

# Light in the darkness – accessibility to palliative care for cancer patients of Chinese background and their families

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## ABSTRACT

**Introduction.** Palliative care addresses the comprehensive needs of advanced-stage cancer patients, enhancing their quality of life. However, due to cultural and linguistic differences, Chinese Australians encounter substantial barriers to accessing these services. **Aim.** This study aimed to investigate the barriers preventing Chinese Australians from accessing palliative care services. **Methods.** Surveys and interviews were conducted with Chinese Australian cancer patients and their caregivers to assess their awareness, understanding, and challenges related to palliative care. **Results.** Among 136 surveyed and eight interviewed participants, a significant lack of awareness and numerous misconceptions about palliative care were evident, with language as the primary barrier despite strong interest in such services. **Discussion.** The results indicate a need to improve the awareness and accessibility of palliative care for the Chinese Australian community. Local health authorities and medical associations should collaborate in developing and disseminating culturally and linguistically appropriate information to increase service uptake among ethnic groups in Australia.

**Keywords:** advance care planning, CALD, Chinese ethnicity, community engagement, cultural barriers, culturally appropriate care, culture-sensitive, end-of-life care, ethnic diversity in healthcare, intercultural understanding, palliative care.

## Introduction

Cancer patients and their families have a high demand for palliative care services<sup>1</sup> due to the complex and multifaceted challenges they face. The primary goal of palliative care service to cancer patients and their families is to enhance their quality of life<sup>2</sup> by addressing the physical, emotional, and spiritual needs of the patients and their carers. Palliative care adopts a patient-centred, family-focused approach, offering individualised and holistic care at the end-of-life stage.<sup>3</sup> This care model relies on multi-discipline collaboration among general practitioners (GPs), nurses, palliative care specialists, oncologists, psychologists, spiritual care practitioners, physiotherapists, and social workers.<sup>4,5</sup> The involvement of different health professionals is essential in delivering comprehensive and supportive care.

China has become the third most common country of birth for Australian immigrants, primarily residing in Sydney.<sup>6</sup> Chinese immigrants share similar beliefs and practices influenced by traditional Chinese culture, and are underrepresented in palliative care service delivery. People from culturally and linguistically diverse communities face unique challenges accessing such health care.<sup>7</sup> This study aimed to investigate the strategies to improve palliative care access for Chinese Australians to guide other minority groups.

## Participants and methodology

The study was approved by the Human Research Ethics Committees of the South Eastern Sydney Local Health District (Ref No. HREC/17/POWH/534). Participants were recruited from the North, East, South, and Southwestern Sydney suburbs.

## WHAT GAP THIS FILLS

**What is known about the topic:** Palliative care significantly enhances the quality of life for advanced-stage cancer patients by addressing their comprehensive needs. The Chinese ethnic population faces substantial barriers in Australia to accessing palliative care services due to cultural and linguistic differences. There is generally a low awareness and many misconceptions about palliative care within ethnic communities, including Chinese Australians.

**What this study adds:** The study highlights the specific challenges faced by Chinese Australian cancer patients and their caregivers in accessing palliative care services. It identifies language as the primary barrier, despite a strong interest in palliative care services among the Chinese ethnic community. The study highlights the need for local health authorities, medical associations, and community groups to develop and disseminate culturally and linguistically appropriate information to improve palliative care service uptake among the culturally and linguistically diverse community.

A survey (Table 1) using Chinese characters and one-to-one in-depth interviews were used (Fig. 1). The survey was modified from a previous paper<sup>8</sup> to leverage its established validity and reliability for robust data collection. Such adaption allowed us to tailor it to the specific cultural and linguistic needs of the Chinese Australian community, while also enabling comparisons with other studies using the original tool. The interview used questions modified from previous publications.<sup>9,10</sup> The frequencies and percentages of categorical variables were analysed using descriptive statistics.

Pearson's Chi-square and Fisher's exact tests were used where applicable (IBM SPSS Statistics 24.0, SPSS Inc., Chicago, IL, USA).  $P < 0.05$  was considered statistically significant. The interviews were conducted in either Cantonese or Mandarin, depending on the dialect in which the participants felt most comfortable communicating. All participants had their cancer diagnoses confirmed in Australia and either received or will receive cancer treatment in Australia.

The inclusion criteria for both the survey and interview were: cancer patients and their caregivers or former caregivers, aged  $\geq 18$  years, speaking Mandarin or Cantonese, willing to provide written informed consent, and having experience with palliative care for those in one-on-one in-depth interviews. The exclusion criteria were being pregnant,  $< 18$  years old, unable to make independent decisions due to their age or legal status, or having cognitive disorders.

## Results

### Demographic data

In total, 136 valid questionnaires were received from 154 Cancer Health seminar attendees at a CanRevive centre (response rate 88%). Over three-quarters were female. More than half were  $> 65$  years old. A total of 80.9% of respondents were born in Mainland China, followed by Hong Kong and Macau (32.4%). Furthermore, 21% received a higher education with a Bachelor's degree or above. Christianity was the most common religion, followed by Buddhism, and Catholicism. Most participants were patients; 104 had recent experiences with cancer (being hospitalised as a patient, having a family member hospitalised, or experiencing the death of a family member/friend);

**Table 1.** Major themes and subthemes.

Major themes (questions in interview guide)	Subthemes
1. Low awareness and misunderstanding of palliative care before/after accessing it (Q 1, 2, 3)	The formal translation of palliative care was never heard of. Participants did not understand the differences between palliative care and the Chinese terms of 'hospice care/terminal care.' This indicated that the professional translation of palliative care is not heard of, and the concept with the 'Chinese term' was not widely introduced. Passively obtained the information of palliative care until a late stage of cancer rather than soon after diagnosing. Participants did not understand the service scope of palliative care: the misunderstanding of palliative care being only pain control, or a patient did not even know it is a home-based palliative care while receiving it. Try to avoid palliative care and think of it as a compelled choice.
2. Hoping to get further information about palliative care and preferred approaches of knowledge delivery (Q 6)	Suggestions on approaches for palliative care knowledge delivery: GP should provide more information; multimedia approaches to provide information, including paper-based booklet and internet.
3. Looking forward to the support/guidance (Q 4)	Technical support of taking care of home-based patients. Spiritual support for the care giver.
4. Cultural/Linguistic barriers identification (Q 4, 7, 10, 12) and suggestions to address the barriers.	Avoid talking about death (Chinese taboos related to death). Language barrier. Suggestions to address the barriers.

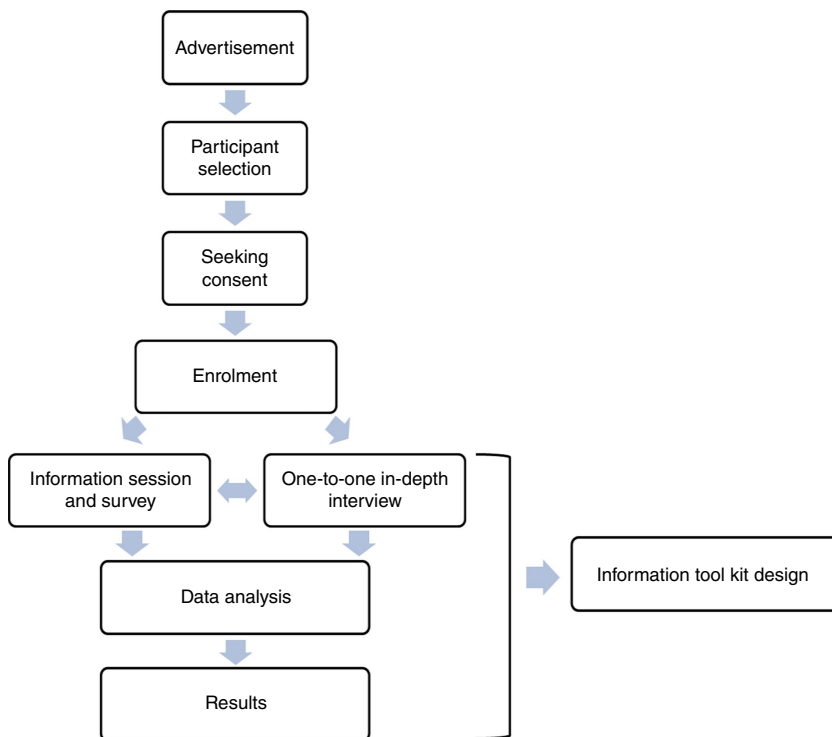


Fig. 1. Project flow chart.

six had multiple experiences, eg family members staying in hospitals and experienced a death of a family member/friend in the past 5 years. Other situations experienced by the respondents were receiving operation/treatment without hospitalisation ( $n = 18$ , 13.2%) and hospitalisation >5 years ago ( $n = 2$ , 1.5%).

Two men and six women, including patients, caregivers, and previous caregivers, were interviewed, three in Mandarin and five in Cantonese. Two caregivers were second-generation immigrants growing up in Australia, while six moved here as adults. Three participants (two patients and one previous caregiver) had poor English proficiency.

### Knowledge of palliative care

In the survey study, over one-quarter of the participants had never heard of palliative care (Table 2). The others seemed unsure about its meaning. Notably, 83.1% of the participants were interested in knowing more about palliative care (Table 2). There were significant differences among patients, caregivers, and previous caregivers in their awareness of palliative care ( $X^2 = 11.3$   $P = 0.02$ ), with awareness highest in previous caregivers (95.5%) and the lowest in patients (66.3%). One patient stated in the survey 'I am worried that receiving palliative care is a label of dying; fear of death'.

Regarding the referral timing, there was no significant difference between patients, caregivers, and previous caregivers ( $X^2 = 12$ ,  $P = 0.74$ , Table 3). Among three participants choosing 'Other' in the survey, two previous caregivers stated in the free text section that 'the patient

**Table 2.** Knowledge and attitudes towards palliative care amongst patients and caregivers.

	Total <i>n</i> (%)	Patient <i>n</i> (%)	CG <i>n</i> (%)	PCG <i>n</i> (%)
<b>Options</b>				
Understood its meaning	45 (33.1)	21 (25.3)	12 (38.7)	12 (54.5)
Unsure about its meaning	56 (41.2)	34 (41.0)	13 (41.9)	9 (40.9)
Never heard of	35 (25.7)	28 (33.7)	6 (19.4)	1 (4.5)
<b>Attitude towards palliative care</b>				
Very or a bit interested	113 (83.1)	64 (47.1)	28 (20.6)	21 (15.4)
Do not care	22 (16.2)	18 (13.2)	3 (2.2)	1 (0.7)
Dislike to talk or think about it	1 (0.7)	1 (0.7)	0 (0.0)	0 (0.0)
Hate to talk or think about it	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
<b>Readiness of signing the end-of-life care documents</b>				
Yes	12 (26.7)	4 (19.0)	4 (33.3)	4 (33.3)
No	32 (71.1)	17 (81.0)	8 (66.7)	7 (58.3)
No response	1 (2.2)	0 (0.0)	0 (0.0)	1 (8.3)

CG, Caregiver; PCG, Previous caregiver. Total participants = 136, total patients = 83, total caregiver = 31, total previous caregiver = 22.

should be referred to palliative care when the general treatments have no therapeutic effect, or the patient is very near the end of lifetime', or 'When the patient's family is unable to help the patient'. One patient wrote, 'According to my situation in the future'.

Interviewed participants also had low awareness/understanding of palliative care. One participant was unaware they were receiving palliative care at the time of the interview. Another was unclear about its meaning and scope, often confusing it with just hospice or end-of-life care and associating it solely with pain management. Due to the misunderstandings, many tended to avoid palliative care, with a belief that palliative care signals imminent death, futility, or abandonment.<sup>11</sup> One patient stated, Another previous caregiver said, One patient suggested.

(After doctor introduced palliative care) I struggled and hesitated ... My husband joked that he could try it and see whether he could get out alive.

... My sister-in-law had the same hesitation as me ... but she came to the view later that when the end is near ..., therefore, accept there was no other choice.

(Health professionals) should make it clear for (patients) that palliative care is for a stage between cancer treatment and end-of-life. It is not equal to waiting for death... It will be good for someone to speak and clarify that various treatment/recovery approaches are available (in palliative care hospitals).

### Difficulties in accessing palliative care

The survey results showed that language difficulties were a major barrier ( $X^2 = 6.6$ ,  $P = 0.88$ ), which hindered

understanding and communication with healthcare professionals. A patient wrote, 'Ideally, PC [palliative care] hospitals with Chinese-speaking staff should be available'. During the interview, a patient stated, 'I was very nervous, (my) English is not good', which is a common phenomenon.

In Chinese culture, discussing death is taboo,<sup>12</sup> a sentiment echoed in interviews, leading to significant resistance to discussing related topics like powers of attorney, wills, and advanced care directives. Consequently, patients, relatives, and health professionals of Chinese background are often hesitant to address these issues during the palliative care stage. One participant remarked, 'My husband has seen several doctors, but none of them has mentioned (palliative care).' Some caregivers refused to discuss palliative care with other relatives/decision-makers due to the same reason. Participants were aware that such traditional taboos might cause problems later on. There appears to be a conflict between being self-aware of cultural issues, particularly regarding harmful taboos, and recognising the benefits of receiving palliative care for their medical conditions.

### Preference for palliative care and end-of-life care

In the survey, 52.7% of patients preferred receiving palliative or end-of-life care either at home or in a hospital, with a greater proportion preferring home (29.1%) over a hospital setting (18.2%). A similar trend was observed among caregivers, with 76% favouring home as the preferred location for palliative or end-of-life care. However, less than half (44%) of respondents considered advance care planning a vital factor in palliative or end-of-life care. Participants identified wills (57%) and power of attorney (45%) as the most critical issues in palliative care and end-of-life stages. Most respondents (63%) also stressed the importance of involving all family members in palliative and end-of-life

**Table 3.** Attitudes on optimal palliative care referral time.<sup>A</sup>

Choices	Total n (%)	Patient n (%)	CG n (%)	PCG n (%)
Immediately following diagnosis	22 (21.8)	9 (16.4)	5 (20.0)	8 (38.1)
Upon commencement of treatment	25 (24.8)	13 (23.6)	6 (24.0)	6 (28.6)
During treatment	23 (22.8)	12 (21.8)	4 (16.0)	7 (33.3)
Upon discharge from chemotherapy or radiotherapy	12 (11.9)	5 (9.1)	3 (12.0)	4 (19.0)
Following surgical discharge from hospital	13 (12.9)	7 (12.7)	3 (12.0)	3 (14.3)
When cancer pain issues arise	57 (56.4)	36 (65.5)	10 (40.0)	11 (52.4)
When care needs become really complex	59 (58.4)	35 (63.6)	13 (52.0)	11 (52.4)
In terminal stage without future treatment	54 (53.5)	33 (60.0)	6 (24.0)	11 (52.4)
Other <sup>A</sup>	3 (3.0)	1 (1.8)	0 (0.0)	2 (9.5)
Total	101 (100)	55 (100)	25 (100)	21 (100)

CG, Caregiver; PCG, Previous Caregiver.

<sup>A</sup>Other issues suggested by participants: 'to reduce suffering'; 'the peace in the heart and support from believes'; 'Counselling for family member'; 'To say some words of farewell and comfort'; 'Last Wish', and 'To calm the patients'.

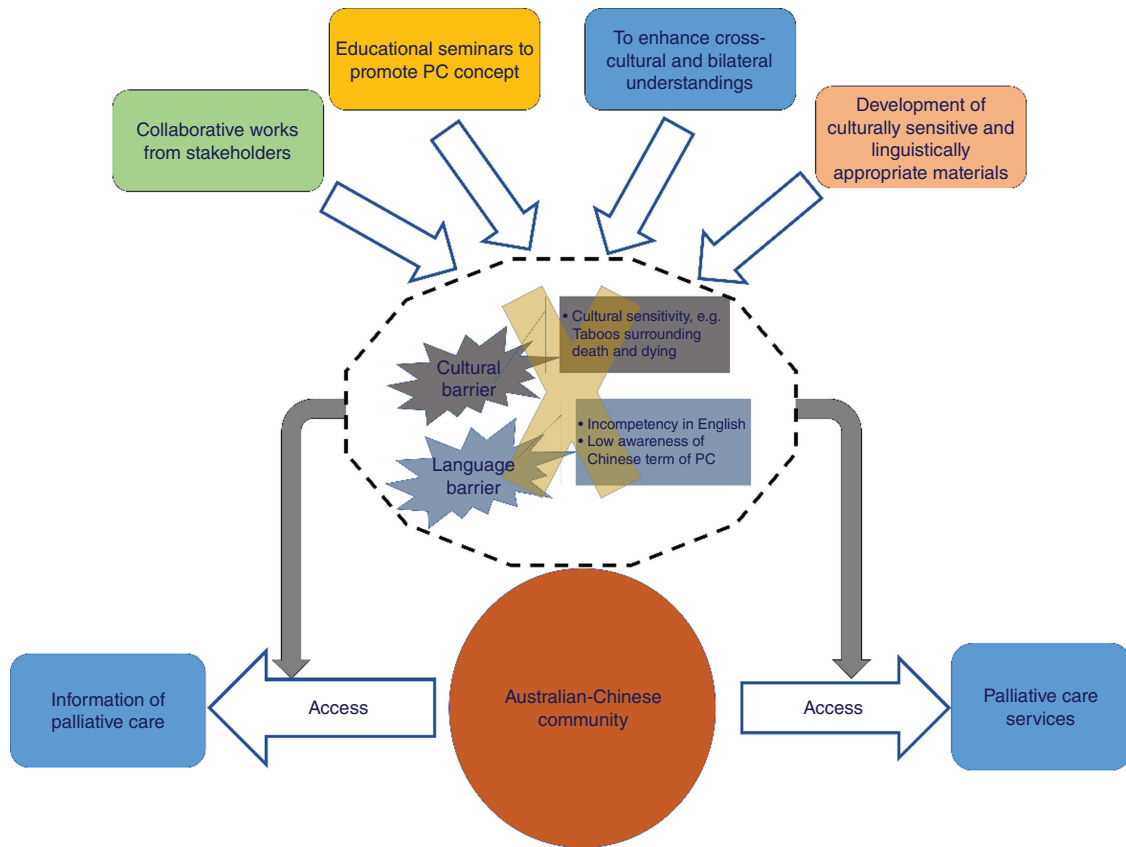


Fig. 2. Barriers and enablers for Chinese cancer patients to access palliative care.

care decisions, highlighting the need for shared decision-making.

Most participants (82/101) agreed on the necessity to express wishes for further medical treatment before the end-of-life stage. The top two choices were ‘I want to undergo the treatment of my choice’ and ‘I want to decide for myself’. This indicates that most participants consider it paramount to be able to exercise independent choice. They also realise those decisions are a heavy responsibility. Therefore, the third choice for preparing an end-of-life plan was ‘I hope not to burden my family with end-of-life decisions’. These responses suggest a potential conflict between individual autonomy and the traditional Confucian hierarchical values often associated with Chinese culture. In Confucianism, there is an emphasis on family roles, filial piety, and collective decision-making, particularly in health-related matters. This cultural framework may prioritise family involvement and hierarchical decision-making over personal autonomy. However, the survey responses indicate that many individuals may value personal choice and autonomy in their palliative care preferences, challenging the stereotype that Chinese individuals adhere strictly to traditional cultural norms. This highlights the complexity of cultural influences on healthcare decisions and the need for personalised care approaches that respect both individual autonomy and cultural values.

### Suggestions on how to address the hurdles

#### Use of interpreters to overcome language barriers

In the survey, participants recommended professional interpreters (71/78 respondents), medical professionals, and cancer support groups. Other suggestions were ‘to address culture issue’ ( $n = 38$ ), ‘To provide hotline support’ ( $n = 1$ ), ‘To provide a home visit’ ( $n = 1$ ), ‘To eliminate the fear of patients and their families by a detailed explanation’ ( $n = 1$ ), and ‘Health professionals shall refer patients to receive palliative care when necessary’ ( $n = 1$ ). Most participants (77%) highlighted the need for health professionals to have a greater understanding of cultural sensitivities relating to palliative/end-of-life care. A previous caregiver stated during the interview that GPs play an important role in ‘providing more information on this aspect (palliative care) ...’ Receiving the information as early as possible was preferred. For example, one previous caregiver stated during the interview,

When my husband and I visited doctors, the GP never mentioned palliative care to us; the doctor-in-charge seemed busy ... At any of the three visits to the hospital, the head nurse did not talk to us about this ... finally,



when (doctors thought) it is possibly the right time for (a palliative care hospital), they still did not go into details.

### **Public educational seminars**

Multiple approaches can help public education. Seminars were recommended during the interview, ‘More educational lectures to introduce palliative care, which we can attend repeatedly for clarification’; ‘inviting palliative care professionals to present a workshop on what they can offer’; and ‘More public lectures in Chinese communities to benefit more for the patients’. Hotline and multimedia services were also suggested, ‘a hotline for raising questions directly’; ‘chances for communication and media promotion to introduce/explain what palliative care is’; and ‘Multimedia broadcasts to make Chinese people more aware’.

### **Ethnic-specified educational materials**

Participants have stressed that educational materials on palliative care should include: (1) Mitigating the fears of death and psychological support; (2) Correcting misconceptions by clearly articulating the differences between palliative and terminal cares; (3) Advanced Care Directives (ACD) preparation, which has a low awareness. Most cancer patients and family caregivers developed a more positive attitude towards ACD after receiving information about them;<sup>13</sup> (4) Support for the home carer. Specifically, professional support and guidance are needed for home caregivers at the end-of-life stage. In addition, more elderly participants prefer the paper-based approach, while younger participants favour digital multimedia dissemination, such as YouTube, Facebook, or WeChat.

### **Limitations of the study**

There are several limitations in this study. The relatively small sample sizes for the survey and interviews may not fully represent the diverse experiences and perspectives within the broader Chinese Australian cancer patient and caregiver community.

This study relied on self-reported data, which can lead to biases in the participants’ interpretation of palliative care. Despite the intention to ensure data validity by modifying a previously published survey, the reliability of the adapted survey requires further evaluation in this specific ethnic population in future studies.

## **Discussion**

### **Low awareness and misunderstanding of palliative care**

Although participants are willing to receive such information, we found a low awareness of and considerable misunderstanding of palliative care in the Chinese

Australian community. Findings from both the survey and interviews indicated that language and cultural differences are the main challenges for Chinese-speaking cancer patients and caregivers in accessing palliative care services. The responses also highlighted the need to address language barriers that caused low awareness and uptake of palliative care.

### **Educational and psychological support needs**

Low awareness and misconceptions about palliative care among Chinese Australians stem from cultural sensitivities and personal inhibitions. Discussing death is taboo, leading to resistance to palliative care, seen primarily as end-of-life treatment. Psychological support, clarifying misconceptions in educational materials, and home care support may help overcome these barriers.

### **Language and cultural barriers**

Most participants are eager to learn about palliative care but face significant language barriers, particularly those who are older, less educated, and speak little English. They also struggle to find written information in Chinese. This highlights the need for materials in culturally and linguistically appropriate formats, a need likely shared by other non-English speaking immigrant groups.

### **Decision-making in palliative care**

Palliative care guidelines typically anticipate home-based care with support from health workers and family, allowing the patient to freely choose the care setting.<sup>14</sup> Survey results show that while patients want to decide on end-of-life matters, families often make final decisions.

### **Challenges in home-based palliative care**

Experience influences caregivers’ preferences, with former caregivers more aware of the challenges of home care. Many patients prefer dying at home, but obstacles like insufficient after-hours support and language barriers for non-English speaking caregivers often make this difficult.<sup>15</sup> Additionally, cultural sensitivities around discussing death lead to delays in addressing critical issues like wills and Advance Care Directives.

### **Culturally sensitive recommendations**

Previous studies have examined the difficulties culturally and linguistically diverse community members face when accessing palliative care in Australia.<sup>16–19</sup> Our study used quantitative and qualitative data to address cancer patients, caregivers, and former caregivers in the Chinese community. We recommend care providers offer culturally sensitive educational seminars and materials in digital and paper using

Chinese, which clarify common misconceptions about palliative care, its benefits, scope, and access guidelines. Health professionals of non-Chinese background need to be equipped with the necessary tools and resources to provide palliative care information in Chinese. This includes offering culturally sensitive educational materials and ensuring that they can effectively communicate key information, either through interpreters or multilingual staff. These strategies can help bridge language barriers, clarify misconceptions, and facilitate timely referrals to palliative care services. Such an approach is essential to ensure that Chinese-speaking patients and their caregivers receive accurate, accessible information that supports informed decision-making, ultimately improving access to and the quality of palliative care within this community.

## Conclusion

This study highlighted the need for linguistically appropriate materials and programmes to encourage Chinese Australians to use palliative care (Fig. 2). The findings and recommendations could benefit other ethnically and linguistically diverse communities in Australia.

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**Data availability.** The data that support this study were obtained from CanRevive by permission. Data will be shared upon reasonable request to the corresponding author with permission from CanRevive.

**Conflicts of interest.** The authors declare no conflicts of interest in this study.

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