Cognitive Stimulation Therapy delivery (CST) for dementia in Hong Kong: randomised controlled trial of virtual versus in-person groups

Tsz Leung Wong

DClinPsy Thesis (Volume 1), 2024

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: [redacted]

Name: Tsz Leung Wong

Date: 14th June 2024

Overview

With a growing number of people living with dementia (PLwD) worldwide, dementia intervention has become a prioritised topic in research and clinical practice. This thesis explores dementia interventions in two key domains: community education to increase public awareness, and non-pharmacological group interventions through cognitive stimulation therapy (CST).

Part I is a systematic review exploring the impact of different community education programmes worldwide on enhancing dementia awareness and reducing dementia-related stigma in the general public. Among the nine identified studies, key types and elements of effective programmes are highlighted, followed by recommendations for future research.

Part II is a randomised controlled trial evaluating the effectiveness of virtual CST (vCST) compared to in-person CST in cognitive function, quality of life, and social functioning in Hong Kong. It is a pioneering study comparing different CST modes and exploring social functioning. The result demonstrates the value of CST in dementia care. It also suggests potential improvements for vCST protocols and provides recommendations for service delivery.

Part III is a critical appraisal reflecting on both the empirical study and the systematic review. It emphasises the integration of Social Graces in ethical research and dementia care, and provides insights for vCST delivery.

Impact Statement

The study contributes to the development of dementia care in academic, clinical as well as advocating societal changes. Focusing on the dementia intervention through community programmes and cognitive stimulation therapy (CST), the study provides valuable insights and recommendations for various stakeholders in society. It informs dementia research with both academic impact and practical implications of interventions.

The systematic review addressed the research gap by evaluating existing community education programmes. It highlighted the role of community programmes in raising dementia awareness and reducing stigma. The implementation of effective programmes can foster a more inclusive and accessible community for people living with dementia (PLwD). The review analysed the quality of existing studies and identified key formats and elements that show significant impacts. It provides valuable insights in the program design and implementation; which the healthcare sector, charity organisations and social enterprises can refer to.

The review identified the involvement of PLwD in the programme design and delivery, empowering vulnerable communities through the co-production process. It also highlighted the importance of dementia-friendly communities that deliver impact for potential public benefit. It could inform public health initiatives and allow policymakers to consider implementing community programmes to change the dementia attitude of the public and contribute to the development of a more inclusive society.

The empirical study used a robust methodological design by employing a randomised control trial with a substantially large sample size. The findings provide an evidence base that supports the delivery of non-pharmacological interventions for PLwD. It enhances the overall wellbeing of PLwD and their families by providing high-quality interventions that target cognitive function, quality of life, and social function.

The evidence of the non-inferiority of virtual CST(vCST) offers an alternative for service provision. A hybrid service delivery can enable higher accessibility of services and adapt to various contexts and PLwD's needs. The recommendations of vCST delivery can benefit healthcare service providers by refining the facilitators' trainings in virtual engagement and the vCST protocols. The cost-effectiveness of CST in dementia care can also influence policymakers in public health decisions. Future studies can develop on these findings and further explore the impact of different modes of CST delivery in diverse settings and the longitudinal effects. To maximise the impact of the current study, these results will be disseminated in relevant journals and conferences.

Table of Content

List of Tables

Part One: Literature Review

Part Two: Empirical Paper

List of Figures

Part One: Literature Review

Part Two: Empirical Paper

Acknowledgements

I would like to express my heartfelt gratitude to my supervisors, Professor Aimee Spector and Dr. Gloria Wong, for their continuous support and guidance throughout the study. Throughout the three years, they have been consistently encouraging, open, supportive and approachable. They always offer me advice and respond to my queries promptly. In addition, their professional knowledge in older adults and dementia have enriched my research experience, which allows me to build up my confidence in this research journey.

I am sincerely grateful to all participants who took part in the research. Without their continual contributions and support, completing the study would have been impossible. It has been my privilege to work with them closely. Their experiences have been immensely important to my research and clinical learning.

I would like to extend my gratitude to Dr. Jacky Choy and the fellows of the research team from the University of Hong Kong for their support and coordination in this study. I appreciate the additional effort required to accommodate our time zone and location differences. I am sincerely thankful for their dedication in the project.

Lastly, but most importantly, my deepest gratitude goes to my parents, family, and friends. They have been nurturing and supporting me across my life. Their love has been the cornerstone throughout all the ups and downs in the previous three years. I also dedicate my research in memory of my late grandmother, who bravely lived with dementia for many years.

Part One: Literature Review

The Impact of Community Education Programmes and Campaigns on Increasing Awareness and Reducing Stigma in dementia: A systematic review

Abstract

Aims: The review examines the impact of different community education programmes and campaigns in enhancing dementia awareness and reducing dementia-related stigma, identifying the most impactful elements targeting the general public.

Methods: 1,152 studies were identified from the electronic databases CINAHL, EMBASE, MEDLINE, PsycINFO, and 84 websites were found from the grey literature search. After screening and assessing for eligibility, nine relevant studies, which encompassed randomised controlled trials (RCT), cross-sectional studies, pre-post studies and qualitative analyses, were included based on specified criteria and evaluated using the Downs and Black Checklist.

Results: Several formats and elements of successful programmes were identified, including the involvement of people living with dementia (PLwD) in co-production, the creation of dementia-friendly communities, the strategic use of community space, the incorporation of digital innovations and art-based interventions, and culturally tailored models. The analysis revealed frequent methodological challenges, particularly regarding generalisability, population representation, the absence of comparison groups and control of potential confounders.

Conclusions: The finding highlights extensive and varied array of intervention programmes, with distinctive features when they involve direct participation from PLwD, utilise innovative and culturally relevant methods, and incorporate robust evaluation mechanisms. It also emphasises the need for methodological rigour and longitudinal studies to ensure the sustainability and effectiveness of these

programmes, aiming for a more informed and compassionate community towards PLwD and their carers.

Introduction

In line with the World Health Organization findings (2021), there is a significant rise in dementia with a global demographic trend towards an ageing population. In 2020, there were over 55 million people globally believed to be living with dementia and a new case diagnosed every three seconds, likely to reach 139 million in the year 2050.

Dementia-related Stigma

Dementia, in spite of its high rate of prevalence, is still heavily stigmatised and brings about different health and wellbeing problems for those living with it and their caregivers (Alzheimer's Disease International, 2019; Nguyen & Li, 2020; Van den Bossche & Schoenmakers, 2022). According to Alzheimer's Disease International (2019), 84% of PLwD reported experiencing certain levels or forms of stigma in their lives.

Traditional research on stigma (Corrigan, 2000; Link & Phelan, 2001) has shown that mental health stigma affects the trajectory and outcomes of mental illness by reinforcing stereotypes and shaping how people living with mental health conditions are perceived and treated. The attribution model (Corrigan et al., 2003) suggests that labels associated with mental illness, alongside symptoms, behaviours, and physical appearance, serve as triggers for stigma. This stigma elicits negative emotional responses, such as fear and anger, which subsequently lead to discriminatory behaviours. The model highlights the connections between cognitive processes, emotional responses, and discrimination, and emphasises the crucial role of targeted interventions. When implemented effectively, these interventions can significantly reduce stigma and its harmful effects on different aspects such as daily living, housing, and access to healthcare services, thereby fostering a more inclusive and supportive society.

Dementia-related stigma refers to the negative attitudes, beliefs, and behaviours directed towards PLwD and their family members, often leading to social exclusion, unfair treatment, discrimination, and a diminished quality of life for those affected (Kahn et al., 2016; Rewerska-Juśko & Rejdak, 2020; Werner et al., 2012). This stigma can manifest in several forms. On a personal level, self-stigma involves PLwD internalising negative beliefs and experiencing a sense of shame (Phillipson et al., 2012; Werner, 2014). At a societal level, public stigma reinforces misconceptions about dementia and contributes to the exclusion of those affected, particularly through its portrayal in mass media (Blay & Peluso, 2010; Low & Purwaningrum, 2020). At the structural level, structural stigma is reflected in institutional policies and practices that disadvantage PLwD and their families (Nolan et al., 2006; Werner, 2014). Common drivers and contributors to the perpetuation of stigma towards PLwD include a lack of knowledge and awareness about the signs and symptoms of dementia (Alzheimer's Australia, 2017; Rosato et al., 2019), stereotypes and misconceptions including language and terminology (Low & Purwaningrum, 2020; Rewerska-Juśko & Rejdak, 2020), and cultural influences on the views on ageing and mental health (Siette et al., 2023; Alzheimer's Disease International, 2019). By developing a comprehensive understanding of the stigma and its underlying drivers, efforts to improve public awareness may contribute to mitigate the impact of dementia-related stigma.

The Impact of Dementia-related Stigma

In a World Health Organisation survey (2012), participants from 25 countries highlighted the negative effect of dementia-related stigma on people living with dementia (PLwD) and their carers. A cross-cultural study (Lion et al., 2019) suggested that stigmatisation can seriously impair the physical and mental wellbeing of PLwD. A longitudinal study (Burgener et al., 2015) further suggested that stigmatisation might increase social isolation, limit autonomy and lower the quality of life. Another cross-sectional study (Van den Bossche & Schoenmakers, 2022) also proposed that stigmatisation impacts not only PLwD but also the mental wellbeing of their family carers.

Furthermore, stigma can be a noticeable obstacle to getting access to essential support, diagnosis, treatment, and relevant information (Stewart et al., 2015; Giebel et al., 2021), indicating the urgent need for intervention programmes aimed at challenging dementia-related stigma. Hence, reducing the dementia-related stigma becomes an important global policy initiative mentioned in the World Health Organization's Global Action Plan (2012).

Raising Dementia Awareness

Rubinstein et al. (2015) reviewed the global response associated with dementia and highlighted the necessity of public dementia awareness projects in addressing stigma. On a global scale, there is increased recognition of the significance of dementia awareness (WHO, 2021). As Alzheimer’s Disease International (2019) highlighted, raising dementia awareness and providing educational interventions at both personal and societal levels are essential for changing people’s attitudes towards dementia.

Dementia awareness refers to the understanding and recognition of the signs and symptoms of dementia and its impact on individuals, families, and communities (Ali et al., 2023). It focuses on efforts to educate the public and raise understanding about factors that contribute to dementia risk, promote primary prevention, early detection and diagnosis (Wittenberg et al., 2017; Heger et al., 2020). Dementia awareness initiatives aim at raising the public understanding of the condition and challenging stigma, which results in more inclusive and compassionate attitudes towards PLwD (Bacsu et al., 2022; Brai et al., 2021) and providing various support services, resources and community programmes for PLwD and their caregivers (Thorsen et al., 2020).

Dementia Awareness Programmes and Campaigns

With reference to the World Dementia Council (2020a), raising public dementia awareness includes a spectrum of dementia-friendly programmes and campaigns targeted towards different demographics. These activities aimed to elevate the prominence of dementia in public discourse, combat stigma, empower the public to interact with PLwD, and provide training. Alzheimer's Disease International (2019) also recommended that community education programmes and campaigns are effective strategies in promoting dementia awareness and changing dementia-related stigma, through educating people about dementia and possibly reducing the widespread prejudice and misunderstanding related to dementia. It also contributed to the development of dementia-friendly community and the promotion of social inclusion through educational events and innovative initiatives (Hung et al., 2021). In practice, these often involve educational campaigns, community events, training programmes, and advocacy work to encourage organisations to improve policies and service delivery at the organisational level (Matsumoto et al., 2021; Heger et al., 2020; Smith et al., 2019; Cahill et al., 2015).

While interpersonal contact has been widely deployed in addressing stigma associated with mental health conditions (Corrigan & Penn, 1999), community programmes focused on the involvement of PLwD have demonstrated efficacy in raising awareness and changing attitudes (Kane et al., 2018; Phillipson et al., 2019; Cheston et al., 2019). Nevertheless, despite the diverse community initiatives and campaigns utilising various methodologies (World Dementia Council, 2020b), there is no consensus on the most effective strategies. Furthermore, the absence of evidence-based evaluation and the influence of self-selection indicates the need for a more comprehensive review that considers both positive and negative experiences, as well as the impact of community education programmes and campaigns.

Aim

In light of the vital nature of addressing dementia as a significant public health challenge, and the critical role of stigma reduction and community awareness initiatives, this systematic review aims to evaluate community-based education programmes and campaigns in fostering awareness, knowledge, attitudes, and challenging stigma related to dementia. The review will address two main questions:

Review Questions:

1) *What types of community education programmes and campaigns have been evaluated, and how effective have they been?*
2) *What are the components and formats of these programmes and campaigns?*

By addressing the above questions, the review aims to provide recommendations for designing and implementing future interventions.

Methods

Search strategy

A systematic review of the literature was conducted using the databases CINAHL, EMBASE, MEDLINE and PsycINFO. The search terms used variations of four terms: dementia, education, community and awareness, which are illustrated in Table 1. The search terms for dementia were ‘Dementia’, ‘Alzheimer*’, ‘cognitive impairment*’, and ‘cognitive declin*’. The search terms for education were ‘educat*’, ‘programme*’ and ‘campaign*’. The search terms for community were ‘community’, ‘public*’, ‘societ*’ and ‘social*’. The search terms for awareness were ‘aware*’, ‘stigma*’, ‘attitude*’, ‘knowledge’, ‘literac*’ and ‘understand*’. The search encompassed the period from the year 2000 through October 2023. A grey literature search was also conducted through Google and charity organizations.

Inclusion and exclusion criteria

The formulation of inclusion and exclusion criteria was guided by the research questions. A PRISMA Flow Diagram (Figure 1) illustrates the process of eliminating studies from the final literature pool. All study designs were included in this review for pragmatic reasons. The initial scoping search identified very few RCTs addressing community education programmes and campaigns aimed at raising dementia awareness. Given the nature of community-based interventions, which are often evaluated through observational studies, qualitative research, pre-post surveys, and mixed-methods approaches, excluding non-RCT designs would result in a loss of valuable insights. A broader inclusion criterion allows for a more comprehensive understanding of these interventions, capturing a wider range of evidence and perspectives. Interpersonal contact approaches are also included in this systematic review as one of the community-based interventions.

Inclusion Criteria

- All types of study designs.
- Any community education programmes or campaigns designed to increase knowledge and awareness of dementia or reduce dementia-related stigma, such as workshops, programmes, or public awareness campaigns.
- Participants of all demographics.
- English articles from the year 2000 to October 2023.
- Studies used either qualitative, quantitative or mixed approaches.

Exclusion Criteria

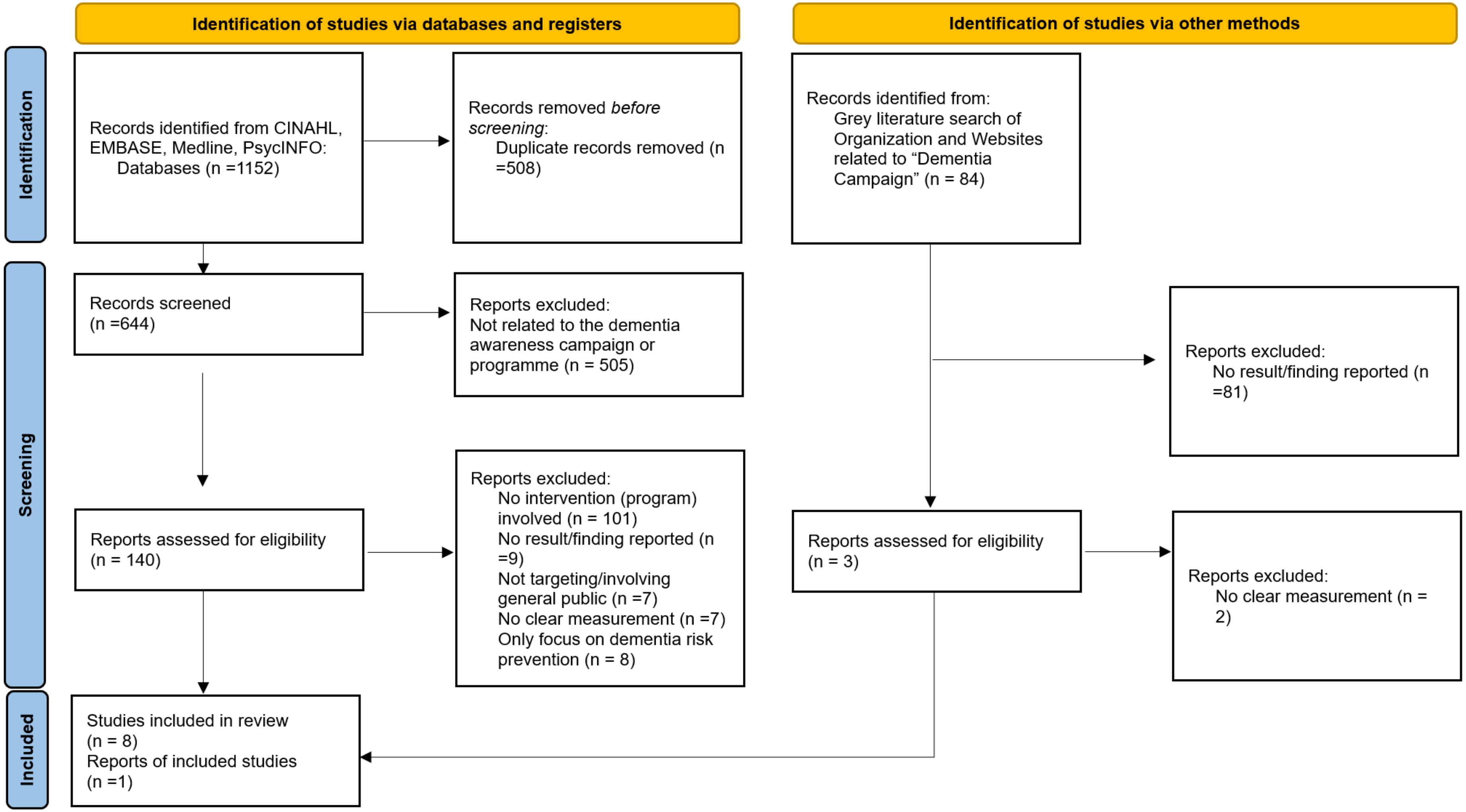
- Studies only included surveys or descriptive data without implementing or detailing any specific intervention or programme aimed at enhancing dementia awareness.
- Studies were not directed toward or involving the general public or community.
- Studies did not report measurable data, outcomes, or results, or where the evaluation of the intervention's effectiveness was absent or unclear.
- Studies exclusively focused on dementia risk prevention, without a primary emphasis on awareness enhancement or stigma reduction.

Table 1. Electronic search strategy

Search Term Category	Terms Applied	Combined with	
Dementia	dementia Alzheimer* cognitive impairment* cognitive declin*	OR	AND
Education	educat* programme* campaign*	OR	
Community	community public* societ* social*	OR	
Awareness	aware* stigma* attitude* knowledge literac* understand*	OR	

Notes: *Denotes truncation, looks for variants of words, e.g. educate and educational

Figure 1: PRISMA Flow Diagram



Study Selection Process

Studies were recorded and managed through EndNote. After removing duplicates, a two-stage selection process occurred based on titles/abstracts and full-text articles. A second reviewer was invited to randomly review 10% of the search database and grey literature. The second reviewer applied the same inclusion and exclusion criteria to cross-check for any potentially missed studies. Following this review, no discrepancies were found. As a result, no additional suggestions were made to the study selection process.

Data Extraction

Data extraction included author(s), study date, intervention details, context, evaluation methods, and descriptive, methodological, and outcome information.

Registration

The systematic review has already been accepted by the PROSPERO register. The registration number is CRD42024444717.

Quality Assessment

The quality assessment of identified studies was conducted using the Downs and Black Checklist (1998), a tool designed to assess the methodological quality of studies across a range of designs, including both randomised and non-randomised studies. It includes different key domains, such as reporting, external validity, bias, confounding, internal validity and power. Through the systematic application of the checklist, the review aimed to ensure a comprehensive examination of the quality of studies. It enabled the consideration of potential biases and the identification of limitations.

Given the broad inclusion criteria of the review, the checklist was chosen for its comprehensiveness and flexibly to accommodate the diverse perspectives across various study designs. For quantitative studies, particularly RCTs, the full checklist was applied, focusing on key elements such as study power, randomisation, and blinding. For non-randomised studies, including pre-post and cross-sectional designs, the checklist emphasised items relevant to these methodologies, such as clarity of reporting, outcome measurement, internal validity, and adjustment for potential confounders. In the case of qualitative studies, certain aspects of the checklist were adapted to account for the specific nature of qualitative research. While acknowledging the limitations of using a quantitatively-focused tool for qualitative designs, the review prioritised areas such as the clarity of reporting objectives, outcome measures, and the characteristics of participants. The specific checklist domains applied to each study design are outlined in Table 3 of the Results section.

Approach to Synthesis

This review adopted a narrative synthesis approach to analyse and integrate the findings from identified studies. With reference to Popay et al. (2006), narrative synthesis examines patterns and relationships across different studies to explore how various factors might impact outcomes. Narrative synthesis was considered in view of the heterogeneity of the identified studies, including the research design, mode of intervention, populations and outcomes. The heterogeneity made a quantitative synthesis like meta-analysis difficult to carry out (NIHR Complex Reviews Support Unit, n.d.). In the current identified studies, methodological approaches were diversified from qualitative studies to different quantitative research, which made the pooling of data nearly impossible. In contrast, by adopting a narrative synthesis approach, the review integrated qualitative insights with quantitative data, enhancing the comprehensive understanding of the topic. It also enabled the inclusion of different research designs and outcome measures, thereby addressing the complexity of dementia awareness programmes and their evaluations more effectively.

In this review, a preliminary synthesis was undertaken by categorising studies based on their key characteristics. Guided by the research questions, themes were identified according to the types of intervention programmes and their effectiveness (Review Question 1), including but not limited to changes in dementia-related knowledge, stigma, and attitudes. Further exploration of the intervention components and formats was then conducted to identify patterns (Review Question 2), such as the prevalence of specific formats in promoting awareness or reducing stigma. With the flexible but structured narrative synthesis approach, it allowed a detailed examination of the strengths and limitations of various dementia education programmes, which provided valuable insights into the ideal characteristics and success factors of interventions.

Results

Summary of Identified Studies

A total of 1152 studies were initially identified through manual searches of different databases. An additional 84 records were sourced through a grey literature search of organisations and websites related to dementia campaigns. Table 2 summarises the nine studies included in the final review which met the inclusion and exclusion criteria. It lists the details of each study, including authors, years, county, summary of programme, study design, sample sizes, measures, outcomes and practical implications.

Characteristics of Identified Studies

Of the nine identified studies, eight were quantitative, including one RCT conducted by Kim et al. (2021). Kontos et al. (2023) included a nested qualitative study within other quantitative studies. Hickey (2019) was the only study identified through a grey literature search.

Two studies were conducted in Europe, four in North America, two in Australia, and one in Asia. The sample sizes varied, ranging from 30 to 1,217 participants, and the demographic backgrounds were diverse, encompassing a range of genders, ages, and ethnicities. The duration of the interventions varied significantly, from a 25-minute session to a two-year national campaign.

In terms of outcome measures, four studies reported findings related to dementia knowledge, six studies reported on attitudes, and two specifically measured outcomes related to stigma. All studies employed different scales and measurements, including eight distinct questionnaires and other qualitative reports. Across the studies, there was a consistent pattern of results indicating improvements in dementia-related knowledge, attitudes, and stigma.

For dementia knowledge, in Hickey (2019), a significant improvement in self-reported knowledge of dementia ($p < 0.001$) and awareness of the modifiable nature of dementia risk ($p < 0.001$) was observed following a national campaign. Similarly, Perales et al. (2020) reported significant increases in both subjective and objective dementia knowledge ($p < 0.001$). Friedman et al. (2016) also demonstrated improved dementia knowledge following in-person educational sessions.

Regarding attitudes toward dementia, Carter et al. (2021) found that the intervention significantly improved attitudes toward dementia ($p < 0.001$), with notable increases in the subscales ‘Hope’ ($p < 0.001$) and ‘Recognition of Personhood’ ($p < 0.001$). Phillipson et al. (2019) reported a significant increase in positive attitudes toward people living with dementia (PLwD). Additionally, studies by Sari et al. (2020) and Cowan (2021) both showed positive changes in dementia attitude scales. For dementia-related stigma, Kim et al. (2021) reported that all groups demonstrated a reduction in stigma from baseline to week 12.

Table 2: Summary of studies included

Authors/Years/Country	Summary of programme	Study Design	N	Measure	Outcome	Practical Implications
Perales et al., (2020). US	Culturally-tailored Alzheimer's disease (AD) knowledge presentation designed for Latinos served by Latino community organisations.	Pretest-posttest study	77 (40 professionals and 37 Latino community members)	Dementia knowledge: subjective and objective AD knowledge	Significant increase in both objective (2.5 units, p < .001) and subjective AD knowledge (1.7 units, p < .001) for the Latino community.	Brief culturally-tailored AD education increases short-term AD knowledge. AD education refined by the Cultural Accommodation Model can empower the Latino community and improve outcomes.
Friedman et al., (2016). Puerto Rico	In-person education sessions at coffee shops and a social media campaign to raise dementia awareness in Puerto Rico.	Mixed-methods approach: pretest-posttest study and social media analysis	51	Dementia knowledge: surveys to assess knowledge about dementia	Improvement in participants' knowledge of AD after the education session.	A hybrid approach addresses both community engagement and digital outreach, enhancing public understanding and interaction.
Hickey, D. (2019). Ireland	"Understand Together" national campaign aimed to increase public knowledge and awareness of dementia	Repeated cross-sectional study	1217 (2016) 1003 (2018)	Dementia knowledge Dementia attitudes: attitudes toward PLwD and their carers	Improved self-reported knowledge of dementia (p <0.001). Increased awareness of the modifiable nature of dementia risk (p <0.001).	The importance of a collaborative approach is highlighted to promote dementia-friendly communities. Public communication and education play a key role in reducing stigma. Ongoing evaluation using both quantitative and qualitative methods can refine public health messaging and improve campaign effectiveness.
Carter et al., (2021). UK	A digital game developed to improve public knowledge and understanding of dementia, co-designed by PLwD and student nurse	Pretest-posttest study	457	Dementia attitudes: ADQ	Significant increase in the ADQ total score from 79.60 to 82.24 (p < .001). Significant increase in the *Hope* from 33.65 to 35.34 and *Recognition of Personhood* subscales from 45.95 to 46.90 (both p < .001).	The potential of using digital games in public education to change the attitude towards dementia is demonstrated. Co-design allows PLwD's priorities of misconceptions to be directly addressed and widely disseminated.
Sari et al., (2020). Japan	Educational program delivered via a Virtual Reality (VR) platform at convenience stores, aimed at improving attitudes towards dementia.	Quasi-experimental design: pretest-posttest study	42	Dementia attitudes: ATDS	Positive changes in attitudes towards dementia (p = .004).	The VR educational programme improves attitudes towards dementia and a sense of community. Programme can be implemented in community facilities to develop dementia-friendly communities.

