Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

Building confidence in dementia care: The experience of Chinese Carers in participation in culturally and linguistically appropriate Carer Support Program

Fung Kuen KOO
Western Sydney University https://orcid.org/0000-0002-5327-4051
Lisa Wong
Western Sydney University https://orcid.org/0000-0003-2716-5107
Hui-Chen (Rita) CHANG
Western Sydney University https://orcid.org/0000-0002-8305-0585
Lynn Chenoweth
UNSW Sydney https://orcid.org/0000-0002-1407-3804
Cindy Tang
Western Sydney University
Cannas Kwok
ckwok@csu.edu.au
Charles Sturt University https://orcid.org/0000-0002-6296-1144

Research Article

Keywords: Self-efficacy, Carer support program, Chinese carers, Social support, Caregiving role, Dementia care, Peer support, Psychoeducation

Posted Date: July 28th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-10491834/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License

Additional Declarations: The authors declare no competing interests.

Abstract

Aim

This study aimed to explore Chinese Australian carers' experiences of participation in a culturally and linguistically adapted Carer Support Program (CSP).

Background

In Australia the majority of care for Chinese people living with dementia is provided by family members and other informal carers. Chinese Australian carers experience substantial stress, owing to cultural obligations, social issues and the complex dementia symptoms they face on a daily basis. There is a critical need for culturally and linguistically tailored support for Chinese carers.

Design

A descriptive design was chosen to obtain qualitative data from Chinese Australian carers.

Methods

Purposive sampling method was used to recruit 43 females and 5 male Chinese Australian carers of people living with dementia who had completed the 8-session culturally and linguistically adapted CSP. Data were collected using focus group interviews to identify carer perceptions of the CSP. Thematic analysis was used to interpret findings.

Findings

Four main themes emerged from the data: 1) the unseen challenges of caregiving; 2) knowledge and experiences lead to stronger self-confidence; 3) the power of peer influence on caregiving; and 4) pursuing better support for carers.

Conclusion

A co-designed Chinese version of CSP was considered beneficial for improving self-efficacy and enhancing carer confidence in fulfilling the caregiving role. Carers identified an urgent need for culturally and linguistic appropriate support services for immigrant Chinese carers to address complex caring issues and unmet health needs.

Introduction

The rapid growth of Australia's ageing population has placed increasing pressure on health and social care systems. Given that dementia prevalence increases exponentially with age, it has become a major global health concern, affecting an estimated 55 million people in 2023 and projected to triple by 2050 (WHO, 2025). As a result, the number of both formal and informal carers of people living with dementia continues to rise.

A substantial body of literature reveals that providing care and support for a person living with dementia is challenging and can be a stressful experience. As such, carer burden has become a major concern, given its

negative impact on the carer's physical, psychological well-being, and overall quality of life (Brookman et al., 2025; Dening, 2023; Thai et al., 2024; Witham et al., 2018). International studies reveal that carers from culturally and linguistically diverse (CALD) backgrounds living in countries that are different in many ways to their own, frequently encounter additional challenges in their caregiving role, compounding the pressure they face (Gilbert et al., 2021; Nielsen et al., 2020; Roche et al., 2021).

Over the last two decades, the Chinese population in Australia has more than tripled, increasing from 330,800 in 2000 to 1.39 million in 2023. The latest statistics indicate that the Chinese community represents the second largest CALD group after Indian migrants in Australia (ABS, 2025). Majority of Chinese immigrants reside in New South Wales, with a population of 581,635 accounting for 7.2% of the state's population (TMHC, 2022). In 2021, 1.9% of people living with dementia in the community in Australia were born in China, placing China among the top six countries of birth among people with dementia. However, as Census data rely on self-reported health conditions, and given the stigma surrounding dementia in many Chinese communities, the true prevalence is likely underestimated (AIHW, 2025).

Cultural norms powerfully shape expectations of the caring role and can contribute to heightened levels of stress. For instance, Yuwen et al. (2023) found that Asian American carers reported higher levels of stress and depression, spent more time providing care, and utilize less formal support services than other groups of carers. Similarly, overseas research on Chinese carers has shown that they experience substantial carer stress, largely driven by cultural expectations such as filial piety, a strong sense of familial obligation, and reluctance to seek outside support which may intensify the emotional and practical burden of care (Chan et al., 2010; Cheung et al., 2022; Sun et al., 2012).

Support for carers is a critical component of effective dementia care, yet in Australia's multicultural setting, most existing support services and resources remain primarily designed for the mainstream English-speaking population. While psychoeducational programs have demonstrated effectiveness in improving carer well-being and self-efficacy, their reach and relevance for CALD communities remain limited. There is a recognised need for culturally and linguistically tailored interventions that align with the values, languages, and lived experiences of communities such as the Chinese diaspora (Xiao et al., 2025). In response, this study undertook a community-partnered project to translate culturally adapt and implement a Chinese version of the Carer Support Program (CSP), an evidence-based intervention underpinned by Self-efficacy Theory (Bandura, 1977). This Chinese CSP was co-designed through a community partnership approach to ensure cultural relevance and acceptability and underpinned by Bandura's self-efficacy theory. To our best, knowledge, this is the first program of its kind in Australia. The processes of its development, implementation, and evaluation have been reported in detail elsewhere. The aim of the present paper is to explore carers' experiences of and perspectives on the program.

Theoretical framework

This study was underpinned by Bandura's (1977) Self-efficacy Theory. Self-efficacy is a belief in one's ability to organise and execute specific tasks (Artino Jr, 2012). Self-efficacy theory is hypothesized that a person gains information to evaluate efficacy beliefs from four main sources: 1) enactive mastery experiences (actual performances) means a person might expect that past successes raise efficacy beliefs in performing similar tasks in the future; (2) observation of others (vicarious experiences) indicates that observing similar others

succeed can create efficacy beliefs in one's own capabilities to gain success through persistence and effort; (3) social persuasion means encouragement and positive feedback from others can strengthen one's resolve to change, if the positive appraisal is within realistic bounds; and 4) physiological and affective states mean one's emotional and physiological states can influence efficacy belief about the ability to perform in a given situation (Artino Jr, 2012).

The Chinese CSP was deliberately designed to engage these sources, for example, through skill-building exercises (mastery), peer sharing (vicarious experience and persuasion), and stress-reduction techniques (affective regulation). This theoretical lens provides a framework for understanding how a culturally and linguistically adapted support program might enhance Chinese carers' self-efficacy, confidence and competence in caring for a family member with dementia.

Methods

4.1 Study aim

This study aimed to explore the experience of Chinese Australian carers in providing care to a family member living with dementia, and to identify their perceptions of a culturally and linguistically adapted Carer Support Program (CSP).

4.2 Research questions

1. How do Chinese Australian carers experience the caregiving role for family members living with dementia?
2. How do Chinese Australian carers perceive the culturally and linguistically adapted Carer Support Program (CSP)?
3. What support is required for Chinese Australian carers of people living with dementia?

4.3 Study Design and setting

A descriptive design was chosen to obtain qualitative data from Chinese Australian carers.

The study was conducted in 2024 in partnership with a Chinese community-based service provider delivering aged care and support programs to culturally and linguistically diverse communities across the Greater Sydney region, Australia. The research was embedded within the organisation's existing service framework to ensure ecological validity and promote engagement with the target population of Chinese Australian carers. Data collection took place at multiple community centre sites of the organisation.

4.4 Participants and recruitment

The target population was Chinese Australian carers residing in Sydney who were currently providing care to a family member with dementia and had recently participated in the culturally and linguistically adapted Carer Support Program (CSP). Inclusion criteria required participants to: (1) self-identify as a Chinese immigrant; (2) be aged 18 years or older; (3) be able to read Chinese and/or speak Cantonese or Mandarin (the two most commonly spoken Chinese languages in Sydney); and (4) be able to provide informed consent. Exclusion

criteria were having participated in any structured carer support program, other than the CSP, within the past five years; currently receiving counselling or psychological support related to their caregiving role; or having a documented diagnosis of a mood or anxiety disorder, severe mental illness, or terminal illness. These criteria were designed to minimise potential confounding bias.

Using a purposive sampling approach, participants were recruited with the assistance of the Chinese partner organisation following the carer's participation in the CSP. Recruitment materials were actively advertised through the organisation's newsletters and social media platform. Carer written informed consent was obtained by the project officer, who served as the primary contact for CSP participants, utilising a QR code for registration and sending SMS reminders of informed consent returns.

4.5 The Carer Support Program

The Chinese version of the Carer Support Program (CSP) was delivered in 2024 as an eight-week face-to-face workshop series held at various sites of the partnership organisation. The original English-language CSP, developed by Chenoweth et al. (2016), is an education program designed to support carers of people living with dementia and underpinned by Self-efficacy Theory. The Chinese CSP was translated from the original English program to Chinese and was co-designed with dementia carers and Chinese Australian health professionals who possessed specialised knowledge of dementia care. The CSP was conducted by team members in either Cantonese or Mandarin, depending on the carer's language requirements. This culturally sensitive and linguistically adapted version of the CSP was tailored to meet the needs of Chinese Australian caregivers and their family members living with dementia.

4.6 Data collection

Carers completed a self-report demographic questionnaire prior to participating in a focus group discussion. Focus group discussion was chosen for this study, as this method permits group dynamics that encourage a level of diversity of opinions from the participants (Nyumb et al., 2018). Five focus groups were conducted with six to 12 carers per group, taking between 30 and 45 minutes. All five focus groups were facilitated by two bilingual researchers who were fluent in both Chinese and English, were experienced health professionals, and had extensive qualitative health research experience. The first two open-ended interview questions were underpinned by Self Efficacy Theory to identify the participant's experiences of caregiving, the perceived benefits of the CSP and suitable carer support requirements (See Table 1). All interviews were audiotaped and transcribed by the bilingual focus group facilitators. Transcripts were translated from Chinese to English and back translation was performed by bi-lingual facilitators to ensure translation accuracy. No personal identifying details or carer characteristics were recorded for focus group data. Pseudonyms were used alongside participants responses to ensure their confidentiality.

Table 1
Examples of Focus Group Interview Questions

Interview questions	Prompts
Question 1: What are the major issues in providing care for your family member (or loved one) with dementia?	• Prompt 1: What are the other challenges to your caregiving role? • Prompt 2: In what way you want to learn the strategies to overcome these barriers/challenges?
Question 2: In what way, do you think the CSP has helped you to change the way how you view your caregiving role?	• Prompt 1: How did the program affect your knowledge or attitude towards caring your family member (or loved one) with dementia? • Prompt 2: How did the program influence your perceived self-efficacy and confidence, and your ability to manage stress in your caregiving role?
Question 3: What supports do you need to help your caregiving role?	• Prompt 1: What other area(s) would you, as a carer, like to know about? • Prompt 2: What other information you would like to include in the program?

4.7 Data analysis

A thematic analysis was conducted following the systematic, six-phase approach outlined by Braun and Clarke (2021). Two research team members (LW, FK) familiarised themselves with the data and independently performed initial manual coding of the data. Coded data extracts were then reviewed and grouped into potential themes by three team members (LW, FK, CK). A thematic map was developed to visualise the relationships between themes and sub-themes. Preliminary themes and sub-themes were discussed and refined iteratively by the entire research team to ensure consensus and analytical rigor. Disagreement was resolved by repeated textual reference, comparison and discussion. (See Figure. 1: Excerpt from the process of thematic analysis). To ensure trustworthiness, analyst triangulation was employed through independent coding and team-based theme development, and participant quotes were used to ground the findings in the data.

4.8 Ethical consideration

Ethical approval

for this study was granted by the University Human Research Ethics Committee (HREC Approval Number: H15461). Prior to data collection, all participants received a detailed information sheet and provided written informed consent before interview. To ensure confidentiality, all data were de-identified upon transcription and pseudonyms were allocated to participant responses to protect their identity. Digital audio recordings and transcripts were stored securely on password-protected university servers, accessible only to the research team.

Findings

A total of 48 CSP carers participated in five focus group interviews, including 43 females and 5 males. Most participants were married (71%) and unemployed or retired (73%) and a majority had low English proficiency level (62%). (See Table 2).

Table 2
Demographic profile of the participants

Characteristics	N (%)
Age range (years)	45–86
Gender	
Female	43 (90)
Male	5 (10)
Other	0
Years living in Australia	1.5–47
Country of birth	
Mainland of China	44 (92)
Hong Kong	3 (6)
Other	1 (2)
Marital status	
Married	34 (71)
Single	11 (23)
Divorced	2 (4)
Widowed	1 (2)
Education level	
Below tertiary	23 (48)
Tertiary or above	23 (48)
Missing	2 (4)
Employment status	
Unemployed/retired	35 (73)
Employed	9 (19)
Missing	4 (8)
English proficiency	
Not at all	1 (2)
Only a Little	29 (61)
Medium	14 (29)
Fluent	2 (4)

Characteristics	N (%)
Very fluent	2 (4)

All participants expressed that the Chinese version CSP was 'helpful' in building self-efficacy and confidence in caregiving, and it inspired them to shape their caregiving role in a positive way. Four main themes emerged from the analysis, including 1) the unseen challenges of caregiving; 2) knowledge and experiences lead to stronger self-confidence; 3) the power of peer influence on caregiving; and 4) pursuing better support for carers. The following findings include examples of participant responses to focus group questions associated with the four themes.

5.1. Theme 1: The unseen challenges of caregiving

Perceived cultural and language barriers

Many participants expressed their concern of social stigma about dementia within the Chinese community, and identified the need to redress this stigma to help carers reach out to others. Language barriers also caused carers difficulties in providing good care to their loved one. A participant explained,

" *Particularly [challenging] for Chinese. A lot of Chinese is not good in English, on top of this, they feel embarrassed towards some traditional beliefs and found it difficult to talk about it [dementia]. For example, it would be difficult to tell people that I have someone having dementia in my family … Others [Australians] will not tease you and they can reach out to help you because there are a lot of good people in Australia." (Participant 1)*

Psychological impact

The majority of participants mentioned that their caregiving experience had a huge impact on their emotions. Before attending the program, carers described their emotional state using words such as '*hard*', *'wronged'*, *'depressed'*, *'helpless'*, *'anxious'*, *'broken down'*, and '*bitter'*. Their primary coping strategy was described as "finding joy in suffering," reflecting a sense of resignation rather than empowerment. Participation in the CSP introduced supportive components, such as breathing exercises, which helped them manage stress more effectively. Without these strategies, many reported that depression would have remained to be a major concern.

"I perform all aspects of care for him, and it is not difficult to me, it is the psychological stress (that matters). When he (care recipient) loses his temper, I would feel anxious and totally break down, how to manage these behaviours? What should I do if he went to his room and slammed the door? My mood was good but because of this minor incidence, I would feel depressed… "[This program] has increased my confidence to be a carer. His [care recipient's] condition has been deteriorating, and I felt so helpless before. I don't know how to conciliate (console) myself. To be honest, I did have depression." (Participant 13)

"[After attending the CSP] I realise that he doesn't mean it, he is not having a bad character because I can compare [his character before the disease], knowing that he is being affected [by the disease]. Sometimes I would

be agitated, but when I calm down, I feel so sorry and guilty. He doesn't mean it, I know it's his disease made him behave like this. I should not be agitated; I should understand him." (Participant 14)

Communication breakdown

Some participants expressed their frustration in communicating with their family member living with dementia. They struggled between guilt and helplessness because they sometimes unintentionally hurt the feelings of their loved one.

"The difficulty I have is communication when he [care recipient] is not in good mood. Sometimes he would lose his temper when he cannot find his stuff, he would say that I better off dead. Then I would criticise him, saying that he could not be suicidal because of trivial. He would go into his room and slam the door without talking to me. I know that after learning [from this program], I always force him to remember things before and question him why he would forget; but now, I understand his symptom, when he said did not remember, he means it... this is in fact a challenge to the carer, I would feel upset, hoping that he can remember which gives him a lot of pressure. Yes, I understand now through learning [from this program]." (Participant 3)

"I attended this program because sometimes, when I look after older people with dementia, he [care recipient] would be unhappy as I said something wrong, but I don't know in what way I have offended him." (Participant 14)

Daily life challenges

Some participants also struggled with assisting daily care to their loved one with dementia and felt challenging to find out the solutions. With the CSP facilitator's explanation of the possible reasons behind the behaviour, the participants felt 'relieved' and identified they needed to 'understand the behaviour more'.

"My partner is diagnosed with Alzheimer's Disease. People with this disease is reluctant to take a shower for sure. He [care recipient] does not take daily shower when he sweats in summer, not even on alternative day. I have no way. My little granddaughter says that grandpa stinks whenever she meets him." (Participant 5)

"The major issue I feel now is that she [care recipient] doesn't feel safe. Yes, just like last night, she slept for one and a half hour and we heard her getting out of bed. My wife attended her immediately. She asked if we were on the cruise, on the ship. She was unhappy because there were a lot of people." (Participant 12)

5.2 Theme 2: Knowledge and experiences lead to stronger self-confidence

Although participants experienced challenges in caregiving, they gained knowledge about dementia and skills in developing self-efficacy for caregiving from the CSP, as it provided a platform for recharging when they were emotionally exhausted. Many participants believed that their stress level was reduced and their self-confidence for their caregiving role was stronger by understanding the biopsychological aspects of dementia and discussing real-life examples with the CSP facilitators.

“The most important detail I learned is that I like to wear in black, but after the program, I realise that people with dementia would regard black colour as a dark hole. Then I change my way, I would put on coloured clothing when she [care recipient] is here. I learned a lot, a lot of details [from this program].” (Participant 26)

“This program is good. It provides examples of patients’ weird thoughts and behaviours such as wandering on the plane, and it teaches us how to examine the reasons behind [the weird thoughts and behaviours). It inspires me when we share ideas with each other, how to examine the reasons behind.” (Participant 7)

“Now after attending this program, we know as carers, how we should apply person-centred care, empathy etc. to look after them [care recipients]. That is, [carers] should not blame them [care recipients] or feel that this is the end of the world.” (Participant 13)

5.3 Theme 3: The power of peer influence on caregiving

The majority of participants emphasised that the CSP provided a place for them to share experiences and feeling with other carers. The encouragement and feedback they learnt from others strengthened their self-confidence, helped them adjust their emotions and inspired them to provide better care to their loved one.

“We provide examples [share our experiences], then we can discuss our approaches [in communication]. As the program facilitators are experienced, they can recommend the best way to communicate [with care recipients].” (Participant 12)

“We have been carers dealing with different types of patients [care recipients], and we have different experiences. We chat with each other and release our pent-up pressure. Moreover, we learn from each other, and I think this is very important. I have been looking for an organisation [support group] like this one, which allow us to gather together, it’s good even just to have casual chat to release our pent-up pressure.” (Participant 8)

“Yes, it is crucial to regulate our emotions [through sharing with other carers]. Now we learn about it [from other carers]and we have to regulate our emotions. Our emotions can also affect their [care recipient’s] emotions... In fact, they [care recipients] can pick up our emotions. Sometimes we do not talk (to them) but they can feel the way we respond to them, the way we look at them.” (Participant 14)

5.4 Theme 4: Pursuing better support for carers

All participants believed that the CSP helped them build confidence in self-care and in providing better care to the person living with dementia. Their suggestions for program improvement fell into two key perspectives: CSP content and support services.

Feedback and suggestions for CSP

One participant mentioned that as dementia was an irreversible condition, it was a social problem. They believed that CSP had offered them support and relevant resources.

“Yes, we have a different perspective towards this disease [dementia] and the patient [care recipient] after listening [attending the program]. This program is helpful, helpful! ...“I feel like I have learned a lot from you [facilitators]. I know I was one step short at that time after listening to you. Yes, it’s really inspiring, it’s inspiring. Therefore, this program is very good with a lot of real-life examples and the solutions.” (Participant 13)

"After attending this program, we know how to guide him [care recipient] to complete the task. For example, if he is reluctant to take a shower, we can persuade him, as long as it works and he accepts it, I think this is okay." (Participant 19)

However, some participants believed that the CSP could be further improved, by recommending further program content and learning activities. For example:

"[It will be good] if we can have discussion in the middle of the lesson, as the content is very rich today. Yes, if we can review what we learned then learn new knowledge, that will be more profound, easier [for us] to accept and remember [what we learned]." (Participant 1)

"Now we know there are different types of dementia. [It will be good to know] what are their specific manifestations. Then we can search for the information. How can I manage this type of dementia? How to prevent it? Now we just have a general idea of dementia, not the specific manifestation." (Participant 26)

"Yes, that means having more resources such as Chinese website for dementia [is better]. We can search for the information if [dementia] happened to us, the available support or if there is anything that can help me, relieve my tension etc." (Participant 19)

The need for health and social support services

Limited, or inflexible, Chinese community services caused carers difficulties in providing good care to their loved one. Participants pointed out that carer support services should not only emphasise knowledge enhancement about dementia, but also provide advice on health and social support service availability and be more flexible in service offerings.

"Yes, we have applied [for 63 days of respite service] if we need to travel, but sometimes we need only one day, such as friend's gathering or go to outskirts, one day is enough. However, the current rules do not allow (one day of respite service), but a minimum two weeks. It will be great if there is any organisation we can send (our care recipient) in the morning and pick (him) up in the evening." (Participant 10)

"My English is not good, but it is a pity that CASS is off on Saturdays and Sundays. They will not answer [phone calls] after 5pm [during weekdays], because it is outside their working hours". (Participant 1)

While participants criticised the limited carer support resources provided by the government, a few participants expressed that they even did not know how and where to seek respite care and financial support for carers. Suggestions for improving service support included the following:

"Yes, council [local government] can intervene ... organise more activities for elderly people, open more activity centres for middle-aged and elderly people. As long as there is an activity centre, middle-aged and elderly people will participate in the activities." (Participant 4)

"It would be beneficial if government can help establish an association for families of people with dementia or other similar associations." (Participant 8)

"For example, organise outdoor activities for both the carers and care recipients once a month. Having these activities allow carers to relax a bit. Otherwise, looking after care recipient, all day long is really depressing." (Participant 11)

Discussion

This qualitative study aimed to understand the experience and perspectives of Chinese Australian carers following their participation in a culturally and linguistically adapted Carer Support Program. The findings illustrate how a culturally tailored intervention can address complex caregiver needs by engaging key sources of self-efficacy, thereby enhancing confidence and competence in the caregiving role. Analysis of focus group interviews after completion of CSP, informed by Self-efficacy theory (1977), developed four main themes: 1) The unseen challenges of caregiving; 2) Knowledge and Experiences lead to stronger self-confidence; 3) The power of peer influence on caregiving; and 4) Pursuing better support for carers.

Consistent with the broader literature on immigrants' health related experiences in Western countries (Zhu et al., 2024; Wong, 2019), cultural beliefs have been identified as a primary factor impacting Chinese carers' help seeking from community resources and limiting their access to existing health care and social services. In line with the findings of Zhao et al. (2023), stigmatized perceptions of dementia appeared as a salient cultural concern among participants in this study. As noted by Kokorelia et al. (2025), the term *"dementia"* or *"Alzheimer's disease"* is frequently associated with mental illness within Chinese culture, often associating feelings of shame and stigma at the family level. Additionally, dementia is commonly construed as a natural part of ageing rather than a neurological disorder warranting professional intervention. Chinese carers in this study tend to assume the caregiving role unquestioningly, influenced by deeply cultural and social norms, which may partly account for the psychological burden and poor quality of life reported by participants.

Our findings further indicate that the language barrier was a significant obstacle for Chinese carers in navigating complex health care systems and accessing supportive services and resources in a host country. This challenge has been widely documented among immigrant populations living in Western countries (Hong et al., 2024; Zhu et al., 2024). Although translated materials are increasingly available, such resources often fail to adequately incorporate cultural beliefs and norms (Lee et al., 2025). The success of the culturally and linguistically adapted CSP, as evidenced in our findings, underscore the importance of cultural appropriate services for Chinese carers (and other CALD carers) living in a host country.

Through acquiring essential dementia-related knowledge, practical caregiving skills, and person-centred care approaches grounded in real-life examples, participants reported increased confidence in responding to unforeseen situations, problem-solving, and accessing appropriate support resources. This enhanced sense of competence and understanding may reduce caregiving-related stress and improve the quality of care provided to people living with dementia, better equipping carers to manage their responsibilities and respond effectively to caregiving challenges (Li et al., 2025).

Notably, participants identified *"finding joy in suffering"* as a primary coping strategy in response to the physical and emotional exhaustion associated with managing their loved ones' behavioural changes and communication challenges. As reported by Liu et al. (2021), the deeply embedded cultural value of filial piety strongly shapes the caregiving experiences of Chinese carers. Internalisation of filial expectations may enable

adult children to focus on the meaningful and positive aspects of caregiving, facilitating acceptance of and adaptation to the caregiving role. These findings underscore that for Chinese carers, challenges are deeply embedded in cultural narratives and systemic accessibility gaps, reinforcing the critical need for services that are both culturally competent and structurally inclusive.

The reported benefits of the CSP can be directly mapped onto Bandura's four sources of self-efficacy, which emphasises the evaluation of efficacy beliefs through enactive mastery experiences, vicarious learning, social persuasion, and physiological and affective states. Enactive mastery experiences were fostered as carers gained practical knowledge and applied new strategies, such as reframing behaviours linked to dementia pathology or adapting communication leading to successful daily interactions. This acquisition of competence is a critical step in transforming a sense of duty into confident caregiving (Jung et al., 2022). Vicarious experiences and social persuasion, central to the third theme, were powerfully facilitated through peer interaction within the program. Sharing experiences and observing peers navigate similar challenges provided normative reassurance and practical modelling, reducing feelings of isolation and building collective confidence. This mirrors findings that peer support is a preferred and effective component for Chinese carers, reducing loneliness and improving coping strategies (Liu et al., 2021). Finally, program components such as the breathing exercises directly addressed participants' physiological and affective states, providing tools to manage the stress and emotional exhaustion vividly described in the first theme. This multifaceted engagement with the sources of self-efficacy explains the CSP's reported impact on reducing helplessness and fostering a more positive caregiving outlook, consistent with the outcomes of the original CSP (Chenoweth et al., 2016).

In a similar vein with previous studies (Liu et al., 2021; Xiao et al., 2022; Yu et al., 2024), our findings indicate that peer support was highly valued and recognised as a beneficial program component. Face to face engagement with peers and trained facilitator from similar cultural backgrounds fostered a strong sense of belonging and being understood, which in turn facilitated culturally safe and sustained engagement with the program. Consistent with prior research, the peer-based CSP approach helped to reduce depressive symptoms and feelings of helplessness, and enhanced self-efficacy, coping capacity, self-care practices, self-confidence, and health-related behaviours (Lai, 2020; Ma & Saw, 2020). These findings highlight the importance of prioritising culturally and linguistically appropriate peer-based relationship building and training in future carer support programs. Furthermore, in light of advances in digital technologies and the growing convenience of online delivery formats, there is a need to examine the acceptability and feasibility of delivering the CSP via online modalities. Such approaches may help address challenges related to individual commitment, geographical constraints, and access to support services, while preserving the core peer-support mechanisms underpinning the program's effectiveness.

While the CSP successfully enhanced personal skills and confidence through these mechanisms, the fourth theme reveals its limits within a broader system of care. Participant feedback on the CSP revealed not only the significant gaps in knowledge regarding dementia prevention, but highlighted the urgency of adopting a multifaceted approach to address the unmet needs of Chinese Australian carers. Consistent with previous research (Liu et al., 2021; Sun et al., 2012), our findings confirm that Chinese carers experience substantial challenges in navigating the mainstream health-care system, while simultaneously demonstrating a strong and enduring commitment to their caregiving roles. Participants described needs involving multiple levels,

including individual, community, organisational, and broader societal resources. These findings suggest that caregiver support should extend beyond a narrow focus on enhancing individual caregiving skills or self-care practices. Rather, effective support must be multidimensional, incorporating accessible and culturally responsive health-care services, financial assistance for the caring role, social supports such as respite care, and well-coordinated community-based services. Chinese community organisations can take a pivotal role in navigating carers to appropriate services, but their capacity requires reinforcement through integrated health and social policy that funds and facilitates culturally appropriate service pathways.

6.1 Implications for practice

The findings offer several key implications for nursing education and clinical practice in multicultural contexts. First, they underscore the necessity of integrating a deep understanding of cultural concepts, such as filial piety and stigma, into nursing curricula. Nurses must be equipped to recognise how these factors shape caregiving experiences and access to services for CALD communities. Second, the successful co-design of the Chinese CSP highlights the critical skill of community partnership. Nurse education should foster competencies in participatory methods and collaborative intervention design with CALD stakeholders. Third, the study points to an advanced practice role for nurses as culturally competent program facilitators and system navigators. Training must therefore develop skills in leading support groups, providing culturally sensitive psychoeducation, and effectively linking carers to community resources. Finally, it is essential to recognise that culturally embedded beliefs, together with the limited availability of culturally and linguistically appropriate health and social care services, may constrain Chinese Australian carers' confidence and willingness to seek support from formal systems. Targeted efforts to increase dementia awareness, improve culturally tailored health literacy, and expand accessible carer support services within Chinese communities are critical to addressing these disparities. Educators must prepare nursing students to address the social determinants of health by advocating for policy and service reforms that create accessible, culturally informed systems of care, ensuring programs like the CSP are supported by an enabling environment.

Strengths and Limitations

This study possesses several notable strengths that enhance the validity and relevance of its findings. Primarily, it reports on the first known experience of a co-designed, culturally, and linguistically tailored Carer Support Program (CSP) for Chinese Australian dementia carers, addressing a significant gap in service provision. These findings complement the main findings of the CSP evaluation study, which used a pre/post intervention design to identify measurable changes in carer self-efficacy and confidence in caregiving, their approach to caregiving and carer health (manuscript in review). The focus group findings help to validate the quantitative results, allowing for elaboration and clarification of these findings, and leading to richer insights on carer experiences and the impact of the CSP for Chinese Australian carers. The community-participatory approach, developed in partnership with a leading Chinese community organisation, ensured the CSP was grounded in the lived realities and preferences of the target population, thereby enhancing its ecological validity and acceptability. Methodologically, the use of focus groups in participants' first language (Cantonese or Mandarin) facilitated rich, nuanced discussions about culturally sensitive topics, while rigorous translation and back-translation procedures safeguarded the integrity of the data.

Despite these strengths, several limitations must be acknowledged. Firstly, as a pioneering program conducted with a specific cultural group through a single community organisation in Sydney, the findings may not be fully generalizable to other Chinese diaspora communities in Australia or to other CALD groups with distinct cultural profiles. Furthermore, the participant sample consisted primarily of first-generation immigrants from Mainland China and Hong Kong, and thus the perspectives of Chinese-speaking carers from other regions (e.g., Taiwan, Southeast Asia) were not captured. Secondly, the study design captured a single post-program snapshot of participants' experiences; while valuable, these perspectives may reflect immediate positive sentiment influenced by group dynamics or social desirability bias, rather than sustained change. The absence of longitudinal follow-up limits our understanding of the CSP's long-term impacts. Future research should employ a multiple method longitudinal design to evaluate sustained outcomes, explore the feasibility and efficacy of online delivery modes to improve accessibility, and intentionally seek the perspectives of carers from diverse Chinese sub-groups and other CALD communities.

Conclusion

This study illuminates the multifaceted challenges faced by Chinese Australian dementia carers and demonstrates the significant value of a co-designed, culturally tailored support program. By engaging the core sources of self-efficacy, the Chinese CSP enhanced carers' knowledge, skills, peer support, and emotional self-management, thereby building confidence in their demanding roles. However, the findings also sound a clear call that psychoeducational programs alone are insufficient. There is a pressing need for an integrated model of support that couples culturally competent carer education with accessible, flexible, and well-resourced community and health services. For nurses, this represents both a challenge and an opportunity to lead in the development, facilitation, and systemic advocacy for truly inclusive dementia care.

References

1. Artino AR Jr (2012) Academic self-efficacy: from educational theory to instructional practice. Perspect Med Educ 11(2):76–85. 10.1007/S40037-012-0012-5
2. Alzheimer's Disease International (2023) *Dementia Statistics.* https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/
3. Australian Bureau of Statistics. [ABS] (2025) *Australian population.* https://www.abs.gov.au/statistics/people/population
4. Australian Institute of Health and Welfare [AIHW] (2025) *Carers of people with dementia.* https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/carers-findings-survey-of-disability-ageing-carers/carers-of-people-with-dementia
5. Australian Institute of Health and Welfare [AIHW] (2025) *Dementia in Australia.* https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/cald-people-with-dementia/dementia-cald-backgrounds
6. Bandura A (1977) Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 84:191–215
7. Braun V, Clarke V (2021) Thematic analysis: A practical guide. Sage
8. Brookman R, Lipson-Smith R, Maurice O, McIlwain N, Hofstaetter L, DiGiacomo M, Ní Chróinín D, Cannings MJ, Harris CB (2025) Caring for people with dementia: mapping the experience and journey from

diagnosis. Gerontologist 65(5):gnaf053. https://doi.org/10.1093/geront/gnaf053

9. Chan WC, Ng C, Mok CC, Wong FL, Pang SL, Chiu HF (2010) Lived experience of caregivers of persons with dementia in Hong Kong: a qualitative study. East Asian Archives Psychiatry 20(4):63–68
10. Chenoweth L, Jeon YH, Stein-Parbury J, White D, McNeil G (2012) Community Carer Coaching Project – An Education Program for the Carers of People with Dementia. University of Technology Sydney, Sydney
11. Chenoweth L, Stein-Parbury J, White D, McNeill G, Jeon YH, Zaratan B (2016) Coaching in self-efficacy improves care responses, health and well-being in dementia carers: a pre/post-test/follow-up study. BMC Health Serv Res 16:166–176. https://doi.org/10.1186/s12913-016-1410-x
12. Cheung G, Su AY, Wu K, Yue B, Yates S, Martinez Ruiz A, Krishnamurthi R, Cullum S (2022) The understanding and experiences of living with dementia in Chinese New Zealanders. Int J Environ Res Public Health 19(3):1280. 10.3390/ijerph19031280
13. Dening KH (2023) Caring for a person living with dementia: identifying and assessing a carer's needs. *British Journal of Community Nursing*, 28(10), 492–496. https://doi.org/10.12968/bjcn.2023.28.10.492. PMID: 37793112
14. Gilbert AS, Antoniades J, Croy S, Thodis A, Adams J, Goeman D, Browning C, Kent M, Ellis K, Brijnath B (2022) The experience of structural burden for culturally and linguistically diverse family carers of people living with dementia in Australia. Health Soc Care Commun 30:e4492–e4503. https://doi.org/10.1111/hsc.13853
15. Hong YA, Shen K, Han HR, Park VT, Lu HK, Cleaveland C (2024) It's a lonely journey': caregiving experiences and psychosocial distress among Chinese American dementia family caregivers. Aging Mental Health 28(3):466–472. https://doi.org/10.1080/13607863.2023.2285918
16. Jung S, Song JA, Kim J, Cheon H, Kim J (2022) Family caregiver competence in managing behavioral and psychological symptoms of dementia: A concept synthesis. Japan J Nurs Sci 19:e12462. https://doi.org/10.1111/jjns.12462
17. Kokorelias KM, Fung WLA, Nekolaichuk E, Wu M, Singh H (2025) Dementia caregiving in Chinese communities in high-income countries: exploring unmet needs and experiences through a qualitative meta-synthesis. Dementia 0(0):1–36. https://doi.org/10.1177/14713012251346598
18. Lai DWL, Li J, Ou X, Li CYP (2020) Effectiveness of a peer-based intervention on loneliness and social isolation of older Chinese immigrants in Canada: a randomized controlled trial. BMC Geriatr 20:356. https://doi.org/10.1186/s12877-020-01756-9
19. Lee H, Tzuang M, Chow TW, Kang Y, Tee BL, Li C, Lam E, Gu Y, Lee SA, Ho PCH, Peavy G, Seo EH, Kim K, Tran B, Chae W, Nguyen D, Vo N, Dang D, Spat-Lemus J, Choi YB, Feldman H, Jun GR, Wang LS, Yu WH, Park VTM (2025) Translation and cultural adaptation of tools to assess diverse Asian American and Asian Canadian subgroups: The Asian Cohort for Alzheimer's Disease (ACAD) Study. Alzheimer's Dementia: J Alzheimer's Association 21e70311. https://doi.org/10.1002/alz.70311. The The Asian Cohort for Alzheimer's Disease Study
20. Li F, Parsons J, Xiao LD, Cheung G (2025) Exploring the perceptions of New Zealand Chinese dementia career on the adapted world health organisation iSupport manual: a qualitative study. Dementia 24(1):133–149. https://doi.org/10.1177/14713012241272893

21. Liu J, Lou Y, Wu B, Mui ACY (2021) I've been always strong to conquer any suffering: challenges and resilience of Chinese American dementia caregivers in a life course perspective. Aging Ment Health 25(9):1716–1724. https://doi.org/10.1080/13607863.2020.1793900
22. Ma KPK, Saw A (2020) An international systematic review of dementia caregiving interventions for Chinese families. Int J Geriatr Psychiatry 35(11):1263–1284. https://doi.org/10.1002/gps.5400
23. Nielsen TR, Nielsen DS, Waldemar G (2020) Barriers to post diagnostic care and support in minority ethnic communities: a survey of Danish primary care dementia coordinators. Dementia 19(8):2702–2713. https://doi.org/10.1177/1471301219853945
24. Nyumba TO, Wilson K, Derrick CJ, Mukherjee N (2018) The use of focus group discussion methodology: Insights from two decades of application in conservation. Methods Ecol Evol 9:20–32. https://doi.org/10.1111/2041-210X.12860
25. Roche M, Higgs P, Aworinde J, Cooper C (2021) A review of qualitative research of perception and experiences of dementia among adults from black, African, and Caribbean background: what and whom are we researching? Gerontologist 61:e195–e208. https://doi.org/10.1093/geront/gnaa004
26. Sun F, Ong R, Bernette D (2012) The Influence of Ethnicity and Culture on Dementia Care giving: A Review of Empirical Studies on Chinese Americans. Am Journal Alzheimer's Disease & Other Dementias 27(1):13–22. https://doi.org/10.1177/1533317512438224
27. Thai GH, Rivette S, Sharman J, Epps F, Masoud S (2024) Dementia caregiver experiences: insights from a telephone-based support program. J Appl Gerontol 43(9):1241–1250. https://doi.org/10.1177/07334648241234745
28. Transcultural Mental Health Centre [TMHC] (2022) NSW Demographic Fact Sheet. https://www.dhi.health.nsw.gov.au/ArticleDocuments/197/NSWDemographicFactSheet%202022.pdf.aspx
29. Witham G, Haigh C, Mitchell D, Beddow A (2018) Carer experience supporting someone with dementia and cancer: a narrative approach. Qual Health Res 28(5):813–823. https://doi.org/10.1177/1049732317736285
30. Wong SWL (2019) *Help-seeking Behaviour of Chinese Carers of People Living with Dementia.* [Doctoral dissertation, University of Technology Sydney] OPTUS at UTS. https://opus.lib.uts.edu.au/bitstream/10453/133300/6/02Whole.pdf
31. World Health Organisation [WHO] (2025) Dementia – Key facts. https://www.who.int/news-room/fact-sheets/detail/dementia
32. Xiao LD, Ye M, Zhou Y, Chang HCR, Brodaty H, Ratcliffe J, Brijnath B, Ullah S (2022) Cultural adaptation of World Health Organisation iSupport for Dementia program for Chinese-Australian caregivers. Dementia 21(6):2035–2052. https://doi.org/10.1177/14713012221110003
33. Xiao L, Ullah S, Yu Y, Meyer C, Chapman M, Chen L, Ping K, McKechnie S, Ottaway M, De Andrade AQ, Ratcliffe J, Whitenhead C, Tran K, Wang Y, Kitson A (2025) Effects of a virtual iSupport Program on carers and people with dementia. Alzheimer's Dement J Alzheimer's Association 21(e70747):1–13. https://doi.org/10.1002/alz.70747
34. Yu Y, Xiao L, Cheng A et al (2024) Chinese-Australian carers' perceived needs and preferences in planning to embed an iSupport for Dementia program in aged care services. Australasia J Ageing 43:512–522. https://doi.org/10.1111/ajag.13287

35. Yuwen W, Chang J, Divina MF, Fan X, Kearns W, Peredo A, Hartzler AL (2022) Comparing caregiving needs in Asian and White family caregivers through a journaling exercise delivered by a conversational agent. *Annual Symposium-American Medical Informatics Association (AMIA), Annual Symposium Proceedings*. 2022, 1208–1216
36. Zhao M, Zhang H, Lin X, You E, Wang H, Lautenschlager NT (2023) Attitudes towards dementia among Chinese adults aged 50 years and older: a comparative study of immigrants living in Melbourne and non immigrants living in Beijing. Int Psychogeriatr 35(1):29–42. https://doi.org/10.1017/S1041610222000527
37. Zhu C, Song B, Walsh CA, Ekoh PC, Qiao X, Xu A (2024) Barriers to accessing health care of older Chinese immigrants in Canada: a scoping review. Front Public Health 12:1445964. https://doi.org/10.3389/fpubh.2024.1445964

Figures

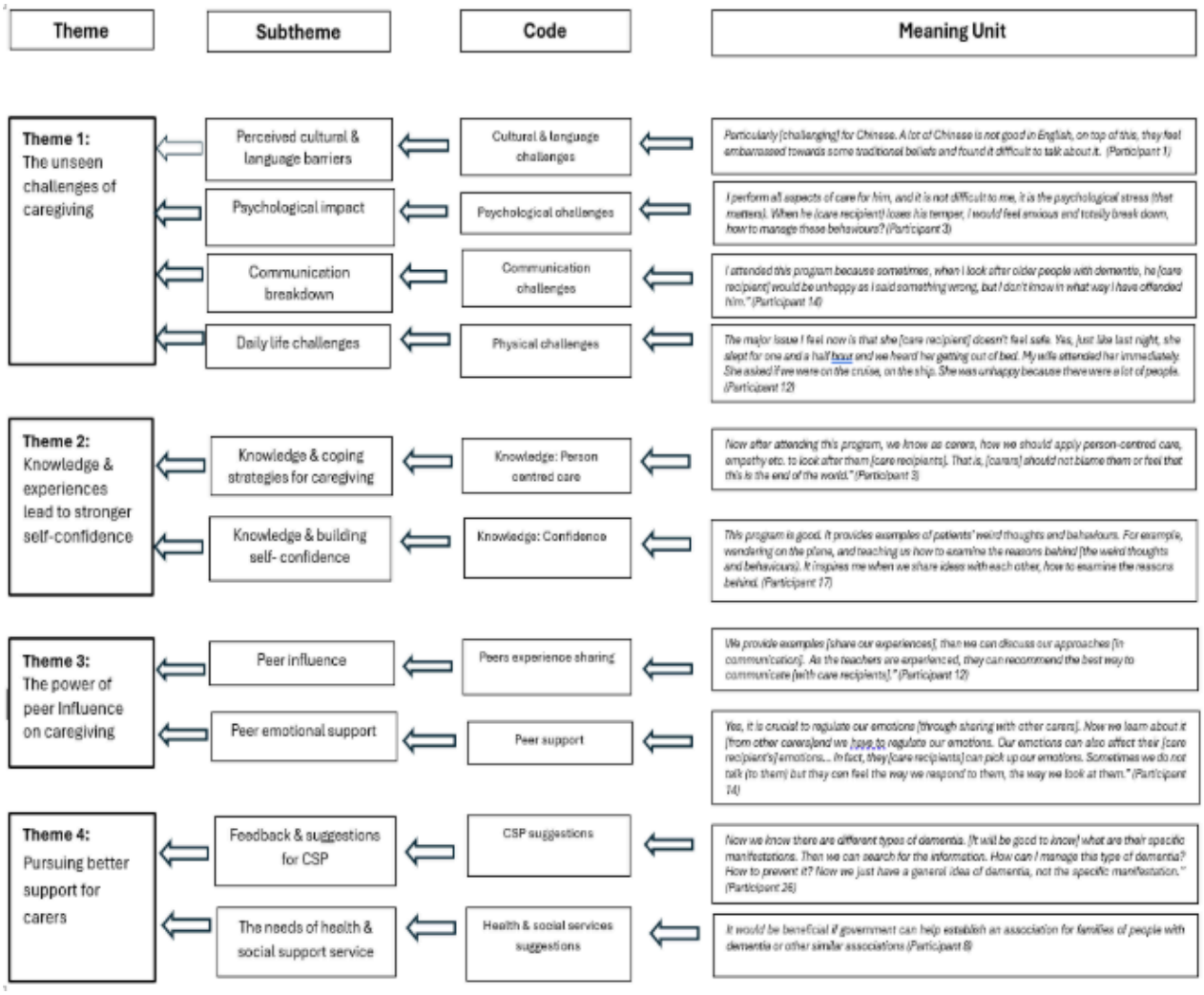


Figure 1

Excerpt of Developed Themes and Subthemes