

Developing Written Information for Cancer Survivors from Culturally and Linguistically Diverse Backgrounds: Lessons Learnt

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ABSTRACT

Australia is a multicultural nation with a large migrant population. Migrants with cancer report inferior quality of life and the need for more information in their own language. This paper describes lessons learnt from developing culturally appropriate written information resources with and for Arabic, Italian, and Vietnamese cancer survivors and carers. The information needs of survivors from these language groups as well as guidelines for the development of written resources for culturally diverse populations were identified through literature review. Community consultation was undertaken with focus groups. The content was developed and tested with health professionals who spoke the appropriate language and focus group participants, ensuring relevance and appropriateness. Resource design and dissemination were informed through community consultation.

A number of key tasks for developing resources were identified as follows: (1) community engagement and consultation; (2) culturally sensitive data collection; (3) focus group facilitators (recruitment and training); (4) content development; (5) translation and review process; (6) design; and (7) sustainability. This project reinforced literature review findings on the importance of cultural sensitivity in the development of resources. Engaging with community groups and incorporating culturally appropriate recruitment strategies optimises recruitment to focus groups and facilitates content development. Stakeholders and lay persons from the intended ethnic-minority communities should be involved in the development and formative evaluation of resources to ensure appropriateness and relevance and in the dissemination strategy to optimize penetration. We believe the lessons we have

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learnt will be relevant to any group intending to develop health information for culturally and linguistic diverse groups.

Key words: Cancer survivorship, culturally and linguistically diverse, information, and support

Introduction

The period after completing treatment for cancer can be one of uncertainty.^[1] For individuals from culturally and linguistically diverse (CALD) backgrounds, additional challenges may be encountered compared to the general population.^[2,3] Even after controlling for socioeconomic status and health insurance coverage, racial/ethnic disparities in health-care utilization and outcomes persist.^[4] Cancer patients from CALD groups report higher psychological distress and inferior quality of life, compared to English-speaking, Australian-born counterparts.^[4,5]

Survivors and others (including carers and family members) involved in the posttreatment phase need information on the probability of disease recurrence, secondary prevention, long-term side effects of treatment, quality of life, and personal finances among other topics.^[5] The written information assists patients and caregivers to retain information.^[6] Written information is known to assist people with cancer in far-reaching ways. This includes allowing them to gain control, reduce anxiety, improve compliance, create realistic expectations, promote self-care and participation, and generate feelings of safety and security.^[7]

For individuals whose native language is not English, issues of health literacy, compounded by issues of language and the specialized vocabulary used to convey health information,^[8] make it particularly difficult to access and utilize health information. CALD cancer survivors report a need for information in their preferred language.^[2,3] These groups are also likely to have information requirements additional to those of native survivors, reflecting the challenges in dealing with foreign health systems and varied levels of acculturation.^[9] In a study with Chinese and Greek migrants with cancer, we found migrants needed information about the predominant differences in health-care attitudes and approaches as well as therapy options, between their country of residence and country of origin. Cultural appropriateness and meaning of words were also identified as an important issue. For example, most CALD cancer patients did not identify with the word “survivor.”^[9]

All migrants are different in terms of health status, health-care experiences, and cultural, social, and environmental determinants of health.^[10] An individual’s culture and primary language will also affect whether and how they seek out health information, where they will look,

what type of information they prefer and how they will interpret this information.^[8]

Guidelines for Development of Information Resources

There is a range of resources and toolkits that set out guidelines for developing general patient information.^[11,12] These state that the need for the publication should be assessed, a clear aim and target audience established and the content should be determined by what consumers want to know.^[12,13] Consumers should be involved in publication development from the outset through consultations to elicit their views and/or through collaborative processes.^[13,14]

Consumer information should be outcome focused, based on best available evidence, developed by multidisciplinary groups including consumers, flexible, and adaptable to varying local conditions, evaluated for their validity and usefulness and updated regularly.^[12,13] Recommendations include using plain language to minimize misinterpretation and improve understanding and creating a simple design that includes visual images^[15] to reduce problems that might arise for those with limited health literacy.^[8]

However, there appear to be very few guidelines for the development of resources for CALD populations in Australia.^[16-18] The three guidelines identified recommend that health-service providers and health-care organizations should support consumers to increase their health literacy through the provision of accessible and comprehensible information.^[19] The guidelines propose that health providers work collaboratively with members of CALD communities to ensure that material which is developed and translated is culturally relevant and appropriate, and disseminated appropriately. The challenges of translating medical terminology into simple terminology have also been highlighted; in some cases, there is no language or conceptual equivalent of certain medical conditions in other cultures.^[10]

There is currently an absence of cancer survivorship resources specifically developed for CALD groups which also incorporate culturally based needs. The few resources available in other languages have generally been translated directly from English and may not be culturally appropriate. Identification of immigrant cancer survivorship issues and modes of accessing information may support development and dissemination of targeted resources for promoting

survivors' education and capacity for finding, choosing, and using existing support options.^[9]

We aimed to develop evidence-based, culturally appropriate, consumer-informed written resources which provided information and education on what to expect when completing cancer treatment with and for Arabic, Italian, and Vietnamese cancer survivors and their carers living in Australia. In this paper, we focus on the lessons learnt from this process to inform future efforts in producing culturally appropriate health information for migrants in their own language. Outcomes from the studies described below will be described elsewhere.