Cowan T. L. (2021). US	In-person Dementia Friends information session developed in the UK and offered in the US.	Pretest-posttest study	80	Dementia attitudes: DAS	Positive changes in total DAS scoring (p < .0001), subscale social comfort (p < .0001), and subscale dementia knowledge (p < .0001), indicating improved attitudes and knowledge towards dementia.	The in-person Dementia Friends information sessions can positively affect participants' attitudes toward dementia, suggesting sessions can be beneficial in broader public health and educational settings.
Kontos et al., (2023). Canada	'Cracked: new light on dementia', a Canadian film focusing on relational caring and reducing dementia-associated stigma.	Qualitative interview and focus group	30	Dementia attitudes: changes in perceptions and experiences in understanding of dementia	Reduced dementia-associated stigma. A better understanding of the experience of PLwD and family dynamics. Immersion allowed participants to envision and engage differently with dementia.	Arts-based education is an effective method for stigma reduction and promoting relational caring. It supports the use of film in educational initiatives for dementia awareness. The transformative power of arts can inspire cultural change in society.
Phillipson et al., (2019). Australia	A multicomponent intervention to create a dementia-friendly community, included research, awareness campaigns, and education co-designed and co-facilitated by PLwD and their carers.	Formative research-repeated cross-sectional study	131 (2014) 174 (2016)	Dementia attitudes: PRISM-PC (Dementia Screening Subscale) Dementia stigma: Modified FSA	Significant increase in positive attitudes of PLwD. Participants in educational events showed significant positive changes regarding views about dementia. Direct involvement of PLwD improved positive attitudes and reduced stigma.	It highlighted the effectiveness of involving PLwD in raising awareness and shaping attitudes. Multi-component dementia-friendly community interventions support research and awareness campaigns.
Kim et al., (2021). Australia	Dementia Stigma Reduction programme aimed to reduce dementia-related stigma through education and virtual contact	Factorial randomised controlled trial	1024	Dementia stigma: modified AQ Dementia knowledge: DKAS	All groups showed a reduction in dementia-related stigma from baseline to week 12. Effects were more pronounced in the *Online Education Groups* (p < .001) and *Online Education + Simulated Contact Groups* (p < .001) immediately following the intervention, and in the *Simulated Contact Groups* (p < .05) and *Online Education + Simulated Contact Groups* (p < .001) at the 12-week follow-up.	The programme enhances dementia knowledge and reduces stigma, particularly benefiting people with higher baseline stigma. Longer durations are required for stigma reduction, while knowledge improvements are immediate.

**Questionnaire Acronyms – ADQ=Approaches to Dementia Questionnaire, AQ=Attribution Questionnaire, ATDS=Attitudes Toward Dementia Scale, DAS=Dementia Attitudes Scale, DKAS=Dementia Knowledge Assessment Scale, FSA= Fraboni Scale of Ageism, PRISM-PC = Perceptions Regarding Investigational Screening for Memory in Primary Care, SCS=Sense of Community Scale*

Table 3: Downs and Black Checklist

Study	Carter, et al., (2021). UK	Friedman et al., (2016). Puerto Rico	Hickey, D. (2019) Ireland	Kim et al., (2021). Australia	Kontos et al., (2023). Canada	Perales et al., (2020). US	Phillipson et al., (2019). Australia	Sari et al., (2020). Japan	Cowan T. L. (2021) US
Reporting									
1. Is the hypothesis/aim/objective of the study clearly described?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
3. Are the characteristics of the subjects included in the study clearly described?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
4. Are the interventions of interest clearly described?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?	No (0)	No (0)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	No (0)	No (0)
6. Are the main findings of the study clearly described?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
7. Does the study provide estimates of the random variability in the data for the main outcomes?	Yes (1)	No (0)	Yes (1)	Yes (1)	N/A (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
8. Have all important adverse events that may be a consequence of the intervention been reported?	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)
9. Have the characteristics of subjects lost to follow-up been described?	No (0)	No (0)	N/A (0)	Yes (1)	No (0)	No (0)	N/A (0)	Yes (1)	No (0)
10. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	N/A (0)	No (0)	Yes (1)	Yes (1)	Yes (1)

Study	Carter, et al., (2021). UK	Friedman et al., (2016). Puerto Rico	Hickey, D. (2019) Ireland	Kim et al., (2021). Australia	Kontos et al., (2023). Canada	Perales et al., (2020). US	Phillipson et al., (2019). Australia	Sari et al., (2020). Japan	Cowan T. L. (2021) US
External validity									
11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	Unable to determine (0)	Unable to determine (0)	Yes (1)	Yes (1)	Unable to determine (0)	Unable to determine (0)	Unable to determine (0)	Unable to determine (0)	Unable to determine (0)
12. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	Unable to determine (0)	Unable to determine (0)	Yes (1)	Yes (1)	Unable to determine (0)	Unable to determine (0)	Unable to determine (0)	Unable to determine (0)	Unable to determine (0)
13. Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
Internal Validity									
14. Was an attempt made to blind study subjects to the intervention they have received?	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)
15. Was an attempt made to blind those measuring the main outcomes of the intervention?	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)	No (0)
16. If any of the results of the study were based on “data dredging”, was this made clear?	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)
17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?	N/A (0)	N/A (0)	N/A (0)	Yes (1)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)
18. Were the statistical tests used to assess the main outcomes appropriate?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	N/A (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
19. Was compliance with the intervention/s reliable?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Unable to determine (0)	Yes (1)	Yes (1)

Study	Carter, et al., (2021). UK	Friedman et al., (2016). Puerto Rico	Hickey, D. (2019) Ireland	Kim et al., (2021). Australia	Kontos et al., (2023). Canada	Perales et al., (2020). US	Phillipson et al., (2019). Australia	Sari et al., (2020). Japan	Cowan T. L. (2021) US
20. Were the main outcome measures used accurate (valid and reliable)?	Yes (1)	Yes (1)	Yes (1)	Yes (1)	N/A (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)
Internal Validity – confounding (selection bias)									
21. Were the subjects in different intervention groups or were they recruited from the same population?	N/A (0)	N/A (0)	N/A (0)	Yes (1)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)
22. Were study subjects in different intervention groups or were they recruited over the same period of time?	N/A (0)	N/A (0)	N/A (0)	Yes (1)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)
23. Were study subjects randomised to intervention groups?	N/A (0)	N/A (0)	N/A (0)	Yes (1)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)
24. Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	N/A (0)	N/A (0)	N/A (0)	Yes (1)	N/A (0)	N/A (0)	N/A (0)	N/A (0)	N/A (0)
25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	Yes (1)	No (0)	Yes (1)	Yes (1)	No (0)	No (0)	No (0)	No (0)	No (0)
26. Were losses of subjects to follow-up taken into account?	No (0)	No (0)	N/A (0)	Yes (1)	No (0)	No (0)	N/A (0)	Yes (1)	No (0)
Power									
27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	Yes (1)	No (0)	No (0)	Yes (1)	N/A (0)	No (0)	No (0)	No (0)	No (0)
Downs and Black Quality Scoring	**13**	**10**	**15**	**23**	**7**	**11**	**11**	**13**	**11**

Yes (1) No (0) N/A (0) Unable to determine (0)

Evaluation by the Downs and Black Checklist

The identified studies were evaluated using the Downs and Black checklist (1998), as presented in Table 3. Each study was systematically reviewed and scored based on criteria such as reporting, validity, and power.

There was considerable variation in the quality scores. Some studies, such as Kim et al. (2021), utilised a multi-arm factorial randomised controlled trial, demonstrating robust methodological techniques and achieving high-quality scoring, which suggested a reduced possibility of bias and greater assurance in the accuracy of their results. The study design, randomisation processes, and outcome measures were well-described, showing strong adherence to quality criteria.

However, most studies struggled with validity, particularly in representing their study populations and addressing potential confounders effectively. Crucially, none of the studies adequately reported on blinding procedures and addressed the potential impact of adverse events. These limitations indicated the need for enhanced methodological rigour.

Reporting

All nine studies clearly described their hypotheses, objectives, and main outcomes. Interventions and subject characteristics were well-documented. Nonetheless, there were gaps in reporting confounders and adverse events, with a majority of studies failing to describe the distribution of principal confounders or important adverse events.

Validity

As many studies were unable to explain whether the study populations were representative of the broader community from which they were recruited, the generalisability of the findings was limited. Thus, in terms of population representation (*Checklist items 11 and 12*), most studies were noted as *Unable to determine*. Moreover, the absence of blinding for study subjects or outcome assessors across all studies indicated potential biases in how outcomes were measured or perceived. Alternatively, appropriate statistical tests were used in most studies to assess main outcomes. The accuracy of main outcome measures was generally confirmed.

Confounding and Selection Bias

Most studies did not consider or adequately adjust for confounding factors in their analyses, which could affect the validity of the findings. A general absence of randomisation and concealment in the interventions was also identified which might have contributed to the selection bias.

Power

The identified studies generally lacked sufficient power to detect clinically important effects, with only two studies (Carter et al., 2021 & Kim et al., 2021) demonstrating the capability to detect a significant difference with a probability value of less than 5%.

It is important to acknowledge that this review includes a wide range of study designs, from RCTs to other quantitative and qualitative studies, with inherent differences in the grade of evidence and risk of bias associated with each design. The RCT by Kim et al. (2021) employed randomisation to minimise bias, representing a higher standard of evidence and a greater capacity to detect significant effects in interventions. In contrast, non-randomised studies, while offering valuable insights into dementia awareness programmes and stigma reduction, generally provide a lower level of evidence due to the absence of randomisation, susceptibility to selection bias, and often limited statistical power. The risk of bias was assessed using the Downs and Black checklist, but it is crucial to recognise that the grades of evidence from these diverse study designs differ substantially. These methodological limitations should be considered in future research to enhance the robustness of study designs and strengthen the validity of findings in dementia awareness programmes.

Types and Effectiveness of Programmes (Review Question 1)

To increase dementia awareness and reduce stigma across global communities, identified studies demonstrated diverse and innovative types of community education programmes. These varied significantly in their methods and mediums, each tailored to effectively address different aspects of awareness and attitudinal changes towards dementia. Four main themes were identified regarding the types of programmes examined in the studies.

Community-Based and In-Person Education Programmes

At the community level, in-person education programmes play a vital role in directly engaging communities. Three of the identified studies emphasised the importance of community-based, in-person education sessions in delivering dementia awareness programmes. All three utilised in-person education as the primary intervention. Two studies measured changes in dementia knowledge, while one assessed change in attitudes towards dementia. All reported positive changes following the intervention.

Friedman et al. (2016) utilised coffee shop sessions in Puerto Rico to educate the public in a familiar and relaxed setting. These sessions facilitated open discussions, making dementia-related information accessible and digestible for the general public. The study implemented a hybrid programme combining in-person education sessions and a social media campaign. The mixed-methods approach, which included surveys and social media analysis, showed significant improvements in participants' knowledge of Alzheimer’s Disease. The social media campaign significantly expanded reach, with the Facebook page engaging 294,109 people and a 64.8% increase in audience reach.

Similarly, Cowan (2021) evaluated in-person Dementia Friends information sessions in the US. Within 80 participants, it showed significant positive changes in social comfort ($p < .0001$), dementia knowledge ($p < .0001$), and overall Dementia Attitudes Scale scores ($p < .0001$). The study by Perales et al. (2020) created an in-person culturally tailored presentation for the Latino community. It demonstrated a significant increase in both objective ($p < .001$) and subjective AD knowledge ($p < .001$) among Latino participants. These studies support the idea that in-person education fosters a direct connection between participants and the presented information, enhancing understanding of dementia and providing support within the community.

Regional and National Campaigns

Two identified studies examined the impact of regional and national campaigns through repeated cross-sectional surveys. Both studies focused on the campaigns as the primary intervention, measuring changes in attitudes towards dementia. One study specifically assessed changes in dementia-related stigma, while the other focused on dementia knowledge. Both studies reported positive changes following the interventions, indicating a lasting impact on the public as a result of regional and national campaigns.

Phillipson et al. (2019) evaluated a dementia-friendly community pilot project in

Australia involving research, awareness campaigns, and education co-designed and facilitated together by PLwD and their carers. The formative research with repeated cross-sectional study of 131 participants in 2014 and 174 in 2016 revealed significant increases in positive perceptions of PLwD and awareness of dementia services, demonstrating sustained effectiveness and community engagement over time.

Hickey (2019) evaluated the outcomes of a national public awareness campaign in Ireland through a repeated cross-sectional study involving 1,217 participants in 2016 and 1,003 in 2018. The finding showed a significant improvement in self-reported knowledge of dementia ($p < 0.001$), awareness of the modifiable nature of dementia risk ($p < 0.001$) and promoted help-seeking intentions ($p < 0.001$) after the national campaign. These studies highlighted the importance of ongoing assessment and adaptation of programmes to ensure they continue to meet community needs effectively.

Digital and Virtual Interventions

In the age of technology, the role of digital and virtual interventions has become more prominent. Three identified studies emphasised the impact of digital and virtual interventions. One study utilised a digital game as the primary intervention, another employed virtual reality, and the third included virtual interactive conversation with PLwD as part of the intervention. Two of the studies measured changes in attitudes towards dementia, while the third specifically assessed changes in dementia-related stigma and knowledge. Despite the variation in outcome measures, all studies reported positive changes following the interventions, highlighting the growing importance of digital and virtual interventions in dementia community education.

Carter et al. (2021) examined the effectiveness of a digital game specially designed to educate people about dementia by simulating the experiences of those living with the condition. Within 457 participants, a significant increase was demonstrated in the Attitudes towards Dementia Questionnaire (ADQ) scores, with total scores rising from 79.60 to 82.24 ($p < .001$), and notable improvements were shown in the Hope and Recognition of Personhood subscales ($p < .001$).

Furthermore, Sari et al. (2020) in Japan employed virtual reality programmes to create immersive experiences that provide a first-hand understanding of the struggle faced by PLwD. They conducted a quasi-experimental study to evaluate the impact of intervention on participants' attitudes towards dementia and their sense of community. It revealed significant positive changes in attitudes towards dementia ($p = .004$) and sense of community ($p < .001$), demonstrating the effectiveness of virtual intervention in fostering dementia-friendly communities.

Kim et al. (2021) introduced a dementia stigma reduction intervention through an online education programme combined with interactive conversations facilitated through pre-recorded video clips. They used a factorial randomised controlled trial with 1,024 participants in Australia, showing a general reduction in dementia-related stigma across all groups, with significant effects in the ‘Online Education group’ and ‘Online Education + Simulated Contact group’ immediately after the intervention, and sustainable effects in the ‘Simulated Contact group’ and ‘Online Education + Simulated Contact group’ at the 12-week follow-up. The study suggested that the intervention effectively enhances dementia knowledge and reduces stigma, particularly for individuals with higher initial levels of stigma. It allowed participants to engage in simulated contact with PLwD and carers, enhancing understanding and empathy through innovative digital initiatives.

Art and Film-Based Interventions

Although only one identified study involved art- and film-based interventions, this theme repeatedly emerged during the screening process, highlighting the potential of such approaches to create meaningful narratives that evoke emotional responses and facilitate public discussion about dementia. Kontos et al. (2023) employed a film that illustrates the lives of PLwD and their families, from diagnosis to long-term care, in order to address the dementia-related stigma and demonstrate the importance of relational caring within communities. Using qualitative interviews and focus groups with 30 participants, the study found that the film significantly reduced stigma by enhancing understanding of the lived experiences of PLwD and their families, promoting a life-affirming perspective on dementia. It highlighted the effectiveness of arts-based education, which allows the audience to be emotionally involved, fosters empathy and alters perceptions and reduces stigma.

Components and Formats of Programmes (***Review Question 2)***

Four components of programmes were identified during the review process, shared across different studies, and emerged as important elements in delivering effective dementia awareness initiatives.

Co-Production and Involvement of PLwD and Carers

Six identified studies included co-production and involvement of PLwD/carers in their programmes. In producing a community-based education program, the involvement of different stakeholders is valued as it enables a genuine representation of the specific needs and concerns of those affected by dementia. Phillipson et al. (2019) highlighted the importance of involving those affected by dementia in the design and execution of their dementia-friendly community project. Carter et al. (2021) co-created the game with the people affected by dementia, which was an authentic representation of their cognitive and social challenges, thereby enhancing the educational effect and fostering empathy among participants. Kim et al. (2021) created video clips about PLwD and carers, which ensured the educational content was not just authentic but also relatable. Similarly, Kontos (2020) adapted co-production in filmmaking to tell the story of the lives of PLwD and their families. These projects engaged those affected by dementia in the creative process to ensure authenticity and emotional resonation with participants. This approach not only improved the programme's effectiveness but also empowered people by giving voice to the ones that were unheard.

Building Up Dementia-Friendly Communities

Seven identified studies highlighted the importance of building up dementia-friendly communities. Creating dementia-friendly communities is paramount to the efforts at reducing stigma and extending the acceptance of people living with dementia, which actually supports by the majority of identified studies. Phillipson et al. (2019) highlighted that community-based participation was an important dimension of their approach, which involved the setting up of the Dementia Advisory Group and Dementia Alliance, launching awareness campaigns and hosting educational events co-designed and facilitated by PLwD and their carers. This kind of participatory approach not only empowers PLwD, but also engages the wider community, which is necessary for the ongoing development of a supporting and inclusive community.

Strategic Use of Community Spaces

Four identified studies involved a strategic use of community spaces in delivering the intervention. With a strategic use of community spaces, the impact and accessibility of dementia programmes can be enhanced significantly. Educational activities become more approachable and less stigmatised when they are integrated into spaces that make up the community life. As illustrated by Friedman et al. (2016), coffee shops were used to host informal educational sessions, which were a part of everyday community life. This approach not only made the sessions more accessible but also integrated the learning process into the natural rhythm of community life, which contributed to engagement enhancement and stigma reduction. Sari et al. (2020) created a virtual reality programme, located in convenience stores in Japan, for the purpose of facilitating the development of dementia-friendly communities. This innovative approach not only utilised a commonplace setting for immersive learning experiences but also normalised the conversation about dementia in daily environments. Furthermore, Perales et al. (2020) conducted their sessions at Latino community organisations, which allowed them to access their target participants in a secure and familiar environment. By conducting sessions in these community-based venues, the programmes leveraged existing social structures and spaces to facilitate learning and engagement.

Employing Culturally Tailored Interventions

Although only one identified study explicitly emphasised culturally tailored interventions, this theme repeatedly emerged during the study screening process, with some studies being conducted in specific countries, using the local language, and referencing particular demographic contexts. Thus, the role of culturally tailored interventions is vital for ensuring the effectiveness of dementia education programmes across different cultures and communities. According to Perales et al. (2020), the outcomes of dementia sessions were enhanced after adapting the educational content and delivery approach to align with the cultural contexts and linguistic needs of the community. The design of the programme was informed by the Latino culture, ensuring the message was not only informative but also resonant with those participants' cultural identities and experiences. This tailored approach recognised and appreciated cultural diversity, which is an essential component for building trust and promoting constructive engagement in educational programmes and in the long run building a dementia-friendly community.

Discussion

Summary of Findings

By critically reviewing the existing literature, the review has identified different types of strategies and campaigns advocating for an enhancement in dementia knowledge and reduction in stigma. These initiatives consist of various modalities, including community-based programmes, in-person education programmes, national campaigns, digital and virtual interventions, as well as art and film-based interventions. The review also stresses the significance of stakeholder involvement during programme design and implementation, the importance of dementia-friendly community, as well as the use of community spaces and culturally tailored intervention to maximise these programmes’ impact and positive outcomes.

Among the interventions reviewed, the study by Kim et al. (2021) distinguished itself through its robust methodology and compelling outcomes. Employing a multi-arm factorial randomised controlled trial, their dementia stigma reduction programme significantly diminished dementia-related stigma and enhanced dementia knowledge through educational and virtual contact strategies. Due to its immediate and sustained effectiveness, this approach is recommended for future implementations across the general public, particularly for individuals initially exhibiting higher levels of stigma.

Implications of Findings

The implications of the findings are essential for the planning of future community programmes and campaigns with the aim of improving dementia awareness and destigmatisation. Each of the key components identified offers a unique advantage that enhances the effectiveness of educational interventions and can significantly inform future efforts.

Digital and Virtual Interventions

The role of digital and virtual interventions in community education programmes is rapidly expanding. Various scoping and systematic reviews (Alsaqqa & Alwawi, 2023; Rodríguez-Rivas et al., 2022; De Santis et al., 2022; Willis et al., 2022) indicated that digital interventions are feasible, acceptable, and effective in promoting public health awareness and addressing stigma. In the context of dementia care, digital interventions have been extensively discussed and implemented to support PLwD and their carers (Klimova et al., 2019; Quail et al., 2021; Knapp et al., 2022). These discussions have highlighted the importance of quality, cost-effectiveness, and equity in intervention, especially during disruptions such as the COVID-19 pandemic. In the realm of community dementia awareness, the use of digital interventions is varied and extends educational outreach through Internet platforms, online classes, mobile apps, virtual reality and interactive games that simulate the challenges faced by those affected by dementia, thereby enhancing public understanding of their conditions (Gruss & Hasnain, 2020; Isaacson et al., 2018; Tsai et al., 2023 & Farrow et al., 2022). Moreover, digital tools can customise and personalise learning experiences to cater to audiences, such as younger generations, whom traditional methods may not effectively engage, allowing for more relevant and engaging interactions.

Art-based Interventions

Different literature and systematic reviews (Letrondo et al., 2023; Schneider, 2018; Cowl & Gaugler, 2014) acknowledged that art-based interventions are creative and effective methods within the context of dementia care. At the community level, these interventions are particularly useful where participatory art practices foster significant community involvement and engagement with people affected by dementia (Ward et al., 2021; Young et al., 2016). Art creates a dynamic platform for storytelling, effectively evoking emotional responses and stimulating dialogue that is crucial for changing perceptions and attitudes towards dementia. By facilitating a deeper emotional connection, art interventions encourage empathy and understanding, bridging the gap between people affected by dementia and the broader community.

Siette et al. (2023) conducted case studies on dementia awareness programmes and discovered that art-based interventions can significantly influence public understanding of dementia. These interventions not only challenge stereotypes about dementia and ageing but also promote an appreciation of cognitive health. Moreover, the adaptability of art across different cultural contexts enhances its effectiveness in global dementia campaigns, making it an accessible medium that meets diverse community needs and fosters a more inclusive and supportive environment.

Co-production and Involvement of PLwD and Carers

The idea of co-production, which involves PLwD and their carers in the process of planning and implementation, is increasingly recognised as important in dementia awareness programmes. In the opinion of the Alzheimer's Society (2024), co-production entails a form of active participation of PLwD in developing programmes or services, and this principle is reflected in many local and worldwide initiatives that promote the creation of dementia-friendly environments. Research showed that involving PLwD and carers results in outcomes that more closely align with their actual needs and preferences, in that way fostering the development of dementia-friendly communities and promoting social inclusion (Phillipson et al., 2019; Hung et al., 2021).

Co-production happens at different levels, ranging from service design and delivery to evaluation. It also extends to public awareness programmes and policy formation. At the service level, West et al. (2022) found that co-production promoted positive feelings among PLwD through the creation of peer engagement as well as reducing stigma and assumptions about the condition. Furthermore, a meta-review by Niedderer et al. (2022) discovered that involvement in the co-design process improved personal wellbeing for PLwD in general. Although service users' involvement is increasingly common at a consultation level, there is significant potential for deeper involvement in the co-design process.

At the societal level, a content analysis by Bosco et al. (2019) revealed that the programmes which had direct involvement from the PLwD were effective in behavioural changes at both micro and macro societal levels, thus leading to a meaningful societal transformation. At the policy-making level, Keogh (2021) advocated the involvement of PLwD and carers in policymaking, but this would require additional time and creativity to maximise their participation.

Overall, the integration of co-production in promoting dementia awareness not only enhances the quality of life for PLwD. The collaborative approach is also necessary for the creation of a truly empowering, inclusive, and supportive community. By providing this space, dementia-related stigma can be significantly reduced with an enhancement of community awareness, consequently fostering a more understanding and inclusive society.

Culturally Tailored Interventions

Culturally tailored interventions are crucial for enhancing the effectiveness of dementia awareness programmes, ensuring that educational efforts are appropriate and resonated across varied cultural contexts. Research (Mahoney et al., 2005 & Cipriani & Borin, 2015) suggests that experiences of dementia are heavily influenced by the cultural contexts in which the person lives, with sociocultural conceptualisations of dementia closely linked to community stigma. Siette et al. (2023) underscored the importance of developing tailored, culturally appropriate interventions to challenge stigma in diverse cultural communities, highlighting the necessity of collaborating with local cultural groups to create inclusive and evidence-based programmes.

The need for such tailored approaches arises from the understanding that cultural beliefs, values, and social norms significantly shape how dementia is perceived and discussed within communities. Numerous community programmes (Askari et al., 2018; Epps, 2020; Nkimbeng et al., 2022; Webkamigad et al., 2020) emphasised culturally tailored interventions, ranging from memory collaborative projects to public education sessions. These programmes value culturally informed practices and extend beyond mere linguistic translation to incorporate culturally specific caregiving practices, religious beliefs and taboos, and community structures into their designs. Materials are made culturally sensitive to address myths about dementia and ageing, thereby enhancing accessibility to specific cultural communities. By adapting programmes to meet the unique cultural needs and communication styles of different groups, these interventions significantly improve engagement and comprehension, thus reinforcing the overall impact of dementia education.

Methodological Limitations of the Identified Studies

The identified studies exhibited substantial methodological limitations that affect both their internal and external validity, thus impacting the reliability and generalisability of their findings. With reference to the Downs and Black Checklist (1998), key issues included inadequate sample representativeness, selection bias, insufficient control over confounding variables and the frequent absence of comparison groups. These limitations highlight a broader issue within community programmes and campaigns research: the need for standardised methodologies to ensure reliable and credible research outcomes. Future research should consider implementing robust sampling techniques, ensuring effective control of confounders, and incorporating control or comparison groups to clearly delineate relationships between interventions and outcomes.

Additionally, a significant gap identified during the scoping process was the lack of proper evaluation in many dementia awareness programmes. Despite the prevalence of local and global awareness campaigns, many studies were excluded due to their lack of evaluation, inadequate measurement, or deficient result reporting after implementation. The absence of systematic evaluation not only undermines the ability to assess the impact of these programmes, but also limits opportunities for learning and improvement. Standardising methodologies across studies, including the adoption of consistent and reliable evaluation protocols, is essential for advancing the field.

