficult to have a personal connection with a computer screen.” (p.168) a few younger caregivers and those who were employed outside of home (Caucasian son, age 53; African American niece, age 47) indicated a preference for a classroom experience. (p.168) She commented that similar online programs may not fit older caregivers: I would recommend it to people who are tech savvy, but I wouldn’t recommend it to someone like my mother or older adults who do not know how to use technology and like the traditional way of interfacing with people. This opinion was shared by a Caucasian son (age 53) and an African American husband (age 66) who expressed apprehension about suitability of the online program for older caregivers. (p.172)	Unequivocal
Videos: helping caregivers understand provision of activities of daily living	Caregivers likewise expressed willingness to view videos focusing on the provision of assistance with activities of daily living throughout dementia stages. (p.170)	Credible
Videos: poor representation of more challenging situations	The Caucasian daughter (age 61) suggested the vignettes did not portray the “messiness of life”—times when a care recipient may not follow caregiver’s guidance, multiple family members involved in caregiving, and families with limited resources: I would have liked to see a daughter or son single caregiver with just a parent, try to make it more identifiable and inclusive . . .. (p.170) several caregivers expressed the wish that the vignettes would portray more complex situations: The Jim and Becky [names of the fictional family] episodes were easy to identify with in most situations; however, Jim was an exceptionally agreeable individual and my husband still has an opinion of his own, which isn’t always the same as mine. I would have liked to see more tips on how to deal with resistance. (Caucasian wife, age 67) (p.170)	Unequivocal
Videos: Poor representation of cultural diversity	One African American niece (age 47) and one Caucasian daughter (age 61) noted lack of diversity in videos: only Caucasian actors and only a few non-Caucasian health care professionals appeared in them. (p.170)	Unequivocal

Findings	Illustration from the study	Evidence
	One [caregiver] with many people meddling in the caretaking, I wish it had been not just Caucasian race, it's not real life, nice suburban setting, my life does not look like that with my mother. (p.170)	
Videos: promotes understanding	"To me the videos are key to the whole class" (member check participant). "Seeing the behaviour depicted by the actors was a great way to better understand and grasp the different stages and how to adjust the level of involvement" (Caucasian daughter, age 66). (p.170)	Unequivocal
Program designs: tailored to meet individual needs	"Much of the material was very basic for me; I would like more information on later stages because that is where it really gets tough." (p.168) "[I] may be younger, more dealing with mother-in-law and children; other people [were] older, a little disconnection in that way." (p.169) there were more strategies for early stages and handling awkward situations in early stages" (Caucasian wife, age 75) (p.169)	Unequivocal
Program design: lack of systematic layout of content and resources	Participants suggested that the manual be laid out more clearly (e.g., include a table of contents and a glossary) and be more precisely coordinated with the videos, videoconference "lectures," and "homework" assignments. For many who attempted to complete all assignments, the lack of clear coordination was frustrating: "It skipped around all over the manual . . . it was a little confusing; the last thing you need is to be confused" (Caucasian wife, age 69). (p.171)	Unequivocal
Content design: relevant and targeted information	"It is much better for those starting off . . . content gives a good picture of the first half of the journey. It does not relate at all to someone caring for a late-stage dementia" (Caucasian husband, age 72). (p.169) "Too much! For me and my situation, it is too hard. Make sure their situation is the right situation—the content was not applicable to me yet." (p.169) "I was the only early stager. . . I am not experiencing what other people are experiencing. Put in more [information for] early stages" (Caucasian wife, age 60). (p.169)	Unequivocal

Findings	Illustration from the study	Evidence
Program design: comprehensive instructions for navigation valued	Although instructions were provided, many caregivers recommended more practice and detailed written and illustrated instructions for video viewing (written instructions were not initially provided for video viewing). (p.169)	Credible
Program design: option for additional materials to share	Participants also asked for extra manuals to share with their family members and hard copies of PowerPoint slides presented during videoconferences. (p.171)	Credible
Program design: convenient for caregivers	"It was great being able to sit in the comfort of my home and interact with everyone. (Caucasian daughter, age 66). (p.168)	Unequivocal
Program design: flexibility of learning	Comments from a rural caregiver (Caucasian wife, age 76), "I live forty of miles from everywhere; it was wonderful," and an urban caregiver (African American wife, age 73), "It was good to be able to do it online rather than trying to get in the car, considering the traffic situation here," confirmed that the online format promoted access for those with travel challenges. (p.167)	Unequivocal
Accessibility: revisiting information when needed	Caregivers could not access the videos after the Tele-Savvy conclusion; however, many stated that they would be willing to rewatch videos, share them with family members, and rewatch them when their care recipient is in a later dementia stage: "Your care recipient is not going through everything when it is discussed" (Caucasian husband, age 72). (p.171)	Unequivocal

Lewis, M. L., Hobday, J. V., & Hepburn, K. W. (2010). Internet-Based Program for Dementia Caregivers. Am J Alzheimers Dis Other Demen, 25(8), 674-679. https://doi.org/10.1177/1533317510385812

Findings	Illustration from the study	Evidence
Peer support: valuing connection for sharing experience	One participant wrote, ''I do not have the option of sharing, or interacting with others. The opportunity for questions related to my situation is not possible (although I was amazed at how often the training content did relate to things we are dealing with even in the early stages).'' (p.677)	Unequivocal
Hearing all perspectives empowers caregivers.	''It is a gentle reference vehicle for understanding Alzheimer's changes. It won't smack you in the face with the fear of what is coming but will prepare you for techniques to cope.''	Unequivocal

Findings	Illustration from the study	Evidence
Program designs: practical and relevant	‘‘Good information; I found myself surprised at being able to relate to a lot of it.’’ Respondents identified the video examples as interesting. (p.677) ‘‘Person with dementia was very interesting and I felt like I could connect with them.’’ (p.677)	Unequivocal
Variety and quality of presenters	‘‘Good information attractively presented by a variety of speakers, both caregivers and experts.’’. (p.677)	Unequivocal
Program designs: Quality of grammar	Participants expressed concerns over spelling errors and navigation difficulties.	Credible
Content design: repetitive	‘‘The same thing repeated over again in each module.’’ (p.677)	Unequivocal
Content designs: optimal length	‘‘The length, I wished I could have watched it in one sitting.’’ (p.677)	Unequivocal
Content design: Information overload	it was a lot of information to take in during one session. (p.678)	Unequivocal
Content designs: additional content required	additional content… such as information about medications and planning for the future decision making. (p.678)	Unequivocal
Program designs: unable to bookmark	‘‘There was no way to mark where I left off each time, so I had to start over each time I returned to the program.’’ (p.677)	Unequivocal
Program designs: easier to navigate and revisit	making it easier to navigate and suggestions for specific edits to the program. (p.678)	Unequivocal
Program designs: hardcopy supplement	Accompany of a workbook for them to view in print. (p.678)	Credible
Program design: flexibility of learning	‘‘I enjoyed having more control over when, where, how long, and how much I worked.’’. (p.677)	Unequivocal

Ploeg, J., McAiney, C., Duggleby, W., Chambers, T., Lam, A., Peacock, S., Fisher, K., Forbes, D. A., Ghosh, S., Markle-Reid, M., Triscott, J., & Williams, A. (2018). A web-based intervention to help caregivers of older adults with dementia and multiple chronic conditions: Qualitative study. JMIR Aging, 1(1), e2-e2. https://doi.org/10.2196/aging.8475

Findings	Illustration from the study	Evidence
Peer support: opportunity for caregivers to interact with each other	It is nice seeing comments from other people, and there should be a lot more of that. Because you end up thinking—and I know it is not the case—but you end up thinking that you are the only one going through it, and then you realize that there is an awful lot of other people doing it, too. [Participant 21, M3] (p.8)	Unequivocal
Peer support: peer confirmation of caregiving activities.	...confirmation that you are not alone. [Participant 345, M1] (p.8) It is what's to be expected, and not anything we did not do, or that we are doing wrong, or that we have not done. [Participant 390, M1] (p.8) In each of the sections, I have well been there. I have been caregiving since 2008, and I have a large care manual that I started writing, and I have accumulated a lot of information...So you know, I have my objectives and I have long-term plans of certain things I am going to do. So, when I look at the website, I think I am pretty well on track. [Participant 23, M1] (p.8)	Unequivocal
Peer support: valuing connection for sharing experience	Some participants commented that adding a feature to MT4C to enable caregivers to connect with one another to share information, experiences, and caregiving strategies would be helpful: ...if you connect with people over the internet say, you know, I am having a really hard time today and somebody can say: "I know what you are going through," that can be good support too, you know? [Participant 399, M3] (p.9)	Unequivocal
The program encouraged caregiver to plan for the future	...look at what is coming and plan for the future. [Participant 372, M3] (p.6) ...But the long-term is what made me think...my husband and myself manage all her medical things, and it [MT4C] made me even realise somebody else needs a list of doctors and [chuckles] you know, things like that...It made me think about personal care in the future because that is long-term care. [Participant 344, M1] (p.6) Participants also talked about anticipating and planning for changes, such as the care recipient's move to assisted living or long-term care; arranging power of attorney; and anticipating changes to their living arrangements, such as making modifications to their existing home to	Unequivocal

