




# Enhancing equitable access to cancer information for culturally and linguistically diverse (CALD) communities to complement beliefs about cancer prognosis and treatment

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## Abstract

**Purpose** Populations affected by cancer from culturally and linguistically diverse (CALD) backgrounds with low English proficiency have poorer health outcomes than the Australian population. They also have limited access to cancer information and may hold health beliefs that affect health-seeking behaviour. A leading cancer support organisation in Australia conducted research with the largest language groups in Australia with the lowest English proficiency to guide the development of appropriate translated resources.

**Method** Six focus groups were conducted with Arabic, Chinese (Mandarin and Cantonese) and Vietnamese speaking cancer survivors, carers and those significantly affected by cancer to understand their health beliefs, information needs and preferred modes of access. Thirteen interviews were also conducted with service providers supporting these communities.

**Results** Communities lacked access to, and knowledge of, cancer information in their language on Australian cancer-related websites. They had easier access to information in their language from overseas health and local ethnic organisations, and from family and friends. Participants trusted health professionals but were dissatisfied with the information and care provided. Cultural beliefs, combined with a lack of information in their language, were not conducive to accessing appropriate information. The impact of beliefs about fate was significant, but they did not rule out using Western treatment or actively seeking cancer information.

**Conclusions** The results reinforce the need to fully explore the cultural beliefs and the structural barriers to accessing cancer information. They also demonstrate that religious-based fatalistic beliefs need not prevent access to information but can co-exist with Western medical treatments.

**Keywords** Cancer information · Culturally linguistically diverse · Beliefs

## Introduction

Cancer is a leading cause of death worldwide; however, understanding risk factors, implementing preventive strategies, early detection and effective management can reduce the

disease burden [1]. Comprehending and accessing information is vital to this process. The ability and skills to do so, in the form of health literacy [2], can improve one's quality of life [3]. Health systems play a role in facilitating patient health literacy by enhancing their capacity to access information [4]. However, accessing information is challenging for culturally and linguistically diverse (CALD) communities. With 34.5% of residents in New South Wales born overseas and 31.5% speaking languages other than English (LOTE) at home, CALD appropriate cancer resources are important [5]. Migrant populations have lower rates of cancer screening, present with later stages of illness, have poorer health outcomes and report more side effects [6–9]. Research that compares the experiences of first generation immigrant patients compared to Australian born found unmet needs were directly

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related to lack of information and support in their language [10, 11]. CALD communities may also be unfamiliar with health systems and have difficulty communicating with health professionals, even with interpreters [12]. Hence, alternative resources that can be understood are vital for good health [7, 10, 11]. Health beliefs and practices may also affect understandings of cancer, health seeking and treatment [8, 13–16]. Information must therefore be provided in a culturally appropriate way to address these needs [15, 17].

Cancer Council Australia (CCA)<sup>1</sup> sought to develop culturally appropriate information resources to address the information needs of CALD communities. Arabic, Chinese and Vietnamese communities were selected as they are the largest LOTE groups in Australia with the lowest English proficiency [5]. Thirty-one per cent Vietnamese, 26% Mandarin, 25% Cantonese and 16% Arabic speakers in Australia speak English “not well” or “not at all”. English proficiency levels were the lowest in 65+ (58%) and 45–54 (33%) age ranges [5].

A CCA literature review on the needs of these three communities reported the existence of religious views of cancer as fatalistic (beyond one’s control), as causing fear and stigma, resulting in negative outcomes, and which could potentially have some impact on accessing health care [15, 18–23]. Across all groups, understandings of cancer were limited, screening services were underused and there was a mistrust of the Western medical system and health professionals [7, 8, 23–27]. Preferred modes of access to health information were family, multicultural health professionals, community support and the Internet [18, 28, 29]. A CCA scan of cancer resources in Arabic, Chinese (simplified and traditional) and Vietnamese found limited availability of online audio and written resources [30]. Many resources were direct translations from English, not addressing variations in cultural understandings [25]. Our research aimed to understand cultural information needs, preferred modes of access and barriers to accessing CALD appropriate resources.