Limitations of the Review

This review faced several limitations that may affect the generalisability, representativeness, and comprehensiveness of its findings. Primarily, due to limited resources, the inclusion criteria were confined to studies written in English, potentially leading to publication bias and the exclusion of relevant papers in other languages.

In addition, there is a limited availability of evaluative studies on dementia awareness campaigns and programmes. It is important to acknowledge that conducting randomised studies in the context of public health campaigns is inherently challenging. These programmes typically occur in real-world settings and target large, diverse populations. Controlling variables such as the target population's exposure to the intervention, the medium of delivery, and environmental influences presents significant difficulties. Moreover, the identified studies utilised distinct designs, content, medium, methodologies, and outcome measures, which posed significant challenges for direct comparisons between the campaigns' results.

Furthermore, it might be challenging to take into consideration a number of variables during the results analysis process, including the country and culture, the time, intensity and duration of intervention, the clinical involvement, and the level of changes. This heterogeneity may limit the ability to synthesise findings and draw meaningful conclusions regarding the efficacy of various dementia awareness initiatives.

The use of the Downs and Black checklist, while providing a structured approach to assess study quality, also has its limitations. The checklist may not fully capture the variety of qualitative research or account for all relevant aspects of study quality, potentially affecting the accuracy of quality assessment. Moreover, the review drew conclusions based on the outcome data from the identified studies without performing additional statistical analysis, as the data were not suitable for meta-analysis. Finally, the absence of robust quality control mechanisms may introduce additional biases that impact the interpretation of findings.

Recommendations for Future Research

Regarding the recommendations for future research, it is crucial to emphasise the need for more RCTs to evaluate dementia awareness programmes and stigma reduction interventions. RCTs, with their capacity to minimise bias through randomisation and control, provide a higher level of evidence, offering more robust insights into the effectiveness of these interventions. Also, there is an imperative need for research on evaluating the long-term impact of dementia awareness initiatives, especially to assess sustainability and effectiveness over time. Longitudinal studies evaluating changes in attitudes, behaviours, and outcomes of the diverse population would offer insights into the impact and enduring effects of community education programmes. Moreover, research exploring the role of new technologies, including digital intervention and virtual reality for the dementia awareness, can identify innovative ways to address stigma and increase public awareness. In addition, there is a research gap for studies reviewing the cost-effectiveness of dementia education programmes regarding healthcare utilisation and allocation of resources. Finally, efforts to address the limitations identified in this review, including language restrictions, methodological heterogeneity, and publication bias, are crucial to enhance the field and ensure the quality of future research findings.

Conclusions

The current systematic review identified several key components of community education programmes, including the involvement of PLwD and carers, establishment of dementia-friendly communities, and application of art and digital technologies. It also highlights the need for culturally tailored interventions and utilisation of community space. The review highlighted methodological shortcomings in the existing studies, which indicate a pressing necessity for future research to consider methodological rigour and systematic evaluation, and conduct longitudinal studies to assess the lasting impact of these interventions. With these advancements, dementia awareness programmes will improve and thereby lead to a community that is more informed and compassionate towards PLwD and their carers.

References

Ali, M. F., Ja'afar, N. I. S., Krishnan, T. G., Zulkifle, M. A. M., Khaidzir, N. K., Jamil, T. R., Man, Z. C., & Aziz, A. F. A. (2023). Dementia awareness among elderly at risk for developing mild cognitive impairment: A cross-sectional study at a university-based primary care clinic. *BMC Geriatrics, 23*(1), 496. https://doi.org/10.1186/s12877-023-04230-4

Alsaqqa, H. H., & Alwawi, A. (2023). Digital intervention for public health: Searching for implementing characteristics, concepts, and recommendations: Scoping review. *Frontiers in Public Health, 11*, 1142443. https://doi.org/10.3389/fpubh.2023.1142443

Alzheimer’s Australia. (2017). *Dementia and the impact of stigma*. Retrieved from https://www.dementia.org.au/files/documents/Dementia-Social-Stigma-Report-2017.pdf

Alzheimer's Disease International. (2019). *World Alzheimer Report 2019: Attitudes to dementia*. London: Alzheimer's Disease International.

Alzheimer's Society. (2024). Co-production for dementia. Retrieved April 14, 2024, from https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/co-production#content-start

Askari, N., Bilbrey, A. C., Garcia Ruiz, I., Humber, M. B., & Gallagher-Thompson, D. (2018). Dementia awareness campaign in the Latino community: A novel community engagement pilot training program with promotoras. *Clinical Gerontologist, 41*(3), 200–208. https://doi.org/10.1080/07317115.2017.1398799

Bacsu, J.-D., Johnson, S., O’Connell, M. E., Viger, M., Muhajarine, N., Hackett, P., Jeffery, B., Novik, N., & McIntosh, T. (2022). Stigma reduction interventions of dementia: A scoping review. *Canadian Journal on Aging / La Revue Canadienne du Vieillissement, 41*(2), 203–213. https://doi.org/10.1017/S0714980821000192

Blay, S. L., & Peluso, E. T. P. (2010). Public stigma: The community's tolerance of Alzheimer disease. *The American Journal of Geriatric Psychiatry*, *18*(2), 163–171.

Bosco, A., Schneider, J., Coleston-Shields, D. M., & Orrell, M. (2019). Dementia care model: Promoting personhood through co-production. *Archives of Gerontology and Geriatrics, 81*, 59–73. https://doi.org/10.1016/j.archger.2018.11.003

Brai, E., Tonacci, A., Brugada-Ramentol, V., D'Andrea, F., & Alberi, L. (2021). Intercepting dementia: Awareness and innovation as key tools. *Frontiers in Aging Neuroscience, 13*, 730727. https://doi.org/10.3389/fnagi.2021.730727

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., Liu, M. F., Riley, R., Einhorn, C. J., Fitzsimmons, S., & Hahn-Swanson, C. (2015). Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part 1. *Dementia, 14*(5), 589–608. https://doi.org/10.1177/1471301213508399

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. Dementia, 14(5), 609-632. https://doi.org/10.1177/1471301213504202

Cahill, S., Pierce, M., Werner, P., Darley, A., & Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. *Alzheimer Disease and Associated Disorders, 29*(3), 255–275. https://doi.org/10.1097/WAD.0000000000000102

Cheston, R., Hancock, J., & White, P. (2019). Does personal experience of dementia change attitudes? The Bristol and South Gloucestershire survey of dementia attitudes. *Dementia, 18*(7-8), 2596-2608.

Cipriani, G., & Borin, G. (2015). Understanding dementia in the sociocultural context: A review. *International Journal of Social Psychiatry, 61*(2), 198-204. https://doi.org/10.1177/0020764014560357

Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: Science and Practice*, *7*(1), 48–67.

Corrigan, P., Markowitz, F. E., Watson, A., Rowan, D., & Kubiak, M. A. (2003). An attribution model of public discrimination towards persons with mental illness. *Journal of Health and Social Behavior*, *44*(2), 162–179.

Corrigan, P. W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist, 54*(9), 765–776.

Cowan, T. L. (2021). College students' and community members' attitudes toward dementia: The impact of dementia friends sessions. *Gerontology & Geriatrics Education, 42*(1), 140-149. https://doi.org/10.1080/02701960.2019.1657859

Cowl, A. L., & Gaugler, J. E. (2014). Efficacy of creative arts therapy in treatment of Alzheimer's disease and dementia: A systematic literature review. *Activities, Adaptation & Aging, 38*(4), 281–330. https://doi.org/10.1080/01924788.2014.966547

De Santis, K. K., Jahnel, T., Matthias, K., Mergenthal, L., Al Khayyal, H., & Zeeb, H. (2022). Evaluation of digital interventions for physical activity promotion: Scoping review. *JMIR Public Health and Surveillance, 8*(5), e37820. https://doi.org/10.2196/37820

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health, 52*(6), 377–384.

Epps, F., Alexander, K., Brewster, G. S., Parker, L. J., Chester, M., Tomlinson, A., Adkins, A., Zingg, S., & Thornton, J. (2020). Promoting dementia awareness in African-American faith communities. *Public Health Nursing, 37*(5), 715–721. https://doi.org/10.1111/phn.12759

Farrow, M., Fair, H., Klekociuk, S. Z., & Vickers, J. C. (2022). Educating the masses to address a global public health priority: The Preventing Dementia Massive Open Online Course (MOOC). *PLoS ONE, 17*(5), Article e0267205. https://doi.org/10.1371/journal.pone.0267205

Friedman, D., Gibson, A., Torres, W., Irizarry, J., Rodriguez, J., Tang, W., & Kannaley, K. (2016). Increasing community awareness about Alzheimer's disease in Puerto Rico through coffee shop education and social media. *Journal of Community Health, 41*(5), 1006-1012.

Giebel, C., Robertson, S., Beaulen, A., Zwakhalen, S., Allen, D., & Verbeek, H. (2021). "Nobody seems to know where to even turn to": Barriers in accessing and utilising dementia care services in England and the Netherlands. *International Journal of Environmental Research and Public Health, 18*(22), 12233. https://doi.org/10.3390/ijerph182212233

Gruss, V., & Hasnain, M. (2020). A smartphone application for educating the public about Alzheimer's disease and related dementias. *Gerontechnology, 19*(3).

https://doi.org/10.4017/gt.2020.19.003.03

Heger, I., Köhler, S., van Boxtel, M., de Vugt, M., Hajema, K., Verhey, F., & Deckers, K. (2020). Raising awareness for dementia risk reduction through a public health campaign: A pre-post study. *BMJ Open, 10*(11), e041211. https://doi.org/10.1136/bmjopen-2020-041211

Hickey, D. (2019). The impact of a national public awareness campaign on dementia knowledge and help-seeking intention in Ireland. Dublin: HSE.

Hung, L., Hudson, A., Gregorio, M., Jackson, L., Mann, J., Horne, N., Berndt, A., Wallsworth, C., Wong, L., & Phinney, A. (2021). Creating dementia-friendly communities for social inclusion: A scoping review. *Gerontology & Geriatric Medicine, 7*, 23337214211013596. https://doi.org/10.1177/23337214211013596

Isaacson, R. S., Seifan, A., Haddox, C. L., Mureb, M., Rahman, A., Scheyer, O., Hackett, K., Caesar, E., Chen, J. L., Isaacson, J., McInnis, M., Mosconi, L., & Safdieh, J. (2018). Using social media to disseminate education about Alzheimer’s prevention & treatment: A pilot study on Alzheimer's Universe (www.AlzU.org). *Journal of Communication in Healthcare, 11*(2), 106-113. https://doi.org/10.1080/17538068.2018.1467068

Kahn, P. V., Wishart, H. A., Randolph, J. S., & Santulli, R. B. (2016). Caregiver stigma and burden in memory disorders: An evaluation of the effects of caregiver type and gender. *Current Gerontology and Geriatrics Research*, *2016*, 8316045. https://doi.org/10.1155/2016/8316045

Kane, A., Murphy, C., & Kelly, M. (2018). Assessing implicit and explicit dementia stigma in young adults and care-workers. *Dementia (London), 19*(5), 1692-1711.

Keogh, F., Carney, P., & O'Shea, E. (2021). Innovative methods for involving PLwD and carers in the policymaking process. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy, 24*(3), 800–809. https://doi.org/10.1111/hex.13213

Kim, S., Richardson, A., Werner, P., & Anstey, K. J. (2021). Dementia stigma reduction (DESeRvE) through education and virtual contact in the general public: A multi-arm factorial randomised controlled trial. *Dementia: The International Journal of Social Research and Practice, 20*(6), 2152-2169.

Klimova, B., Valis, M., Kuca, K., & Masopust, J. (2019). E-learning as valuable caregivers' support for PLwD - A systematic review. *BMC Health Services Research, 19*(1), 781. https://doi.org/10.1186/s12913-019-4641-9

Knapp, M., Shehaj, X., Wong, G., Hall, A., Hanratty, B., Robinson, L., Todd, C., & Wittenberg, R. (2022). Digital technology to support PLwD and carers. NIHR Older People and Frailty Policy Research Unit. Retrieved from https://documents.manchester.ac.uk/display.aspx?DocID=60761

Kontos, P., Grigorovich, A., Dupuis, S. L., Colobong, R., Gray, J., Jonas-Simpson, C., & Serota, A. (2023). Projecting a critique of stigma associated with dementia on screen: The impact of a Canadian film on the importance of relational caring in the community. *The Gerontologist*. https://doi.org/10.1093/geront/gnad045

Letrondo, P. A., Ashley, S. A., Flinn, A., Burton, A., Kador, T., & Mukadam, N. (2023). Systematic review of arts and culture-based interventions for PLwD and their caregivers. *Ageing Research Reviews, 83*, 101793. https://doi.org/10.1016/j.arr.2022.101793

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363–385.

Lion, K. M., Szcześniak, D., Bulińska, K., Evans, S. B., Evans, S. C., Saibene, F. L., d'Arma, A., Farina, E., Brooker, D. J., Chattat, R., Meiland, F. J. M., Dröes, R.-M., & Rymaszewska, J. (2019). Do PLwD and mild cognitive impairments experience stigma? A cross-cultural investigation between Italy, Poland, and the UK. *Aging & Mental Health*. https://doi.org/10.1080/13607863.2019.1577799

Low, L. F., & Purwaningrum, F. (2020). Negative stereotypes, fear, and social distance: A systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics*, *20*(1), 1–16. https://doi.org/10.1186/s12877-020-01754-x

Mahoney, D. F., Cloutterbuck, J., Neary, S., & Zhan, L. (2005). African American, Chinese, and Latino family caregivers' impressions of the onset and diagnosis of dementia: Cross-cultural similarities and differences. *The Gerontologist, 45*(6), 783–792. https://doi.org/10.1093/geront/45.6.783

Matsumoto, H., Maeda, A., Igarashi, A., Weller, C., & Yamamoto-Mitani, N. (2021). Dementia education and training for the general public: A scoping review. *Gerontology & Geriatrics Education, 44*, 1-31. https://doi.org/10.1080/02701960.2021.1999938

Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia, 19*(2), 148-181. https://doi.org/10.1177/1471301218800122

NIHR Complex Reviews Support Unit. (n.d.). *Narrative synthesis and synthesis when you can't perform a statistical meta-analysis*. http://nihrcrsu.org/guidance/narrative_synthesis/

Niedderer, K., Orton, L., & Tournier, I. (2022). An overview of current practices and approaches to codesigning services with and for PLwD towards developing a framework for best practice. In Lockton, D., Lenzi, S., Hekkert, P., Oak, A., Sádaba, J., & Lloyd, P. (Eds.), *DRS2022: Bilbao, 25 June - 3 July, Bilbao, Spain*. https://doi.org/10.21606/drs.2022.463

Nkimbeng, M., Rosebush, C. E., Akosah, K. O., Yam, H., Russell, W. N., Bustamante, G., Albers, E. A., Shippee, T. P., Sasikumar, A. P., & Gaugler, J. E. (2022). The immigrant memory collaborative: A community-university partnership to assess African immigrant families' experiences with dementia. *International Journal of Environmental Research and Public Health, 19*(7), 4075. https://doi.org/10.3390/ijerph19074075

Nolan, L., McCarron, M., McCallion, P., & Murphy-Lawless, J. (2006). *Perceptions of stigma in dementia: An exploratory study*. Alzheimer Society of Ireland, School of Nursing and Midwifery, Trinity College Dublin.

Perales, J., Moore, W. T., Fernandez, C., Chavez, D., Ramirez, M., Johnson, D., Resendez, J., Bueno, C., & Vidoni, E. D. (2020). Feasibility of an Alzheimer's disease knowledge intervention in the Latino community [Neurological Disorders & Brain Damage 3297]. *Ethnicity & Health, 25*(5), 747-758.

Phillipson, L., Hall, D., Cridland, E., Fleming, R., Brennan-Horley, C., Guggisberg, N., Frost, D., & Hasan, H. (2019). Involvement of PLwD in raising awareness and changing attitudes in a dementia-friendly community pilot project. *Dementia (London, England), 18*(7-8), 2679–2694. https://doi.org/10.1177/1471301218754455

Phillipson, L., Magee, C., Jones, S., & Skladzien, E. (2012). *Exploring dementia and stigma beliefs: A pilot study of Australian adults aged 40 to 65 years*. Alzheimer's

Australia. Retrieved from https://www.dementia.org.au/sites/default/files/20120712_US_28_Stigma_Report.pdf

Popay, J., Roberts, H. M., Sowden, A. J., Petticrew, M., Arai, L., Rodgers, M., & Britten, N. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC Methods Programme* (Version 1).

Quail, Z., Bolton, L., & Massey, K. (2021). Digital delivery of non-pharmacological intervention programmes for PLwD during the COVID-19 pandemic. *BMJ Case Reports, 14*(6), e242550. https://doi.org/10.1136/bcr-2021-242550

Rewerska-Juśko, M., & Rejdak, K. (2020). Social stigma of people with dementia. *Journal of Alzheimer's disease: JAD*, *78*(4), 1339–1343. https://doi.org/10.3233/JAD-201004

Rodríguez-Rivas, M. E., Cangas, A. J., Cariola, L. A., Varela, J. J., & Valdebenito, S. (2022). Innovative technology-based interventions to reduce stigma toward people with mental illness: Systematic review and meta-analysis. *JMIR Serious Games, 10*(2), e35099. https://doi.org/10.2196/35099

Rosato, M., Leavey, G., Cooper, J., De Cock, P., & Devine, P. (2019). Factors associated with public knowledge of and attitudes to dementia: A cross-sectional study. *PloS one*, *14*(2), e0210543. https://doi.org/10.1371/journal.pone.0210543

Rubinstein, E., Duggan, C., Van Landingham, B., Thompson, D., & Warburton, W. (2015). A call to action: The global response to dementia through policy innovation. Retrieved from https://www.imperial.ac.uk/media/imperial-college/institute-of-global-health-innovation/public/Dementia.pdf

Sari, D. W., Igarashi, A., Takaoka, M., Yamahana, R., Noguchi-Watanabe, M., Teramoto, C., & Yamamoto-Mitani, N. (2020). Virtual reality program to develop dementia-friendly communities in Japan. *Australasian Journal on Ageing, 39*(3), e352–e359. https://doi.org/10.1111/ajag.12797

Schneider, J. (2018). The arts as a medium for care and self-care in dementia: Arguments and evidence. *International Journal of Environmental Research and Public Health, 15*(6), 1151. https://doi.org/10.3390/ijerph15061151

Siette, J., Dodds, L., Catanzaro, M., & Allen, S. (2023). To be or not to be: Arts-based approaches in public health messaging for dementia awareness and prevention. *Australasian Journal on Ageing*. Advance online publication. https://doi.org/10.1111/ajag.13235

Siette, J., Meka, A., & Antoniades, J. (2023). Breaking the barriers: Overcoming dementia-related stigma in minority communities. *Frontiers in Psychiatry, 14*, 1278944. https://doi.org/10.3389/fpsyt.2023.1278944

Smith, S. J., Parveen, S., Sass, C., Drury, M., Oyebode, J. R., & Surr, C. A. (2019). An audit of dementia education and training in UK health and social care: A comparison with national benchmark standards. *BMC Health Services Research, 19*(1), 711. https://doi.org/10.1186/s12913-019-4510-6

Stewart, H., Jameson, J. P., & Curtin, L. (2015). The relationship between stigma and self-reported willingness to use mental health services among rural and urban older adults. *Psychological Services, 12*(2), 141–148. https://doi.org/10.1037/a0038651

Thorsen, K., Dourado, M. C. N., & Johannessen, A. (2020). Awareness of dementia and coping to preserve quality of life: A five-year longitudinal narrative study.

International Journal of Qualitative Studies on Health and Well-being, 15(1), 1798711. https://doi.org/10.1080/17482631.2020.1798711

Tsai, C.-M., Hsu, T.-C., & Hsieh, C.-J. (2023). A virtual reality intervention to improve formal caregivers' understanding of community-dwelling PLwD: A pilot study. *Contemporary Nurse*. https://doi.org/10.1080/10376178.2023.2259495

Van den Bossche, P., & Schoenmakers, B. (2022). The Impact of Dementia's Affiliate Stigma on the Mental Health of Relatives: A Cross Section Survey. *Frontiers in Psychology, 12*, 789105. https://doi.org/10.3389/fpsyg.2021.789105

Ward, M. C., Milligan, C., Rose, E., Elliott, M., & Wainwright, B. R. (2021). The benefits of community-based participatory arts activities for PLwD: A thematic scoping review. *Arts & Health, 13*(3), 213–239. https://doi.org/10.1080/17533015.2020.1781217

Webkamigad, S., Warry, W., Blind, M., & Jacklin, K. (2020). An approach to improve dementia health literacy in indigenous communities. *Journal of Cross-Cultural Gerontology, 35*(1), 69–83. https://doi.org/10.1007/s10823-019-09388-2

Werner, P. (2014). Stigma and Alzheimer's disease: A systematic review of evidence, theory, and methods. In P. W. Corrigan (Ed.), *The stigma of disease and disability: Understanding causes and overcoming injustices* (pp. 223–244). Washington, DC, US: American Psychological Association.

Werner, P., Mittelman, M. S., Goldstein, D., & Heinik, J. (2012). Family stigma and caregiver burden in Alzheimer's disease. *The Gerontologist*, *52*(1), 89–97. https://doi.org/10.1093/geront/gnr117

West, J., Birt, L., Wilson, D., Mathie, E., & Poland, F. (2022). A case study of co-production within a mental health recovery college dementia course: Perspectives of a person with dementia, their family supporter, and mental health staff. *Frontiers in Rehabilitation Sciences, 3*, 920496. https://doi.org/10.3389/fresc.2022.920496

Willis, V. C., Thomas Craig, K. J., Jabbarpour, Y., Scheufele, E. L., Arriaga, Y. E., Ajinkya, M., Rhee, K. B., & Bazemore, A. (2022). Digital health interventions to enhance prevention in primary care: Scoping review. *JMIR Medical Informatics, 10*(1), e33518. https://doi.org/10.2196/33518

Wittenberg, R., Karagiannidou, M., & Knapp, M. (2017). Primary prevention of dementia: Barriers and facilitators. Public Health England, London, UK.

World Dementia Council. (2020a). Defining dementia friendly initiatives: Presenting a global evidence base for dementia friendly initiatives.

World Dementia Council. (2020b). Methodology, bibliography and survey data: Presenting a global evidence base for dementia friendly initiatives.

World Health Organization. (2012). Dementia: A public health priority. Geneva: World Health Organization. Retrieved from https://www.who.int/publications/i/item/dementia-a-public-health-priority

World Health Organization. (2021). Global status report on the public health response to dementia. Geneva. Retrieved from https://iris.who.int/bitstream/handle/10665/344701/9789240033245-eng.pdf

Young, R., Camic, P. M., & Tischler, V. (2016). The impact of community-based arts and health interventions on cognition in PLwD: A systematic literature review. *Aging & Mental Health, 20*(4), 337–351. https://doi.org/10.1080/13607863.2015.1011080

Part 2: Empirical Paper

Cognitive Stimulation Therapy delivery (CST) for dementia in Hong Kong: randomised controlled trial of virtual versus in-person groups

Abstract

Aims: This study aimed to evaluate the effectiveness of Cognitive Stimulation Therapy (CST) delivered in-person and virtually on cognitive function, quality of life, and social functioning for people living with dementia (PLwD) in the Hong Kong context. It also compares the impact between virtual CST (vCST) and in-person CST groups and considers their implementation.

Methods: A randomised controlled trial was conducted with 144 participants randomly assigned to in-person and vCST interventions. Each intervention followed the same CST principles and structure, consisting of 14 sessions in total. Cognitive function (ADAS-Cog), quality of life (QoL-AD), and social functioning (HKSF-DEM) were assessed at baseline (T0) and post-intervention (T1). Repeated measures and mixed-design ANCOVAs were used in data analysis while controlling age, gender, and years of education.

Results: Significant improvements in overall social functioning and the time PLwD spent with others were shown in the in-person CST condition. No significant difference was found in cognitive function and quality of life between in-person and vCST groups. The results suggest that vCST is non-inferior to in-person CST in maintaining cognitive function and quality of life. In-person CST is more effective in enhancing social function.

Conclusion: The study indicates the potential benefits of in-person CST in improving social functioning and supports the use of vCST as a viable alternative, ensuring access to service for those facing barriers to in-person participation. We recommend a hybrid model to capture the benefits of each mode. Future research should consider the refinement of vCST protocols, including control groups, and conducting

longitudinal studies to further explore the effectiveness and inclusiveness of CST interventions.

Introduction

Pandemic Impact on Dementia Populations

Since the impact of COVID-19 in 2019, the world has been learning how to survive in the post-pandemic era. Research shows that people living with dementia (PLwD) are more vulnerable than others to infection, severe health consequences, or even fatal outcomes after infections (Numbers & Brodaty, 2021; Pisaturo et al., 2021). PLwD were particularly affected during the pandemic due to limited cognitive function and self-care ability, along with a number of chronic medical conditions (Mok et al., 2020), resulting in a deterioration of behavioural and psychological symptoms, as well as increased carer stress within the dementia community (Dai et al., 2020; Dubey et al., 2023). In addition, the social restriction policies reduced the health services and social support received by PLwD, leading to a negative impact on care and quality of life, as well as a shift towards technology-based support (Masterson-Algar et al., 2022).

Cognitive Stimulation Therapy: Effective Treatment for Dementia

According to the Lancet Public Health report by Dementia Forecasting Collaborators (2022), the global number PLwD is projected to increase dramatically from 57.4 million in 2019 to 152.8 million by 2050. This significant rise indicates the pressing need for evidence-based interventions to assist the growing dementia population. The National Institute for Health and Care Excellence (NICE) (2018) recommends Cognitive Stimulation Therapy (CST) as the manualised non-pharmacological group intervention for individuals with mild to moderate dementia. CST aims to enhance cognitive and social functioning through various multisensory stimulation and implicit learning activities conducted in group settings. It focuses on information processing rather than knowledge teaching and promotes personhood alongside the application of cognitive skills in everyday contexts. It is guided by 18 key principles, including mental stimulation, implicit learning, a focus on opinions rather than facts, engagement with the present moment ("here and now"), person-centred approaches, maximising individual potential, fostering relationships, and promoting choice, respect, and inclusion. (Spector et al., 2020).

CST is typically delivered in small groups of six to eight people, comprising 14 sessions over a seven-week period. Each session addresses different themes aimed at stimulating various cognitive domains. The therapy focuses on enhancing memory, thinking skills, and social interaction through enjoyable and meaningful activities. The intervention involves group-based activities designed to engage participants in mentally stimulating tasks, such as discussions, games, physical exercises, word association, creative arts, orientation, financial tasks, and reminiscence (Spector et al., 2020).