Method – Process of Developing Resources

Three processes were undertaken: first relevant literature on survivorship was reviewed; second, qualitative research on information needs of our target populations was conducted and third, consumers were engaged to iteratively review and revise the content and format of written resources. A steering committee comprising of both health professionals and consumers oversaw the project.

Literature review

A rapid literature review was undertaken to assess as follows: (1) existing national and international CALD survivorship information resources; (2) literature regarding the development of information resources for the target CALD communities, and (3) conceptualization of cancer survivorship among this population; Medline and CINAHL were utilized to search for relevant published articles between the years 1996 and 2014. Search terms included neoplasm, cancer, survivor, aftercare, non-English speaking, ethnic group, culture, culturally or linguistically diverse, consumer health information, patient education, publications, attitudes, health knowledge, perception, Vietnamese, Arabic, and/or Italian. The review found minimal existing (1) resources for CALD survivors; (2) guidelines for the development of patient information resources, and (3) literature regarding how Arabic, Italian and Vietnamese populations conceptualize survivorship.

Engagement with community groups and leaders and focus groups

We undertook a qualitative study of cancer survivors and their carers from the target populations to understand the information and support needs of people from these language groups in the months and years after completing cancer treatment, in addition to determining the most appropriate dissemination strategy for the developed

resources. Ethics Committee approval was received from participating centers for this study.

Relationships were formed to engage with Arabic, Italian, and Vietnamese community groups within Victoria.

Focus groups and semi-structured interviews with survivors and carers were held for each language group. Participants were identified through a range of strategies including hospital patient databases (patients who had consented to participate in research who spoke the relevant languages) and engagement from community groups and leaders. Five focus groups were undertaken (two each in Arabic and Vietnamese and one in Italian). Additional one-on-one interviews were undertaken with Arabic cancer survivors (in their language). Bilingual facilitators experienced in focus group facilitation were utilized for the focus groups and interviews. In total, 39 participants were consulted regarding their information needs while recovering from a cancer diagnosis [Table 1].

Information development

Draft resources were developed with information collected from both the literature review and the focus groups. These were then reviewed in both English and the appropriate language to assess appropriateness, accuracy, and completeness. Both the English and translated resources were reviewed by members of the project steering committee as well as health professionals and community group workers identified by both the project manager and the steering committee who spoke both languages. The consultation was also undertaken with broad ethnic groups such as the Centre for Culture Ethnicity and Health and the Ethnic Communities Council of Victoria to ensure that both content and layout of the resources was appropriate to the audience. Minimal changes were required to the content after the initial review by the steering committee. Focus group participants were reengaged and asked to complete a study-developed questionnaire about the appropriateness and quality of the resource. Feedback

Table 1: Participation characteristics

| Characteristics | Arabic (n=11) | Italian (n=7) | Vietnamese (n=21) | Total |
|----------------------|------------------|------------------|----------------------|-------|
| Participant details | | | | |
| Cancer survivor | 10 | 3 | 13 | 26 |
| Carer | 1 | 4 | 8 | 13 |
| Total | 11 | 7 | 21 | 39 |
| Male | 5 | 4 | 8 | 17 |
| Female | 6 | 3 | 13 | 22 |
| Total | 11 | 7 | 21 | 39 |
| Participation type | | | | |
| Focus group | 8 | 7 | 21 | 36 |
| Individual interview | 3 | | | 3 |
| Total | 11 | 7 | 21 | 39 |

from this process was incorporated into the final version of the resources.

Methods - Lessons Learnt

A steering committee met regularly throughout the process of resource development. Investigators documented challenges through the project. A separate meeting was held where the items were discussed, and consensus was reached.

Results

Community engagement and consultation

Community engagement is critical for ensuring relevant resources are developed which will be utilized by the target audience.^[20] An engagement strategy to initiate and maintain relationships with community groups was the essential first step to ensure adequate consultation and input into the resource, widespread community endorsement, dissemination of the resource, and finally to support sustainability. Engagement with other organizations that have or may be undertaking work with these communities, to understand and learn from their experiences and prevent duplication of efforts, was vital. Consultations with community groups highlighted that they may already be overburdened. Remuneration to groups should also be considered. Face-to-face engagement was most effective and valued. Feedback from community groups and focus group participants highlighted the importance of clarifying what both the community and individuals would gain from participating in the process, for example, additional education and information available for their communities in their first language and the opportunity for individuals to share their experiences.

Culturally sensitive data collection

How information is collected from the target communities should be carefully considered. A range of strategies may be required. In our experience, focus groups were effective because they allowed individuals to share their experiences and be reminded of topics through others' stories. Individual phone interviews were also conducted when informants were unable to attend focus groups. Community organizations may be able to advise on the optimal mode of data collection. Consultation with our community liaisons indicated that some survivor groups might be reluctant to participate in a focus group because of the stigma associated with a cancer diagnosis and reluctance to reveal their diagnosis in public. Hence, telephone interviews using an interpreter were used as an alternative means of collecting information.