Findings	Illustration from the study	Evidence
	accommodate the needs of the care recipient or moving to be closer to family and other forms of support. (p.6)	
Program facilitator: benefit of a link person /facilitator	having a person available to answer caregivers' questions by telephone, and (3) having a navigator to "be that bridge" [Participant 373, M3] to help the caregiver identify and access resources that meet their specific needs. (p.9)	Unequivocal
Journal activities as part of the program for reflection	You can type down something and type it in, and then it is almost like a diary. And then kind of go back and go, "Hmm, I wonder, why did I put it that way? [Participant 322, M1] (p.5) It [MT4C] allowed me to write down stuff that I have not stopped to write down, and I found that that was very helpful...just the opportunity to write down my story and how things have gone. It is not something a caregiver takes time to do, and it is really important...It makes you think of stuff that you sort of put in the back of your brain, and it makes you put it down in front of you.[Participant 1, M1](p.5) it made me take a deeper, inner look at myself, which I seldom do because I am more focusing on [name of spouse] than I am on myself. I have always found it a little difficult to focus on myself anyhow...it gave me a little chance of soul-searching and analysing what I am doing and assessing some of the things I need to revise in my own thinking. So, I found it very challenging and interesting. [Participant 301, M1](p.5) ...the place where you had to make a list of the things that help you get through the day, [What Helps Me?] because I think it is such a negative situation. It's so exhausting, physically and mentally and emotionally, that you could forget about that. So, in the sense that it made you sit and think about it, I think that was a positive thing. [Participant 349, M3](p.5)	Unequivocal
Journal activities aid self-care	Well, the writing down of the stressful things that were happening, just the fact that I was able to share things and not keep them to myself, kind of thing. As I say, when all this happens, I am on my own, and just the fact that I can share it is, you know, even if nobody reads it, the fact that I have took it out of my mind, there. So, I did really find that helpful. [Participant 330, M3] (p.5) I just found it more, therapeutic, I think, than anything else, to write down those things that I needed to think about. [Participant 383, M1] (p.5)	Unequivocal

Findings	Illustration from the study	Evidence
	I did do some of the ones [sections of the website] of taking care of myself and... that is one of my big things is that I understand that I really have to take care of myself because I cannot help [name of spouse] if I am not well. [Participant 337, M1] (p.5)	
Insufficient time for program participation	lack of time to use the site due to the demands of caregiving and other responsibilities. As one caregiver explained: The amount of time you had to sit and write things down, type things in, and to be honest with you, the more time I spend on the computer, the more [name of spouse] approaches me and saying “What are you doing? Why aren’t you sitting with me?” [Participant 353, M3] (p.9)	Unequivocal
Relevant content: applicable to caregivers’ situation	And even though I did a lot of research, some of the stuff in there I had not found before helped me. [Participant 11, M1] (p.7) I like the fact that you give out the telephone numbers and the contact information, national contacts, I think that is great! That is information worth something to me. [Participant 365, M3] (p.8) The Resources that one meant more to me than anything else; that’s probably where I spent most of the time, the links to the legal stuff; I needed that because I wanted to find out about Powers of Attorney. [Participant 350, M3] (p.8)	Unequivocal
Relevant content: detailed dementia progression	And it [MT4C] gives you the information and very detailed description of each level of, where they are at in their dementia process. I found that was much better than what other sites that I have read...so I was better able to reassess where I thought my husband was at, compared to other sites where I have used essentially the same sort of tool, but not worded in such a way that was really as helpful as it is on your site. [Participant 1, M1] (p.7)	Unequivocal
Program designs: need for locally relevant information	adding a directory of services that is searchable by postal code (p.9).	Unequivocal
Program designs: Very organised layout	Caregivers found the layout of MT4C to be “very well organized” [Participant 342, M3] (p.9)	Unequivocal
Program designs: consideration of literacy levels	Some caregivers suggested improvements to make MT4C more user-friendly. These included reducing the use of medical language and adjusting literacy levels and providing an overview of	Unequivocal

Findings	Illustration from the study	Evidence
	the content of the site. As one participant stated: ...it is a lot of text, and the literacy level. Oh, the other thing is it's only in English...you need to make the language a bit simpler. [Participant 331, M3] (p.9)	
Content design: relevant and targeted information	For example, several participants indicated that they were already familiar with available resources and had already used or were using community-based services to answer their questions and address their caregiving concerns. (p.8) ...didn't really need it [MT4C] at this point. [Participant 379, M3] (p.8) I feel like I am not there yet; Mom's still early, so some of the things are a bit more advanced, talking about getting help and that sort of thing. We are not at that stage yet so I could see maybe as things progress that maybe I would be going back here to have kind of it as another resource. I think that is probably the main thing, is I feel like I do not need it yet. [Participant 345, M1] (p.8) One caregiver who had been caring for her 89-year-old mother for almost 4 years expressed how she felt that the Toolkit could not help her because: I have figured out everything on my own. [Participant 35, M1] ... I am at the end now. And for somebody new into the dementia journey, I think it is a great tool...right now, because I am emotionally wrecked, physically, financially it [MT4C] cannot help me now [laughs]. [Participant 35, M3] (p.9)	Unequivocal
Program design: flexibility of learning	...something I could look at and use part of it or some of it, a little of it or none of it, but it gave me that basis to...sort of a mode of attack of how I was going to handle the situation. [Participant 301, M3] (p.7)	Unequivocal

APPENDIX 6 RESULTS OF META-SYNTHESIS

Findings	Category	Synthesised findings
The program encouraged caregiver to plan for the future (U)	Encouraging future planning	Synthesised finding 1: Online learning as an empowering experience
Feeling of being supported by program providers (U)	Empowered through knowledge and support	
Hearing all perspectives empowers caregivers (U)		
Program facilitator: benefit of a link person /facilitator (U)	Facilitating accessing and utilising the program	
Online class: like a real classroom (U)	Unexpectedly fun	
Streamlined program provided positive learning experience (U)		
Inspiring texts (U)	Inspiring	
Journal activities as part of the program for reflection (U)	A chance for reflection and self-care	
Journal activities aid self-care (U)		
Peer support: opportunity for caregivers to interact with each other (U)	Peer interactions	Synthesised finding 2: Peer support
Peer support: poor group interactions (U)		
Peer support: Lack of equal opportunity to contribute (U)		
Peer support: More interaction and discussions required (U)		
Peer support: peer confirmation of caregiving activities (U)	Peer confirmation of caregiving activities.	
Peer support: Reduced feelings of isolation (U)		
Peer support: remaining in contact post-program (U)		
Peer support: Preference for longer duration (U)	Peer connections	
Peer support: valuing connection for sharing experience (U)		
Videos: related to disease progression (U)	Video content and display	Synthesised finding 3: Satisfactory and unsatisfactory program contents
Videos: helping caregivers understand the provision of activities of daily living (C)		
Video: relevant structure and content (C)		
Videos: Poor representation of cultural diversity (U)		
Videos: poor audio quality (C)		
Videos: poor representation of more challenging situations (U)		
Videos: poor visual display quality (U)		
Videos: promotes understanding (U)		
Relevant content: Information for the start of the caregiving journey (U)	Information applicability	
Relevant content: accommodating caregivers learning needs (C)		
Relevant content: applicable for other family members (C)		
Relevant content: applicable to caregivers’ situation (U)		

Findings	Category	Synthesised findings
Program designs: practical and relevant (U)		
Program designs: need for locally relevant information (U)		
Program designs: tailored to meet individual needs (U)		
Program design: lack of comprehensiveness (C)		
Variety and quality of presenters (U)		
Content design: relevant and targeted information (U)		
Program designs: user friendly text (C)	Visual layout	Synthesised finding 4: Satisfactory and unsatisfactory technical design
Program designs: Very organised layout (U)		
Program design: Learning unit structure (C)	Structure	
Program design: lack of systematic layout of content and resources (U)		
Program designs: Quality of grammar (C)	Language and literacy	
Program designs: consideration of literacy levels (U)		
Program design: negative case scenario (U)	Program content	
Program design: Quizzes not suitable (C)		
Content design: repetitive (U)		
Content designs: optimal length (U)		
Content design: information overload (U)		
Content designs: additional content required (U)		
Program designs: unable to bookmark (U)	functionality	
Program designs: easier to navigate and revisit (C)		
Program design: easy to navigate (U)		
Program design: convenient for caregivers (U)		
Program design: flexibility of learning (U)		
Program design: comprehensive instructions for navigation valued (U)	supplementary material	
Program design: option for additional materials to share (C)		
Program designs: hardcopy supplement (C)		
Accessibility: revisiting information when needed (U)	Accessibility	
Accessibility: enhanced reach of program (U)		
Difficulties with site access and navigation (U)	Difficulties in accessing online program	Synthesised finding 5: Challenges encountered in online programs
Low level of computer literacy contributed to access difficulties (U)		
Technical issues precluded engagement (C)	Reason for non-user	
Too stressed to take part (U)		
Insufficient time for program participation (C)		
Personal preference for hard copy (U)		