Research over the past two decades has demonstrated that CST can significantly enhance cognitive function and quality of life for PLwD (Chen, X., 2022; Lobbia et al., 2019; Piras et al., 2017; Saragih et al., 2022; Spector et al., 2003; Woods et al., 2012). A recent meta-analysis of randomised controlled trials (RCT) by Desai et al. (2024) found that CST significantly improves global cognitive ability, working memory, mood, neuropsychiatric symptoms, communication, language comprehension, and quality of life for PLwD. Additionally, Matsuda et al. (2010) suggested that CST is particularly beneficial when combined with dementia medication. Various studies have also conducted cost-effectiveness analyses and economic evaluations, indicating that CST is cost-effective, with potential annual net benefits of approximately £54.9 million to the UK according to 2011 costs (D'Amico et al., 2015; Knapp et al., 2006; Knapp et al., 2022; Matrix Evidence, 2011). Knapp et al. (2022) further projected that the future costs of CST by 2040 would remain below the cost-effectiveness threshold recommended by NICE.

The Shift to Virtual CST During the Pandemic

Despite the availability of evidence-based interventions, the inaccessibility of services for PLwD remains a significant concern, leading to delayed diagnosis, inadequate care, and poor health outcomes (Bayly et al., 2020; Giebel et al., 2021; Stephan et al., 2018), particularly in remote areas with limited mobility and transportation issues (Pike et al., 2018). The situation highlights the need to consider digital interventions in dementia care (Cuffaro et al., 2020).

During the COVID-19 pandemic, there was a significant increase in the use of remote service delivery in mental healthcare (Patel et al., 2021), which not only spurred technological advancements in virtual mental healthcare services, but also led to greater familiarity and expertise with virtual interventions among service providers (Lee & Lee, 2021). To reduce barriers for PLwD with limited mobility in accessing services and treatment, virtual dementia care has gained popularity, particularly in service delivery, training, education and group intervention, which facilitates social connections and the development of community-based services (Lorenz et al., 2019; Mok et al., 2020).

Concurrent with this trend in service development, PLwD are becoming more accustomed to accessing remote services. A cross-sectional study in developed countries found that over half of PLwD and their carers use telecommunication devices to access the internet in their daily lives (Guzman-Parra et al., 2020). Additionally, a systematic review by Goodall et al. (2021) suggested that using technology meets their social and emotional needs.

The development of virtual CST (vCST) has aligned with the evolving model of service delivery and the needs of PLwD. Perkins et al. (2022) developed and tested a new framework for vCST as an alternative to traditional in-person CST, especially valuable during situations like the COVID pandemic where in-person contact was restricted. The study indicated that vCST could be effectively delivered through online platforms, improving feasibility and accessibility for PLwD who are unable to attend in-person sessions. A recent national audit (Fisher et al., 2023) reported increasing provision of vCST in memory clinics across the UK following the pandemic. Over half of the surveyed clinics initiated vCST services, and 80% of these would continue to provide a hybrid intervention after the pandemic. Qualitative feedback emphasised participant enjoyment, enhanced digital confidence, and improved accessibility of services.

Current Research Gaps

Despite the positive outlook, gaps remain in research, particularly concerning the long-term effectiveness and social functioning of vCST compared to traditional in-person methods. Whilst the meta-analysis by Desai et al. (2024) demonstrated significant improvements in communication and social interaction with in-person CST, there is no literature focusing on changes in social functioning within vCST groups. Given the prevalence of face-to-face activities and interactions in in-person groups, it is expected that virtual groups might result in less social engagement. The audit report by Fisher et al. (2023) revealed opportunities and obstacles in virtual delivery. While some service users appreciated the reduced social isolation and enhanced social stimulation through virtual groups, others felt the absence of in-person social interactions diminished their experience, leading to lower satisfaction due to reduced peer support and social stimulation. This highlights the complexities and varied user experiences associated with virtual engagement compared to traditional in-person methods.

Existing research has demonstrated the benefits of in-person CST compared to treatment as usual (Chen X., 2022; Desai et al., 2024; Spector et al., 2003; Sun et al., 2022). When evaluating the effectiveness of in-person versus vCST, a non-inferiority trial design was chosen to determine whether vCST achieves an effect that is not significantly worse than in-person CST within a predefined margin. This approach is particularly relevant when an alternative intervention offers additional benefits, i.e. increased accessibility for vCST, while ensuring that differences in the delivery mode do not compromise clinical effectiveness. Unlike equivalence trials, which seek to prove identical outcomes between interventions, the current study focuses on exploring whether vCST maintains a comparable level of efficacy, even if minor variations in outcomes are observed. Thus, the non-inferiority design allows for a more flexible and clinically meaningful comparison between in-person and vCST delivery.

CST Delivery in Hong Kong Context

In Hong Kong, while CST is typically delivered in person at community or daycare centres, a local study by Dai et al. (2020) showed that the majority (72%) of PLwD are capable of using basic telecommunication devices, while 45% of family carers are willing to facilitate online services for PLwD. Another local study by Ho et al. (2015) indicated that carers appreciate online learning opportunities due to their convenience. Despite the prevailing recommendation for in-person group CST, it is crucial to explore the comparative effectiveness of vCST.

A qualitative study result (Wong, 2021) suggested that PLwD adapted well to online interventions, maintaining similar levels of attention as those in in-person sessions. Caregivers also noted that virtual sessions offered more convenience by saving travel time and resolving transportation difficulties. Further research by Hui (2022) on the effectiveness of individual vCST showed high feasibility, low attrition, and increased attendance, with significant improvements in cognitive function and mood levels. However, research comparing the effectiveness of virtual and in-person group CST interventions in an Asian context remains limited.

Aim

The current study aims to evaluate the effectiveness of vCST and in-person CST on cognitive function, quality of life, and social functioning in the context of Hong Kong. It also compares the impact of vCST and the in-person CST groups and considers their implementations.

The following hypotheses are posited:

- H1: There will be significant improvements in cognitive function, quality of life and social functioning in PLwD in both vCST and in-person groups between T0 (baseline) and T1 (post-intervention).

Furthermore, the study hypothesises that the effectiveness of the vCST groups will be non-inferior to that of the in-person CST groups for cognitive function and quality of life, but a significant difference will be demonstrated in social functioning:

- H2: The cognitive function and quality of life of PLwD in the vCST group will be non-inferior to that of the in-person CST group.

- H3: There will be a significant difference in social functioning between PLwD in the vCST group and those in the in-person CST group.

Methods

Overview

This current study mainly focused on examining the effects of two different intervention modes (virtual vs. in-person) and changes over two time points (baseline vs. post-intervention). The data were obtained from an ongoing RCT research project at the University of Hong Kong (HKU) focusing on vCST and carer support in Hong Kong. A team of researchers at HKU was involved in the research design, recruitment, assessment and intervention. I participated in conducting 31 assessments and delivered two vCST groups for the whole project. I also led the data analysis with support from the team.

Ethical approval and considerations

Ethical approval was obtained by the HKU research team and approved by the Human Research Ethics Committee (HREC) of HKU, with approval number EA2004006. The research was also registered at ClinicalTrials.gov with clinical trial registration number NCT05783414. The study involved vulnerable adults diagnosed with mild or moderate dementia, who were considered capable of giving informed consent unless a formal mental capacity assessment determined otherwise. Carers were also involved in the consent process to support the participants. Consent was obtained in a dyadic format, involving both PLwD and their carer. Both parties completed consent forms. All participants were assured of their anonymity and confidentiality throughout the research process.

Service User Involvement

In the early stages of the project, service users were involved through a participatory design approach. This included the recruitment of PLwD who had participated in the vCST group before, along with family carers and service providers who facilitated the virtual interventions. Their feedback was instrumental in refining the project and vCST protocols, as well as adjusting certain activities and methods of delivery in comparison to the traditional in-person groups.

Prior to randomisation, detailed information about the potential benefits, possible side effects, and alternative treatments were provided to the participants. They retained the right to withdraw from the study at any point without any impact on their usual care. Those who did not consent to participate continued to receive standard care within their respective service units.

Participants

Power analysis for this study was guided by previous research conducted by Woods et al. (2012). Their meta-analysis reported effect sizes of 0.37 for ADAS-Cog and 0.41 for QoL-AD, derived from a non-inferiority margin. Assuming equal sizes for each group, power calculations were conducted using the G*Power 3 software (Faul et al., 2007). These calculations were based on achieving 80% power and a one-sided 97.5% confidence interval. Consequently, the estimated sample size required for this study was 126 participants. The sample size was proposed to be 144 to accommodate attrition.

PLwD who have been clinically diagnosed with mild to moderate levels and reside within the community, were recruited for this study. Recruitment was facilitated through non-governmental organizations (NGOs) and service units associated with CST facilitators in Hong Kong.

Inclusion Criteria:

- Clinical diagnosis of mild to moderate dementia and residing in the community.
- Ability to see, hear, and communicate adequately to engage fully throughout the group sessions.
- Have the capacity to make decisions regarding their participation in desired activities.
- Be capable of travelling to the centre with a caregiver’s assistance.
- Able to access the necessary technology, with support from a caregiver if needed.

Exclusion Criteria:

- Unable to communicate or engage in the intervention due to significant auditory or visual impairments, or other severe physical or mental conditions.

Procedures and Design

Eligible PLwD were identified and recruited from various elderly service centres. Utilising a single-blind cluster randomisation approach, participants were randomly assigned to either in-person or virtual intervention groups. The HKU research team used a block randomisation with a block size of six. The assessors conducting the assessments were blinded to the group allocation. The allocation list was password-protected and only accessible by the designated investigator.

Each group underwent a seven-week intervention period, with assessments at baseline (T0) and after the intervention (T1) with the PLwD and their carers. Both groups were led by certified CST facilitators.

The in-person group met for a total of 14 sessions, with two sessions scheduled every week, and consisted of six participants per group. It followed an evidence-based group CST protocol adapted to Hong Kong Chinese culture (Spector et al., 2017). Modifications were introduced to account for cultural differences and to align the intervention with local practices (Wong et al., 2018). For instance, using Chinese idioms conveying positive messages, along with symbolic gestures such as greetings and adapted word games, encourages verbal interaction while respecting cultural traditions. Furthermore, in traditional Chinese culture, older adults may be more reserved when sharing personal opinions due to a conservative social context. Consequently, initial discussions are embedded within collaborative group activities that begin with sharing objective information, thereby fostering social harmony. In addition, focusing on practical tasks that resonate with the Chinese emphasis on pragmatism, such as utilising a token system with physical gifts to motivate participation and provide visible recognition, has been shown to improve engagement (Wong et al., 2018).

Conversely, the virtual group adhered to the same CST protocol as the in-person group but included adjustments to some activities and methods of delivery to suit the virtual format (Perkins et al., 2022). The size of these groups ranged from three to four participants.

Video and audio recordings were made during assessment and group intervention sessions for data analysis. Informed consent for recording was obtained in advance, and participants might withdraw their consent to use these recordings at any time. All recordings were securely stored on password-protected computers and were accessible only to authorised HKU staff.

For those attending traditional in-person CST groups, infection control measures as mandated by the Hong Kong government and the service provider were enforced. These measures included wearing face masks, using non-shared materials, maintaining minimal personal contact, and practising social distancing with a reduced capacity at the venue.

Data Collection

Data collection involved in-person interviews conducted with both PLwD and their carers at two time points: baseline (T0) and post-intervention (T1). These assessments were administered by trained assessors. Consent forms were signed by both the PLwD and their carers prior to participation, ensuring informed consent from both parties. Demographic information, including age, gender, and years of education, was reported by the carers. The corresponding outcome measures were completed by both the PLwD and their carers, and administered by an assessor.

Independent variables:

1. The mode of intervention: Virtual Group Intervention vs In-person Group Intervention
2. Time: T0 (baseline, 0 week) vs T1 (post-intervention, 7 weeks)

Dependent variables:

1. Cognitive function
2. Quality of life

3. Social functioning

Outcome Measures

1. Cognitive Function: This was assessed by the Alzheimer's Disease Assessment Scale–Cognitive Subscale, Chinese version (ADAS-Cog). It is validated and proven reliable among the elderly Hong Kong Chinese population (Chu et al., 2000). It includes 11 tasks designed to evaluate memory, attention, orientation, praxis, comprehension, language, and other cognitive functions which often decline in PLwD. The total score varies from 0 to 70, with higher scores representing more severe cognitive impairment.
2. Quality of Life: This was evaluated by the Quality of Life in Alzheimer's Disease (QoL-AD) scale tailored for PLwD. The Chinese version of the QoL-AD is validated in the Hong Kong Chinese context (Chan et al., 2011). It comprises 13 items assessing various aspects including physical health, energy, emotion, living condition, memory, family relationships, marriage, peers, overall self-perception, household chores, enjoyment, finance, and life in general. Response options range from poor (1) to excellent (4), and the total score varies from 13 to 52, where higher scores reflect a better quality of life. In the current study, we included a self-reported version and a carer-reported measure according to their observation of PLwD.
3. Social Functioning: This was measured by the Hong Kong Social Functioning in Dementia Scale (HKSF-DEM), which was adapted to the Hong Kong Chinese context (Chui, 2020). It consists of 20 items and is designed to assess the social functioning of PLwD. It evaluates the extent of PLwD's engagement with social networks and their participation in social activities. Questions address the

frequency of meeting others, communication through phone or computer, and the quality of relationships. The total score varies from 0 to 51, with higher scores representing better social functioning. In the present study, we included a self-reported version as well as a carer-reported version according to their observation of PLwD. The scale can be further divided into three subscales, which includes 1) spending time with others, 2) communicating with others, and 3) sensitivity to others with reference to an exploratory factor analysis (Budgett et al., 2019).

Data Analysis

Data analysis was conducted using SPSS Version 29.

To ensure the validity and reliability of the findings, potential confounding variables, specifically age, gender, and years of education, were controlled in the data analysis. Controlling for these variables aimed to isolate the effect of the intervention itself, allowing for a more accurate evaluation and comparison of its impact. These factors are known to potentially influence cognitive function, dementia onset and the outcomes of interventions, making them potential confounders in the analysis. Cognitive function typically declines with age, as age is a key predictor of both cognitive deterioration and dementia progression (Ben Hassen et al., 2022; Luchesi et al., 2021). Additionally, gender differences are evident in dementia prevalence and treatment responses (Beam et al., 2018; Shaw et al., 2021). Education level is frequently used as a measure of cognitive reserve, with individuals who have higher educational attainment generally displaying stronger baseline cognitive performance and experiencing slower cognitive decline (Cha et al., 2024; Sharp & Gatz, 2011). By controlling for age, gender, and education level, the study could more accurately evaluate the effectiveness of in-person and vCST, ensuring that the results reflect the true impact of the interventions without being influenced by these confounding factors.

A series of repeated measures Analysis of Covariance (ANCOVA) was employed to evaluate the changes in intervention outcomes for both vCST and in-person CST groups respectively, from baseline (T0) to post-intervention (T1), while controlling for age, gender, and years of education of PLwD. The alpha level was set at .05, with time (T0/T1) as the within-subjects factor.

Additionally, a series of mixed-design ANCOVAs was employed to compare the changes in intervention outcomes between the vCST and in-person CST groups, while controlling for age, gender, and years of education of PLwD. The alpha level was set at .05, with time (T0/T1) as the within-subjects factor and CST mode (virtual/in-person) as the between-subjects factor.

Data were included in the analysis only if PLwD or their carers completed both the baseline and follow-up assessments. Data were excluded if PLwD withdrew from the study at any point.

Results

Sample

A Consort Flow Diagram (Figure 1) illustrates the process of recruitment and data collection. In total, 144 participants were recruited. 72 participants were randomly allocated to the virtual group and in-person group respectively, across a total of 24 virtual and 12 in-person groups. 18 participants (12.5%) dropped out in the process due to health, family, commuting and technical issues. Of the dropout participants, ten

(13.9%) were from the virtual groups and eight (11.1%) were from the in-person groups. Specifically, eight participants reported technical concerns, six reported time clashes or excessive travelling time, one felt discouraged after assessment, two reported physical conditions, and one reported low motivation. These participants attended the baseline assessment but subsequently dropped out before completing the group intervention. Listwise deletion was applied to ensure consistency in the sample, resulting in the exclusion of participants who did not complete the intervention and the follow-up assessment from the data analysis.

126 participants (87.5%) finished the CST intervention. Four PLwD and five carers did not attend the post-intervention interview, while two pairs of them were from the same dyads and excluded from the result and data analysis. No data imputation procedures were employed for the dropout or missing data. Eventually, 124 samples were ready for data analysis.

Figure 1: Consort Flow Diagram

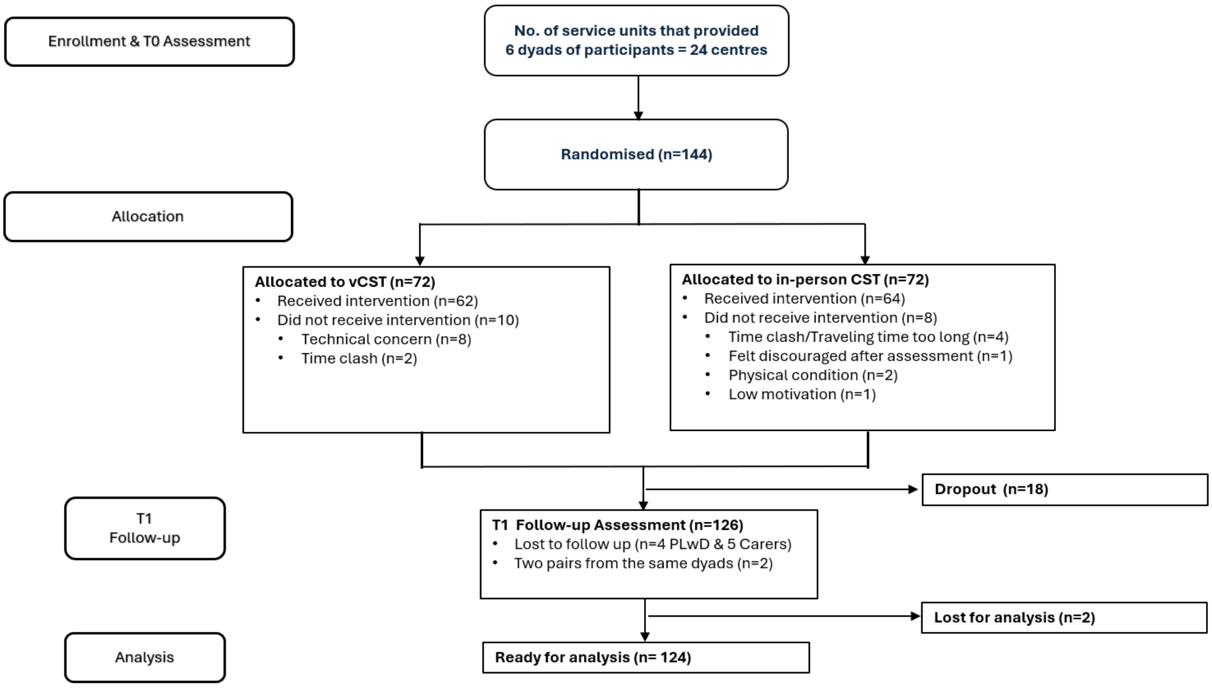


Table 1 shows the demographic information of participants. Overall, the demographic data indicates a predominantly female sample (67.7%) with a mean age of 80.46 years old and varying levels of education from zero to twenty years.

Table 1. Demographic Information

Measure	Total (n=124)	vCST (n=61)	In-person CST (n=63)
Gender			
Female (%)	84 (67.7%)	43 (70.5%)	41 (65.1%)
Male (%)	40 (32.3%)	18 (29.5%)	22 (34.9%)
Age (years)			
Mean	80.46	79.98	80.92
Std. Deviation	7.85	7.89	7.85
Range	38 (60-98)	34 (61-95)	38 (60-98)
Years of Education			
Mean	6.63	6.59	6.67
Std. Deviation	4.98	5.00	5.01
Range	20 (0-20)	20 (0-20)	19 (0-19)

Hypothesis 1: There will be significant improvements in cognitive function, quality of life and social functioning in PLwD in both vCST and in-person groups between T0 (baseline) and T1 (post-intervention).

1) *Evaluation of the pre-post changes in vCST group after controlling demographical information*

Table 2 illustrates the results of a series of repeated measures ANCOVAs to compare various cognitive function, quality of life, and social functioning measures before and after the vCST intervention, controlling for age, gender, and years of education. Overall, there were no statistically significant changes in cognitive function, quality of life, and social functioning before and after the vCST intervention, controlling for age, gender, and years of education.

Table 2. Pre-post intervention changes in vCST group after controlling age, gender and education

Measure	T0 Mean (SD)	T1 Mean (SD)	F(df1, df2)	p-value	Partial η²
ADAS-Cog	19.99 (10.11)	19.77 (11.74)	1.052 (1, 55)	.309	.019
QoL-AD (self-reported)	32.59 (5.36)	32.80 (6.29)	2.345 (1, 55)	.131	.041
QoL-AD (carer-reported)	27.73 (4.24)	27.83 (4.18)	0.000 (1, 55)	.984	.000
HKSF-DEM (self-reported)	26.27 (5.25)	25.75 (4.53)	0.956 (1, 55)	.332	.017
HKSF-DEM Subscale 1 (self-reported)	7.75 (3.41)	7.71 (3.09)	0.458 (1, 55)	.501	.008
HKSF-DEM Subscale 2 (self-reported)	8.32 (2.76)	8.12 (3.20)	1.458 (1, 55)	.232	.026
HKSF-DEM Subscale 3 (self-reported)	10.20 (2.32)	9.92 (1.51)	0.274 (1, 55)	.603	.005
HKSF-DEM (carer-reported)	24.19 (5.87)	25.41 (5.18)	0.148 (1, 55)	.702	.003
HKSF-DEM Subscale 1 (carer-reported)	8.97 (2.92)	9.78 (3.16)	0.992 (1, 55)	.324	.018
HKSF-DEM Subscale 2 (carer-reported)	6.56 (4.07)	7.17 (3.95)	1.471 (1, 55)	.230	.026
HKSF-DEM Subscale 3 (carer-reported)	8.66 (2.45)	8.46 (2.11)	0.195 (1, 55)	.661	.004

Acronyms: ADAS-Cog: Alzheimer's Disease Assessment Scale–Cognitive Subscale; QoL-AD: Quality of Life in Alzheimer's Disease; HKSF-DEM: Hong Kong version of Social Functioning in Dementia Scale

2) Evaluation of the pre-post changes for in-person CST group after controlling demographical information

Table 3 illustrates the results of a series of repeated measures ANCOVAs to compare various cognitive function, quality of life, and social functioning measures before and after an in-person CST intervention, controlling for age, gender, and years of education. Overall, the repeated measures ANCOVAs indicate no statistically significant changes in cognitive function and quality of life measures after controlling for age, gender, and years of education. Additionally, there were no significant differences in overall social functioning as per self-reported (p = .222) or carer-reported scores (p = .612). However, a significant change was identified in the self-reported HKSF-DEM Subscale 1, $\mathrm{F}(1,59)=4.414$, p=.040, partial η^2 =.070, with an observed power of .542, indicating a significant improvement after the intervention. This suggested that the in-person CST intervention led to significant improvements for PLwD, particularly in spending time with other people.

Table 3. Pre-post intervention changes in in-person CST group after controlling age, gender and education

Measure	T0 Mean (SD)	T1 Mean (SD)	F (df1, df2)	p-value	Partial η²
ADAS-Cog	20.87 (10.05)	21.58 (12.03)	3.506 (1, 59)	.066	.056
QoL-AD (self-reported)	31.76 (5.53)	31.27 (5.92)	0.081 (1, 59)	.777	.001
QoL-AD (carer-reported)	27.29 (4.99)	27.85 (5.44)	3.214 (1, 58)	.078	.053
HKSF-DEM (self-reported)	25.43 (5.03)	26.52 (5.36)	1.522 (1, 59)	.222	.025
HKSF-DEM Subscale 1 (self-reported)	7.43 (2.92)	8.84 (3.34)	4.414 (1, 59)	.040	.070
HKSF-DEM Subscale 2 (self-reported)	7.57 (2.97)	8.10 (2.99)	0.000 (1, 59)	.993	.000
HKSF-DEM Subscale 3 (self-reported)	10.43 (1.88)	9.59 (1.69)	0.688 (1, 59)	.410	.012
HKSF-DEM (carer-reported)	25.63 (5.21)	27.13 (5.00)	0.260 (1, 58)	.612	.004
HKSF-DEM Subscale 1 (carer-reported)	10.00 (2.62)	10.47 (2.67)	1.359 (1, 58)	.249	.023
HKSF-DEM Subscale 2 (carer-reported)	6.97 (3.53)	7.50 (3.51)	0.143 (1, 58)	.706	.002
HKSF-DEM Subscale 3 (carer-reported)	8.66 (2.04)	9.16 (2.33)	0.014 (1, 58)	.905	.000

Hypothesis 2: The cognitive function and quality of life of PLwD in the vCST group will be non-inferior to that of the in-person CST group.

Table 4 illustrates the results of a series of mixed-design ANCOVAs to evaluate the effect of CST mode (virtual vs. in-person) on cognitive function and quality of life over time (T0 vs. T1) after controlling for age, gender, and years of education. Overall, the mixed-design ANCOVAs indicated that the interaction between time and CST mode was not significant for cognitive function, $F(1,116)=0.174$, $p=.677$, partial $\eta^2=.002$; for quality of life self-reported by PLwD, $F(1,116)=0.102$, $p=.750$, partial $\eta^2=.001$, and for PLwD's quality of life reported by carers, $F(1,115)=0.115$, $p=.735$, partial $\eta^2=.001$. These results suggest that the changes over time in cognitive function and quality of life did not differ significantly between the vCST and in-person groups. The result indicates that the vCST intervention is non-inferior to the in-person CST intervention in terms of cognitive function and quality of life. This demonstrates that vCST can be as effective as in-person CST in maintaining or improving cognitive function and quality of life for PLwD.

Table 4. Comparing the effect of CST mode on cognitive function and quality of life after controlling age, gender and education

Measure	F (df1, df2)	p-value	Partial η^2
ADAS-Cog	0.174 (1,116)	.677	.002
QoL-AD (self-reported)	0.102 (1,116)	.750	.001
QoL-AD (carer-reported)	0.115 (1,115)	.735	.001

Hypothesis 3: There will be a significant difference in social functioning between PLwD in the vCST group and those in the in-person CST group.

