

# Perceived information needs and social support of Chinese-Australian breast cancer survivors

C. Kwok · K. White

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## Abstract

**Background** Both informational and social support are vital components in achieving a high quality of life as a cancer survivor. The study aims to explore the perceptions of information needs and social support among Chinese-Australian breast cancer survivors and how these resources impacted their cancer experience.

**Methods** Three focus groups were conducted with 23 Chinese-Australian women diagnosed with breast cancer in their native language (Mandarin and Cantonese). Each interview was translated and transcribed. Content analysis was used to uncover the major themes.

**Result** Themes for information needs were identified as (1) using linguistically appropriate information, (2) the need for culturally sensitive information for the management of expected side effect and promotion of recovery and (3) the need for information on signs and symptoms of recurrence. Families were described as a primary source of multifaceted social support, although it was challenging to obtain. Support groups were also an important support source, but health care professionals were not identified as a source of support.

**Conclusion** Our study has provided practical insight into the information needs and social support of Chinese women with breast cancer. These findings can be used to inform the development of linguistically and culturally tailored support and survivorship interventions for this vulnerable population.

**Keywords** · Information needs · Social support · Chinese-Australian breast cancer survivors

## Introduction

Instilling feelings of shock, grief, uncertainty and loss of control, a cancer diagnosis is often regarded with more fear than diagnoses of other pathologies [1]. Under these circumstances, informational and social supports have been identified as being vital to helping women to cope with their condition [2–4]. Informational support is of particular importance because it not only increases the patient's involvement in the decision-making process and, thus, induces greater satisfaction with treatment choices [5, 6], but also reduces feelings of uncertainty and helps decrease emotional anxiety [4]. In addition, information makes women feel empowered to fight their cancer and improves communication with families [7].

Extensive research efforts have been focused on the information needs of breast cancer patients. However, studies in this area are largely confined to Caucasian population, and there is some evidence that physicians provide less informational support to minority women with breast cancer [8–10]. Little is known about how Chinese-Australian breast cancer patients perceive their information needs in a health care system where English is the dominant language. A previous study indicates that many Chinese-Australian women who migrated from Hong Kong and China found their breast cancer experience as one of cultural and linguistic isolation. A combination of factors including limited overall knowledge about cancer and cancer treatment, lack of knowledge about how to navigate the health care system and language and cultural barriers means that many in this group are poorly served in relation to access to cancer care and quality of life in cancer survivorship [11].

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C. Kwok (✉)  
University of Western Sydney, Sydney, Australia  
e-mail: c.kwok@uws.edu.au

K. White  
University of Sydney, Sydney, Australia

Providing appropriate and comprehensive informational support for Chinese-Australian women<sup>1</sup> with breast cancer demands that attention be given not only to the issue of language, but also to the cultural backgrounds of the women. Evidence suggests that many Chinese women tend to subscribe to more myths about breast cancer than do Caucasian women [12, 13]. Studies also indicate that many Chinese immigrant women have less knowledge of breast cancer risk factors and believe that they are not at risk of breast cancer because of their ethnic origins [14, 15]. An understanding of the information needs of this group could be used to inform the development of cancer-related information policies and interventions in ways that will begin to meet the needs and challenges of the Chinese-Australian community.

Social support, defined as a feeling that one is cared for, loved, valued and is part of a network of communication and mutual obligation [16], has been identified as the most significant factor in the psychosocial adjustment of women with breast cancer [17–19]. A good system of social support has been correlated with less post-operative depression [20], longer survival rates [21], greater psychological well-being and decreased fear of recurrence [22]. Studies also demonstrate that social support buffers the impact of diagnosis on the quality of life of survivors [20, 21].

Perceptions of the importance of social support may vary across ethnic groups [8, 20]. For example, Chinese-American women have been reported that they rarely discussed emotional issues with friends or sought professional help after being diagnosed with breast cancer [23]. Similarly, studies reveal that Chinese cultural beliefs relating to the central role of family have been connected to fewer help-seeking behaviours and lower levels of social support among breast cancer survivors. As a result, women's loneliness and a lack of social support appear to be major barriers to maintaining good quality of life during survivorship [24, 25]. Again, to date, most research has investigated these issues in relation to Caucasian women with breast cancer, with implications for the understanding of the needs and sources of support in other populations.