Other approaches include community meetings, personalized, and translated letters of invitation, messages

on community social media pages and endorsement through community leaders. Community leaders may be able to facilitate recruitment. In our work, this was undertaken through two main approaches: (1) asking the leaders to phone a contact list of known cancer survivors and personally invite them to attend a focus group and (2) community leaders promoting the focus group directly to community members. Holding the focus groups in a community setting (at a language based community centre or an area with a high number of community members) was a successful strategy to boost attendance because of familiarity and ease of location and community leader endorsement.

Focus group facilitators (recruitment and training)

We found it was important to carefully select focus group facilitators, as they are critical to the quality of data collected. Facilitators were identified through university language departments, community leaders or recommendations from colleagues who had previously undertaken projects with the target languages. We found that bilingual facilitators with prior experience and relevant knowledge to be rare. It may be necessary to provide training to facilitators/interviewers around cultural competency and facilitation skills. We developed a training program for facilitators. Training was undertaken face-to-face with an experienced qualitative researcher and the project manager. During the training, facilitators were given the opportunity to practice scenarios and ask questions as well as gain a greater understanding of the topic area. Feedback from this session from facilitators was that they felt the session gave them greater confidence to facilitate the session.

There was a high cost associated with transcribing and translating focus group recordings. This barrier was overcome by engaging National Accreditation Authority for Translators and Interpreters (NAATI) accredited interpreters to listen to the recordings and identify the key themes. These interpreters were identified as having relevant health knowledge and expertise through the NAATI register. Future projects may consider having a translator present during the focus group to translate the discussions verbally in tandem to the group to minimize cost and allow for faster access to the focus group content.

Content development

Feedback from focus groups identified a clear need for specific written information relating to the time after treatment, in their own language and specific to their own culture and community.

Engaging with not-for-profit organizations with experience and expertise in the development of culturally-sensitive resources was helpful. Evaluation of our

projects highlighted that early engagement of the translation service was valuable. The service was able to provide information regarding translation costs, the translation process and how this impacts on the design of the resource.

Finally, a professional editorial review should be undertaken to ensure the resource meets relevant editorial guidelines including reading levels. Undertaking editorial review of the initial draft before translation and community consultation ensures that costs associated with retranslation are minimized.

Translation and review process

Review by consumers, community leaders, bilingual health professionals, and the steering committee is critical. This process ensured that the content of the resources was appropriate, relevant, and aligned with focus group findings. Investing time for this review process enabled identification of concepts that may not translate correctly. For example, in the Arabic resource, it was noted that the use of the word “sexuality” could be perceived as cancer treatment would make a heterosexual become homosexual. All phrases that included “sexuality” were changed to “sexual health.”

Design and format

A considered decision was made for the resources to be designed as bilingual (relevant language plus English) booklets and factsheets. Consumers approved of the dual translation of the resources considering them appropriate for “the entire family” (cross-generational families may have differing levels of comfort with English and the relevant language) and useful in different settings, especially for education purposes to enable health professionals to easily identify relevant topics.

A key aspect of information development is typesetting-physically arranging the text in preparation for publication. Early consultation with both the translation company and the designer should take place before design commencing to identify any additional requirements there may be with the language in which the resource has been translated.

Editorial support from an experienced editor during the design stage is also beneficial to aid and support copy fitting (fitting text to the required space by cutting or expanding the copy or space and by the use of different design elements). If images are used, their cultural appropriateness should be considered. If available, it is recommended that the resource receives a final sign off by a community leader or bilingual health professional before printing to ensure that the end product is appropriate.

Development of bilingual resources increased the length of the resource and printing and design costs which impacted on the budget. Projects might look to set a

maximum number of pages to be printed early in the project to ensure the project is completed within budget.

Dissemination and sustainability

It is critical that a dissemination strategy is developed to ensure the resource will reach the target audience. All language groups suggested in-language radio or print media and distribution through their oncologist or general practitioner and local church or community groups.

Ensuring a resource contains up to date information and maintains currency is critical. The ongoing upkeep of translated resources is more expensive and the process more involved than an English resource. Hence, the final important task is to develop a plan about how the resource will be updated in the future and continue to be made available to the target audience.

Conclusions

While there is a known increased health burden in the migrant population both in Australia and overseas and a demonstrated need for written information that is culturally and linguistically appropriate, there are few information and support resources available for these community groups. There has been increasing recognition that there is a need to provide tailored information and support for these groups including around the survivorship phase.

There is currently limited guidance regarding how to develop patient information and resources that are responsive to the needs of various CALD communities; there remains a need for better guidelines for this process. We developed a process which has been utilized and tested in other resource development projects.

We identified a number of key tasks in the development of resources with and for culturally and linguistically diverse communities. Importantly, engagement and consultation is required to develop culturally appropriate resources. The project also highlights the need to develop resources that are responsive to unmet information needs and are culturally-appropriate and sensitive. We would encourage others developing resources to also share their learnings.

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Conflicts of interest

There are no conflicts of interest.

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