Reducing disparity in outcomes for immigrants with cancer: a qualitative assessment of the feasibility and acceptability of a culturally targeted telephone-based supportive care intervention

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Purpose: Australia has one of the most culturally diverse populations in the world. Immigrant cancer patients' poorer outcomes compared to English-speaking patients confirm the need for culturally sensitive supportive care interventions. The aim of this study was to (1) identify cultural sensitivities important to the acceptability of a telephone-based supportive care intervention (2) identify cultural barriers and facilitators to intervention participation.

Methods: Patients and carers attending Chinese or Arabic cancer support groups were recruited. Two focus groups comprising 12 patients and 4 carers and two telephone interviews were conducted in the participants' own language. A semi-structured interview format was utilised to determine potential cultural sensitivities that may influence intervention delivery format as well as patients' willingness to participate in telephone-based supportive care interventions. Content analysis confirmed similar themes across groups.

Results: The intervention was viewed favourably as a means of providing information and support in the patient's language. Cultural considerations included assurances of confidentiality, as cancer is not openly discussed within communities. An Initial face-to-face contact was highlighted as the most important factor facilitating participation. Participants also recommended the inclusion of patient-initiated calls as part of the intervention.

Conclusions: This study provides cultural insights relevant to the development of a culturally sensitive telephone-based supportive care intervention for Arabic and Chinese speaking cancer patients. Participants highlighted the need for face-to-face contact and inclusion of patient-initiated calls as important methodological considerations.

Key words: focus groups, migrants, cancer, cultural sensitivity, supportive care interventions.

Introduction:

Australia has one of the most culturally diverse populations in the world. Twenty-four percent of Australians were born overseas and 2.8% of the total population speak English poorly or not at all. [1] Overall, 3.2% of immigrants to Australia come from Chinese or Arabic-speaking countries. US and UK studies confirm immigrant cancer patients have poorer outcomes compared to English-speaking patients [2], with lower screening and survival rates [3, 4], higher rates of reported side-effects [5], poorer quality of life [6] and greater distress. [7, 8] Significantly, poorer outcomes are reported to be unrelated to social economic status. [2] Limited data from Australian studies suggest similar outcomes for Australian migrants. [9] Reasons for these disparities are multi-faceted but reflect differing cultural and religious beliefs and illness conceptualisations, as well as practical barriers to care, such as language difficulties, a lack of knowledge about the healthcare system and poor doctor-patient communication.

The poorer outcomes and high levels of unmet need experienced by immigrant groups suggest a need for interventions that are sensitive to the specific cultural needs of these patients. Telephone-based supportive care in the patient's own language is one strategy that may have utility in addressing patients' information and support needs in a culturally sensitive but cost effective manner. In a research context, telephone-based supportive care interventions delivered to English-speaking cancer patients have been effective in reducing unmet need and assisting with care co-ordination [10]. Similar programs in the US have addressed either migrants' psychosocial issues or patient navigation issue and shown some benefits. [11, 12] Our group has developed a telephone-based, culturally sensitive supportive care programme (CALD-CONNECT) which involves 5 calls over the first 6 months after diagnosis. However in line with MRC recommendations for developing and evaluating complex interventions [13], prior to implementation, the feasibility and acceptability of the intervention was assessed to determine barriers to participation within the target cultural groups. The aim of this study was to: (1) identify cultural sensitivities important to the acceptability of the intervention (2) identify cultural barriers and facilitators to intervention participation.

Methods:

Patients and family members attending community-based Chinese-speaking or a hospital-based Arabic-speaking cancer support groups in Sydney, Australia were invited to participate in a focus group conducted in their native language, or if unable to attend, in a semi-structured telephone interview. Participants were provided with information about the study translated into their native language and written consent was obtained. The discussions were moderated by researchers fluent in either Chinese (Cantonese and Mandarin) or Arabic. A semi-structured interview format was utilised. Participant views and experiences were elicited to determine potential cultural sensitivities that may influence intervention delivery format as well as patients' willingness to participate in telephone-based supportive care interventions. Participant discussions were digitally-recorded, translated and transcribed. A conventional content analysis was conducted [14]. Three researchers (JS, PB and MS) developed the coding schedule and themes and subthemes emerged from the coded data. Recruitment continued until theoretical saturation was achieved.