Findings	Category	Synthesised findings
Personal preference of actual social contact with others (U)	Personal preference for non-online program	

APPENDIX 7 SYSTEMATIC REVIEW RECOMMENDATIONS FOR PRACTICE

Recommendation	JBI Grade
Online psychoeducation program providers should offer tailored information to meet caregivers’ learning needs. This can be done by encouraging caregivers to self-diagnose their learning needs and self-select relevant learning content with the support of health and social care professionals or program facilitators.	**A**
Online psychoeducation programs need to be designed to facilitate social connectedness among caregivers in the programs so that they can share their experiences and help each other. This can be achieved by offering virtual support groups, discussion forums or private communication groups using social media software or applications.	**A**
Program facilitators who are trained health or social care professionals should be utilised to engage caregivers in the program and provide individualised support.	**A**
Programs should integrate multi-modality teaching materials such as text, video, discussion board and supporting group meetings to attract learners at the cognitive information processing level.	**A**
Asynchronised online learning and teaching is recommended to accommodate a broader audience, especially working caregivers.	**A**
The program contents should be developed based on the education needs analysis of caregivers. Program providers should continuously evaluate the quality and relevancy of the information presented to ensure caregivers’ confidence in the programs, hence enhancing the utilisation.	**A**
Initial training and ongoing technical support for caregivers are needed when implementing online psychoeducation programs. A program should be accompanied by hardcopy instructions to support caregivers when there are technical issues.	**A**
Research should also pay attention to informal caregivers’ experiences using online psychoeducation programs using mixed-method or qualitative research methods.	**A**

APPENDIX 8 RANDOMISED CONTROLLED TRAILS STUDY PROTOCOL

Xiao *et al. BMC Health Services Research* (2022) 22:762
https://doi.org/10.1186/s12913-022-08148-2

BMC Health Services Research

STUDY PROTOCOL **Open Access**

Creating 'Partnership in iSupport program' to optimise family carers' impact on dementia care: a randomised controlled trial protocol

Lily Xiao[1*], Ying Yu[1], Julie Ratcliffe[1], Rachel Milte[1], Claudia Meyer[1,2,3,4], Michael Chapman[5], Langduo Chen[1,6], Shahid Ullah[7], Alison Kitson[1], Andre Queiroz De Andrade[8], Elizabeth Beattie[9], Henry Brodaty[10], Sue McKechnie[11], Lee-Fay Low[12], Tuan Anh Nguyen[13], Craig Whitehead[6], Bianca Brijnath[13,14], Ronald Sinclair[15] and Diana Voss[6]

Abstract

Background: The majority of people with dementia are cared for by their family members. However, family carers are often unprepared for their caring roles, receiving less education and support compared with professional carers. The consequences are their reduced mental and physical health and wellbeing, and that of care recipients. This study protocol introduces the 'Partnership in iSupport program' that includes five interventional components: managing transitions, managing dementia progression, psychoeducation, carer support group and feedback on services. This health services research is built on family carer and dementia care service provider partnerships. The aims of the study are to evaluate the effectiveness, cost-effectiveness and family carers' experiences in the program.

Methods: A multicentre randomised controlled trial will be conducted with family carers of people living with dementia from two tertiary hospitals and two community aged care providers across three Australian states. The estimated sample size is 185 family carers. They will be randomly assigned to either the intervention group or the usual care group. Outcomes are measurable improvements in quality of life for carers and people with dementia, caregiving self-efficacy, social support, dementia related symptoms, and health service use for carers and their care recipients. Data will be collected at three time points: baseline, 6 months and 12 months post-initiation of the intervention.

Discussion: This is the first large randomised controlled trial of a complex intervention on health and social care services with carers of people living with dementia in real-world practice across hospital and community aged care settings in three Australian states to ascertain the effectiveness, cost-effectiveness and carers' experiences of the innovative program. We expect that this study will address gaps in supporting dementia carers in health and social care systems while generating new knowledge of the mechanisms of change in the systems. Findings will strengthen proactive health management for both people living with dementia and their carers by embedding, scaling up and sustaining the 'Partnership in iSupport program' in the health and social care systems.

Trial registration: The Australian New Zealand Clinical Trials Registry (ANZCTR). ACTRN12622000199718. Registered February 4th, 2022.

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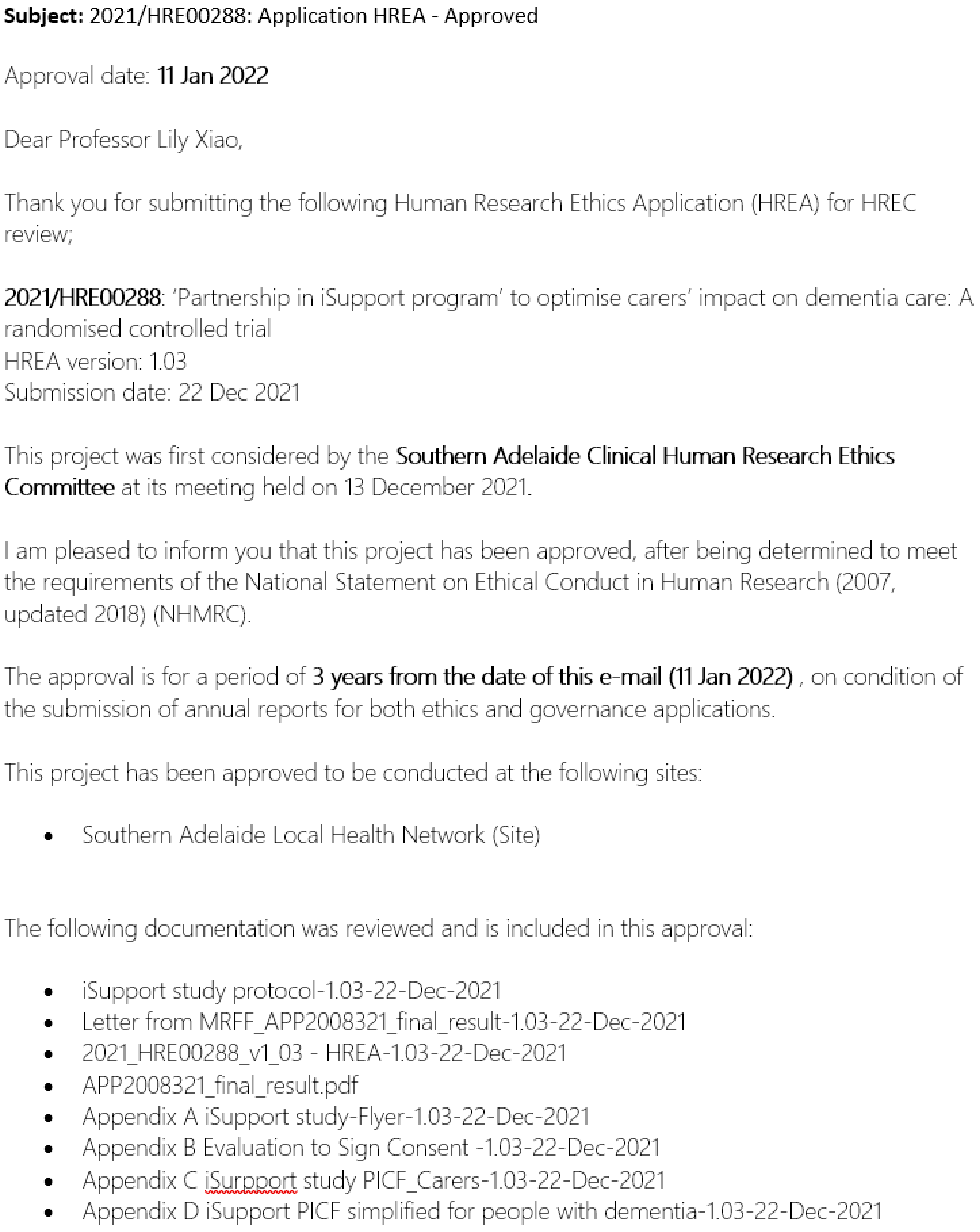
*Correspondence: lily.xiao@flinders.edu.au

[1] College of Nursing and Health Sciences, Flinders University, Bedford Park, South Australia 5042, Australia
Full list of author information is available at the end of the article

APPENDIX 9 SOUTHERN ADELAIDE CLINICAL HUMAN RESEARCH ETHICS COMMITTEE APPROVAL LETTER



Subject: 2021/HRE00288: Application HREA - Approved

Approval date: **11 Jan 2022**

Dear Professor Lily Xiao,

Thank you for submitting the following Human Research Ethics Application (HREA) for HREC review;

2021/HRE00288: 'Partnership in iSupport program' to optimise carers' impact on dementia care: A randomised controlled trial
HREA version: 1.03
Submission date: 22 Dec 2021

This project was first considered by the **Southern Adelaide Clinical Human Research Ethics Committee** at its meeting held on 13 December 2021.