Ethnic Chinese now form the largest immigrant group in Australia from any non-English speaking country, and their numbers are continuing to grow rapidly, with those born in mainland China and Hong Kong increasing nearly 12-fold

<sup>1</sup> It needs to be recognized that Chinese-Australian women are not a homogenous group. Among other factors, they vary in terms of education level, age, length of stay in Australia, English language competence and social-economic status. Nonetheless, we have found a remarkable similarity in the attitudes and experiences of many of these women. In social science research, there is always a tension between idiographic and nomothetic explanations. In this article, we have focused on commonalities rather than outliers and diversity in order to provide those responsible for clinical services with a general understanding of this group. Having said that, we warn against stereotyping patients, each of whom needs to be treated as an individual.

between 1981 (when they numbered 25,200) and 2008 (when the population had increased to 313,600) [26]. However, emigration poses dangers for Chinese women; previous research has demonstrated that their risk of developing breast cancer increases by 40 % following migration to Australia [27]. This means that an increasing number of Chinese-Australian women are likely to contract breast cancer and that in turn means that there will also be an increasing number of survivors because not all cases are fatal.

The current lack of data on the experience and needs of Chinese-Australian women with breast cancer does not allow for culturally appropriate planning of supportive survivorship care for this population. This study aims to address this gap by exploring the perceptions of information needs and social supports of these women and how these perceptions impact their cancer experience. To the best of our knowledge, this research is the first of its kind within this population.

## Methods

### Study design

As noted above, we did not identify previous research on this topic and thus adopted a qualitative study design. Qualitative approaches are more appropriate in the early, exploratory phase of a research topic and facilitate a deeper, richer understanding of the experience via open dialogue between the researcher and the participants [28]. In particular, qualitative methods emphasize the importance of describing the participants' worldview about the perceptions of information needs and social supports and how these impacted their cancer experience.

### Sampling/recruitment

Eligible participants were Chinese women who had been diagnosed with breast cancer at least 6 months prior to the time of recruitment and their having completed adjuvant chemotherapy, surgery or radiotherapy. Women taking tamoxifen ( $n=7$ ) were included since this was seen to be a non-invasive treatment of significantly lengthy duration. Other criteria were having English, Cantonese or Mandarin as a primary language and did not have any mental health conditions that might have affected their responses. Twenty-three participants were recruited from a Chinese cancer support group in Sydney.

### Data collection

Ethical approval was obtained from the principal investigator's university prior to the data collection. Focus group interviews were employed as a vehicle for collecting data since these provided a non-threatening environment which enabled the perceptions and personal experiences of a special issue or

topic to be explored [29]. As evident in previous research [30], Chinese breast cancer patients were comfortable to disclose their concerns and share feelings in a group environment in which people spoke the same language and shared the same culture and disease experience. Written consent was obtained prior to the focus group interview. At the interview sessions, participants were informed that they had the right not to respond to any question.

Three focus group interviews were conducted. Groups were organised according to the women's primary language: two groups were conducted in Cantonese and one in Mandarin.<sup>2</sup> The groups met on the premises of a cancer support group in order to provide a familiar environment. A semi-structured interview guide was used to facilitate the focus group discussions. Questions included: "What is your feeling about the information you received?" and "Can you share with us what social support you have experienced?" Focus group interviews lasted between 90 min and 2 h. Prior to the interviews, participants were requested to fill in a questionnaire which recorded demographic data and medical information.

#### Data analysis

The initial analysis was conducted by the authors using the methods recommended by [31]. Firstly, the entire transcripts were read several times to gain a general sense of the participants' experiences in terms of informational needs and perceived social support. Next, line-by-line reading was employed, and meaningful statements and paragraphs were identified and coded. Codes with a similar meaning were grouped together into main themes. The transcripts were read again to verify the codes and themes. The text was analysed independently by the two authors, who then compared and contrasted their findings to ensure codes were mutually exclusive. The same codes were retained, similar codes were combined and the revised codes were discussed and revised again until agreement was reached. The data was analysed using the same mechanism for social support and information needs independently and then integrated in the interpretation as appears in the "Discussion" section.