Results:

Two focus groups (1.5 – 2 hours) and two telephone interviews were conducted. Six Cantonese-speaking patients, six Arabic-speaking patients and four spouse caregivers participated in the focus groups. Two Mandarin-speaking patients elected to participate in a telephone interview. Participants were predominately female (67%), with a mean age of 60.1 years. Patients had a range of cancers (listed in Table 1). Four main themes emerged from group discussions: (1) intervention relevance and acceptability (2) participation facilitators

(3) participation barriers and (4) role definition for intervention delivery

Intervention Relevance and Acceptability

Overall the concept of a telephone-based intervention was viewed favourably by participants as a means of providing information and support in the patient's language. All participants perceived their poor English, lack of familiarity with the health system, limited understanding about cancer and treatment and uncertainty about specialist roles and responsibilities had negatively impacted on the quality of their cancer care. Participants believed the proposed intervention could address these issues faced by non-English speaking patients within the Australian healthcare system.

The telephone-based delivery model was viewed positively as it provided a means of accessing information and support without having to attend further appointments. This was perceived as important for patients in active treatment and/or who were unwell and was also perceived as cost effective. Of particular benefit to patients was the ability to discuss individual needs and receive information and support tailored to these specific issues. The five call structure of the intervention provided multiple opportunities to ask questions or raise issues of concern. Participants also perceived patients would also find the calls reassuring.

> *if your phone call service, in which the callers can speak Chinese, can inform us of these types of aid, especially within the first three months [of diagnosis]… and give us information on what kinds of government or private resources we can access, it will be a lot better. . and also help us to cope with physical [e.g. financial] and psychological issues, it will be good. (Chinese participant).*

Participation Facilitators

Although the telephone-based delivery was acceptable, participants recommended an initial face-to-face contact with the person delivering the intervention as an important factor to facilitate participation. This was seen as crucial by both focus groups, as culturally there is a reluctance to discuss sensitive information with a stranger. The initial face to face contact was perceived as a way for potential participants to access whether the person delivering the intervention understood their fears and anxieties. Several participants perceived the intervention role should also extend at that initial contact at the time of diagnosis, to that of a patient advocate, attending patient appointments and facilitating patient consultations.

> *You need somebody as first point of contact, somebody who speak their language and explain everything from A to Z and then the phone call[s] (Arabic participant)*

Participants also recommended that at least one patient-initiated call be incorporated into the call schedule. This option would provide patients with access to assistance in times of high need between scheduled calls.

> *Maybe later you realise what your problems and questions are…it would be good if you could call them and ask (Chinese participant).*

Participation Barriers

Language proficiency was reported to be a key factor in patients' willingness to participate in the intervention. Native speakers were viewed more favourably as their understanding extended to cultural considerations. Concern about confidentiality was highlighted as a potential barrier to participation. Culturally, cancer is not discussed openly within either community and there was some fear information may be disseminated to others if the person delivering the intervention was from the same community.

> *For Chinese people, you don’t even want to tell some of your relatives or friends too much…except for your immediate family, otherwise you won’t talk about it too much… some people even keep it from their parents. But… the person you report to is directly helping you. But you have to let the patient know how their personal information provided will be kept confidential, including their concerns*… (Chinese participant).

Within the Arabic community, some families also prefer to withhold cancer information from the patient, to reduce distress. Other families conduct discussions in the presence of their religious leader rather than with the medical team. These families would not accept a stranger discussing cancer with the patient.