I am pleased to inform you that this project has been approved, after being determined to meet the requirements of the National Statement on Ethical Conduct in Human Research (2007, updated 2018) (NHMRC).

The approval is for a period of **3 years from the date of this e-mail (11 Jan 2022)** , on condition of the submission of annual reports for both ethics and governance applications.

This project has been approved to be conducted at the following sites:

- Southern Adelaide Local Health Network (Site)

The following documentation was reviewed and is included in this approval:

- iSupport study protocol-1.03-22-Dec-2021
- Letter from MRFF_APP2008321_final_result-1.03-22-Dec-2021
- 2021_HRE00288_v1_03 - HREA-1.03-22-Dec-2021
- APP2008321_final_result.pdf
- Appendix A iSupport study-Flyer-1.03-22-Dec-2021
- Appendix B Evaluation to Sign Consent -1.03-22-Dec-2021
- Appendix C iSurpport study PICF_Carers-1.03-22-Dec-2021
- Appendix D iSupport PICF simplified for people with dementia-1.03-22-Dec-2021

- Appendix D iSupport PICF simplified for people with dementia-third party consent-1.03-22-Dec-2021
- Appendix E MBS and PBS Participant Consent Form-third-party consent form-1.03-22-Dec-2021
- Appendix E MBS and PBS Participant Consent Form-1.03-22-Dec-2021
- Appendix F iSupport study survey-1.03-22-Dec-2021
- Appendix F.1 Demographic information-1.03-22-Dec-2021
- Appendix F.2 QoL-12-Item Short-Form Health Survey (SF-12)-1.03-22-Dec-2021
- Appendix F.3 The Revised Scale for Caregiving Self-efficacy_tracked changes-1.03-22-Dec-2021
- Appendix F.3 The Revised Scale for Caregiving Self-efficacy-1.03-22-Dec-2021
- Appendix F.4 The Quality of Social Support Scale-1.03-22-Dec-2021
- Appendix F.5 Revised Memory and Behaviour Problems Checklist-1.03-22-Dec-2021
- Appendix F Survey questionnaire (combined)_tracked changes-1.03-22-Dec-2021
- Appendix F.6 QOL-AD-family version-1.03-22-Dec-2021
- Appendix G The resource utilization for dementia care (RUD) questionnaire-1.03-22-Dec-2021
- Appendix H Withdrawal of Consent-1.03-22-Dec-2021

Application Documents - (Please note : Due to security reasons, this link will only be active for 14 days.)

Clinical trial specific information:
The processes used by the Southern Adelaide Clinical Human Research Ethics Committee to review multi-centre research proposals have been certified by the National Health and Medical Research Council.

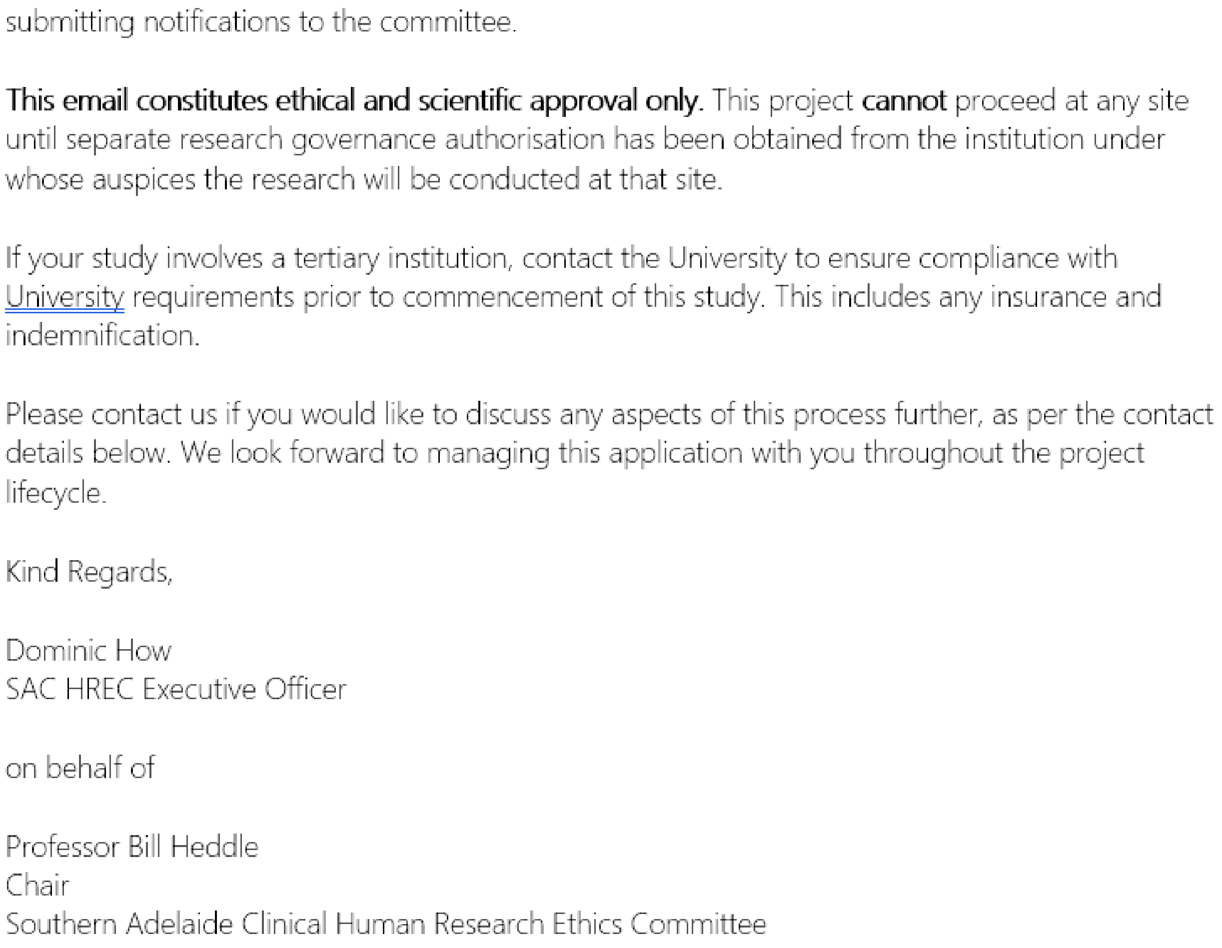
All clinical trials approved by the Southern Adelaide Clinical Human Research Ethics Committee must comply with the *NHMRC Guidance on Safety Monitoring and Reporting in Clinical Trials Involving Therapeutic Goods* (November 2016). The Southern Adelaide Clinical Human Research Ethics Committee must be notified within 72 hours of any Urgent Safety Measures (USMs) occurring at any approved sites.

Confidentiality of the research participants must be maintained at all times as required by law.

A report and a copy of any published material should be forwarded to the Southern Adelaide Clinical Human Research Ethics Committee at the completion of the project. If the project is discontinued before its completion, the committee must be advised immediately and provided with reasons for discontinuing the project.

We wish you all the best with the project and remind you that any changes to the application and safety reports will need to be submitted and reviewed by the Southern Adelaide Clinical Human Research Ethics Committee prior to implementation.

You must immediately report to the HREC anything that may change the ethics or scientific integrity of the project. Please be aware of the Research GEMS user guides to assist with



submitting notifications to the committee.

This email constitutes ethical and scientific approval only. This project **cannot** proceed at any site until separate research governance authorisation has been obtained from the institution under whose auspices the research will be conducted at that site.

If your study involves a tertiary institution, contact the University to ensure compliance with University requirements prior to commencement of this study. This includes any insurance and indemnification.

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below. We look forward to managing this application with you throughout the project lifecycle.