Table 5 illustrates the results of a series of mixed-design ANCOVAs to evaluate the effect of CST mode (virtual vs. in-person) on social functioning over time (T0 vs. T1) after controlling for age, gender, and years of education. Based on the results presented, the interaction effects between time and CST mode for various social functioning measures revealed a mix of significant and non-significant findings. While a majority of social functioning measures showed a non-significant interaction, there was a significant interaction between time and CST mode for overall social functioning self-reported by PLwD, F(1,116)=5.146, p=.025, partial η2=.042, with an observed power =.614. This suggested that the change in social functioning over time differed significantly between the vCST and in-person groups, while in-person CST can be more effective than vCST in maintaining or improving social functioning for PLwD.

Similarly, for the HKSF-DEM Subscale 1, a significant interaction between time and CST mode was found, F(1,116)=5.742, p=.018, partial η2=.047, with an observed power=.661. This result suggested that the mode of CST delivery influenced the changes in PLwD's time spending with others (HKSF-DEM Subscale 1), demonstrating that in-person CST can be more effective than vCST in maintaining or improving PLwD's time spending with others.

Table 5. Comparing the effect of CST mode on social functioning after controlling age, gender and education

Measure	F (df1, df2)	p-value	Partial η²
HKSF-DEM (self-reported)	5.146 (1, 116)	.025	.042
HKSF-DEM Subscale 1 (self-reported)	5.742 (1, 116)	.018	.047
HKSF-DEM Subscale 2 (self-reported)	1.961 (1, 116)	.164	.017
HKSF-DEM Subscale 3 (self-reported)	0.507 (1, 116)	.478	.004
HKSF-DEM (carer-reported)	0.157 (1, 115)	.692	.001
HKSF-DEM Subscale 1 (carer-reported)	0.267 (1, 115)	.606	.002
HKSF-DEM Subscale 2 (carer-reported)	0.000 (1, 115)	.992	.000
HKSF-DEM Subscale 3 (carer-reported)	2.292 (1, 115)	.133	.020

Discussion

Summary

Changes in Social Functioning (Hypothesis 1)

The current study aimed to assess the effectiveness of in-person and vCST. Considering limited previous research exploring changes in social functioning, this provides the first quantitative study to evaluate the effects of different CST modes on the social functioning of PLwD. The results revealed a significant improvement in the in-person group, particularly in the amount of time PLwD spent with others assessed by the HKSF-DEM Subscale 1. Subscale 1 assesses the frequency of contact with family and friends, community involvement, and recreation and sports activities. These results indicate that the effects of CST on social functioning may extend to other aspects of the PLwD’s life, underlining the importance of utilising such therapeutic interventions in dementia care.

The possible mechanisms underlying the effectiveness of CST may relate to its holistic design and key principles. The CST programme incorporates principles such as stimulating language, involvement, being person-centred, and building and strengthening relationships (Spector et al., 2020). The programme activities involve a lot of communication, emotional expression, perspective-taking, and social integration. They might foster communication skills through discussions and interactive tasks, which are vital in enhancing social functioning.

In addition, CST emphasises opinions over facts, inclusion and respect (Spector et al., 2020). It provides an inclusive environment for PLwD to feel safe, alleviate feelings of isolation and encourage social interaction. Thus, PLwD would have more opportunities to interact with others, practise and enhance their communication skills within the groups. The change in social behaviour could possibly extend outside the group sessions to their daily lives.

Changes in Cognitive Functioning and Quality of Life (Hypothesis 1)

The study results did not show a significant improvement in cognitive functions and quality of life for PLwD after the intervention. When interpreting these within-group findings, the issue of statistical power should not be overlooked. While the study was primarily powered to test between-group non-inferiority hypotheses, which aimed to assess whether the vCST was non-inferior to the in-person CST, the same level of power was not extended to the within-group comparisons (Hypothesis 1). As a result, these analyses may have been underpowered to detect significant changes within each group over time. The power calculation was focused on detecting between-group differences with sufficient sensitivity. However, the power needed to detect within-group effects, which were the pre- and post-intervention differences within each group, was not a primary consideration in the primary research design. This lack of adequate power may explain why significant changes were not observed within the groups, even though meaningful trends were evident in some cases.

Moreover, the results should be interpreted under the context of dementia, a neurodegenerative condition characterised by a gradual decline in cognitive and overall functioning with different trajectories (Baker et al., 2017). In fact, some research (Geschwind, 2016; Hermann & Zerr, 2022) has reported cases of rapid cognitive decline in certain dementia patients over a short period. The initial CST trial (Spector et al., 2003), which was adequately powered, demonstrated a slight cognitive deterioration in the control group from baseline to follow-up, suggesting a natural, though small, decline. Another RCT study (Sheetal & Mathew, 2024) also reported significant cognitive decline in control groups not receiving CST over a period of just two months. The current study was not comparing changes to treatment-as-usual groups or no-treatment control groups, which would reflect the natural deterioration seen in dementia. The lack of significant results might be explained by dementia's progressive nature, where dementia interventions are often more focused on slowing decline rather than complete alleviation or reversal of deficits (Laver et al., 2016; Kane et al., 2017).

Although there were no statistically significant improvements, the potential benefits of CST should not be disregarded. Given the progressive nature of dementia, the interventions did not result in any significant decline in cognition or quality of life. This outcome is critical as maintaining stability in these measures is beneficial. The principle of 'doing no harm' applies in dementia care suggesting that CST is a safe and proper intervention for clinical practice. It contributes to the maintenance of cognitive functions and quality of life among PLwD.

In conclusion, despite the lack of significant changes in cognitive function and quality of life, the results still indicated the potential of CST in preserving these areas, not to mention the importance of maintaining existing function when dealing with a progressive disease like dementia.

Comparison between vCST and in-person CST

This study is the first RCT that seeks to compare the two CST modes. The comparable dropout rates across the in-person (11.1%) and vCST (13.9%) groups might imply that PLwD are not less committed in receiving virtual interventions. vCST could be considered as a viable alternative to in-person regarding participant commitment.

While considering the adequacy of power, the power calculation for this study was based on the assumption that 126 participants would provide sufficient power (80%) to detect a non-inferiority effect between in-person and vCST groups. Given that only 124 participants completed both pre- and post-assessment, which was slightly fewer participants than the target sample size, resulting in a minor shortfall. This difference represents less than a 2% shortfall in the planned sample size. Although this is only a small deviation, it is acknowledged that achieving the target sample size is ideal for maintaining the study's originally calculated power.

Furthermore, as this study obtained secondary data from an ongoing HKU research project, the potential to reach the target sample size remains. As additional participants will be included, further analyses will be conducted to ensure enough sample size and provide an even stronger foundation to justify the non-inferiority conclusion.

1) Comparing Cognitive Function and Quality of Life (Hypothesis 2)

The results provided evidence for the hypothesis that the effect on cognitive functioning and quality of life among PLwD in the vCST group would be non-inferior to the in-person CST group. This suggests that vCST can be as effective as in-person CST and may serve as a possible alternative for dementia care when face-to-face contact is infeasible.

One possible factor may be associated with the consistency across the therapeutic content between in-person and virtual CST (Perkins et al., 2022). Key treatment components, which are aimed at enhancing cognition and the quality of life, are maintained throughout both delivery approaches. In addition, the vCST protocol was refined with the support of PLwD, carers, CST group facilitators, and dementia service managers, and field-tested across different countries (Perkins et al., 2022). With this thorough development and testing, the therapeutic components are retained and help sustain cognitive function and quality of life.

Another possible factor may relate to the involvement of the family and carers in the group process. Carers were frequently involved in the vCST delivery process and might be responsible for addressing technology concerns and supporting the participants regularly. This increased carer involvement might help create a more supportive environment, which might also add to the CST therapeutic processes. Furthermore, Fisher et al. (2023) revealed that one of the significant challenges of vCST is the digital accessibility and literacy of PLwD. Carers, who are physically present, may provide technical assistance and emotional support to reduce frustration or anxiety whenever PLwD encounter technological barriers. This would enable PLwD to focus on the therapeutic materials rather than struggling with the technology.

2) Comparing Social Functioning (Hypothesis 3)

The results provided evidence for the hypothesis that there would be a significant difference in social functioning between the two CST modes, with in-person CST being more effective in maintaining or improving the overall social functioning (HKSF-DEM) and the amount of time PLwD spent with other individuals (HKSF-DEM Subscale 1).

A likely explanation could be the direct social contact inherent in face-to-face sessions. Being physically present in a group setting provides more opportunities for spontaneous and natural interactions. In face-to-face interaction, it is easier to perceive and respond to eye contact, body language and physical gestures. In contrast to vCST, these non-verbal elements are generally less salient or distorted by screen-based interaction.

Furthermore, in-person sessions might allow for a better-organised setting, which might indirectly encourage interaction. The physical environment is helpful for more natural interaction than in a virtual environment, in which technical challenges and connectivity issues might disrupt the process.

In addition, in-person sessions include more multisensory stimulation, which is difficult to imitate fully in an online format. CST intervention emphasises physical movement, providing triggers and stimulating executive functioning which involves multisensory activities such as music, art, creative games and physical exercises (Spector et al., 2020). These are best delivered face-to-face because all the participants are able to engage, interact and respond to the stimuli, which in turn can foster social interaction and engagement.

It is noteworthy that significant results were observed only in the self-reported scale, while the carer-reported scale did not show significant results. The subjective experiences of PLwD are crucial to consider in the current research. Although carers may have differing perspectives, it is a meaningful finding that in-person social interactions were associated with increased self-reported social functioning, in contrast to online contacts.

In fact, discrepancies often arise between the self-assessments of PLwD and the evaluations provided by their carers across various studies (Dourado et al., 2016; Engel et al., 2024; Landeiro et al., 2018; Reamy et al., 2011). These differences may be attributed to the profound impact of cognitive changes experienced by PLwD on their self-awareness and communication abilities, leading to misinterpretations of their needs and experiences (Dourado et al., 2016; Farina et al., 2020). Conversely, carers may be influenced by the caregiving challenges and burdens, resulting in a more negative assessment that may overlook the positive aspects of the PLwD's life (Moon et al., 2016; Reamy et al., 2011). On the one hand, caregiver evaluations are essential due to their comprehensive understanding of the caregiving context and dementia-related symptoms. On the other hand, it is vital to prioritise the first-hand experiences of PLwD, as these encapsulate their personal sense of well-being and autonomy. Achieving a balance between these perspectives is crucial, as both offer valuable insights into clinical practice and research settings.

Insights into vCST

1) *Effectiveness of vCST*

The present study provides meaningful insights into the effectiveness of vCST. It suggests that vCST is at least as effective as face-to-face CST at the end of treatment with regard to cognitive functioning, quality of life, and certain domains of social functioning. These findings are important given that no previous research has directly compared the two CST modes. The similarity in cognitive and quality of life outcomes implies that vCST can effectively maintain these crucial areas of functioning, offering a comparable therapeutic benefit to in-person sessions.

2) *Refinement of Protocols*

While this study indicates that vCST is as effective as in-person CST in terms of cognitive function and quality of life, it suggests refining the vCST protocols to further enhance the social functioning outcomes. Possible refinements could consider more interactive elements that would help to mimic face-to-face communication, such as more interactive activities and using more multisensory group materials. It is also crucial to train the facilitators in utilising the multimedia and handling technical issues that may affect the participants' experience. Additionally, offering more support and guidance to carers in accessing the technology can reduce barriers to delivering vCST.

3) *Improving Accessibility*

Considering the accessibility of intervention, vCST offers practical benefits especially when face-to-face contact is limited in situations like the pandemic and infection control. Virtual sessions allow PLwD to remain under intervention and maintain a degree of interaction and engagement, which is preferable to complete isolation. In addition, vCST can be especially beneficial for PLwD who cannot attend the in-person sessions due to transportation problems or physical disabilities. This extends a broader coverage of the population, especially reaching the people who were previously inaccessible.

4) Development of Hybrid Service Model

Regarding the service model, the findings underline the value of a hybrid approach that offers in-person and virtual groups respectively, aligning with the recommendations by Fisher et al. (2023). The enhancement in social functioning affirms the role of in-person CST in dementia care, while vCST provides a solution for PLwD who cannot attend in-person sessions, ensuring they still receive quality interventions virtually. This approach incorporates the strengths of the two modes, considering accessibility and the benefits of direct interactions, which offer more alternatives for PLwD to meet their own needs.

With empirical support from the current study, PLwD have alternative access to evidence-based non-pharmacological interventions. It further provides insights into refining the protocols for vCST delivery, improving accessibility and enhancing service development. From a macro perspective, these advances help reduce the financial burden on health and social care systems and decrease the exposure of vulnerable groups to infectious diseases.

Strengths and Limitations

The current study has some limitations that need to be considered. Regarding the recruitment, there might be selection bias as participants were current members of elderly community centres, and likely already receiving services or more engaged with social workers, which might not represent the broader population of PLwD. The actual sample size (124) was slightly below the number derived from power analysis (126) due to dropouts and this might have compromised the power of the study. Although the results support the non-inferiority hypothesis, concerns remain about the ability to draw definitive conclusions regarding the non-inferiority of the vCST intervention. The possibility that the lack of significant differences is due to the slightly limited power cannot be entirely ruled out. It is important to note that this study is based on secondary data analysis, and ongoing data collection in the HKU research project is expected to address these limitations, ultimately providing a more robust evaluation of non-inferiority.

In terms of the methodology, the study did not include a no-treatment or treatment-as-usual condition to compare CST interventions to standard treatment or care. While not having a control condition might be viewed as a limitation, the efficacy of CST compared to a control condition has been very well established from other trials (Chen X., 2022; Desai et al., 2024; Spector et al., 2003). Apart from that, as a cluster RCT, the current study did not make adjustments for the effect of clustering, which may have introduced potential bias. Participants within the same group were recruited from the same centre, and they might share similarities that could influence the outcome and affect the generalisability of the findings. A multilevel or mixed-effects model should be considered in future studies to adjust for clustering effects. Regarding cofounding variables, although the study was controlled for age, gender, and years of education, other potential variables, such as the severity of dementia, comorbid health conditions, mood level and the type of social support received, were not considered. Such factors could affect the results and should be considered in further research.

For data analysis, there were no data imputation procedures for the dropout or missing data. Instead, they were excluded from the data analysis. While this listwise deletion approach upheld the integrity of the analysed data, it raises potential concerns regarding internal validity. Excluding data without employing imputation procedures reduces the effective sample size and may compromise the generalizability of the findings, particularly if characteristics of those who dropped out differ from those who completed the intervention. Moreover, this method may introduce bias in estimates if the reasons for dropout are associated with variables under study, such as changes in cognition or quality of life.

A correction for multiple comparisons was not applied in the current study due to the exploratory nature of certain analyses, which aimed to generate new insights and identify potential trends. However, given the number of analyses conducted, it is important to acknowledge that the absence of such corrections increases the risk of Type I errors, potentially affecting the interpretation of significant within-group findings. As an ongoing research project, particularly with increasing sample sizes, applying correction methods such as the Bonferroni correction or False Discovery Rate control may be beneficial for the future interpretation.

In terms of the intervention, the technological barriers faced by the vCST group, including internet connection issues and technical literacy levels of PLwD/carers, might have influenced the effectiveness of the virtual intervention. The current study might also have excluded people with limited digital literacy, as evidenced by the dropout of some participants after being assigned to the virtual intervention groups.

Implications for Future Research and Practice

Future research could use a more diverse sample from various settings to improve the generalizability of the findings. To measure CST effects more independently from other factors that could influence outcomes, future studies should consider controlling for additional confounding variables as mentioned above.

Comparative intervention studies of CST implemented in homes, community centres, and residential care facilities can offer meaningful recommendations for adapting interventions to different contexts and participants. As highlighted in the most recent Census (2023) conducted in Hong Kong, there are nearly 70,000 vulnerable older adults residing in residential care or institutional settings. They differ from home conditions and might particularly benefit from further research. In addition, future research could consider the use of long-term impact studies or longitudinal studies where follow-up assessments could be conducted at different time points after the intervention to evaluate the long-term effectiveness.

To improve vCST service provision, future research should explore better practices, such as considering the value of a hybrid service model that includes in-person and virtual groups, simulating in-person group interaction, utilising multimedia tools and enhancing technical resolution. As such, future research can contribute to the further advancement of service delivery, eventually improving the effectiveness of interventions and the overall wellbeing of PLwD.

Conclusions

Considering the global trend of digital healthcare interventions, this study is pioneering in understanding vCST delivery. While the results show that vCST is non-inferior to in-person CST in maintaining cognitive function and quality of life, in-person CST demonstrates a significant impact in enhancing social functioning. They indicate the importance of direct human interaction in dementia care, highlighting the indispensable role of in-person CST intervention. Meanwhile, the flexibility and accessibility of vCST make it a viable alternative for those unable to attend in-person sessions. A hybrid service model could be a future direction that leverages the benefits of both modes, ensuring high-quality dementia care is accessible to all PLwD. Future research should consider refining vCST protocols and exploring longitudinal and comparative studies across various settings to enhance the implementation of CST interventions further. These recommendations can lead to more effective, inclusive, and sustainable dementia care practices, ultimately improving the lives of PLwD and their carers.

References

Baker, E., Iqbal, E., Johnston, C., Broadbent, M., Shetty, H., Stewart, R., Howard, R., Newhouse, S., Khondoker, M., & Dobson, R. J. B. (2017). Trajectories of dementia-related cognitive decline in a large mental health records derived patient cohort. *PloS one*, *12*(6), e0178562. https://doi.org/10.1371/journal.pone.0178562

Bayly, M., Morgan, D., Froehlich Chow, A., Kosteniuk, J., & Elliot, V. (2020). Dementia-related education and support service availability, accessibility, and use in rural areas: Barriers and solutions. *Canadian Journal on Aging = La Revue canadienne du vieillissement*, *39*(4), 545–585. https://doi.org/10.1017/S0714980819000564

Beam, C. R., Kaneshiro, C., Jang, J. Y., Reynolds, C. A., Pedersen, N. L., & Gatz, M. (2018). Differences between women and men in incidence rates of dementia and Alzheimer's disease. *Journal of Alzheimer's Disease*, *64*(4), 1077–1083. https://doi.org/10.3233/JAD-180141

Ben Hassen, C., Fayosse, A., Landré, B., Raggi, M., Bloomberg, M., Sabia, S., & Singh-Manoux, A. (2022). Association between age at onset of multimorbidity and incidence of dementia: 30 year follow-up in Whitehall II prospective cohort study. *BMJ (Clinical research ed.)*, *376*, e068005. https://doi.org/10.1136/bmj-2021-068005

Budgett, J., Brown, A., Daley, S., Page, T. E., Banerjee, S., Livingston, G., & Sommerlad, A. (2019). The social functioning in dementia scale (SF-DEM): Exploratory factor analysis and psychometric properties in mild, moderate, and severe dementia. *Alzheimer's & dementia (Amsterdam, Netherlands)*, *11*, 45–52. https://doi.org/10.1016/j.dadm.2018.11.001

Census and Statistics Department, Hong Kong Special Administrative Region. (2023).

Thematic report: Older persons. 2021 Population Census Office. Published in February 2023. Retrieved from https://www.censtatd.gov.hk/en/EIndexbySubject.html?scode=600&pcode=B1120118

Cha, H., Farina, M. P., Chiu, C. T., & Hayward, M. D. (2024). The importance of education for understanding variability of dementia onset in the United States. *Demographic research*, *50*, 733–762. https://doi.org/10.4054/demres.2024.50.26

Chan, I. W., Chu, L. W., Lee, P. W., Li, S. W., & Yu, K. K. (2011). Effects of cognitive function and depressive mood on the quality of life in Chinese Alzheimer's disease patients in Hong Kong. *Geriatrics & Gerontology International, 11*(1), 69-76.

Chen, X. (2022). Effectiveness of cognitive stimulation therapy (CST) on cognition, quality of life and neuropsychiatric symptoms for patients living with dementia: A meta-analysis. *Geriatric nursing (New York, N.Y.)*, *47*, 201–210. https://doi.org/10.1016/j.gerinurse.2022.07.012

Chui, K. C. M. (2020). *Hong Kong SF-DEM: Hong Kong version of the Social Functioning in Dementia Scale*. University College London. https://www.ucl.ac.uk/psychiatry/sites/psychiatry/files/hong_kong_sf-dem.pdf

Chu, L. W., Chiu, K. C., Hui, S. L., Yu, G. K., Tsui, W. J., & Lee, P. W. (2000). The reliability and validity of the Alzheimer's Disease Assessment Scale Cognitive Subscale (ADAS-Cog) among the elderly Chinese in Hong Kong. *Annals of the Academy of Medicine, Singapore, 29*(4), 474-485.

Cuffaro, L., Di Lorenzo, F., Bonavita, S., Tedeschi, G., Leocani, L., & Lavorgna, L. (2020). Dementia care and COVID-19 pandemic: A necessary digital revolution.

Neurological Sciences, 41(8), 1977-1979.

D'Amico, F., Rehill, A., Knapp, M., Aguirre, E., Donovan, H., Hoare, Z., Hoe, J., Russell, I., Spector, A., Streater, A., Whitaker, C., Woods, R. T., & Orrell, M. (2015). Maintenance cognitive stimulation therapy: An economic evaluation within a randomised controlled trial. *Journal of the American Medical Directors Association, 16*(1), 63-70. https://doi.org/10.1016/j.jamda.2014.10.016

Dai, R., Zhang, A. Y., & Wong, G. (2020). The impact of COVID-19 on formal and informal dementia care in Hong Kong. In *34th International Conference of Alzheimer's Disease International*.

Desai, R., Leung, W. G., Fearn, C., John, A., Stott, J., & Spector, A. (2024). Effectiveness of Cognitive Stimulation Therapy (CST) for mild to moderate dementia: A systematic literature review and meta-analysis of randomised control trials using the original CST protocol. *Ageing research reviews*, *97*, 102312. Advance online publication. https://doi.org/10.1016/j.arr.2024.102312

Dourado, M. C., Sousa, M. F., Santos, R. L., Simões, J. P., Neto, Nogueira, M. L., Belfort, T. T., Torres, B., Dias, R., & Laks, J. (2016). Quality of life in mild dementia: patterns of change in self and caregiver ratings over time. *Revista Brasileira de Psiquiatria, 38*(4)*,* 294–300.

Dubey, S., Das, S., Ghosh, R., Dubey, M. J., Chakraborty, A. P., Roy, D., Das, G., Dutta, A., Santra, A., Sengupta, S., & Benito-León, J. (2023). The Effects of SARS-CoV-2 Infection on the Cognitive Functioning of Patients with Pre-Existing Dementia. *Journal of Alzheimer's disease reports*, *7*(1), 119–128. https://doi.org/10.3233/ADR-220090

Engel, L., Sokolova, V., Bogatyreva, E., & Smith, S. (2024). Understanding the influence of different proxy perspectives in explaining the difference between self-rated and proxy-rated quality of life in people living with dementia: A systematic literature review and meta-analysis. *Quality of Life Research*, *33*, 2055–2066.

Farina, N., King, D., Burgon, C., & Banerjee, S. (2020). Disease severity accounts for minimal variance of quality of life in people with dementia and their carers: Analyses of cross-sectional data from the MODEM study. *BMC Geriatrics*, *20*, 232.

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior research methods*, *39*(2), 175–191. https://doi.org/10.3758/bf03193146

Fisher, E., Proctor, D., Perkins, L., Felstead, C., Stott, J., & Spector, A. (2023). Is virtual cognitive stimulation therapy the future for people with dementia? An audit of UK NHS memory clinics during the COVID-19 pandemic. *Journal of Technology in Behavioral Science*, 1–8. Advance online publication. https://doi.org/10.1007/s41347-023-00306-5

GBD 2019 Dementia Forecasting Collaborators. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: An analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health, 7*(2), e105–e125. https://doi.org/10.1016/S2468-2667(21)00249-8

Geschwind, M. D. (2016). Rapidly progressive dementia. *Continuum (Minneapolis, Minn)*, *22*(2, Dementia), 510–537. https://doi.org/10.1212/CON.0000000000000319

Giebel, C., Robertson, S., Beaulen, A., Zwakhalen, S., Allen, D., & Verbeek, H. (2021). "Nobody seems to know where to even turn to": Barriers in accessing and utilising dementia care services in England and the Netherlands. *International Journal of Environmental Research and Public Health*, *18*(22), 12233.

Goodall, G., Taraldsen, K., & Serrano, J. A. (2021). The use of technology in creating individualized, meaningful activities for people living with dementia: A systematic review. *Dementia, 20*(4), 1442-1469.

Guzman-Parra, J., Barnestein-Fonseca, P., Guerrero-Pertinez, G., Anderberg, P., Jimenez-Fernandez, L., Valero-Moreno, S., & Mayoral-Cleries, F. (2020). Attitudes and use of information and communication technologies in older adults with mild cognitive impairment or early stages of dementia and their caregivers: Cross-sectional study. *Journal of Medical Internet Research, 22*(6), e17253.

Hermann, P., & Zerr, I. (2022). Rapidly progressive dementias—Aetiologies, diagnosis and management. *Nature Reviews Neurology*, *18*, 363–376. https://doi.org/10.1038/s41582-022-00659-0

Ho, D. W. H., Mak, V., Kwok, T. C. Y., Au, A., & Ho, F. K. Y. (2015). Development of a web-based training program for dementia caregivers in Hong Kong. *Clinical Gerontologist, 38*(3), 211-223.

Hui, E. K., Wong, G., Tischler, V., Yuan, S., Leung, W. G., Saunders, R., Suen, L. W., & Spector, A. (2022). Virtual individual cognitive stimulation therapy in Hong Kong: A mixed methods feasibility study. *Geriatric nursing (New York, N.Y.)*, *47*, 125–134. Advance online publication. https://doi.org/10.1016/j.gerinurse.2022.07.010

Kane, R. L., Butler, M., Fink, H. A., Brasure, M., Davila, H., Desai, P., Jutkowitz, E., McCreedy, E., Nelson, V. A., McCarten, J. R., Calvert, C., Ratner, E., Hemmy, L. S., & Barclay, T. (2017). Interventions to prevent age-related cognitive decline, mild cognitive impairment, and clinical Alzheimer’s-type dementia. *Agency for Healthcare Research and Quality*. Retrieved from https://www.ahrq.gov

Knapp, M., Bauer, A., Wittenberg, R., Comas-Herrera, A., Cyhlarova, E., Hu, B., Jagger, C., Kingston, A., Patel, A., Spector, A., Wessel, A., & Wong, G. (2022). What are the current and projected future cost and health-related quality of life implications of scaling up cognitive stimulation therapy? *International Journal of Geriatric Psychiatry*, *37*(1), 10.1002/gps.5633. https://doi.org/10.1002/gps.5633

Knapp, M., Thorgrimsen, L., Patel, A., Spector, A., Hallam, A., Woods, B., & Orrell, M. (2006). Cognitive stimulation therapy for people with dementia: Cost-effectiveness analysis. *The British Journal of Psychiatry: The Journal of Mental Science*, *188*, 574–580. https://doi.org/10.1192/bjp.bp.105.010561

Landeiro, F., Walsh, K., Ghinai, I., Mughal, S., Nye, E., Wace, H., Roberts, N., Lecomte, P., Wittenberg, R., Wolstenholme, J., Handels, R., Roncancio-Diaz, E., Potashman, M. H., Tockhorn-Heidenreich, A., Gray, A. M., & ROADMAP Group (2018). Measuring quality of life of people with predementia and dementia and their caregivers: a systematic review protocol. *BMJ open*, *8*(3), e019082.