> *so in our background some families keep it from them [the patient] (Arabic participant).*

Cultural considerations for the intervention

Participants held strong views regarding the skills required to deliver the intervention. In addition to providing information and acting as an emotional support, participants considered the person delivering the intervention also needed to act as a cultural broker. They would be required to understand and acknowledge patients’ traditional view of care and also explain the principles of western medicine where they differed from the traditional view. Although the information needs of patients were reported to be generally similar to those of English - speaking patients, the Chinese group reported they struggled with treatment adherence during chemotherapy due to severity of side effects. This group suggested providing information related to side effect management as well as emotional support was an important part of the role.

Members of the Arabic-speaking group highlighted an understanding of the role religion plays in cancer diagnosis and the impact of religious conceptualisations of cancer as important. Several members of the Arabic-speaking group also highlighted that the gender of the person delivering the intervention was important, as discussing sensitive issues with the opposite sex would be difficult. Other members of the group perceived that if the person was knowledgeable, gender would not be an issue.

Discussion

This focus group study provided important information, based on participant cancer experiences and cultural insights, to assist the development of culturally sensitive telephone-based supportive care interventions. There was considerable congruence of themes between the two migrant groups. Consistent with previous reports [15, 16], language difficulties and a lack of knowledge about the healthcare system were found to contribute to psychological distress and unmet supportive care need. The proposed telephone-based intervention delivered in a patient's native language was perceived as an acceptable methodology for addressing the needs of Chinese and Arabic-speaking patients.

Based on their own experiences and understanding of the cultural complexities within communities, participants identified several important methodological considerations to facilitate participation, including the need for an initial face to face meeting between the patient and the researcher delivering the intervention and the inclusion of patient initiated calls. The language skill and cultural understanding of the researcher delivering the intervention was an important determinant of willingness to participate.

The importance of a sense of kinship has previously been reported to influence the quality of communication and the ongoing relationship between patients and oncologists [17].

Face to face meetings were perceived as an important addition to the methodology as they provided an opportunity for patients to assess the communication skill of the staff-member and also a way to establish an ongoing relationship prior to the first intervention call.

Language difficulties and a lack of familiarity with the healthcare system can limit access to care and result in a sense of isolation among patients [17]. Scheduling calls to coincide with times of need and the inclusion of at least one patient-initiated call during the intervention has the potential to facilitate patient understanding and reduce anxiety.

Concern regarding confidentiality was identified as a potential barrier to participation, as cancer has traditionally not been openly discussed within Chinese and Arabic-Australian communities [18-20]. This non-disclosure is reportedly related to fear or stigma [19-21] and in some circumstances may also extend to the patient themselves. While the majority of participants in this study held the view that patients should be informed of their cancer diagnosis, within the wider community family members can act as gatekeepers, protecting the patient from the news of a cancer diagnosis. Such practices may limit the acceptability of any proposed intervention. Of note our own data shows that the majority of patients wish full and open disclosure. [22]

The results of this study need to be considered in light of several limitations. Firstly, given the heterogeneity of Chinese and Arabic speaking communities in Australia, the small number of participants in this study may not reflect the views of all groups within these communities, although we did observe saturation of themes. Factors such as age, religious beliefs and acculturation may also influence the way in which cancer is discussed and therefore participation in such an intervention. A second limitation is the recruitment methods employed which may have influenced the study results. All participants were recruited through cancer support groups; this may have resulted in a bias towards more proactive patients, therefore overestimating the acceptability of the intervention within the wider community.

Conclusion

The focus group findings provide cultural insights relevant to the development of a culturally sensitive telephone-based supportive care intervention for Arabic and Chinese speaking cancer patients. The importance of face to face contact in the recruitment phase of the study and the need for patient-initiated calls are important methodological considerations. In addition to cultural awareness of illness conceptualisations, navigating issues of confidentiality will be challenging for intervention staff.

Conflict of Interest

The authors have no financial or personal relationships with other people or organisations that could bias their involvement in this study. The authors have full control of the study data, which is available for review.

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Table 1: Patient Clinical Information

Cancer Site	No. Participants (n=14)
Breast	4
Brain	1
Colon	1
Gynaecological	2
Haematological	1
Head & Neck	1
Lung	1
Lymphoma	1
Prostate	2