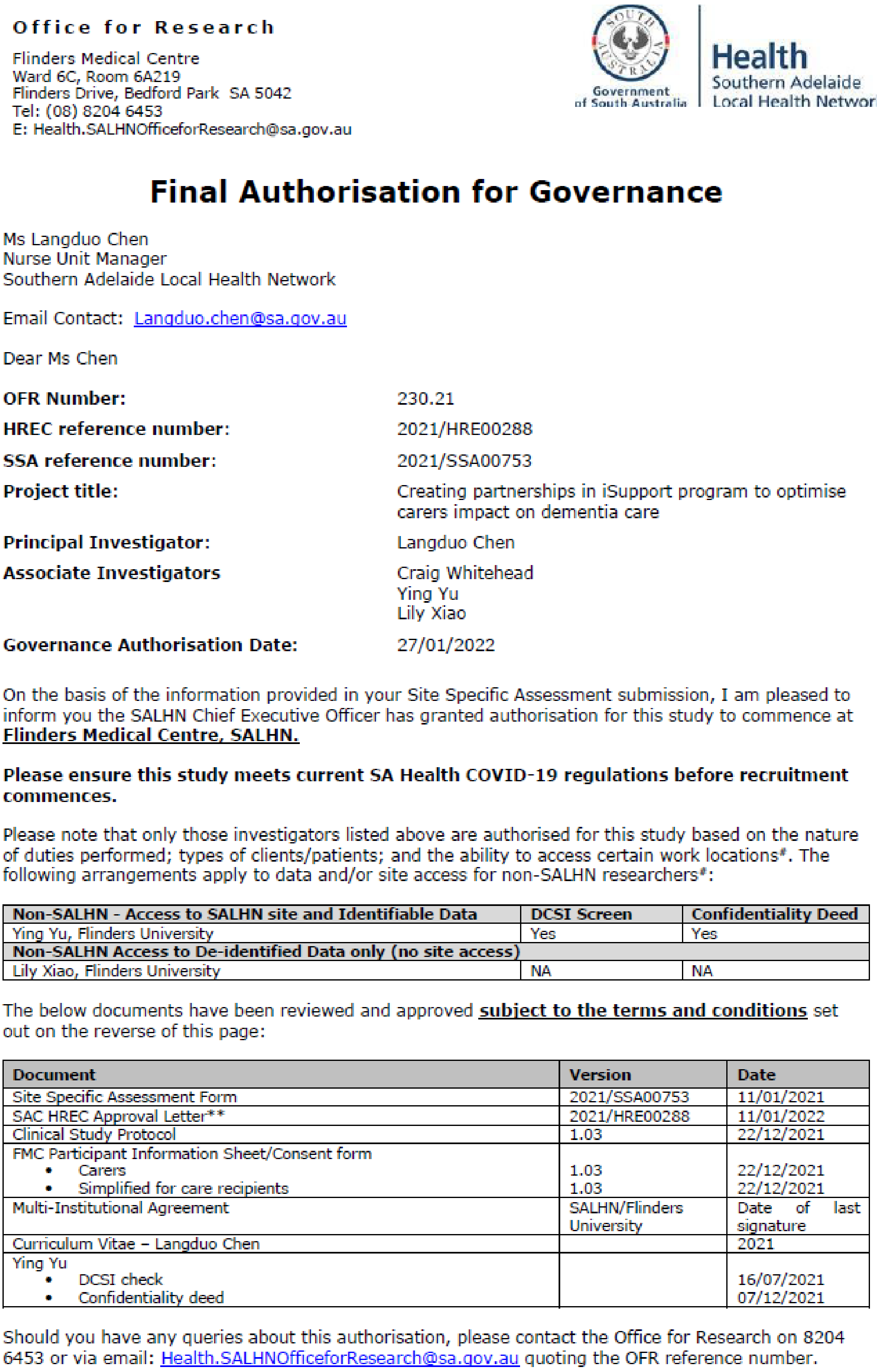
Kind Regards,

Dominic How
SAC HREC Executive Officer

on behalf of

Professor Bill Heddle
Chair
Southern Adelaide Clinical Human Research Ethics Committee

APPENDIX 10 SITE SPECIFIC ASSESSMENT GOVERNANCE AUTHORISATION LETTER



Office for Research

Flinders Medical Centre
Ward 6C, Room 6A219
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
Health
Southern Adelaide
Local Health Network

Final Authorisation for Governance

Ms Langduo Chen
Nurse Unit Manager
Southern Adelaide Local Health Network

Email Contact: Langduo.chen@sa.gov.au

Dear Ms Chen

OFR Number:	230.21
HREC reference number:	2021/HRE00288
SSA reference number:	2021/SSA00753
Project title:	Creating partnerships in iSupport program to optimise carers impact on dementia care
Principal Investigator:	Langduo Chen
Associate Investigators	Craig Whitehead Ying Yu Lily Xiao
Governance Authorisation Date:	27/01/2022

On the basis of the information provided in your Site Specific Assessment submission, I am pleased to inform you the SALHN Chief Executive Officer has granted authorisation for this study to commence at **Flinders Medical Centre, SALHN.**

Please ensure this study meets current SA Health COVID-19 regulations before recruitment commences.

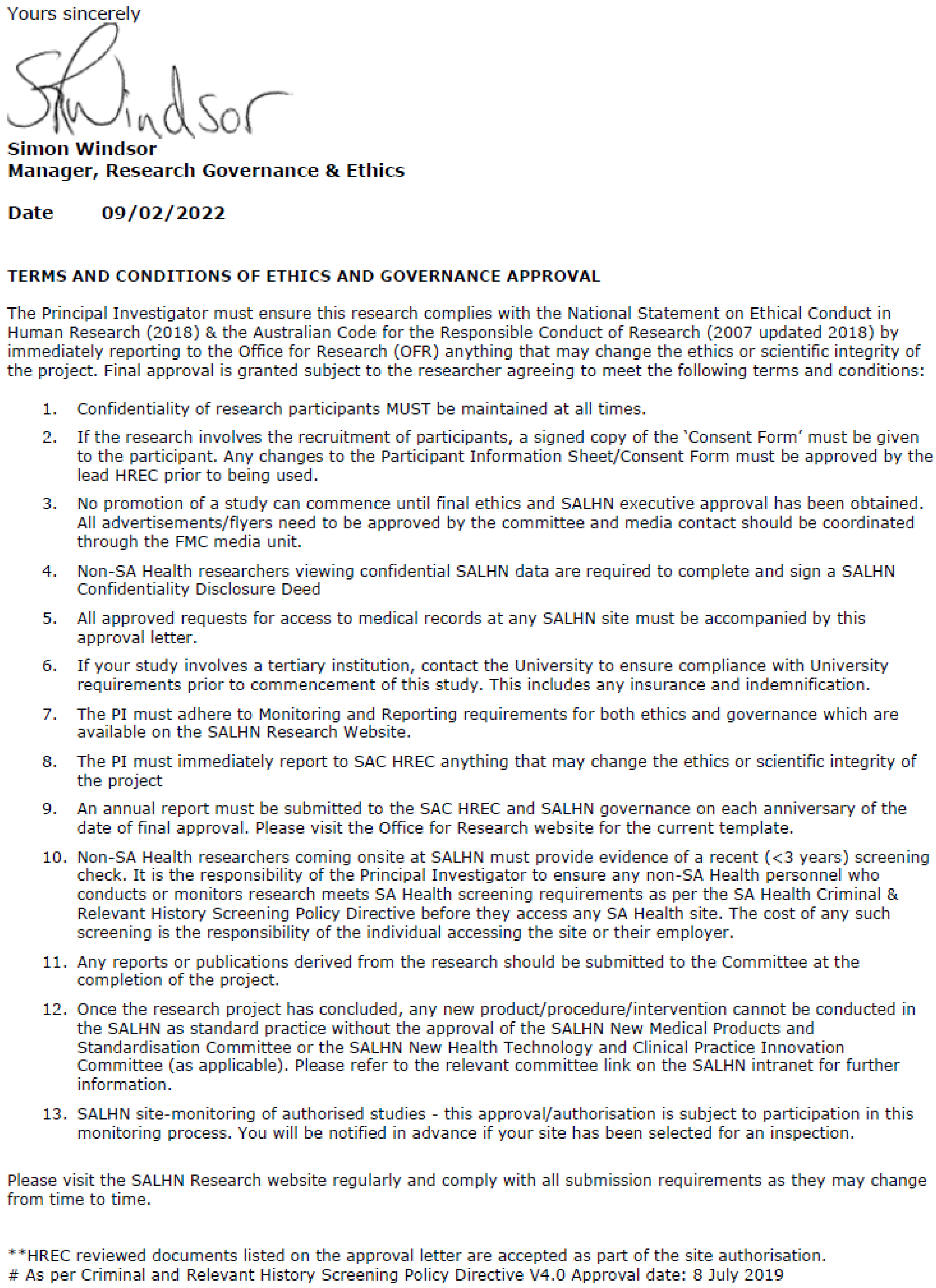
Please note that only those investigators listed above are authorised for this study based on the nature of duties performed; types of clients/patients; and the ability to access certain work locations#. The following arrangements apply to data and/or site access for non-SALHN researchers#:

Non-SALHN - Access to SALHN site and Identifiable Data	**DCSI Screen**	**Confidentiality Deed**
Ying Yu, Flinders University	Yes	Yes
Non-SALHN Access to De-identified Data only (no site access)		
Lily Xiao, Flinders University	NA	NA

The below documents have been reviewed and approved **subject to the terms and conditions** set out on the reverse of this page:

Document	**Version**	**Date**
Site Specific Assessment Form	2021/SSA00753	11/01/2021
SAC HREC Approval Letter**	2021/HRE00288	11/01/2022
Clinical Study Protocol	1.03	22/12/2021
FMC Participant Information Sheet/Consent form • Carers • Simplified for care recipients	 1.03 1.03	 22/12/2021 22/12/2021
Multi-Institutional Agreement	SALHN/Flinders University	Date of last signature
Curriculum Vitae – Langduo Chen		2021
Ying Yu • DCSI check • Confidentiality deed		 16/07/2021 07/12/2021

Should you have any queries about this authorisation, please contact the Office for Research on 8204 6453 or via email: Health.SALHNOfficeforResearch@sa.gov.au quoting the OFR reference number.