The rigour of the study was achieved through the following strategies. The interview guide was given to a panel of experts in cancer care to ensure that the questions were in line with the study aim. All focus group interviews were conducted by the PI to ensure consistency in the manner of data collection. Interviews were audio-recorded and translated and were then transcribed into English for data analysis. The translation and transcribing was done by the PI who is fluent in English, Cantonese and Mandarin. Back translation [32] was done by another bilingual person. To ensure accuracy, transcribed data

were checked against the interview recordings independently by the PI and a trained research assistant. To increase validity of findings, findings were provided to some participants who agreed to receive a copy of the report and give feedback to confirm the interpretation and correctness.

## Findings

### Participant demographics

The demographic characteristics and clinical information of the 23 women who participated are presented in Table 1. In summary, the women's ages ranged from 35 to 68 (mean=56)

**Table 1** Demographic characteristics and clinical information of participants ( $n=23$ )

Characteristic	Number (%)
Age (mean)	56 (SD=2.5)
Country of birth	
Hong Kong	5 (21.7)
Mainland China	10 (43.5)
Others	8 (34.8)
Length of stay in Australia	
<10 years	3 (13.0)
10 to 19 years	7 (30.4)
20 to 29 years	11 (47.8)
≤30 years	2 (8.7)
Marital status	
Single	4 (17.4)
Married	16 (69.6)
Divorced/separated	1 (4.3)
Widowed	2 (8.7)
English proficiency	
Good	2 (8.7)
Average	5 (21.7)
Little	15 (65.2)
Not at all	1 (4.3)
Family history of breast cancer	
Yes	3 (13)
No	20 (87)
Stage of disease	
Stage 0	5 (21.7)
Stage 1	6 (26.1)
Stage 2	6 (26.1)
Stage 3	4 (17.4)
Stage 4	2 (8.6)
Time since diagnosis	
<1 year	6 (26.1)
1–2 years	11 (47.8)
2–3 years	5 (21.7)
3–4 years	1 (4.3)

<sup>2</sup> We wish to emphasize that there were no significant differences between the three groups.

while most had immigrated to Australia from mainland China ( $n=10$ , 44 %) and Hong Kong ( $n=5$ , 22 %). The duration of residence in Australia varied from 6 to 30 years, a majority were married ( $n=16$  or 70 %) and nearly all had children ( $n=21$  or 91 %). More than half spoke either little ( $n=15$  or 65 %) or no English ( $n=1$  or 4.3 %).

#### Perceived information needs

##### *The need for linguistically appropriate information*

Almost all women recalled receiving written information about cancer and cancer treatment from health care professionals, usually a surgeon. Given the fact that all information they received was in English, the overwhelming experience was one of frustration arising from their inability to understand this information. A clear desire for linguistically appropriate information was expressed by almost all women ( $n=21$ ). This was particularly the case among those with limited English proficiency ( $n=16$ ), as being unable to understand the information hampered their ability to gain a sense of control over what was happening to them.

I and my family knew nothing about cancer. After being given the diagnosis, we of course wanted as much information as possible about its treatment and everything else. Yes, the doctor did give us many pamphlets, but they were all in English so we couldn't understand them. There was nothing in Chinese you know. It was so frustrating. I was made anxious enough by the diagnosis, but the worst part was the feeling of losing control because of the lack of information.

What was I supposed to do with all that English information? I couldn't read it and didn't understand it at all. I felt at a total loss in the situation.

##### *The need for culturally sensitive information for management of expected side effects and promotion of recovery*

In addition to wanting the information in their own language, all participants stressed the importance of having information that was relevant to their cultural background for managing expected side effects of their treatment and promoting recovery. Given that food therapy plays a significant role in Chinese culture, many participants expressed a strong desire for information on diet in relation to the management of symptoms, promotion of recovery and prevention of cancer recurrence.

I remember receiving information about how to manage nausea and vomiting as a result of chemotherapy. It was suggested that patients do not take dairy products. But that information is not relevant to us [Chinese]. I never

have any dairy products in my diet, unlike the local people who drink a lot of milk in their coffee and tea and eat cheese cake or something like that. So that kind of information is not relevant to what we [Chinese] want to know. You know that in our Chinese culture, we always use a lot of food remedies. People eat congee when they don't feel well, or use ginger to help car sickness. My sister cooks a lot of Chinese soup for me during the chemotherapy which we believe is really helpful in neutralizing the effect of drugs. I needed more of this kind of information in our Chinese context to promote recovery.

It is vital to note that even women with good English proficiency expressed similar desires for culturally sensitive information:

You know, we (Chinese) are different and our needs are different too. The information I want should be in our Chinese context. I know I could take an anti-emetic for nausea but I wanted to know what good natural remedies could help or what's good to eat to promote recovery and prevent recurrence. I could find no such information.

##### *The need for information on signs and symptoms of recurrence*

Many participants were aware of their lack of knowledge about the disease and the expected side effects of treatment. Their constant uncertainty about expected "normal" post-treatment recovery caused them much anxiety. Their statements on this issue indicated they felt a strong need for information about signs and symptoms of a recurrence of the cancer.

I knew nothing about breast cancer. So even though the doctor said after the treatment that I was clear of the cancer, I continued to worry about recurrence and I wanted to know what signs or symptoms I should look for. It is important to have information on the expected side effects of the treatment and about what is normal. I get really panicky whenever I feel something here or there on my body.

Every little ache and pain made me constantly nervous and anxious for a long time. I would have random back pains that completely freaked me out. It is important to have information on a list of symptoms to watch out for... certain things to be on the alert list.

#### Perceived social support

Given the role of family as a central unit in Chinese culture, it is not surprising that families were described as the main

sources of social support for these women. Although support from sources outside can be important, very few women mentioned friends in this regard and none mentioned health professionals.

### *Family*

Given the central role of family in Chinese culture, it is not surprising that almost all women in this study identified family as their primary source of support during their breast cancer experience. Most married women ( $n=18$ ) reported that their husbands and children were their greatest source of support. Family support was perceived in various forms which appeared equally important to participants.

Psychological support by family members was observed as noteworthy to the participants particularly when confronting the disease and future with uncertainty. Psychological reassurance and emotional support were the key elements.

I am so pleased that I had my family by my side all the time. Without them, I don't think I could have gone through my battle with cancer.

My eldest sister was the most important source of support to me during this struggle. She was always with me and never left me alone.

My husband was so supportive. He always said: "Don't worry, whatever happens, I will be with you."

The physical presence and company of family members appeared to be an important psychological support, particularly for women with limited English proficiency and immobility. Family members facilitated communication with health care providers and also provided transport to and from treatment sites.

My daughter drove me to all my medical appointments. She gave me not only psychological support but also translated for me.

I was so glad that my daughter was with me all the time in the hospital when I had surgery. Otherwise I would have been very scared as I couldn't communicate with the doctors and nurses.

Given the traditional gender role in Chinese culture that males seldom attend housework in general, many women expressed deep appreciation for the domestic support at home of family members, particularly husbands, when they took over the housework and looked after children during and after cancer treatment.

Even though my husband doesn't like housework, he did nearly all of it while I was having cancer treatment.

I very much appreciated the way my sister helped me by looking after my children while I was in hospital. Her help made my life so much easier.

On the other hand, this kind of support was limited for women who had little or no extended family in Australia ( $n=15$ ).

Yes, my husband was very supportive and he did whatever he could. Still, he had to go to work as he is the breadwinner. Then there was no one to help. Honestly, I had to rely on myself most of the time and I had to keep taking care of my children even when I was feeling so sick from the chemotherapy. Who else could help me? I wished my family was over here.

I was so helpless over here [in Sydney] you know. My children were too young and no one really could look after them. If this [breast cancer] had happened in China where my family is, I am sure the situation would have been much better.

However, for some women, the willingness of their family members to provide support was sometimes an added source of anxiety because they felt they were a burden and thus tried not to be too demanding.

Sometimes I try not to demand too much as I feel like a burden to them (husband and son).

I didn't share too much with my family as I didn't want them to worry about me.

### *Chinese cancer support groups*

Chinese cancer support groups were also reported as another important source of social support which was more helpful in some ways than family support as group members were often more knowledgeable and understanding than family members.

Sometimes it was hard to share with family and friends because unlike the other women in the support group, they don't really understand your feelings and concerns. In the group we understood each other very well, because we had all gone through similar experiences.

This support group was very useful particularly because there was so little information in Chinese available outside. The information we shared was so relevant to what I wanted to know.

I did try the local cancer support group but I didn't like it at all. Because of different cultural backgrounds, I found that we (Chinese women and Caucasian women) are different. For instance, I never thought about cosmetic breast surgery, but they did. The support I found in here



(Chinese cancer support group) was something I never found in the local one.

### *Friends*

Only two women mentioned friends as a source of support. These women were either single or widowed, or had no female family members.

I am lucky that I had my good friend was with me all the time, otherwise, I don't know how I could have got through this tragedy as my parents were too old to help or support me. I couldn't even tell them when I went to hospital for surgery.

However, other women in the study did not expect support or help from friends.

Friends are friends, but they also have their families to look after so it's too hard for them to offer help, you know. Either they have got to work or they live too far from where I stay.

I did not want to tell my friends that I got breast cancer because they might respond in a negative way e.g. I am contagious or whatever. I did not want additional stress.

## **Discussion**

That cancer survivors from minority cultures are poorly represented in the current literature means that little is known about the challenges they face. Our study, the first of its kind, has highlighted the information needs of Chinese breast cancer survivors, particularly in relation to culturally and linguistically appropriate information about management of expected side effects and promotion of recovery. Participants in this study also expressed the need for information on signs and symptoms of recurrence.

Language barriers created important difficulties for most Chinese-Australian breast cancer survivors in our study who faced major challenges in understanding the information they were given by both in printed form and by health care professionals. This is similar to the experience of immigrant Chinese women in the USA and seems common among immigrant women in English-speaking Western countries [9, 23]. It was clear from the participants that the lack of culturally sensitive and linguistically appropriate information resulted in frustration and feelings of isolation. This is a serious issue because a body of literature suggests that providing breast cancer patients with adequate information and support is an essential component of quality survivorship care [2–4, 33]. Despite Australia officially being a multicultural society, the available

information about breast cancer treatment and post-surgical management is almost entirely in English and, therefore, incomprehensible to women with poor English proficiency.

A study by Yi and colleagues demonstrates that English proficiency was positively associated with quality of life among Chinese-American breast cancer survivors [34]. Even though examining the influence of acculturation (length of stay in Australia and English proficiency) on perception of information needs was not the focus of our study, the finding particularly striking in our study is the strong desire for culturally sensitive and relevant information especially for managing the disease and promoting recovery by the majority of participants, regardless of English proficiency. The statements of the women in our focus groups demonstrate that they believed it to be very important to have information relevant to their culture. This is consistent with studies among their counterparts in the USA [10, 23] and other women from minority groups with breast cancer [3, 35]. But we also argue that the production of culturally sensitive materials and communication must go beyond simply translating existing English material because such material is likely to be ignored if it is not culturally relevant. Taking the cultural beliefs and practices of the audience into account is the first step to the provision of tailor-made informational support. This is particularly important as studies have demonstrated that failure to account for cultural and linguistic issues can result in resistance to information provided to breast cancer patients in the target group [10, 36].

Our study underscored several additional themes characterizing areas of particular importance to Chinese-Australian breast cancer patients. Support groups and survivorship interventions developed for this population should be responsive to participants' needs for more information on the role of diet in relation to promotion of recovery and prevention of cancer recurrence and signs and symptoms of recurrence. Given the belief and popularity of food therapy in Chinese culture, our findings reveal that the use of specific foods to counter illnesses and maintain health and well-being was a natural part of the cultural practices of Chinese women living in Australia regardless of how long they have resided here and, indeed, their level of English language proficiency. This is consistent with the beliefs of their counterparts worldwide [9, 23, 36]. Having a desire for information about signs and symptoms of recurrence appears common and important to all cancer patients regardless of culture [7, 37]. However, this need may be more urgent for Chinese cancer patients as they generally lack overall knowledge about cancer [12, 14].

In accordance with the findings of other studies [18–20], family was seen as a central source of social support to the participants. Consistent with what has been demonstrated in a previous work [38], family support in this study extended beyond the psychological to assistance with domestic tasks; this included serving as ad hoc interpreters<sup>3</sup> and taking care of

day-to-day family needs. Acting as an interpreter by family members raises questions about how families cope with the added responsibility in addition to providing extensive support and care to their loved one suffering from breast cancer. Further research in this area is essential to assess and meet family members' support needs.

However, the willingness of their family members to provide support was sometimes an added source of anxiety because the women felt they were a burden and thus tried not to be too demanding. This finding is parallel to the recent study describing Chinese cancer patients' anxiety about becoming a burden to the family, compounding their own distress [10, 23]. Family support was also sometimes limited and difficult to obtain because participants' immediate families in Sydney tended to be small and extended family members were in their home country. This indicates that health care professionals should be concerned about the lack of family support experienced by some breast cancer survivors from this cultural background and also be aware of their feelings of lack of social support.

A study by Tsai and colleagues indicate that acculturation is positively related to social support among Chinese-American immigrant women with breast cancer [40]. Despite that fact that the majority of women in this study have been in Australia for more than 10 years, we argue that length of stay in Australia is not necessarily related to acculturation. Indeed, most women in our study were not comfortable speaking English, and all chose to participate in a cancer support group for Chinese women. It is not uncommon for some Chinese immigrants to live in Australia for decades and barely speak any English whatsoever. Even those who can function in English may assimilate in other ways. Inconsistent with breast cancer literature relating to the Caucasian population [18, 20], only a couple of women in this study experienced or expected support from friends. This is largely due to the fact that in Chinese culture, discussion of issues of illnesses such as cancer is traditionally confined to the family circle and seeking help outside of the family is often viewed as inappropriate [23]. Furthermore, cancer is often stigmatized and regarded as a contagious disease in Chinese culture [12]. It is not uncommon that Chinese cancer patients would not disclose their diagnosis to people other than their direct family [9, 23] or, in this case, members of a support group. Our observation demonstrates that social and cultural meaning of breast cancer contributes to the women's reluctance in this study to elicit social support from friends.

However, one source of social support outside their families that obviously played an important role in helping the

women to cope was a formal support group comprising a number of women with similar cancer experiences. That such a group was found to be helpful was probably due to the way they compensated for the difficulties participants experienced in obtaining help from what they regarded as their primary means of support, their extended family living outside Australia. Consistent with extensive research demonstrating the beneficial effects of formal support groups on psychosocial outcomes and quality of life for women with breast cancer [20, 22, 41], our study confirmed that cancer support groups can do much to reduce participants' feelings of isolation and alienation. That participants can meet and discuss with others who understand their cancer experience helps women to express their feelings and thus counteracts the tendency of some Chinese people to avoid the expression of emotions, which is seen as sign of weakness and disruptive of social harmony. This finding also concurs with that of the study by Chan et al. [41] and Cheng et al. [25] conducted in Hong Kong. For the women in this study, support groups filled an important need by providing culturally relevant information about cancer and care, which helped to counterbalance the current lack of culturally sensitive and linguistically appropriate information and resources for Chinese cancer patients. This is in agreement with the recent study conducted by Kwok and Ho [30].

Unfortunately, although there are numerous breast cancer support groups catering to the Caucasian population, we are aware of only two Chinese support groups in Sydney, despite its large Chinese population. This is concerning, as women from minority ethno-cultural backgrounds may be reluctant to participate in groups composed largely of Caucasian women [3, 35, 42]. This supports our finding that women with experience of both Chinese and non-Chinese support groups preferred the former. Considering the limited sources of social support available to Chinese cancer patients, expanding the number of Chinese cancer support groups in Sydney would help to provide increased access to this source of support.

A strength of our study was that the researchers shared the culture and spoke the language of the participants, which helped to establish rapport with them and led to the collection of rich descriptive data. However, as the study sample was selected from a breast cancer support group, it did have the potential for bias, particularly regarding the views of support groups as a source of support and willingness to participate. In addition, our participants were women with breast cancer within 5 years of survival, and thus, the findings may not be applicable to survivors with long-term survivorship.

## Conclusions

Chinese cancer patients, particularly in Western countries, are poorly represented in survivorship care literature which means that little is known about the challenges they face in obtaining

<sup>0</sup> We note that best practice guidelines recommend that health practitioners use professional interpreters rather than family members [39]. However, where these services are not available or used, our participants were reassured by the availability of family members to perform this function.

information and social support after cancer diagnosis. Our study addresses an important gap in the research literature by providing practical insight into the information needs and social support of Chinese women with breast cancer. Furthermore, these findings also provide further groundwork for future research and the development of linguistically and culturally tailored support and survivorship interventions for this vulnerable population.

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**Conflict of interest** The authors declare that there is no conflict of interest related to this research and there is no financial relationship with the organisation that sponsored the research. The authors have full control of all primary data and allow the journal to review the data if requested.

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