Laver, K., Dyer, S., Whitehead, C., Clemson, L., & Crotty, M. (2016). Interventions to delay functional decline in people with dementia: A systematic review of systematic reviews. *BMJ Open, 6*(4), Article e010767. https://doi.org/10.1136/bmjopen-2015-010767

Lee, S. M., & Lee, D. (2021). Opportunities and challenges for contactless healthcare services in the post-COVID-19 era. *Technological Forecasting and Social Change, 167*, 120712.

Lobbia, A., Carbone, E., Faggian, S., Gardini, S., Piras, F., Spector, A., & Borella, E. (2019). The efficacy of cognitive stimulation therapy (CST) for people with mild-to-moderate dementia: A review. *European Psychologist, 24*(3), 257–277. https://doi.org/10.1027/1016-9040/a000342

Lorenz, K., Freddolino, P. P., Comas-Herrera, A., Knapp, M., & Damant, J. (2019). Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia (London), 18*(2), 725-741. https://doi.org/10.1177/1471301217691617

Luchesi, B. M., Melo, B. R. S., Balderrama, P., Gratão, A. C. M., Chagas, M. H. N., Pavarini, S. C. I., & Martins, T. C. R. (2021). Prevalence of risk factors for dementia in middle- and older- aged people registered in Primary Health Care. *Dementia & neuropsychologia*, *15*(2), 239–247. https://doi.org/10.1590/1980-57642021dn15-020012

Masterson-Algar, P., Allen, M. C., Hyde, M., Keating, N., & Windle, G. (2022). Exploring the impact of Covid-19 on the care and quality of life of people with dementia and their carers: A scoping review. *Dementia (London, England)*, *21*(2), 648–676. https://doi.org/10.1177/14713012211053971

Matrix Evidence. (2011). *An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia*. Coventry: National Health Service (NHS) Institute for Innovation and Improvement.

Mok, V. C. T., Pendlebury, S., Wong, A., Alladi, S., Au, L., Bath, P. M., Biessels, G. J., Chen, C., Cordonnier, C., Dichgans, M., Dominguez, J., Gorelick, P. B., Kim, S., Kwok, T., Greenberg, S. M., Jia, J., Kalaria, R., Kivipelto, M., Naismith, S. L., Salvadori, E., Smith, E. E., Van Boxtel, M., & Werring, D. J. (2020). Tackling challenges in care of Alzheimer's disease and other dementias amid the COVID-19 pandemic, now and in the future. *Alzheimer's & Dementia, 16*(11), 1571-1581.

Matsuda, O., Shido, E., Hashikai, A., Shibuya, H., Kouno, M., Hara, C., & Saito, M. (2010). Short-term effect of combined drug therapy and cognitive stimulation therapy on the cognitive function of Alzheimer's disease. *Psychogeriatrics : the official journal of the Japanese Psychogeriatric Society*, *10*(4), 167–172. https://doi.org/10.1111/j.1479-8301.2010.00335.x

Moon, H., Townsend, A., Dilworth-Anderson, P., & Whitlatch, C. (2016). Predictors of discrepancy between dementia care dyads on the care recipients' quality of life. *The Gerontologist*, *56*(Suppl 3), 192–193.

National Institute for Health and Care Excellence. (2018). *Dementia: Assessment, management and support for people living with dementia and their carers*. Retrieved from https://www.nice.org.uk/guidance/ng97

Numbers, K., & Brodaty, H. (2021). The effects of the COVID-19 pandemic on people with dementia. *Nature Reviews Neurology, 17*(2), 69-70.

Patel, R., Irving, J., Brinn, A., Broadbent, M., Shetty, H., Pritchard, M., Downs, J., Stewart, R., Harland, R., & McGuire, P. (2021). Impact of the COVID-19 pandemic on remote mental healthcare and prescribing in psychiatry: an electronic health record study. *BMJ open*, *11*(3), e046365. https://doi.org/10.1136/bmjopen-2020-046365

Perkins, L., Fisher, E., Felstead, C., Rooney, C., Wong, G. H. Y., Dai, R., Vaitheswaran, S., Natarajan, N., Mograbi, D. C., Ferri, C. P., Stott, J., & Spector, A. (2022). Delivering Cognitive Stimulation Therapy (CST) Virtually: Developing and Field-Testing a New

Framework. *Clinical interventions in aging*, *17*, 97–116. https://doi.org/10.2147/CIA.S348906

Pike, K. E., Chong, M. S., & Hume, C. H. (2018). Providing online memory interventions for older adults: A critical review and recommendations for development. *Australian Psychologist, 53*(5), 367-376. https://doi.org/10.1111/ap.12345

Piras, F., Carbone, E., Faggian, S., Salvalaio, E., Gardini, S., & Borella, E. (2017). Efficacy of cognitive stimulation therapy for older adults with vascular dementia. *Dementia & neuropsychologia*, *11*(4), 434–441. https://doi.org/10.1590/1980-57642016dn11-040014

Pisaturo, M., Calò, F., Russo, A., Camaioni, C., Giaccone, A., Pinchera, B., Gentile, I., Simeone, F., Iodice, A., Maggi, P., & Coppola, N. (2021). Dementia as risk factor for severe coronavirus disease 2019: A case-control study. *Frontiers in Aging Neuroscience*, *13*, 698184. https://doi.org/10.3389/fnagi.2021.698184

Reamy, A. M., Kim, K., Zarit, S. H., & Whitlatch, C. J. (2011). Understanding discrepancy in perceptions of values: Individuals with mild to moderate dementia and their family caregivers. *The Gerontologist*, *51*(4), 473–483.

Saragih, I., Imanuel, S., Saragih, I., & Lee, B.-O. (2022). Effects of cognitive stimulation therapy for people with dementia: A systematic review and meta-analysis of randomized controlled studies. *International Journal of Nursing Studies, 128*, Article 104181.

Sharp, E. S., & Gatz, M. (2011). Relationship between education and dementia: an updated systematic review. *Alzheimer disease and associated disorders*, *25*(4), 289–304. https://doi.org/10.1097/WAD.0b013e318211c83c

Shaw, C., Hayes-Larson, E., Glymour, M. M., Dufouil, C., Hohman, T. J., Whitmer, R. A., Kobayashi, L. C., Brookmeyer, R., & Mayeda, E. R. (2021). Evaluation of selective survival and sex/gender differences in dementia incidence using a simulation model. *JAMA Network Open*, *4*(3), e211001. https://doi.org/10.1001/jamanetworkopen.2021.1001

Sheetal, S., & Mathew, R. (2024). Cognitive Stimulation Therapy in Dementia - Are We Sufficiently Stimulated?. *Annals of Indian Academy of Neurology*, *27*(1), 9–10. https://doi.org/10.4103/aian.aian_227_23

Spector, A., Thorgrimsen, L., Woods, B., & Orrell, M. (2017). *Making a difference: An evidence-based group program to offer cognitive stimulation therapy (CST) to people with dementia; The manual for group leaders* (G. H. Y. Wong, Trans.). Hong Kong University Press. ISBN: 978-988-8390-74-8.

Spector, A., Thorgrimsen, L., Woods, B., & Orrell, M. (2020). *Making a difference: An evidence-based group programme to offer cognitive stimulation therapy (CST) to people with dementia* (New ed.). Hawker Publications.

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *The British journal of psychiatry : the journal of mental science*, *183*, 248–254. https://doi.org/10.1192/bjp.183.3.248

Stephan, A., Bieber, A., Hopper, L., Joyce, R., Irving, K., Zanetti, O., Portolani, E., Kerpershoek, L., Verhey, F., de Vugt, M., Wolfs, C., Eriksen, S., Røsvik, J., Marques, M. J., Gonçalves-Pereira, M., Sjölund, B. M., Jelley, H., Woods, B., Meyer, G., &

Actifcare Consortium (2018). Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. *BMC geriatrics*, *18*(1), 131. https://doi.org/10.1186/s12877-018-0816-1

Sun, Y., Zhang, X., & Wang, Z. (2022). Comparative effectiveness of 3 settings of cognitive stimulation therapy on cognition and quality of life for people with dementia: A systematic review and network meta-analysis. *Journal of the American Medical Directors Association*, *23*(3), 461-467.e11. https://doi.org/10.1016/j.jamda.2021.11.015

Wong, G. H. Y. (2021). Dementia social care at home via information and communication technology. In *Promoting One Health in a Challenging Era*. Hong Kong.

Wong, G. H. Y., Yek, O. P. L., Zhang, A. Y., Lum, T. Y. S., & Spector, A. (2018). Cultural adaptation of cognitive stimulation therapy (CST) for Chinese people with dementia: multicentre pilot study. *International journal of geriatric psychiatry*, *33*(6), 841–848. https://doi.org/10.1002/gps.4663

Woods, B., Aguirre, E., Spector, A. E., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *The Cochrane database of systematic reviews*, (2), CD005562.

Part Three: Critical Appraisal

Introduction

This critical appraisal outlines my reflections on my research journey, focusing on my empirical paper- Cognitive Stimulation Therapy delivery (CST) for dementia in Hong Kong: randomised controlled trial of virtual versus in-person groups. It also relates to the topic of my systematic analysis that aims at improving dementia awareness and reducing dementia stigma in the community. I begin by discussing how my previous experiences informed the study and shaped my initial aspirations. The appraisal then delves into reflections on overseas collaboration, assessment processes, and the integration of Social Graces into both the research and practice. Finally, I offer recommendations for virtual CST (vCST) delivery based on insights gained from the intervention process.

Previous Experiences that Influenced the Study

My research journey was closely related to my personal and professional experience. My research project is not solely academic research but includes my initial aspiration and observation of lives related to older adult populations.

Personal Lived Experience

Regarding my personal experience, my research is greatly influenced by my lived experience of having a family member living with dementia for years. I witnessed the struggle of my grandmother after her diagnosis of dementia for more than ten years. I also witnessed the hardship that my mother faced, when offered care and support to my grandmother, especially with the emotional toll associated with dementia care. This personal connection that has been rooted in me since my adolescence contributed to my initial aspiration towards older adults and dementia care.

Dementia has been a constant presence in my family. I witnessed the deterioration of cognitive ability, behavioural as well as personality changes that my grandmother experienced. These changes not only impacted her mental health but also impacted her quality of life over time. Although she lived with the family, she felt much isolated and faced a lot of stigma because of misunderstandings within the wider family and the community. This experience urged me to explore effective social intervention and community education programmes. In addition, my mother, as a carer, suffered from physical exhaustion, emotional burn-out and social stigma, indicating the vast need for effective carer support in the dementia caring journey.

Clinical Experience

My clinical experience as a medical social worker in Hong Kong and a trainee clinical psychologist in the UK contributed significantly to my research journey. Through my clinical work with older adults, I recognised a lot of deterioration in cognitive ability and social functioning. While working within a systemic approach, I revealed a significant service gap in dementia care in terms of accessibility and availability of cognitive and social interventions. According to the latest Census in Hong Kong (2023), there were more than 1.45 million older adults in 2021. It is projected that about one-third of the population will be aged 65 or above by 2041, with estimates suggesting that almost one-tenth of this elderly population will be living with dementia, with reference to a mental health report (2017). This rising population with unmet needs in Hong Kong motivated me to explore possible solutions in dementia care. I recognised that although there were some available local interventions for older adults in Hong Kong, little research has been done, and the accessibility is also limited. Many older adults were not able to access the services due to physical disability or lack of community support. This observation in my clinical work drove me to explore ways to improve service accessibility with the advancement of technology.

Societal Context and Challenges

Societal changes, particularly with the increasing emigration of residents from Hong Kong in recent years, added additional considerations for my research. The backgrounds of many emigrants are middle-class, well-educated professionals in their 30s-40s. This mass emigration wave has left many older adults behind, resulting in a change in the family and social structures. Moreover, many people who left Hong Kong were healthcare professionals, which created a service gap in professional care for older adults in Hong Kong. This shift has marked the necessity of considering effective online and cross-regional interventions. This demographical change has led to the exploration of vCST with the potential to transcend geographical barriers, allowing emigrants who are professionals to offer intervention to address the service gap. The virtual intervention could provide flexibility and accessibility to address the logistical challenges and scarcity of Hong Kong professional resources.

Reflecting on my position within the research, it is clear that my personal and professional experiences have profoundly influenced my initial aspirations. With the societal changes, I hope the current project can contribute to the development of CST intervention and dementia services in Hong Kong. Ultimately, I hope it can improve the wellbeing of older adults in Hong Kong and potentially serve as a reference for other countries that face similar challenges.

Reflections on Overseas Collaboration

As a part of a large-scale project at the University of Hong Kong (HKU), my empirical study involved a close collaboration with the HKU research team. This has been an enriching overseas collaboration and has offered me valuable insights into my research skills and learning experience.

One of the important learning points of international collaboration was the importance of planning and flexibility to accommodate across different time zones. Research is not only about numbers and statistics. It involves a lot of coordination work, including research meetings, information sharing and collaborative analysis. Often, we had to arrange the meeting in the early morning or late evening to accommodate our schedules. This experience highlighted the importance of effective time management and adaptability. Moreover, most of our meetings and communications were online. It differed from face-to-face interaction, which requires utilising the digital communication platform to ensure a productive partnership.

Overseas collaboration also allowed me to learn more about data privacy and security. I had the opportunity to deepen my understanding of the privacy regulations in both Hong Kong and the UK, from the security of data transmission to the storage of data according to the protocol. This collaboration has enriched my knowledge of data protection methods and standards, which are essentially important in different kinds of research.

Regarding the different research timeframes at UCL and HKU, flexibility and proactive planning were essential milestones in my research journey. There were variations in project deadlines, academic calendars, manpower resources and administrative process in managing the research project. In retrospect, providing a clear timeline at the initial stage and open communication in the progress were crucial strategies to ensure a smooth cooperation. Regular check-in and progress review were also essential to keep everything on track.

In conclusion, I found the overseas cooperation with HKU to be a fulfilling experience for me. Many insights and practical skills were learned in the process, not only related to the research techniques but also the project management abilities. The remote communication style and understanding of international standards will undoubtedly benefit my future academic and professional development.

Reflections on Assessment

The assessment in my project is not only about data collection. The assessment process offered me valuable insights into how to work with older adults and carers, as well as practical challenges faced in dementia research.

Conducting In-Person Assessments

In the assessment phase, I had the privilege to travel back to Hong Kong and conduct in-person assessments with older adults. It was an important component in my research, enabling me to directly engage with older adults and their carers. During the process, I gained a first-hand understanding of how dementia impacted their cognitive function, quality of life, and social function. These precious opportunities allowed me to observe their subtle behaviours and non-verbal cues which might be overlooked in virtual settings. The in-person assessment was also crucial in facilitating a rapport-building process. By creating a supportive and secure environment with the participants, the researchers could obtain a more honest and accurate response during assessment.

Leveraging Interviewing Skills

Interviewing people living with dementia (PLwD) requires specific techniques and considerations which share similarities with clinical interventions. During my assessment, I referred to previous research and specifically considered several factors, including informed consent, liaison with family and community services, and addressing symptoms of physical conditions and dementia (Samsi & Manthorpe, 2020). My previous clinical experience with older adults has proven valuable and contributed to effective assessment. Before the interviews, I tried to set up a comfortable environment for PLwD with limited environmental stimulation or distraction. During the interviews, I utilised different communication strategies to facilitate their expression of thoughts and feelings, which included using simple and straightforward language, allowing more time for responses, being responsive and attentive to their emotional changes. These techniques are essential not only for the data collection process but also highlight the importance of a person-centred dementia research approach.

In conclusion, the journey of conducting assessment allowed me to gather necessary data and equipped me to be a more compassionate dementia researcher who addresses the diversified needs of PLwD. In retrospect, I found that it enhanced my understanding of the complexity of dementia research and helped me develop transferable skills as a scientific practitioner.

Reflection on Social Graces from Research to CST Delivery

In working with older adults, in particular with those living with dementia, it is important to mindfully consider how different Social Graces (Anderson et al., 2010) impact their lives and wellbeing. This sensitivity allows me to conduct the research respectfully and ethically. During my research journey, I have identified several key areas within Social Graces, including culture, gender, ageism, class, education, and power dynamics.

Understanding Cultural Context with Cultural Sensitivity

Although I share the same ethnic background as my participants, I am always aware of the diverse cultural experiences within the older adult population in Hong Kong. Many participants were not born or raised in Hong Kong but came from mainland China in their later lives, bringing different childhood histories or even dialects. With cultural sensitivity, I was attentive to any cultural norms, traditions, and values that influenced their understanding and engagement with CST. For example, when I was incorporating reminiscence activities into the sessions, I always handled potentially sensitive topics such as childhood trauma and sociopolitical changes with care. I also incorporated accessible and respectful language in CST delivery, ensuring all session activities were framed in a culturally appropriate manner.

Gender Considerations

The experience of ageing and dementia is significantly influenced by gender. For instance, females not only show a higher incidence of dementia (Alzheimer's Association, 2017) but also often take up a substantial share of caregiving responsibilities in traditional Chinese culture. Gender stereotypes and disparities have remained prevalent in Chinese society. Thus, understanding these gender-specific experiences was essential in my research journey. During my interactions with participants, I tried my best to ensure that questions and conversations were free from gender bias and stereotypes. Moreover, acknowledging the additional caring burdens female caregivers might face, I realised it is important to address their caregiving roles and responsibilities as part of their identity. This acknowledgement helped foster an environment of understanding and empathy.

Challenging Ageist Attitudes and Promoting Positive Ageing

Ageism can subtly affect how older adults are treated and perceived, not only in the research process but also in the broader society. In addition, dementia is still heavily stigmatised, which impacts the wellbeing of PLwD (Alzheimer's Disease International. 2019; Nguyen & Li, 2020). In contrast, CST promotes a positive ageing attitude with person-centred and strength-based approaches. It focuses on PLwD's capabilities rather than their cognitive or physical deficits. PLwD's needs are addressed by tailored activities and adapted interventions with reference to the key CST principles (Spector et al., 2020), which include providing person-centred interventions, offering choices, and ensuring respect and inclusion. PLwD are empowered by respecting their choices and preferences. It helps them feel valued, listened to and understood, which enhances their engagement in the group.

Socioeconomic Status and Education Level

Socioeconomic status and education level significantly affect the accessibility of healthcare services and resources (McMaughan et al., 2020; Zajacova & Lawrence, 2018). It should be noted that participants in the empirical study varied from limited literacy to postgraduate levels. It is crucial to address digital exclusion, in particular for participants from a lower socioeconomic and educational background with potentially lower digital literacy (Dodge et al., 2014). This should be well-considered in research studies involving virtual interventions. In order to address digital exclusion, the research project ensured that technical support was available in elderly community centres. Digital devices were subsidised and provided to all participants. Additionally, to value the input of PLwD and carers, compensations were offered for their time. Furthermore, regarding the varied educational background, the intervention was carefully designed to ensure inclusion, for example, using simple language, visual aids and repeating key information to ensure a smooth communication and group process.

Navigating Power Dynamics and Promoting Service User Involvement

In conducting research, I always find it vital to acknowledge the inherent power imbalance between researchers and participants, especially when working with a vulnerable population. Thus, empowerment plays a key role in ethical research practice, aligning with CST delivery principles. I hoped to empower participants by involving them in the group decision process and valuing their input. Their involvement in my project was not only about providing research data, but also developing a sense of control and ownership over their participation. At the research level, the study emphasised informed consent and transparency about the research aims. Sessions and interviews were scheduled with a priority to PLwD and their family, while accommodating their daily routine. In the early phase of the research, a participatory design approach was adopted to refine the vCST protocols according to the experience of PLwD and carers. At the CST delivery level, the group practice values participants' involvement and building mutual trust. Participants were involved in co-designing the group's name, song and norms setting. Activities were adjusted according to their interests, and feedback was collected at the end of every session. Careful consideration was made to accommodate any physical or cognitive limitations in order to enhance their comfort and wellbeing. Last but not least, I found that expressing genuine interest and concern for their wellbeing proved to be vital in addressing the power difference and building a respectful relationship.

Recommendations for the Sessions

In retrospect, my research journey involved many considerations to ensure adequate support for every participant, especially in delivering virtual intervention. I tried to consolidate several key recommendations when providing virtual sessions as follows:

Engagement in Virtual Sessions

I cannot deny that virtual sessions can sometimes feel less engaging compared to in-person sessions. In order to maintain attention and interest, it is helpful to include interactive activities and multimedia resources. By utilising the advantages of the online platform, sessions should consider using more videos, music, colourful slides and interactive games, which can increase participants' involvement. Adjustment according to the physical and cognitive levels is also essential to ensure sessions are both stimulating and accessible to everyone.

Carer Involvement

Carers play an indispensable role in the delivery of virtual sessions. From my experience, extensive liaison work is often required before and after sessions. In handling the online platform, clear instructions and training for carers are crucial to secure a smooth delivery as they are the ones who set up the laptop or tablet at home. Regular check-ins and reminders have proven helpful in addressing concerns or technical problems. With sufficient carer support, carers could feel more confident and prepared to assist in virtual interventions.

Systemic Approach

Adopting a systemic approach when working with elderly community centres is crucial. Regular communication with key workers ensures that participants receive the necessary support outside the session. Post-intervention follow-up and long-term support provided by key workers are vital for the wellbeing of participants. In practice, centres can offer additional resources, such as lending digital devices or providing spaces for in-person sessions. This systemic approach encourages enduring and comprehensive support available for participants before and after the group intervention.

Handling Absence of Sessions

Recognising both the challenges and commitments of PLwD in attending the sessions is vital. It poses an additional challenge for virtual facilitators when they may not see the carers frequently. Thus, when a participant does not attend sessions frequently, it may indicate an engagement difficulty or other healthcare issues that can be overlooked. Facilitators should contact the carers and the community centres to render necessary support. This practice helps to ensure that PLwD remains supported even in virtual settings.

Handling Emotional Difficulties Virtually

Emotions are normal responses; their expression is an important part of the group process. Some sessions might evoke intense emotions, in particular when conducting reminiscence activities and associating difficult memories. It is crucial to create a safe and supportive environment where these emotions are allowed to be expressed securely. Information related to any previous trauma or sensitive topics should be collected from the carer during the recruitment phase. Building a strong rapport from the beginning also helps handle emotional responses effectively.

Inviting Feedback

Facilitators are advised to collect feedback at the end of each session. This empowering process allows participants to share their thoughts and suggestions openly. By proactively asking and incorporating feedback, sessions can be improved and stayed relevant to the needs of the participants.

Technical Support

In delivering virtual sessions, it is critical to ensure the availability of technical support. Facilitators should receive training in handling basic technical issues related to the online platform and tablet. This can help prevent disruptions and allow sessions to run smoothly.

Conclusions

Reflecting on my thesis journey, I discovered how my personal and professional experience informed my position in research and dementia care. They are foundations of my professional development, influencing my initial aspirations and deeply enhancing my understanding of PLwD. In the process, I engaged in meaningful overseas collaborations which broadened my horizon in research. The reflection in assessment and integration of Social Graces allowed me to conduct research in an ethical and respectful manner. My reflections on this research have solidified my commitment to providing compassionate and person-centred dementia care. The insights are not only research-related but are transferrable to my clinical practice as a scientific practitioner. With recommendations on the service delivery, I hope that dementia care service can be further advanced and enhance the wellbeing of PLwD and their carers in Hong Kong and worldwide.

References

Alzheimer’s Association. (2017). Alzheimer’s disease facts and figures. *Alzheimers Dement 2017, 13*, 325–373.

Alzheimer's Disease International. (2019). *World Alzheimer report 2019: Attitudes to dementia*. London: Alzheimer's Disease International.

Anderson, E., Fredman, G., & Stott, J. (2010). *Being with older people: A systemic approach*. Routledge.

Census and Statistics Department, Hong Kong Special Administrative Region. (2023). *Thematic report: Older persons*. 2021 Population Census Office. Published in February 2023. Retrieved from https://www.censtatd.gov.hk/en/EIndexbySubject.html?scode=600&pcode=B1120118

Dodge, H. H., Katsumata, Y., Zhu, J., Mattek, N., Bowman, M., Gregor, Wild, K., & Kaye, J. A. (2014). Characteristics associated with willingness to participate in a randomized controlled behavioral clinical trial using home-based personal computers and a webcam. *Trials,* 15, 508.

McMaughan, D. J., Oloruntoba, O., & Smith, M. L. (2020). Socioeconomic status and access to healthcare: Interrelated drivers for healthy aging. *Frontiers in Public Health*, *8*, 231. https://doi.org/10.3389/fpubh.2020.00231

Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia, 19*(2), 148-181. https://doi.org/10.1177/1471301218800122

Review Committee on Mental Health. (2017). *Mental health review report*. Secretary for Food and Health, Hong Kong SAR Government. Retrieved from https://www.healthbureau.gov.hk/download/press_and_publications/otherinfo/180500_mhr/e_mhr_full_report.pdf

Samsi, K., & Manthorpe, J. (2020). *Interviewing people living with dementia in social care research*. NIHR School for Social Care Research. https://www.sscr.nihr.ac.uk/publication/mr022/

Spector, A., Thorgrimsen, L., Woods, B., & Orrell, M. (2020). *Making a difference: An evidence-based group programme to offer cognitive stimulation therapy (CST) to people with dementia* (New ed.). Hawker Publications.

Zajacova, A., & Lawrence, E. M. (2018). The relationship between education and health: Reducing disparities through a contextual approach. *Annual Review of Public Health*, *39*, 273–289. https://doi.org/10.1146/annurev-publhealth-031816-044628

Appendices

Appendix A. Downs and Black Checklist

Reporting

1. Is the hypothesis/aim/objective of the study clearly described?
2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?
3. Are the characteristics of the subjects included in the study clearly described?
4. Are the interventions of interest clearly described?
5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?
6. Are the main findings of the study clearly described?
7. Does the study provide estimates of the random variability in the data for the main outcomes?
8. Have all important adverse events that may be a consequence of the intervention been reported?
9. Have the characteristics of subjects lost to follow-up been described?
10. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?