Yours sincerely

S Windsor

Simon Windsor
Manager, Research Governance & Ethics

Date 09/02/2022

TERMS AND CONDITIONS OF ETHICS AND GOVERNANCE APPROVAL

The Principal Investigator must ensure this research complies with the National Statement on Ethical Conduct in Human Research (2018) & the Australian Code for the Responsible Conduct of Research (2007 updated 2018) by immediately reporting to the Office for Research (OFR) anything that may change the ethics or scientific integrity of the project. Final approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. Confidentiality of research participants MUST be maintained at all times.
2. If the research involves the recruitment of participants, a signed copy of the 'Consent Form' must be given to the participant. Any changes to the Participant Information Sheet/Consent Form must be approved by the lead HREC prior to being used.
3. No promotion of a study can commence until final ethics and SALHN executive approval has been obtained. All advertisements/flyers need to be approved by the committee and media contact should be coordinated through the FMC media unit.
4. Non-SA Health researchers viewing confidential SALHN data are required to complete and sign a SALHN Confidentiality Disclosure Deed
5. All approved requests for access to medical records at any SALHN site must be accompanied by this approval letter.
6. If your study involves a tertiary institution, contact the University to ensure compliance with University requirements prior to commencement of this study. This includes any insurance and indemnification.
7. The PI must adhere to Monitoring and Reporting requirements for both ethics and governance which are available on the SALHN Research Website.
8. The PI must immediately report to SAC HREC anything that may change the ethics or scientific integrity of the project
9. An annual report must be submitted to the SAC HREC and SALHN governance on each anniversary of the date of final approval. Please visit the Office for Research website for the current template.
10. Non-SA Health researchers coming onsite at SALHN must provide evidence of a recent (<3 years) screening check. It is the responsibility of the Principal Investigator to ensure any non-SA Health personnel who conducts or monitors research meets SA Health screening requirements as per the SA Health Criminal & Relevant History Screening Policy Directive before they access any SA Health site. The cost of any such screening is the responsibility of the individual accessing the site or their employer.
11. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
12. Once the research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable). Please refer to the relevant committee link on the SALHN intranet for further information.
13. SALHN site-monitoring of authorised studies - this approval/authorisation is subject to participation in this monitoring process. You will be notified in advance if your site has been selected for an inspection.

Please visit the SALHN Research website regularly and comply with all submission requirements as they may change from time to time.

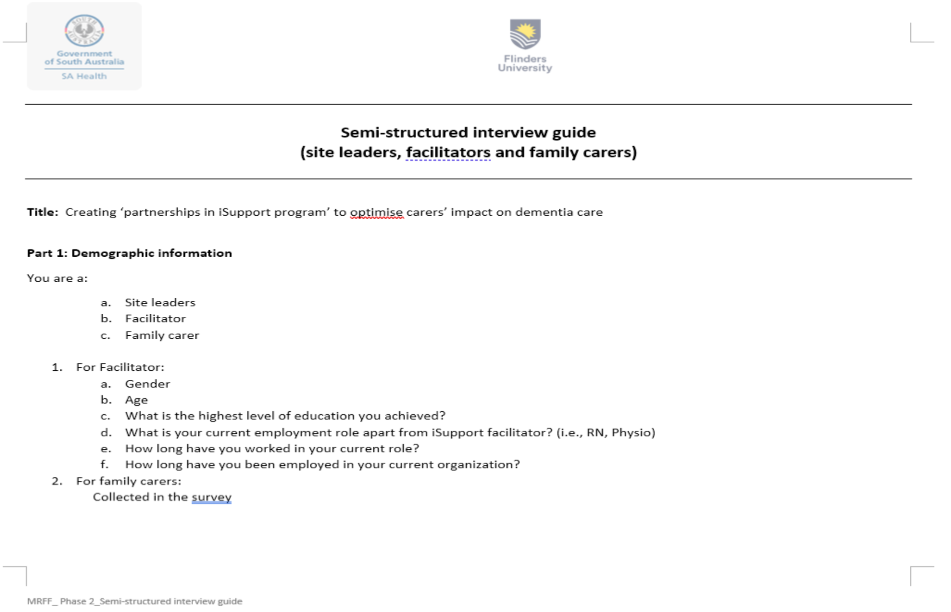
**HREC reviewed documents listed on the approval letter are accepted as part of the site authorisation.
As per Criminal and Relevant History Screening Policy Directive V4.0 Approval date: 8 July 2019

APPENDIX 11 EXAMPLE OF PHASE 1 CONTENT ANALYSIS

Suggested Strategies	Grouping

Education on managing triggers/challenging behaviours	*Education and support on changed behaviours*	**Prevent and/or manage dementia-related symptoms and changed behaviours.**
Practical strategies to try when person with dementia is angry and/ or insulting, or perhaps very confused and upset.		
Empower significant other to identify and deal with changed behaviours - promote early identification of triggers and development of early strategies		
Education relating to the specific dementia and behaviours traits that may be relevant to the carer		
How to reduce the pace of deterioration		
Support with coping with the dementia symptoms and support with the personality of the person with dementia.		
Being available for behaviour advice		
Making the most of the abilities of the person with dementia.	*PLWD and meaningful activities*	***Support carers to engage PLWD in meaningful activities***
Finding out what they would like to do or go to and haven't been able to do. Perhaps arrange a nice outing for them, to be away from home.		
Develop a Dementia Specific, Practical, Idea and Activities Bank		
Listing Dementia specific, practical aids for ADLs		
Research best new developments in personal care management, aids ...presently lacking dignity		
Facilitate day to day routine		
Encourage the sense, smell, and sound of nature, Arts and music		
Provide carers with tools to increase people's engagement in significant activities		
Learning how to keep a positive outlook on life in the times when the person with dementia has temporarily changed into a rather obnoxious human being.	*Care for carers' mental health*	**Improve carers' mental health through self-care, education and counselling**
Provide significant others emotional support in regarding to accepting the diagnosis of dementia		
Assist significant others to deal with guilty and grief		
interaction via text messages, videos etc at least once a week		
Offer different levels of support depending on the carers individual journey	*Enable carers to have positive experiences*	
Experiencing first-hand what it's like to be a carer		
Support Person allocated to family/carer - first line of contact		
A point of contact if experiencing difficulties.		
Transition to the diagnosis		
Relaxation activities		
Not sure but carers definitely need support!		

APPENDIX 12 PHASE 2 SEMI STRUCTURED INTERVIEW GUIDE



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Semi-structured interview guide
(site leaders, facilitators and family carers)

Title: Creating 'partnerships in iSupport program' to optimise carers' impact on dementia care

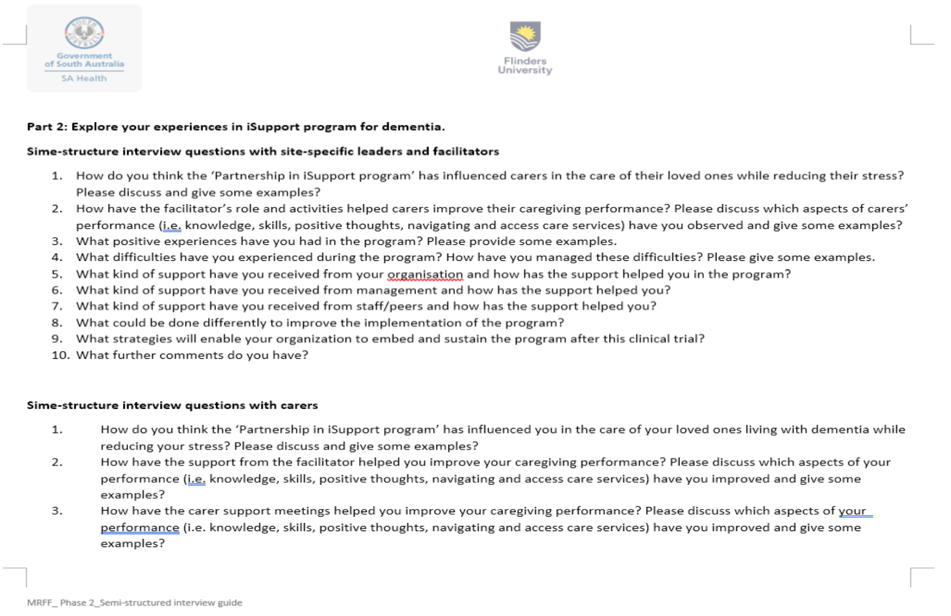
Part 1: Demographic information

You are a:

- a. Site leaders
- b. Facilitator
- c. Family carer

1. For Facilitator:
    - a. Gender
    - b. Age
    - c. What is the highest level of education you achieved?
    - d. What is your current employment role apart from iSupport facilitator? (i.e., RN, Physio)
    - e. How long have you worked in your current role?
    - f. How long have you been employed in your current organization?
2. For family carers:
    Collected in the survey

MRFF_ Phase 2_Semi-structured interview guide



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Part 2: Explore your experiences in iSupport program for dementia.