## Methodology

The study design was qualitative, based on an interpretative phenomenological paradigm [31, 32]. This approach investigates the research participants’ understanding and constructed meanings of experience [33] and acknowledges the contextual knowledge base of the researchers in the analysis process [31, 34]. A steering committee with representatives from state-based cancer councils and the targeted CALD communities oversaw

<sup>1</sup> There are cancer councils in all states of Australia, as well as the leading organisation Cancer Council Australia, who have translated cancer information on their websites to help prevent cancer, assist in early detection and ensure effective management of cancer.

this study. Bilingual Research Assistants were employed to conduct two focus groups per language group, and participants were conveniently selected through sending invitations to community groups and networks [35]. Participants consisted of cancer survivors, carers, relatives, friends and others to take a whole of community approach. Focus groups were recorded, interpreted into English by an accredited service and then transcribed. The Research Consultant and Project Officer conducted thirteen interviews with service providers in English who were purposively selected to understand access barriers and to supplement the six focus groups. These sample sizes were consistent with qualitative approaches and scientific review of the project [36, 37]. Ethics approval was obtained from the Cancer Council NSW Ethics Committee (No 311).

Focus group and interview transcripts were coded and analysed to identify themes [31]. The qualitative software NVivo [38] assisted this process [34, 39]. To enhance research transparency [40], themes were presented to the steering committee and at a workshop with research participants. Methods are outlined further in Appendix 1 using consolidated criteria for reporting qualitative research (COREQ) [41] (Supplementary Material).

## Results

Six focus groups were conducted in locations across Sydney. Participants represented diverse religions and ages and were mainly from low socioeconomic groups with mixed genders (except for the Arabic groups<sup>2</sup>) (Table 1). Thirteen interviews were conducted with service providers assisting those affected by cancer in the language-specific communities (Table 2).

We derived three themes from the data: the impact of health beliefs and understandings of appropriate treatment; access to information in different languages; and facilitating access to culturally appropriate local information.

### Impact of health beliefs and understandings

Participants discussed how various cultural factors and treatment preferences affected access to information.

### Associations of cancer with death and stigma

All service providers from the three communities reported that cancer is often associated with death, so people are resistant to gain more information due to fear and misconceptions. Spiritual beliefs about cancer being caused through karma may also inhibit health seeking.

<sup>2</sup> Separate male and female focus groups were held for the Arabic speaking focus groups in accordance with the NSW Cancer Council Human Ethics Committee requirements.

**Table 1** Demographics of focus groups conducted with Chinese (Mandarin and Cantonese), Arabic and Vietnamese communities

Language	Number	Gender	Experience with cancer	Country of birth	Age group	Religion	Time in Australia	Language spoken at home
Chinese	10	3 Male 7 Female	1 Personal 2 Friend 3 Relative 3 Relative/friend 1 Personal/relative	8 China 2 Vietnam	51–65: 6 66–74: 4	1 Christian 3 Buddhist 6 None	0–2 years: 16–10 years: 2 > 10 years: 7	8 Mandarin 2 Mandarin/Cantonese/ English/Vietnamese
Chinese	10	4 Male 6 Female	2 Personal 3 Friend 2 Relative 3 None	10 China	18–25: 1 51–65: 2 66–74: 7	2 Christian 8 None	0–2 years: 1 6–10 years: 5 >10 years: 4	6 Mandarin 4 Mandarin/Cantonese
Arabic	5	5 Male	4 Personal 1 Relative	2 Egypt 2 Lebanon 1 Iraq	51–65: 1 66–74: 4	2 Christian 3 Muslim	6–10 years: 1 >10 years: 4	5 Arabic
	9	9 Female	3 Personal 2 Friend 2 Relative 1 Carer 1 Not stated	6 Egypt 2 Lebanon 1 not stated	26–35: 3 36–50: 1 51–65: 2 66–74: 3	6 Christian 3 Muslim	0–2 years: 1 3–5 years: 1 6–10 years: 2 > 10 years: 5	7 Arabic 2 English/Arabic
Vietnamese	15	6 Male 9 Female	6 Personal 1 Relative 2 Carer 2 Personal/carers 4 None	15 Vietnam	51–65: 6 66–74: 8 >75: 1	3 Christian 11 Buddhist 1 None	3–5 years: 1 >10 years: 14	14 Vietnamese 1 Vietnamese/English
	19	2 Male 17 Female	1 Personal 1 Friend 3 Relative 2 Carer 12 None	19 Vietnam	26–35: 2 36–50: 2 51–65: 5 66–74: 8 2—blank	1 Christian 15 Buddhist 3 None	0–2 years: 2 6–10 years: 4 >10 years: 11 2—blank	4 Vietnamese/English 14 Vietnamese 1 Cantonese