External validity

11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?
12. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?
13. Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?

Internal Validity

14. Was an attempt made to blind study subjects to the intervention they have received?
15. Was an attempt made to blind those measuring the main outcomes of the intervention?

16. If any of the results of the study were based on “data dredging”, was this made clear?
17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?
18. Were the statistical tests used to assess the main outcomes appropriate?
19. Was compliance with the intervention/s reliable?
20. Were the main outcome measures used accurate (valid and reliable)?

Internal Validity – confounding (selection bias)

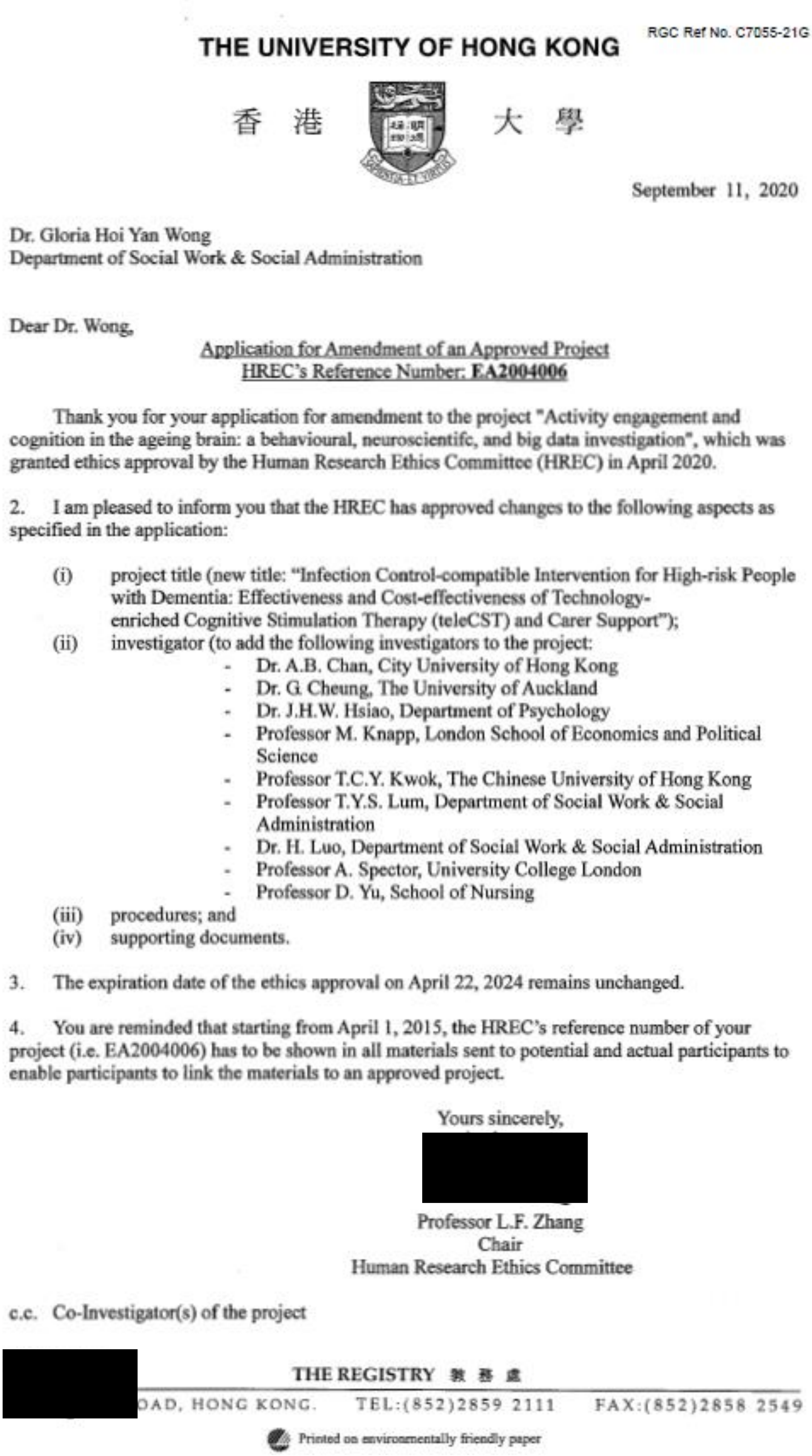
21. Were the subjects in different intervention groups or were they recruited from the same population?
22. Were study subjects in different intervention groups or were they recruited over the same period of time?
23. Were study subjects randomised to intervention groups?
24. Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?
25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?
26. Were losses of subjects to follow-up taken into account?

Power

27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?

Scoring: Yes (1) No (0) N/A (0) Unable to determine (0)

Appendix B. Ethical Approval Letter



RGC Ref No. C7055-21G

THE UNIVERSITY OF HONG KONG

香 港 大 學

September 11, 2020

Dr. Gloria Hoi Yan Wong
Department of Social Work & Social Administration

Dear Dr. Wong,

Application for Amendment of an Approved Project
HREC's Reference Number: **EA2004006**

Thank you for your application for amendment to the project "Activity engagement and cognition in the ageing brain: a behavioural, neuroscientifc, and big data investigation", which was granted ethics approval by the Human Research Ethics Committee (HREC) in April 2020.

2. I am pleased to inform you that the HREC has approved changes to the following aspects as specified in the application:

(i) project title (new title: "Infection Control-compatible Intervention for High-risk People with Dementia: Effectiveness and Cost-effectiveness of Technology-enriched Cognitive Stimulation Therapy (teleCST) and Carer Support");

(ii) investigator (to add the following investigators to the project:
  - Dr. A.B. Chan, City University of Hong Kong
  - Dr. G. Cheung, The University of Auckland
  - Dr. J.H.W. Hsiao, Department of Psychology
  - Professor M. Knapp, London School of Economics and Political Science
  - Professor T.C.Y. Kwok, The Chinese University of Hong Kong
  - Professor T.Y.S. Lum, Department of Social Work & Social Administration
  - Dr. H. Luo, Department of Social Work & Social Administration
  - Professor A. Spector, University College London
  - Professor D. Yu, School of Nursing

(iii) procedures; and

(iv) supporting documents.

3. The expiration date of the ethics approval on April 22, 2024 remains unchanged.

4. You are reminded that starting from April 1, 2015, the HREC's reference number of your project (i.e. EA2004006) has to be shown in all materials sent to potential and actual participants to enable participants to link the materials to an approved project.

Yours sincerely,

[redacted]

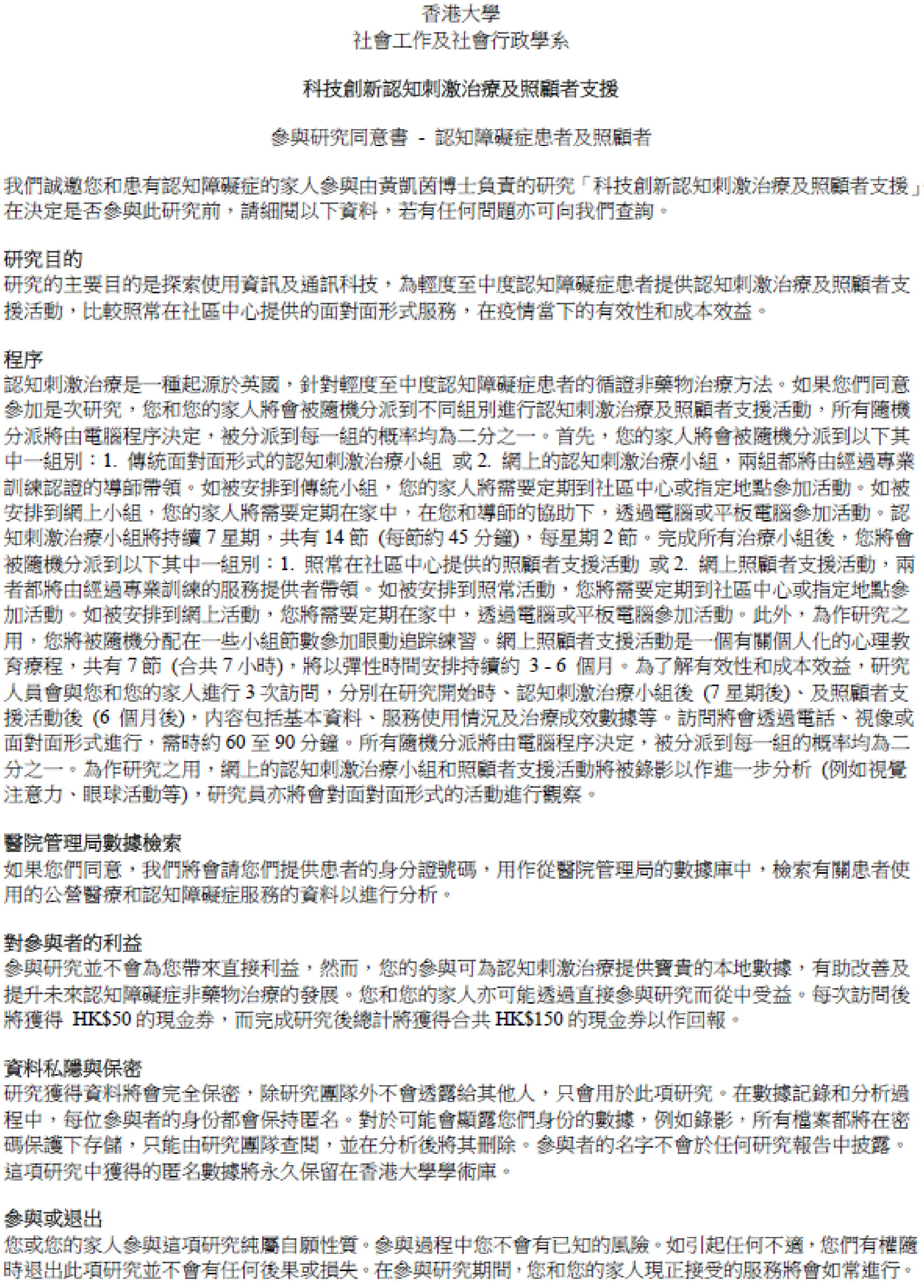
Professor L.F. Zhang
Chair
Human Research Ethics Committee

c.c. Co-Investigator(s) of the project

THE REGISTRY 教 務 處
[redacted]OAD, HONG KONG. TEL:(852)2859 2111 FAX:(852)2858 2549

Printed on environmentally friendly paper

Appendix C. Information Sheet and Consent Form



香港大學
社會工作及社會行政學系

科技創新認知刺激治療及照顧者支援

參與研究同意書 - 認知障礙症患者及照顧者

我們誠邀您和患有認知障礙症的家人參與由黃凱茵博士負責的研究「科技創新認知刺激治療及照顧者支援」。在決定是否參與此研究前，請細閱以下資料，若有任何問題亦可向我們查詢。

研究目的

研究的主要目的是探索使用資訊及通訊科技，為輕度至中度認知障礙症患者提供認知刺激治療及照顧者支援活動，比較照常在社區中心提供的面對面形式服務，在疫情當下的有效性和成本效益。

程序

認知刺激治療是一種起源於英國，針對輕度至中度認知障礙症患者的循證非藥物治療方法。如果您們同意參加是次研究，您和您的家人將會被隨機分派到不同組別進行認知刺激治療及照顧者支援活動，所有隨機分派將由電腦程序決定，被分派到每一組的概率均為二分之一。首先，您的家人將會被隨機分派到以下其中一組別：1. 傳統面對面形式的認知刺激治療小組 或 2. 網上的認知刺激治療小組，兩組都將由經過專業訓練認證的導師帶領。如被安排到傳統小組，您的家人將需要定期到社區中心或指定地點參加活動。如被安排到網上小組，您的家人將需要定期在家中，在您和導師的協助下，透過電腦或平板電腦參加活動。認知刺激治療小組將持續 7 星期，共有 14 節 (每節約 45 分鐘)，每星期 2 節。完成所有治療小組後，您將會被隨機分派到以下其中一組別：1. 照常在社區中心提供的照顧者支援活動 或 2. 網上照顧者支援活動，兩者都將由經過專業訓練的服務提供者帶領。如被安排到照常活動，您將需要定期到社區中心或指定地點參加活動。如被安排到網上活動，您將需要定期在家中，透過電腦或平板電腦參加活動。此外，為作研究之用，您將被隨機分配在一些小組節數參加眼動追踪練習。網上照顧者支援活動是一個有關個人化的心理教育療程，共有 7 節 (合共 7 小時)，將以彈性時間安排持續約 3 - 6 個月。為了解有效性和成本效益，研究人員會與您和您的家人進行 3 次訪問，分別在研究開始時、認知刺激治療小組後 (7 星期後)、及照顧者支援活動後 (6 個月後)，內容包括基本資料、服務使用情況及治療成效數據等。訪問將會透過電話、視像或面對面形式進行，需時約 60 至 90 分鐘。所有隨機分派將由電腦程序決定，被分派到每一組的概率均為二分之一。為作研究之用，網上的認知刺激治療小組和照顧者支援活動將被錄影以作進一步分析 (例如視覺注意力、眼球活動等)，研究員亦將會對面對面形式的活動進行觀察。

醫院管理局數據檢索

如果您們同意，我們將會請您們提供患者的身分證號碼，用作從醫院管理局的數據庫中，檢索有關患者使用的公營醫療和認知障礙症服務的資料以進行分析。

對參與者的利益

參與研究並不會為您帶來直接利益，然而，您的參與可為認知刺激治療提供寶貴的本地數據，有助改善及提升未來認知障礙症非藥物治療的發展。您和您的家人亦可能透過直接參與研究而從中受益。每次訪問後將獲得 HK$50 的現金券，而完成研究後總計將獲得合共 HK$150 的現金券以作回報。

資料私隱與保密

研究獲得資料將會完全保密，除研究團隊外不會透露給其他人，只會用於此項研究。在數據記錄和分析過程中，每位參與者的身份都會保持匿名。對於可能會顯露您們身份的數據，例如錄影，所有檔案都將在密碼保護下存儲，只能由研究團隊查閱，並在分析後將其刪除。參與者的名字不會於任何研究報告中披露。這項研究中獲得的匿名數據將永久保留在香港大學學術庫。

參與或退出

您或您的家人參與這項研究純屬自願性質。參與過程中您不會有已知的風險。如引起任何不適，您們有權隨時退出此項研究並不會有任何後果或損失。在參與研究期間，您和您的家人現正接受的服務將會如常進行。

疑問與查詢

如有任何疑問，請與本研究人員楊嘉怡小姐聯絡 (電話: 3910 2117; 電郵: kymag880@hku.hk)。如想知道更多有關研究參與者的權益，請聯絡香港大學研究操守委員會 (電話: 2241 5267; 研究參考編號: EA2004006)。

如您們同意參與這項研究，請填寫以下回條：

參與者同意聲明

請✓以下選項

我們已閱讀，或有人向我們說明，及我們明白以上內容。 □
我們已有機會對不明白的部分進行提問，並獲得解答。 □
我們明白參與這項研究純屬自願性質，我們有權隨時退出此項研究並不會有任何後果或損失。 □
我們(我和患有認知障礙症的家人)同意參與是項研究。 □
我們(我和患有認知障礙症的家人)同意在研究過程中被錄影或觀察以作分析之用。 □
我們(我和患有認知障礙症的家人)同意提供患者的身分證號碼以作醫院管理局數據檢索之用。 □

我們 希望 / 不希望* (*請刪去不適用者)香港大學的研究團隊在研究結束後聯絡我們，與我們分享研究結果及未來相關的研究資訊。

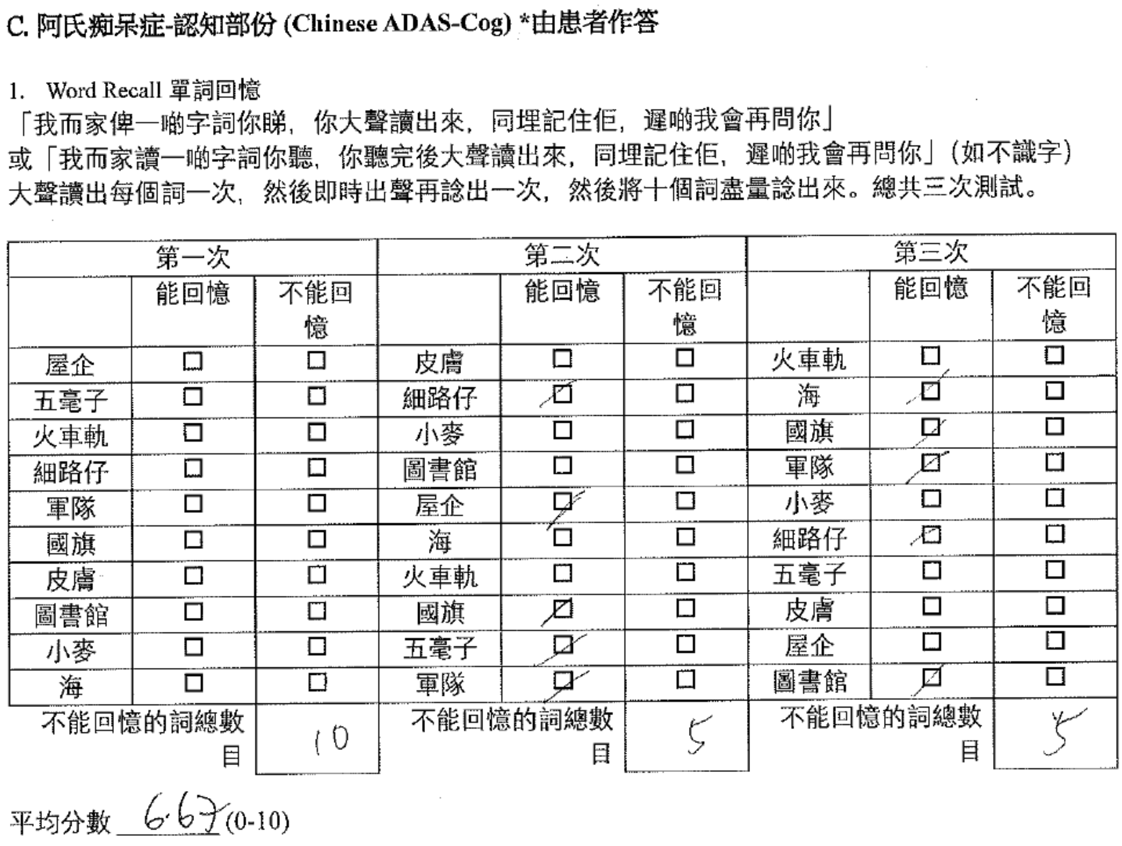
被照顧者姓名	被照顧者簽名	日期
照顧者姓名	照顧者簽名	日期

研究員簽名

我已向參加者解釋此研究及解答他／她的問題。我相信他／她明白以上資料及同意參與此研究。

研究員姓名	研究員簽名	日期

Appendix D. ADAS-Cog Chinese Version



C. 阿氏痴呆症-認知部份 (Chinese ADAS-Cog) *由患者作答

1. Word Recall 單詞回憶

「我而家俾一啲字詞你睇，你大聲讀出來，同埋記住佢，遲啲我會再問你」
或「我而家讀一啲字詞你聽，你聽完後大聲讀出來，同埋記住佢，遲啲我會再問你」（如不識字）
大聲讀出每個詞一次，然後即時出聲再諗出一次，然後將十個詞盡量諗出來。總共三次測試。

第一次			第二次			第三次		
	能回憶	不能回憶		能回憶	不能回憶		能回憶	不能回憶
屋企	□	□	皮膚	□	□	火車軌	□	□
五毫子	□	□	細路仔	☑	□	海	☑	□
火車軌	□	□	小麥	□	□	國旗	☑	□
細路仔	□	□	圖書館	□	□	軍隊	☑	□
軍隊	□	□	屋企	☑	□	小麥	□	□
國旗	□	□	海	□	□	細路仔	☑	□
皮膚	□	□	火車軌	□	□	五毫子	□	□
圖書館	□	□	國旗	☑	□	皮膚	□	□
小麥	□	□	五毫子	☑	□	屋企	□	□
海	□	□	軍隊	☑	□	圖書館	☑	□
不能回憶的詞總數目		10	不能回憶的詞總數目		5	不能回憶的詞總數目		5

平均分數 6.67 (0-10)

2. Naming Objects and Fingers 物品名稱和手指名稱

每位測試者會逐一看 12 件物品，每件看一次，然後說出它的名稱。問題如下:
「這件物件叫做甚麼名稱？」或「這是甚麼？」或「呢樣係乜」。可能加少許提示:

物品	標準指示	正確	不正確
花	生長於花園的生物	□	□
床	睡眠時用	□	□
銀雞（哨子）	你吹它會有聲出	□	□
鉛筆	寫字用	□	□
嘟嘟	BB 的玩具	□	☑
面具	用來遮面	□	□
鉸剪	可以剪紙	□	□
梳	頭髮用	□	□
荷包	放錢用	□	□
口琴	樂器一種	□	□
聽筒	醫生用嘅儀器	□	☑
夾	用黎拿東西的工具	□	□
被訪者說出他（她）右手每一隻手指的名稱			
手指公		□	☑
食指（第二隻手指）		□	□
中指		□	☑
無名指（第四隻手指）		□	☑
手指尾		□	☑
		總共	6

分數: □ 0 = 0 – 2 樣東西錯了
□ 1 = 3 – 5 樣東西錯了
☑ 2 = 6 – 8 樣東西錯了
□ 3 = 9 – 11 樣東西錯了
□ 4 = 12 – 14 樣東西錯了
□ 5 = 15 – 17 樣東西錯了

3. Commands 口頭指令

在每一句指令讀出後，便要求被訪者做到以下行動。若做不到或做錯，便重新再讀一次指令。

指令	正確	不正確
握緊拳頭（左手或右手）	☑	□
先指一下屋頂，跟住指一下地下	☑	□
在枱上面放一支鉛筆，手錶和啤牌，然後說出以下指令		
將支鉛筆放係啤牌上面，跟住將佢放番原位	□	☑
將隻手錶放係鉛筆旁邊，跟住反轉張啤牌	□	☑
合埋隻眼，用兩隻手指敲自己每邊膊頭兩下	□	☑
	總共	3

要完成每一個在劃線上的動作，才代表完成指令。

分數： □ 0 = 全對
□ 1 = 1 錯； 4 對
□ 2 = 2 錯； 3 對
☑ 3 = 3 錯； 2 對
□ 4 = 4 錯； 1 對
□ 5 = 全錯

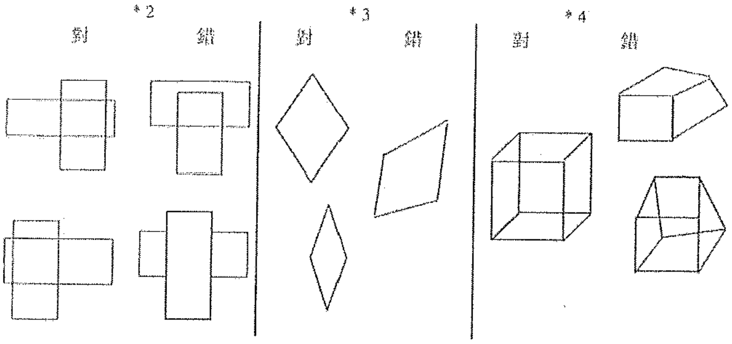
4. Constructional Praxis (Pencil and eraser) 繪圖行為（鉛筆和擦膠）
「呢到有一個圖形，你試下係呢張白紙上面畫一個同樣嘅圖」
每次容許兩次試畫。若果兩次皆不能畫出圖形，便作「錯」。

	對	錯（或畫不到）
圓形	☑	□
兩個重疊的長方形	□	☑
菱形	□	☑
立方形	□	☑
	「錯」的總數	3

分數：□ 0 = 全對
□ 1 = 1 形狀錯
□ 2 = 2 形狀錯
☑ 3 = 3 形狀錯
□ 4 = 全錯
□ 5 = 完全畫不到；畫了一部份；字而非圖形

附註：畫正確的圖形才可以取得分數。圖形的大小；隔線的闊窄；形狀的長短都不會計算在內。評分準則如下：

1. 圖形：要連續畫，沒有斷口的
2. 兩個重疊的長方形：圖形是四邊，重疊，如下*2。
3. 菱形：圖形是四邊；四邊邊界是差不多相同長度；上下對稱，如下*3。
4. 立方形：圖形是有三面體（正面及內線）對角線要平衡，如下*4。



5. Ideational Praxis 意向指令行為

「呢到有一封寫好嘅信。我想你將信摺好，放入信封入面。跟住將信封封口。在信封上寫上你自己的名和地址，再貼上郵票。」

如他（她）做不到或不明白，可以重複說出指示。

	對	錯（或做不到）
摺信	□	□
將信放入信封裡	□	□
封口	□	□
寫上姓名、地址	□	☑
表示郵票貼的位置	□	☑
	總數	2

分數：□ 0＝全對
- □ 1＝1 個步驟做不到
- ☑ 2＝2 個步驟做不到
- □ 3＝3 個步驟做不到
- □ 4＝4 個步驟做不到
- □ 5＝5 個步驟做不到

6. Orientation 認知行為

作此測試之前，先拿走（或遮蓋）時鐘，手錶或日曆。

	對	錯（沒有答）		對	錯（沒有答）
全名（必須正確）	☑	□	年（必須正確）	□	☑
星期幾（必須正確）	□	☑	季節（±2 星期）	□	☑
日期（±1 天）	□	☑	時間（±1 小時）	□	☑
月份（必須正確）	□	☑	地點（例如醫院）	☑	□
				總分(0-8)	6

註：可以接受的答案包括日期（±1 天），季節（下一季的一週之內或上季的兩週之內），時間（1 小時之內），地點（可以說出地點部份的名稱）。

7. Words Recognition 認字

「我而家俾一啲字你睇，你大聲讀出來同埋記住佢」或「而家讀一啲字詞你聽，你聽完跟我講一次，然後記住佢」(如病人不識字，由職員讀出)

甲) 第一次

河流	事件	皇后	位置	鴿子	信心
雨傘	提示	飛彈	代理權	龍蝦	標準

完成測試上述 12 個字後，便說：「我而家再俾另一啲字你睇，有一啲字頭先你已經睇過，有啲就冇睇過，你話番俾我聽有冇睇過啦？」或「我而家再讀另一啲字俾你聽，有一啲字頭自你已經聽過，有啲就冇聽過，你話番俾我聽，有冇聽過？」(如病人不識字，由職員讀出)

「呢個字有冇睇過（聽過）？」然後「呢個呢？」
如病人不記得問題，可以重複問題。請記下每次的提示。

乙) 第二次（展示誦讀同樣的 12 個字)

河流	事件	皇后	位置	鴿子	信心
雨傘	提示	飛彈	代理權	龍蝦	標準

丙) 第三次（展示誦讀同樣的 12 個字)

河流	事件	皇后	位置	鴿子	信心
雨傘	提示	飛彈	代理權	龍蝦	標準

深色是先前看過（聽過）的名。在病人的答案中。圓形代表錯的答案。若要重複問題，便在提示一方格以表示。

	有 (看過)	沒有 (新的)	提示		有 (看過)	沒有 (新的)	提示		有 (看過)	沒有 (新的)	提示
粟米	⊘	□	☒	河流	□	○	□	植物	⊘	□	□
努力	⊘	□	□	官員	⊘	□	☒	河流	□	○	☒
舞會	⊘	□	□	思想	⊘	□	☒	數量	○	□	☒
河流	□	⊘	□	事件	□	○	□	事件	□	○	□
愚蠢	⊘	□	□	皇后	□	○	□	皇后	□	○	□
儲物櫃	○	□	☒	位置	□	○	☒	工業	⊘	□	☒
事件	□	○	□	營地	○	□	□	位置	□	○	□
皇后	□	○	□	命運	⊘	□	□	時機	⊘	□	□
位置	□	○	□	高爾夫球	○	□	☒	鴿子	□	⊘	☒
品質	⊘	□	☒	鴿子	□	○	□	搖籃	⊘	□	☒
日落	⊘	□	□	信心	□	○	□	平凡	⊘	□	□
鴿子	□	○	☒	准許	⊘	□	☒	歌手	⊘	□	☒
信心	□	○	☒	雨傘	□	⊘	□	信心	□	○	□
雨傘	□	○	□	提示	□	⊘	□	雨傘	□	○	□
寓言	⊘	□	□	飛彈	□	⊘	☒	假設	⊘	□	☒
獵犬	○	□	☒	水泡	⊘	□	☒	提示	□	○	☒
成語	⊘	□	☒	概念	⊘	□	☒	飛彈	□	○	☒
提示	□	○	□	代理權	□	⊘	□	代理權	□	○	□
飛彈	□	○	□	鋼琴家	⊘	□	☒	繩結	⊘	□	□
珠寶	⊘	□	□	龍蝦	□	○	□	分別	⊘	□	☒
代理權	□	○	□	性別	⊘	□	□	龍蝦	□	⊘	☒
龍蝦	□	○	□	標準	□	○	☒	桶	⊘	□	☒
標準	□	⊘	☒	子彈	⊘	□	☒	標準	□	○	□
欺騙	⊘	□	□	智力	⊘	□	☒	法令	⊘	□	☒
	12		8		14		12		13		13

分數＝錯的總數或「12」（以最少為答案）

	分數	提示（次數）
第一次	12	8
第二次	14	12
第三次	13	13
分數（0 - 12）（註：三次的平均數）	13	總共提示：33

8. Remembering Testing Instructions (recall test instructions) 記憶問題和拍示的評分級別

在問題 7 的測試過程中，評估病人記憶問題的能力。

分數：☑ 0＝不用提醒
- □ 1＝非常輕微；忘記一次
- □ 2＝輕微；提示兩次
- □ 3＝中等；提示三至四次
- □ 4＝嚴重；提示五至六次
- ☑ 5＝非常嚴重；提示七次以上

9. Spoken Language Ability 口語表達的能力

對被訪者口語表達能力給予一個整體總評分（如清晰程度，容易明白的程度等質素）

分數：☑ 0＝無困難
- □ 1＝非常輕微困難
- □ 2＝輕微困難（少於四分之一）
- □ 3＝中等困難（四分之一至一半）
- □ 4＝中等嚴重（一半以上）
- □ 5＝非常嚴重（只能說單字或沒有內容的說話）

（有沒有語言障礙：有 □；沒有 □）

10. Word-finding Difficulty in Spontaneous Speech 說話時的用字缺陷

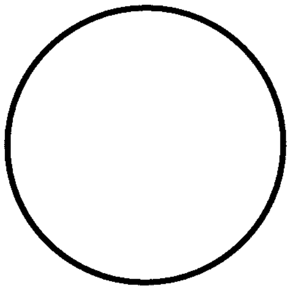
評估被訪者說話時是否有選詞方面的困難

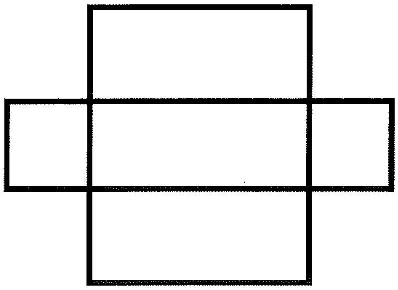
分數：☑ 0＝用字無困難
- □ 1＝非常輕微困難
- □ 2＝輕微困難（用其他字替代）
- □ 3＝中等困難（少了一些字又不會用其他字代替）
- □ 4＝中等嚴重（少了許多字）
- □ 5＝非常嚴重（差不多完全沒有內容；空調的發音；說 1 或 2 字）

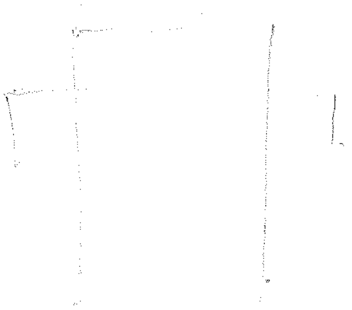
11. Comprehension of Speech 理解語言的能力
評估病人理解語言的能力。口頭指令的行動不用計算在內。
分數：☑ 0 = 無困難
□ 1 = 非常輕微；1 – 2 次不明白
□ 2 = 輕微；3 – 5 次不明白
□ 3 = 中等；要重複說多次
□ 4 = 嚴重；只能答是否等
□ 5 = 非常嚴重；很少適當地回答問題，而又不是因語言貧乏原因

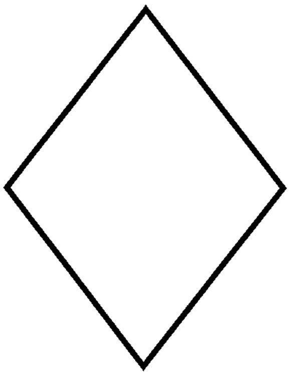
阿氏痴呆症 – 認知部份(ADAS-Cog)
總分（0 – 70）：43.33

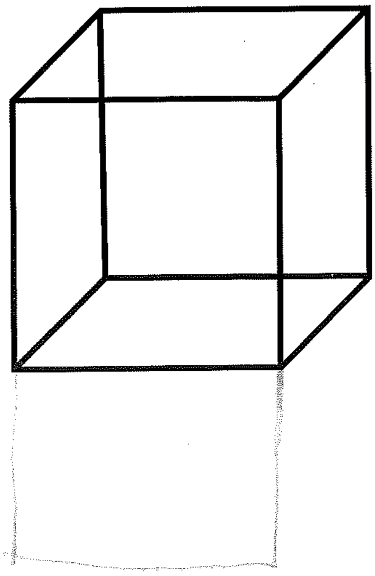
附註：注意力不集中
12.評估病人有沒有集中注意力接受測試，或注意力受到分散的情況。
分數：□ 0 = 無
□ 1 = 非常輕微；一次
□ 2 = 輕微；兩至三次
□ 3 = 中等；四至五次
☑ 4 = 嚴重；大部份時間不能集中精神
□ 5 = 非常嚴重；完全不能完成測試的工作



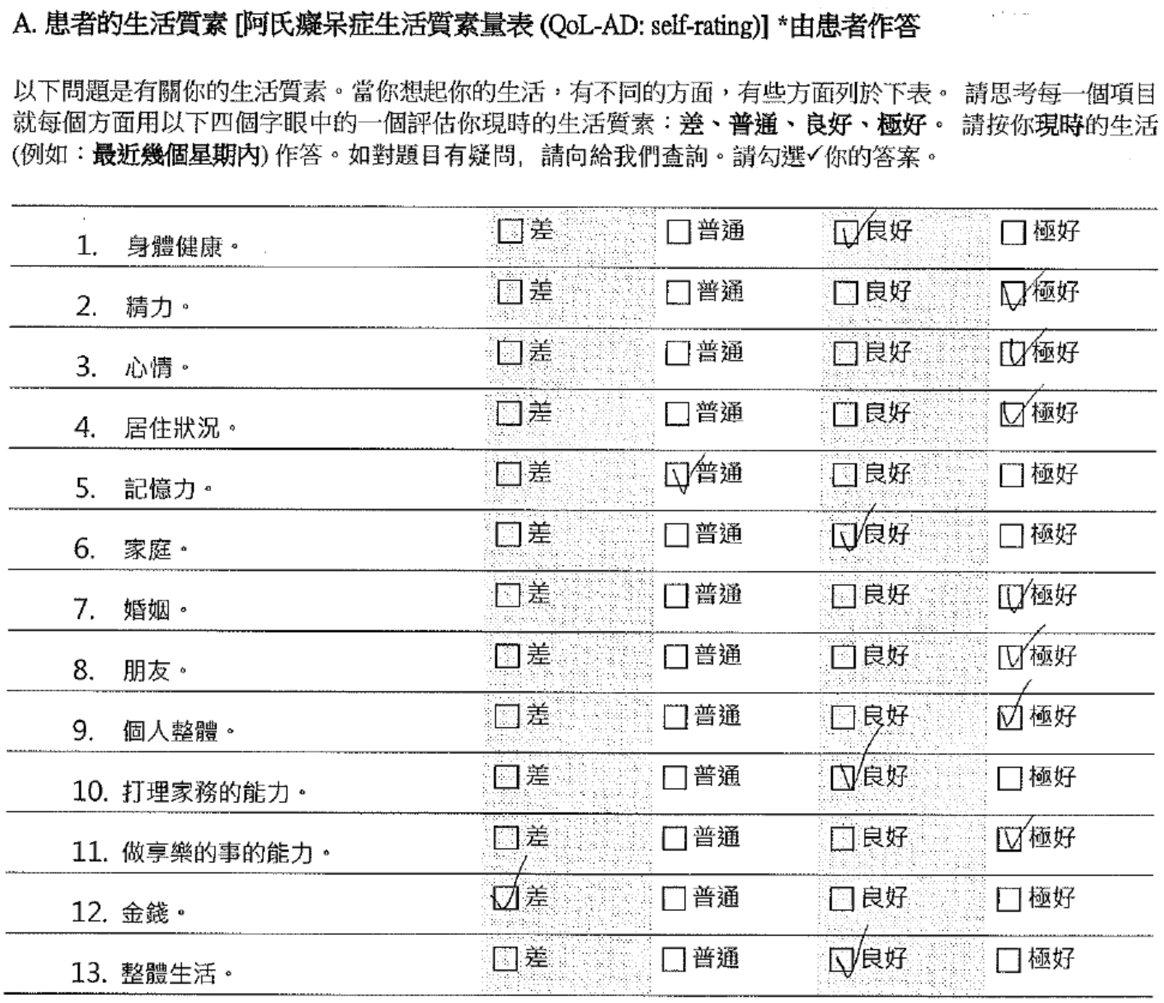








Appendix E. QoL-AD self-reported

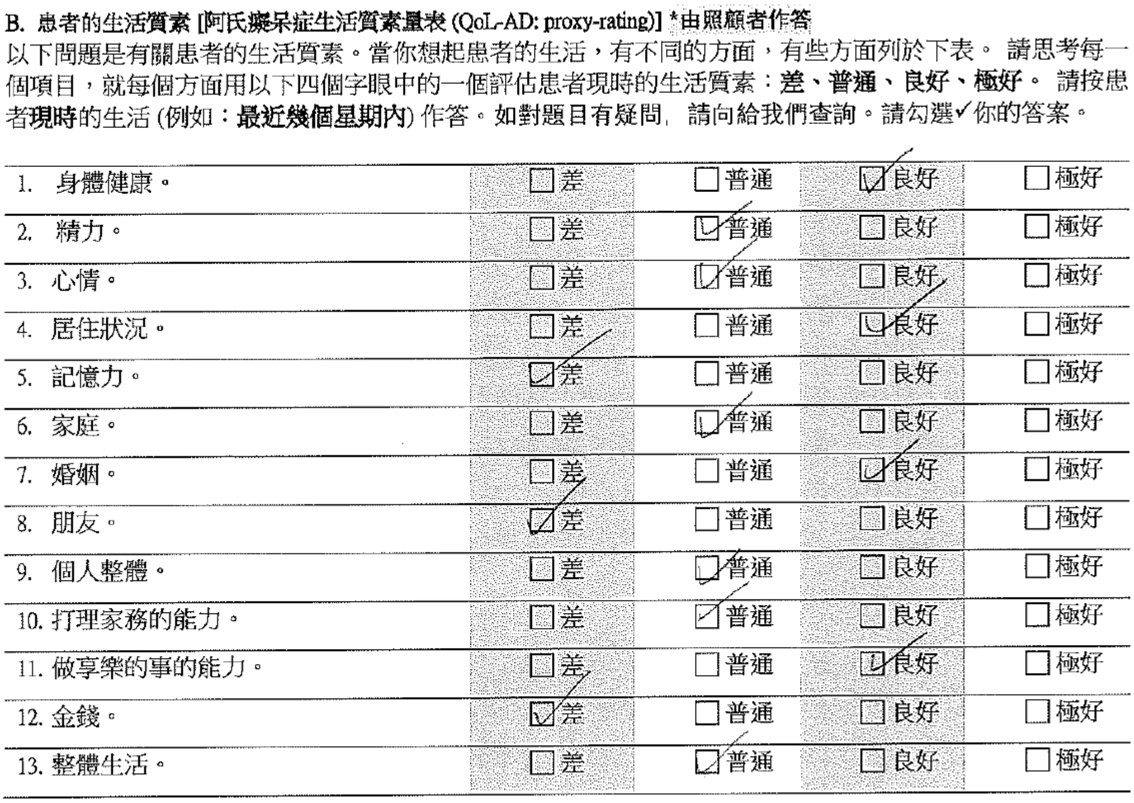


A. 患者的生活質素 [阿氏癡呆症生活質素量表 (QoL-AD: self-rating)] *由患者作答

以下問題是有關你的生活質素。當你想起你的生活，有不同的方面，有些方面列於下表。 請思考每一個項目，就每個方面用以下四個字眼中的一個評估你現時的生活質素：**差、普通、良好、極好**。 請按你**現時**的生活(例如：**最近幾個星期內**) 作答。如對題目有疑問，請向給我們查詢。請勾選✓你的答案。

1. 身體健康。	□差	□普通	☑良好	□極好
2. 精力。	□差	□普通	□良好	☑極好
3. 心情。	□差	□普通	□良好	☑極好
4. 居住狀況。	□差	□普通	□良好	☑極好
5. 記憶力。	□差	☑普通	□良好	□極好
6. 家庭。	□差	□普通	☑良好	□極好
7. 婚姻。	□差	□普通	□良好	☑極好
8. 朋友。	□差	□普通	□良好	☑極好
9. 個人整體。	□差	□普通	□良好	☑極好
10. 打理家務的能力。	□差	□普通	☑良好	□極好
11. 做享樂的事的能力。	□差	□普通	□良好	☑極好
12. 金錢。	☑差	□普通	□良好	□極好
13. 整體生活。	□差	□普通	☑良好	□極好

Appendix F. QoL-AD carer-reported

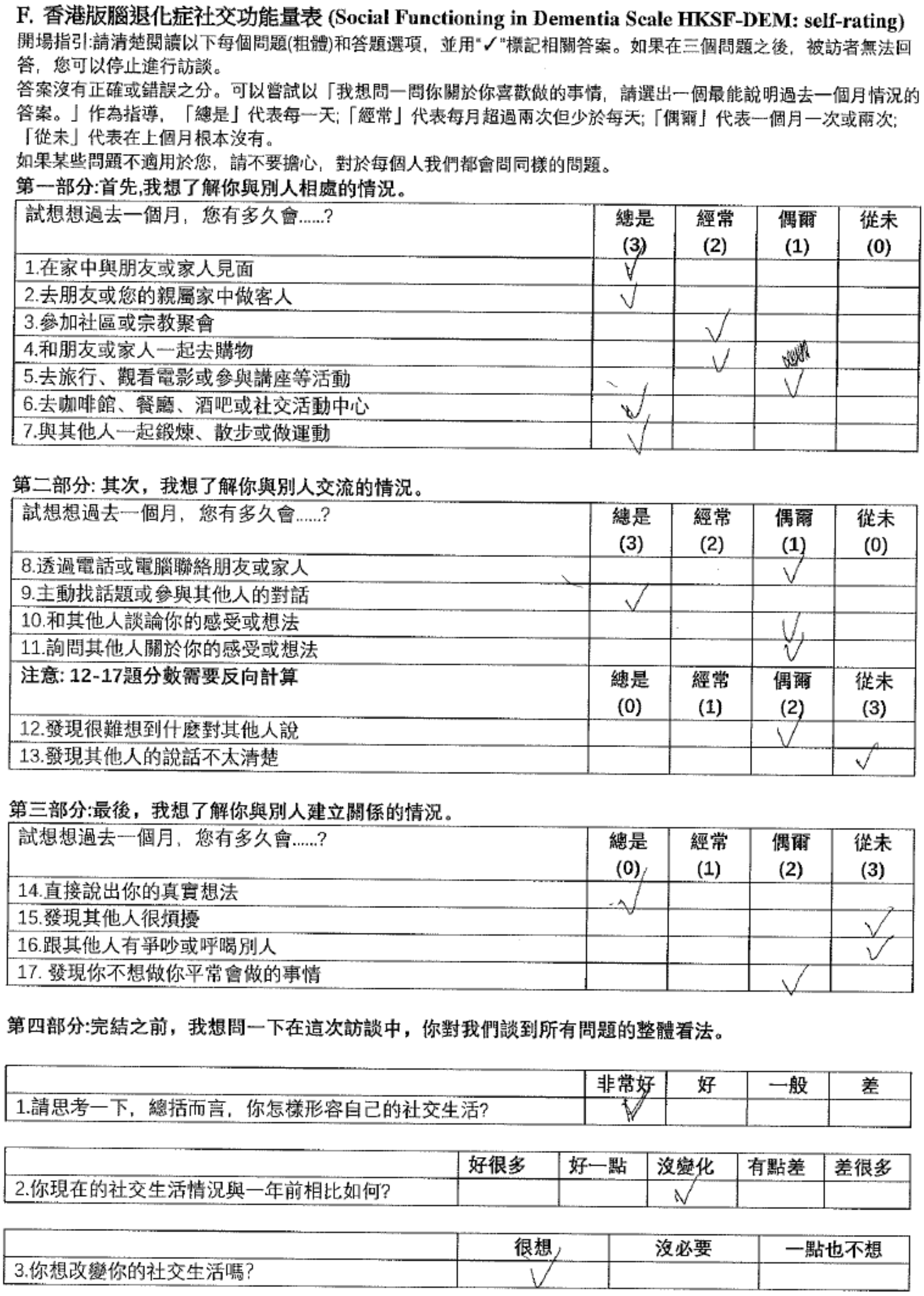


B. 患者的生活質素 [阿氏癡呆症生活質素量表 (QoL-AD: proxy-rating)] *由照顧者作答

以下問題是有關患者的生活質素。當你想起患者的生活，有不同的方面，有些方面列於下表。 請思考每一個項目，就每個方面用以下四個字眼中的一個評估患者現時的生活質素：**差、普通、良好、極好**。 請按患者**現時**的生活 (例如：**最近幾個星期內**) 作答。如對題目有疑問，請向給我們查詢。請勾選✓你的答案。

1. 身體健康。	□差	□普通	☑良好	□極好
2. 精力。	□差	☑普通	□良好	□極好
3. 心情。	□差	☑普通	□良好	□極好
4. 居住狀況。	□差	□普通	☑良好	□極好
5. 記憶力。	☑差	□普通	□良好	□極好
6. 家庭。	□差	☑普通	□良好	□極好
7. 婚姻。	□差	□普通	☑良好	□極好
8. 朋友。	☑差	□普通	□良好	□極好
9. 個人整體。	□差	☑普通	□良好	□極好
10. 打理家務的能力。	□差	☑普通	□良好	□極好
11. 做享樂的事的能力。	□差	□普通	☑良好	□極好
12. 金錢。	☑差	□普通	□良好	□極好
13. 整體生活。	□差	☑普通	□良好	□極好

Appendix G. HKSF-DEM self-reported



F. 香港版腦退化症社交功能量表 (Social Functioning in Dementia Scale HKSF-DEM: self-rating)

開場指引:請清楚閱讀以下每個問題(粗體)和答題選項，並用"✓"標記相關答案。如果在三個問題之後，被訪者無法回答，您可以停止進行訪談。

答案沒有正確或錯誤之分。可以嘗試以「我想問一問你關於你喜歡做的事情，請選出一個最能說明過去一個月情況的答案。」作為指導，「總是」代表每一天;「經常」代表每月超過兩次但少於每天;「偶爾」代表一個月一次或兩次;「從未」代表在上個月根本沒有。

如果某些問題不適用於您，請不要擔心，對於每個人我們都會問同樣的問題。

第一部分:首先,我想了解你與別人相處的情況。

試想想過去一個月，您有多久會......?	總是 (3)	經常 (2)	偶爾 (1)	從未 (0)
1.在家中與朋友或家人見面	✓			
2.去朋友或您的親屬家中做客人	✓			
3.參加社區或宗教聚會		✓		
4.和朋友或家人一起去購物		✓		
5.去旅行、觀看電影或參與講座等活動			✓	
6.去咖啡館、餐廳、酒吧或社交活動中心	✓			
7.與其他人一起鍛煉、散步或做運動	✓			

第二部分: 其次，我想了解你與別人交流的情況。

試想想過去一個月，您有多久會......?	總是 (3)	經常 (2)	偶爾 (1)	從未 (0)
8.透過電話或電腦聯絡朋友或家人			✓	
9.主動找話題或參與其他人的對話	✓			
10.和其他人談論你的感受或想法			✓	
11.詢問其他人關於你的感受或想法			✓	
注意: 12-17題分數需要反向計算	總是 (0)	經常 (1)	偶爾 (2)	從未 (3)
12.發現很難想到什麼對其他人說			✓	
13.發現其他人的說話不太清楚				✓

第三部分:最後，我想了解你與別人建立關係的情況。

試想想過去一個月，您有多久會......?	總是 (0)	經常 (1)	偶爾 (2)	從未 (3)
14.直接說出你的真實想法	✓			
15.發現其他人很煩擾				✓
16.跟其他人有爭吵或呼喝別人				✓
17. 發現你不想做你平常會做的事情			✓	

第四部分:完結之前，我想問一下在這次訪談中，你對我們談到所有問題的整體看法。

	非常好	好	一般	差
1.請思考一下，總括而言，你怎樣形容自己的社交生活?	✓			

	好很多	好一點	沒變化	有點差	差很多
2.你現在的社交生活情況與一年前相比如何?			✓		

	很想	沒必要	一點也不想
3.你想改變你的社交生活嗎?	✓		

Appendix H. HKSF-DEM carer-reported

F. **香港版認知障礙症社交功能量表 (Social Functioning in Dementia Scale HKSF-DEM: carer rating)**

開場指引:請清楚閱讀以下每個問題(粗體)和答題選項，並用"✓"標記相關答案。如果在三個問題之後，被訪者無法回答，您可以停止進行訪談。

答案沒有正確或錯誤之分。可以嘗試以「我想問一問你關於你________(你的親人/認知障礙症人士)喜歡做的事情，請選出一個最能說明________(你的親人/認知障礙症人士)過去一個月情況的答案。」

作為指導，「總是」代表每一天;「經常」代表每月超過兩次但少於每天;「偶爾」代表一個月一次或兩次;「從未」代表在上個月根本沒有。

如果某些問題不適用於________(你的親人/認知障礙症人士)，請不要擔心，對於每個人我們都會問同樣的問題。

第一部分:首先,我想了解________(你的親人/認知障礙症人士)與別人相處的情況。

試想想過去一個月，________(你的親人/認知障礙症人士)有多久會.....?	總是 (3)	經常 (2)	偶爾 (1)	從未 (0)
1.在他/她自己家中與朋友或家人見面	✓			
2.去朋友或您的親屬家中做客人				✓
3.參加社區或宗教聚會		✓		
4.和朋友或家人一起去購物				✓
5.去旅行、觀看電影或參與講座等活動				✓
6.去咖啡館、餐廳、酒吧或社交活動中心				✓
7.與其他人一起鍛煉、散步或做運動			✓	

第二部分:其次,我想了解________(你的親人/認知障礙症人士)與別人交流的情況。

試想想過去一個月，________(你的親人/認知障礙症人士)有多久會.....?	總是 (3)	經常 (2)	偶爾 (1)	從未 (0)
8.透過電話或電腦聯絡朋友或家人				✓
9.主動找話題或參與其他人的對話		✓		
10.和你或其他人談論他/她的感受或想法		✓		
11.詢問你或其他人關於他/她的感受或想法		✓		
注意: 12-17題分數需要反向計算	**總是 (0)**	**經常 (1)**	**偶爾 (2)**	**從未 (3)**
12.發現他/她的談話主題(內容)有限	✓			
13.發現他/她和別人持續對話出現困難。			✓	

第三部分:最後，我想了解________(你的親人/認知障礙症人士)與別人建立關係的情況。

試想想過去一個月，________(你的親人/認知障礙症人士)有多久會.....?	總是 (0)	經常 (1)	偶爾 (2)	從未 (3)
14.直接說出他/她的真實想法		✓		
15.被其他人做過的事或說過的話激怒		✓		
16.跟其他人有爭吵或呼喝別人		✓		
17.為了拒絕做他們常做的事而找理由		✓		

第四部分:完結之前，我想問一下在這次訪談中，你對我們談到所有問題的整體看法。

	非常好	好	一般	差
1.請思考一下，總括而言，你怎樣形容他/她的社交生活?				✓

	好很多	好一點	沒變化	有點差	差很多
2.他/她現在的社交生活情況與一年前相比如何?		✓			

	很想	沒必要	一點也不想
3.你想他/她的社交生活有所改變嗎?	✓		

Appendix I. CST Session Themes

Session Themes	
1. Physical games 體能活動	8. Being creatives 創意
2. Sound 聲音	9. Categorising objects 物件分類
3. Childhood 童年往事	10. Orientation 導向
4. Food 食物	11. Using money 金錢運用
5. Current affairs 時事	12. Number game 數字遊戲
6. Faces/ scenes 面孔 / 景物	13. Word game 文字遊戲
7. Word associations 文字聯想	14. Team game 小組比賽