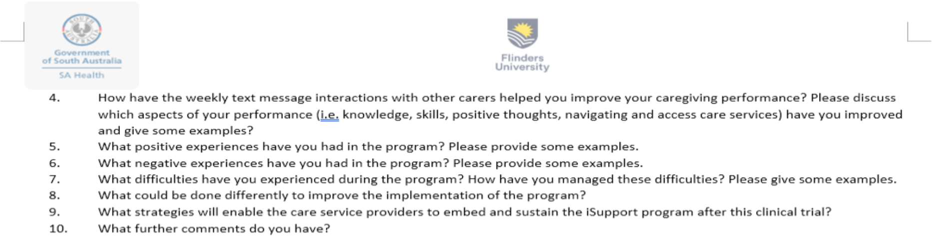
Sime-structure interview questions with site-specific leaders and facilitators

1. How do you think the 'Partnership in iSupport program' has influenced carers in the care of their loved ones while reducing their stress? Please discuss and give some examples?
2. How have the facilitator's role and activities helped carers improve their caregiving performance? Please discuss which aspects of carers' performance (i.e. knowledge, skills, positive thoughts, navigating and access care services) have you observed and give some examples?
3. What positive experiences have you had in the program? Please provide some examples.
4. What difficulties have you experienced during the program? How have you managed these difficulties? Please give some examples.
5. What kind of support have you received from your organisation and how has the support helped you in the program?
6. What kind of support have you received from management and how has the support helped you?
7. What kind of support have you received from staff/peers and how has the support helped you?
8. What could be done differently to improve the implementation of the program?
9. What strategies will enable your organization to embed and sustain the program after this clinical trial?
10. What further comments do you have?

Sime-structure interview questions with carers

1. How do you think the 'Partnership in iSupport program' has influenced you in the care of your loved ones living with dementia while reducing your stress? Please discuss and give some examples?
2. How have the support from the facilitator helped you improve your caregiving performance? Please discuss which aspects of your performance (i.e. knowledge, skills, positive thoughts, navigating and access care services) have you improved and give some examples?
3. How have the carer support meetings helped you improve your caregiving performance? Please discuss which aspects of your performance (i.e. knowledge, skills, positive thoughts, navigating and access care services) have you improved and give some examples?

MRFF_ Phase 2_Semi-structured interview guide



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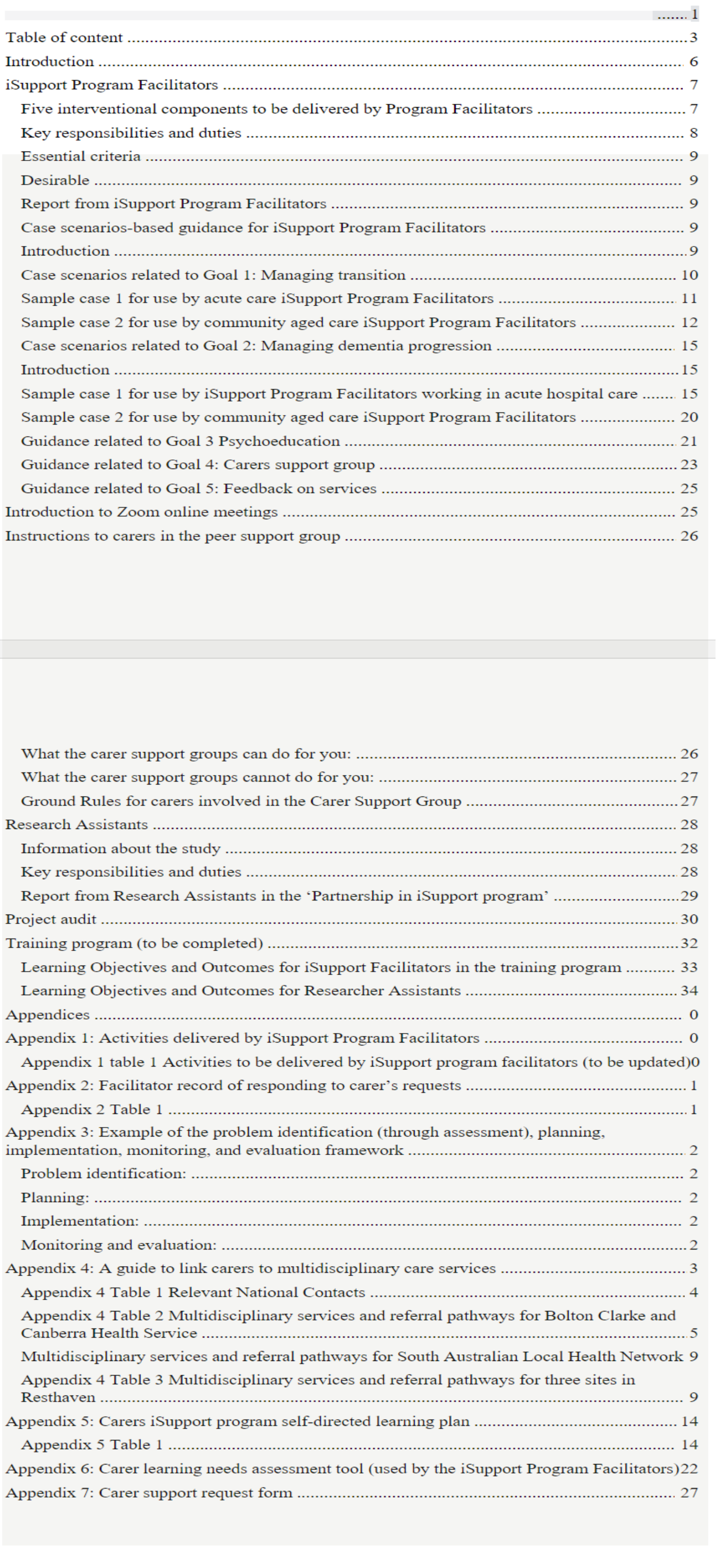
4. How have the weekly text message interactions with other carers helped you improve your caregiving performance? Please discuss which aspects of your performance (i.e. knowledge, skills, positive thoughts, navigating and access care services) have you improved and give some examples?
5. What positive experiences have you had in the program? Please provide some examples.
6. What negative experiences have you had in the program? Please provide some examples.
7. What difficulties have you experienced during the program? How have you managed these difficulties? Please give some examples.
8. What could be done differently to improve the implementation of the program?
9. What strategies will enable the care service providers to embed and sustain the iSupport program after this clinical trial?
10. What further comments do you have?

APPENDIX 13 EXAMPLE OF PROJECT IMPLEMENTATION MANUAL

Partnership
in iSupport



Sample case 1 for use by acute care iSupport Program Facilitators

Information about Mrs. Kathy Smith

Mrs. Kathy Smith is 80 years old and was diagnosed with dementia 3 months ago. She is receiving a Home Care Package level 2. She was admitted to a geriatric ward in a hospital 3 days ago due to increased confusion and witnessed fall at home. After investigations in the ward, she was diagnosed with UTI. Now she is on an oral antibiotic and the medical team plans to discharge her home. However, her confusion is not improving. She is agitated, wandering at night, looking for the toilet and has occasionally wet the bed. She has not used an incontinence pad before.

Kathy has diabetes and hypertension which are managed by oral medication. She lives with her husband, Mr. Bob Smith. She has three adult children and five grandchildren who live interstate. Prior to her retirement, she was a primary school teacher. She likes gardening by herself and with her family and friends.

Information about the carer: Mr. Bob Smith

Mr. Bob Smith is also 80 years old and has become the primary carer for Kathy since she was diagnosed with dementia. He received an information pack about resources available from Dementia Australia from staff at the memory clinic. However, he has not had time to search for further information. So far, he has not attended any dementia care education sessions for carers as he is too busy with his carer's role to attend other activities. Bob was a high school teacher prior to his retirement. He likes to garden and organises gardening shows with family friends. He routinely searches the internet for information about plants and uses email to communicate with family and friends.