In the Arabic culture, cancer is a scary thing ... we don't say the name 'cancer' ... Like it's contagious ... The fact that there is little information about the background of cancer, why people get cancer, health risks ... some people, even to this day, believe that they got cancer because of bad things they did in the past ... Even educated people don't want to know about it. (Arabic speaking provider)

A lack of information in their language about the full range of causes and prognosis of cancer reinforced an understanding of cancer as inevitably resulting in death. Stigma and shame also discouraged people talking about cancer openly, so hearing about it at a late stage further reinforced the perception of poorer outcomes.

For Vietnamese communities, service providers discussed moral understandings about the cause of cancer.

**Table 2** List of service providers interviewed working with the language groups

Language group	Date	Position
Chinese	13/7/17	Can Revive worker
Cantonese and Mandarin speaking	4/8/17	Multicultural health worker
	24/8/17	Former bilingual counsellor, Cancer Council NSW
	14/9/17	BRA1, CALD resource project, CCA
	6/10/17	BRA2, CALD resource project, CCA
Arabic	21/7/17	Facilitator, Arabic-speaking cancer support group
	4/8/17	Community development worker
	14/9/17	Community worker at Arab Council Australia
Vietnamese	11/8/17	Facilitator, Vietnamese-speaking cancer support group
	18/10/17	Worker, Vietnamese Community in Australia, NSW Chapter
	8/10/17	Vietnamese Women's Association representative
	20/10/17	Bilingual community health educator

“If you have cancer, this may be ... because you are immoral ... you have to pay for your bad behaviour ... That’s why cancer is stigmatised, because it’s strongly related to the punishment of God.”

The Vietnamese focus groups and interviews revealed a lack of awareness and confusion about the cause of cancer including that it was contagious, which contributed to increased stigma.

Arabic service providers indicated variability in the amount of information patients desired about their condition due to connotations with death. An Arabic service provider reported that information should include “Giving them real facts but also allowing a bit of hope”. As explained by a focus group participant, doctors in the Middle East may not fully disclose information to remain positive.

[A full diagnosis] would affect the patient emotionally... make him depressed, unable to cope and fight the illness.

Chinese service providers also discussed the shame and stigma people felt when diagnosed with cancer. It was noted that these views were strongest with the older population, some of which were afraid and superstitious believing that talking about ‘cancer’ may increase the likelihood of getting it. Thus, their children may not tell them they have cancer, as “cancer back in their time was death”. A patient may know they have cancer, but not want to discuss it. Service providers reported that these views are gradually changing due to increased prevalence of the disease and increased awareness of positive outcomes compared to in the past.

### Fatalistic beliefs about cancer

The participants revealed that there were religious beliefs held about fate determining one’s health. An Arabic-speaking service provider explained, some people think that if diagnosed with cancer they should accept their fate, “If God is going to give to me, I’ll deal with it”. For example, fate assisted a cancer patient to stay strong through radiotherapy by believing that only God could determine his outcome. Meanwhile his family believed he would die:

I had faith at that time. There is a God, and God is the one who will really decide what my end would be ... During that time I was reassuring my children and my family that everything would be fine ... Whatever my destiny is, I should accept [it]. After I finished the radiotherapy, then the specialist told me, ‘You are fine, 100% good.’ Arabic focus group

In this instance the patient’s spiritual beliefs co-existed with using the prescribed Western treatment. In some cases, however, these beliefs may conflict.

Arabic service providers discussed the need for health professionals to understand the importance of maintaining religious and cultural beliefs during their medical treatment. Access to bilingual counsellors who are familiar with their religious and cultural beliefs was preferred to English-speaking counsellors using an interpreter. An Arabic bilingual counsellor explained the importance of being able to understand the culture:

[A patient] called me ... and said, ‘I’m diagnosed with cancer and I had a dream. I was supposed to have an operation, [but] I said [to the hospital staff], “Don’t touch me, I’m going to have a miracle, St Mary will cure me.” She was so upset as [the hospital staff] thought she had a mental problem ... I just said to her, ‘The doctor is going to hold God’s hand when they do the operation’.

The Vietnamese and Chinese service providers spoke about communities believing that previous bad deeds and/or karma could contribute to a misfortune such as a diagnosis of cancer. As explained by a Chinese service provider, people with cancer may feel shame and be delayed in seeking help:

“It takes a while for them to look for support and they think they have done something wrong or something in the family [that was] passed down.”

### Understandings and preferences of appropriate treatment

Participants discussed preferences for different medical procedures and thus expectations of health care. Chinese participants held specific beliefs about appropriate treatment and revealed their unfamiliarity with the health system in Australia. They felt that the Australian medical system was slow compared to China as doctors see more patients and are therefore perceived as more experienced and efficient. Focus group participants explained, long waiting lists were potentially delaying a diagnosis of cancer:

In China, you did not need to make any appointment. If you felt ill, you just went [to the hospital] straight away ... that’s why my mom was not happy with the system here ... she went back to China for treatment.

While there was some dissatisfaction with the health system in Australia, some participants reported that the emotional support provided by Chinese health professionals in Australia was also inadequate. Some Chinese participants with cancer said they needed more assistance with emotional support. While others said the Chinese community may be unfamiliar with such services, which were not easily available in China.

If a patient goes to the hospital ... the cancer treatment is focused on the body. For the patient's mental health, in China, they could not offer any treatment or counselling.

Participants disclosed that Chinese-speaking GPs in Australia, like those back in China, do not give enough social support. There were reports of Chinese doctors in Australia refusing to refer patients to counsellors or social workers.

For the Vietnamese and Chinese communities, there were also preferences for alternative treatments including Traditional Chinese Medicine (TCM). For Vietnamese communities, there was a strong interest in herbal medicines to treat cancer, such as pawpaw leaf juice and aloe vera. Herbal treatments were used separately or in combination with Western treatment. Vietnamese focus group participants said that traditional medicine helped longevity when combined with Western treatment.

[It's] because we had a combination of Eastern and Western medicine that my older brother could last for seven years, then he died.

Vietnamese service providers discussed some patients refusing Western treatment, as they disliked 'strong' medicine such as chemotherapy, preferring natural treatments.

The thing with my community is that sometimes they don't trust Western medicine and that's a problem ... They hear ... "You need to keep a certain diet" ... But to me it's not going to be sufficient to combat the disease. There are some people who renounce Western medicine and are just on the [herbal] tea.

The Arabic speaking service providers discussed the need for health professionals to consider the physical and psychological well-being of the patient when delivering news. The doctor could find out the type of support desired and work with the family to prepare for the news. This information also needs to be culturally appropriate and staged.

### Access to information in different languages

The research indicated a lack of access to cancer information in their communities. Current sources included ethnic media, family, friends, GPs and through the health system.

#### Ethnic media

Participants in the study were unaware of translated information on Australian cancer council (CC) websites and were most likely to receive information from overseas sources or through ethnic specific media (television, radio and newspapers). Sometimes this information was not applicable to the

local context; for example, Chinese community organisations CanRevive and CanCare provide information which has been adapted from China/Hong Kong but do not provide local health service information. As explained by a Chinese participant:

I have tried to browse online regarding information on breast cancer. Most of the information I got was in English, but then I also tried to find some information in Chinese. Unfortunately, I couldn't find much ... I'm not sure whether Australia has breast cancer information in Chinese. All the information in Chinese is from China.

Arabic participants also discussed using Arabic media from both Australia and overseas to learn about cancer.

Some Vietnamese participants searched overseas websites and Vietnamese media for cancer information primarily about herbal cures. A Vietnamese service provider warned of the dangers of accessing mainly information about herbal/traditional medicines, rather than Western treatments.

The ethnic media is very powerful and people who promote herbal medicines get access to people that way. When you open a [Vietnamese] newspaper, you will see a lot of advertisements, more than Western medicines. People can only access Western medicine through General Practitioners.

### Role of family, friends and communities

Family and friends assisted participants with cancer through promoting emotional support, helping understand information and translating English documents. Participants felt that this assistance enhanced outcomes and slowed their illness.

Family also played a key role in filtering information for the benefit of the patient. An Arabic-speaking focus group participant spoke of his relationship with this doctor and his daughter's role in contacting the doctor to filter this information for him.

[I] trusted that doctor in terms of his ability to treat me. My daughter is the one who gave me the information at that time about everything.

CALD-specific community organisations provided information in different languages through public events, assisting clients with screening kits and filling in forms. However, they lacked awareness of available translated resources on CC websites.



## GPs and the health system

Within the health system, the research revealed a lack of CALD appropriate information, services and follow-up. Participants said that they respected and trusted doctors but were frustrated because they could not provide more information in their language, promote screening and give timely access to specialists. Hospitals had minimal language-specific written information, but bilingual volunteers, counsellors and nurses tried to provide written translated information. All communities spoke about the need for more counselling and appeared to understand the important role it could play in treatment. This support could “help the patient to live a little bit longer” (Vietnamese focus group). Sometimes patients contacted the appropriate services but were still unable to navigate them to meet their care needs. Patients in the focus groups who have had contact with CCs, for example, did not know about services, such as the Cancer Information and Support Services.

## Facilitating access to culturally appropriate local information

Participants discussed the preferred content of cancer prevention messages and how information should be provided.

### Content of messages

Focus group participants from all communities stated that they wanted more information about prevention, causes and early symptoms of cancer. Service providers cautioned that this information should address misunderstandings such as the belief that cancer only exists if there are symptoms or that it is always hereditary. All providers recommended that information contains positive messages such as ‘early diagnosis will enable you to live a long life with your family’ and ‘God gave you a body and you need to look after it’. When diagnosed, focus group participants said that they wanted information in their language about estimated prognosis, survival rates, treatment options and support. This would help dispel the myth that all cancers are fatal. The focus of messaging varied somewhat between the groups. The results indicated that newly arrived migrants and Chinese participants would benefit from information about the health system in Australia. Vietnamese focus group participants wanted information about correct dosage of herbal medicines and Chinese service providers wanted information about how to safely combine TCM with Western cancer treatment.

### Promotion and delivery of resources

Communities suggested that resources reach a broad audience including those with low English proficiency through videos

featuring doctors/specialists and survival stories. Service providers reinforced the need for more connection between CCs, GPs, hospitals, multicultural health networks and greater promotion of CC resources to multicultural organisations and communities. As explained by a Chinese service provider:

You need coordination, continuity, and connection. The triple C. ... If you do not have the right connection and continuity, then you start all over again.

## Discussion

The research confirmed previous research that the targeted communities lacked access to cancer resources in their language [10–12, 18]. Cultural beliefs, combined with a lack of English proficiency, and a lack of available information in their language from mainstream cancer organisations impacted on access to cancer information. Rather than dismissing cultural beliefs, health professionals should acknowledge them and negotiate culturally acceptable forms of treatment.

### Cultural beliefs and health seeking

The research confirmed that traditional views of cancer as being fatal, untreatable and contagious may hinder access to cancer information [18, 22, 23]. However, such views are changing with greater awareness. Other literature discusses the concept of karma and bad luck as a cause of cancer within the Vietnamese and Chinese communities [15, 25, 42], and the research reflected this. These beliefs may deter people from seeking treatment [8, 20, 21, 26, 29, 43], and contribute to stigma and shame, which could further defer people [16]. If there is more clarity about cancer, it will not be considered only a fatal disease, and hope will be raised [22].

Literature has discussed the role of fatalistic beliefs as potentially reducing the agency of people to seek health information [8, 15, 18, 44]. However, a clear link between fatalistic beliefs and reduced health seeking has been inconclusive [15, 16]. The research demonstrated that positive messages in cancer resources were valued by participants. Although some Arabic-speaking participants had a strong belief in God determining their fate, they also believed that there was hope and the possibility of successful outcomes. Fatalistic views not only exist in CALD communities but in the general population [16, 45]. Faith could work with medicine to assist coping with a serious illness [46], not deter health seeking but as a way of accepting cancer. Traditional and Western health beliefs can co-exist during treatment [25, 47], with people demonstrating personal agency and wanting to get screened [45].

## Access to appropriate information

While access to translated resources from CCs was limited, there was higher access to information in participants' language from overseas websites and ethnic-specific organisations. This meant information was not local and there was no consistency over the type of health information provided. The importance of multicultural organisations [18, 23, 24, 28] and family and friends providing information in language [18, 30, 43, 48] was reinforced in this research.

Understandings of health literacy have traditionally been based on the ability of individuals to access and seek information [2]. However, the role of family and friends as assisting in enhancing health literacy is acknowledged [33], especially for communities that are more collectively orientated. This research has indicated that some communities may require the involvement of family in receiving and filtering information and making decisions to ensure the best outcomes. More communally based approaches to health care therefore need to be considered when addressing health needs of CALD communities.

While the literature discussed the CALD communities' mistrust and dissatisfaction with Western medicine and practitioners [12, 26, 49], the research revealed communities had a lot of trust in their doctors. Frustration was however expressed at their lack of cancer support service information and timely access to specialists. There was dissatisfaction and unfamiliarity with Western medicine and sometimes a preference for traditional medicines. There were also cases of dissatisfaction with Chinese doctors in Australia who were dismissive of providing emotional support.

The research also revealed a lack of understanding of the Australian health system especially for the Chinese participants. The need for assistance navigating the health system was reinforced in the literature as contributing to poorer outcomes [11, 18, 25, 27, 28, 50]. The significant differences between Australian health systems and other countries indicate a need for targeted cancer information for certain migrant groups. This demonstrates the importance of mainstream cancer services actively engaging with multicultural networks and media to provide culturally and linguistically appropriate cancer information [15, 51].

## Significance

This research contributes to the literature about fatalism, religion and its effect on health seeking. It highlights that religious beliefs can be complementary to accessing health information and health care and that health promotion campaigns should recognise that health belief systems can co-exist with Western treatment. CALD communities do not distrust health professionals but they were dissatisfied with health care and the provision of information. The research also demonstrates that online information cannot just be translated but needs to

be culturally appropriate and communities directed to it to improve health outcomes. This highlights the importance of community engagement with vulnerable populations in their own language to assist in health promotion, as they are not the targeted recipients of mainstream messages. Communities trust health professionals but were frustrated and dissatisfied with the treatment and support received.

## Limitations

The findings in this paper reflect the experiences of participants involved and may not be representative of whole communities. Convenience sampling of focus group participants may have skewed the results to participants who were easily accessible to recruit through established networks. The number of focus groups conducted was limited due to funding constraints, so the service provider interviews supplemented the findings. Additional research could further explore the effect of religious beliefs on preferred forms of cancer treatment.

## Conclusions

This research has demonstrated the myriad of factors affecting access to information for CALD communities including health beliefs, coping strategies, structural barriers to available information and the important role of family and community in providing information. CALD populations gained most information from culture- and language-specific sources and organisations both internationally and locally. However, they are not effectively accessing local information linked to state cancer services. These factors contribute to poorer access to health care, treatment and poorer satisfaction. In order that information is accessible, it needs to be promoted and linked to CALD communities and organisations. It should also be culturally appropriate, address beliefs and misconceptions and not just be a translation of existing materials. Faith and cultural beliefs should not be discounted but seen as complementing health messages.

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**Code availability** Not applicable.

**Author contribution** All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Cathy O'Callaghan with support by Gayathri Dharmagesan. The first draft of the manuscript was written by Cathy O'Callaghan and all authors commented on subsequent versions of the manuscript. All authors read and approved the final manuscript.

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**Data Availability** The data that support the findings in this study are available from the corresponding author upon reasonable request.

## Declarations

**Ethics approval** Ethics approval was obtained from the Cancer Council NSW Ethics Committee (No 311) and included scientific review.

**Consent to participate** Not applicable.

**Consent for publication** Not applicable.

**Competing interests** The authors no competing interests.

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