Mr. Smith has contacted his iSupport program Facilitator for support. What is your plan to help Bob manage the transition from hospital to home?

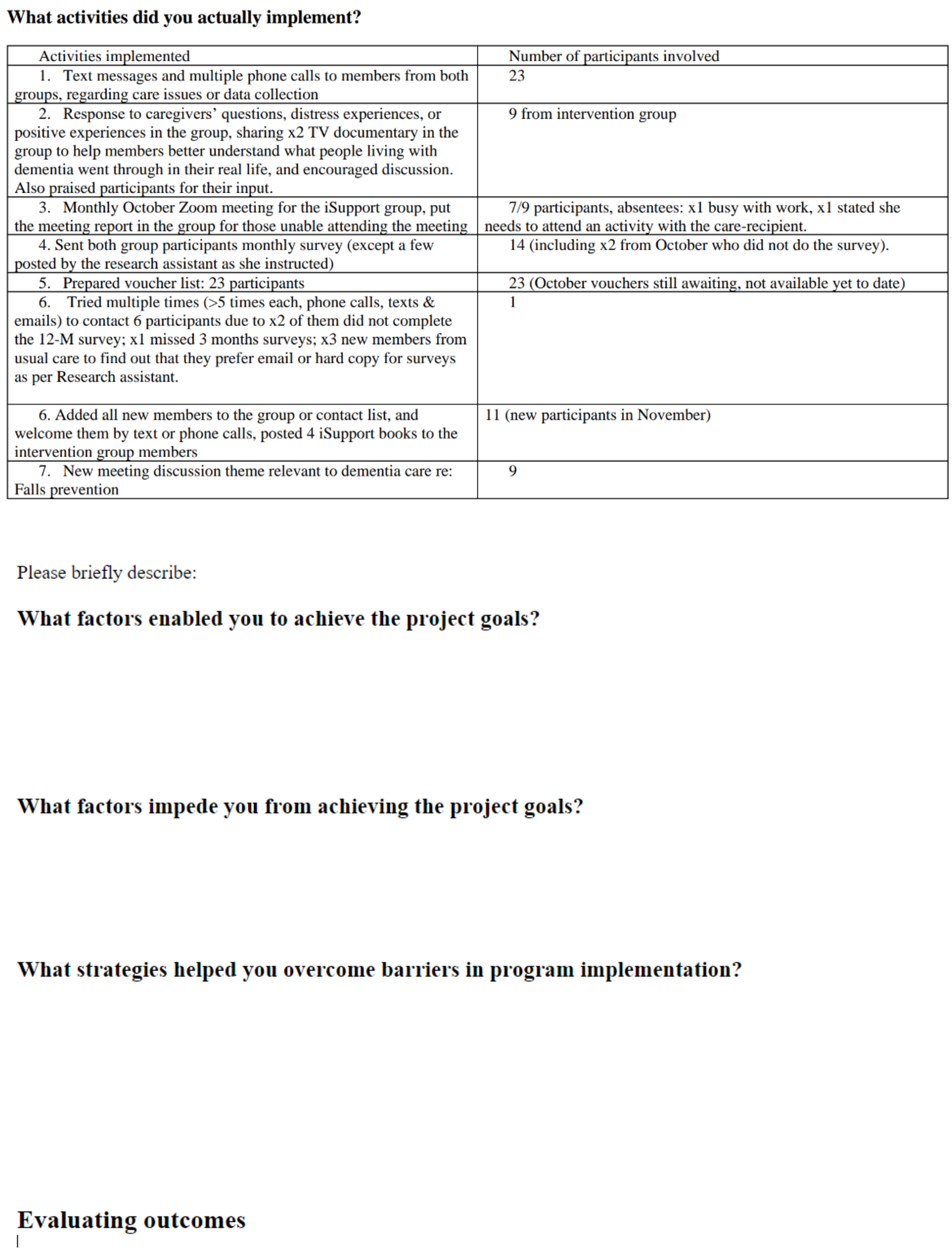
Recommended iSupport Program Facilitator's intervention

The iSupport Program Facilitator will apply the problem identification (through assessment), planning, implementation, monitoring, and evaluation framework (Appendix 3). The following interventions are recommended:

The iSupport Facilitator will identify problems, plan actions to address the problems, monitor and evaluate these actions:

- Support Mr. Smith by assessing and exploring if he can safely cope with Mrs. Smith's current condition.
- Collaborate with the discharge nurse when planning to meet Mr. Smith's needs for support in managing hospital to home transitional care.
- In collaboration with the discharge nurse and the multi-disciplinary team identify relevant services that could smooth the hospital to home transition and reduce likelihood of readmission to hospital. 'A guide to link carers to multidisciplinary care services' tool (Appendix 4) could be used to identify appropriate services.
- Work with Mr. Smith and the discharge nurse to identify a possible discharge date. Provide education to Mr. Smith about the potential risks during the transition.
- Guide Mr. Smith to select relevant learning units from the iSupport Program. The Facilitator can review the 'Carers iSupport self-directed learning plan' (Appendix 5) to identify Mr. Smith's changed learning needs. Suggested learning units need to be relevant to Mrs. Smith's dementia-related symptoms (i.e., wandering at night, agitation and incontinence).
    - The Facilitator is recommended to use the 'Carer learning needs assessment tool' (Appendix 6), however, any evidence-based assessment tool can be used.
- Encourage Mr. Smith to document comprehensive information about Mrs. Smith's care, including medication, daily routine, his preferences in ADLs and social and leisure activities, in his 'iSupport program manual for informal carers'. This can then be used for future transitions.
- Work with Mr. Smith to record problems in his 'iSupport program manual for informal carers' and discuss possible solutions with him in follow-up meetings.
- After discharge, if needed, the Facilitator will meet Mr. Smith weekly via Zoom or phone to discuss any concerns he may have and support him in problem-solving, referring him to relevant services and resources as required.
- During the project period, Mr. Smith will be encouraged to seek help from the facilitator by email using the Carer support request form (Appendix 7), WhatsApp or phone.
- Introduce Mr. Smith to the monthly carer group via Zoom and WhatsApp and encourage Mr. Smith to interact with other carers to share experiences and help each other.
- Complete project documentation as required.

APPENDIX 14 EXAMPLE OF ISUPPORT FACILITATOR’S PORTFOLIO



What activities did you actually implement?

Activities implemented	Number of participants involved
1. Text messages and multiple phone calls to members from both groups, regarding care issues or data collection	23
2. Response to caregivers’ questions, distress experiences, or positive experiences in the group, sharing x2 TV documentary in the group to help members better understand what people living with dementia went through in their real life, and encouraged discussion. Also praised participants for their input.	9 from intervention group
3. Monthly October Zoom meeting for the iSupport group, put the meeting report in the group for those unable attending the meeting	7/9 participants, absentees: x1 busy with work, x1 stated she needs to attend an activity with the care-recipient.
4. Sent both group participants monthly survey (except a few posted by the research assistant as she instructed)	14 (including x2 from October who did not do the survey).
5. Prepared voucher list: 23 participants	23 (October vouchers still awaiting, not available yet to date)
6. Tried multiple times (>5 times each, phone calls, texts & emails) to contact 6 participants due to x2 of them did not complete the 12-M survey; x1 missed 3 months surveys; x3 new members from usual care to find out that they prefer email or hard copy for surveys as per Research assistant.	1
6. Added all new members to the group or contact list, and welcome them by text or phone calls, posted 4 iSupport books to the intervention group members	11 (new participants in November)
7. New meeting discussion theme relevant to dementia care re: Falls prevention	9

Please briefly describe:

What factors enabled you to achieve the project goals?

What factors impede you from achieving the project goals?

What strategies helped you overcome barriers in program implementation?

Evaluating outcomes

APPENDIX 15 PHASE 2 CARERS IN THE INTERVENTION GROUP SATISFACTION SURVEY

Site code _____ Personal code_____ Month___________

How many units in iSupport manual have you completed?

____

If you have not completed any units in the iSupport manual, can you please explain the reason?

____

Carer in the iSupport group satisfaction survey

Items	1	2	3	4	5	6
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	N/A
1.My facilitator motivates me to learn from the online iSupport program.						
2.My facilitator helped me identify learning units of the iSupport that are relevant to my situation.						
3.My facilitator helped me identify healthcare/social care services my care recipient and/or myself need.						
4.My facilitator motivates me to participate in the care support group meeting.						
5.I am satisfied with the carer support group meeting.						
6.My facilitator motivates me to interact with other carers on a weekly basis.						
7.I am satisfied with the weekly carer interactions via chat and text messages.						
8.My facilitator respond to my request for support on a timely manner.						
9.I am satisfied with the individualised support my facilitator provided to me.						
10.Overall, I am satisfied with the support my facilitator provided to me.						

Other comments: