

Challenges in Cancer Self-management of Patients with Limited English Proficiency

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ABSTRACT

Objective: This paper summarizes the barriers and challenges in cancer care reported from a validation project of a self-management intervention handbook from Chinese-American cancer patients with limited English proficiency (LEP). **Methods:** Seven health-care providers (HCPs) and 16 Chinese-American cancer survivors with LEP were invited to validate a self-management intervention handbook through networking sampling method. Bilingual versions were developed and validated using the repeated translation process. Online and paper-based survey and interview were conducted to collect information on the perception of barriers and experiences on cancer care. Data were analyzed by the content analysis method. **Results:** The HCPs reported a bilingual self-management handbook which is useful and feasible for patient self-management. The challenges in giving cancer care to LEP patients included: patients do not engage in discussion, different cultural health beliefs, unable to

speak to patients in their primary language, and patients are less likely to discuss emotional and social challenges during treatments. The common barriers and experiences during cancer care included: limited understanding about treatment/medication and side effects, language barriers such as unable to communicate to make the decision, unable to understand information related to resources and do not know what questions to ask, and do not know what to expect during their cancer treatment. **Conclusions:** The current findings highlight the need of cancer self-management support for culturally diverse LEP cancer patients. Further research can include applying the supportive intervention to all LEP cancer patients.

Key words: Cancer, Chinese-American, limited English proficiency, self-management

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Introduction

Cancer demographics in the USA is culturally diverse with growing new immigrants from various cultural backgrounds.^[1,2] Some patients, particularly those from nonmainstream cultural backgrounds, can experience delays in seeking health care, and exhibit a lack of appropriate health-seeking behaviors and symptom management.^[3-7] For cancer patients with limited English proficiency (LEP), communication can be the main barrier to health care because accessibility to health care is determined by the ability of the patient to interact with the health-care system on various occasions, rather than the accessibility to health care due to insurance status.^[8,9] The complexity of the health-care system, varying expectations for cancer care and provider–patient relationships, and lack of knowledge and support resources can all impede daily management of care.^[2,10] For patients who are unfamiliar with the health-care system, these tasks and processes can be daunting.^[2]

Studies have suggested that LEP is associated with breast cancer symptom distress and reduced breast cancer screening.^[11-14] Along with patients, health-care providers (HCPs) also report feeling that they are unable to communicate as effectively with LEP clients and admit to providing less patient-centered care due to language barriers.^[15,16] Aside from language barriers, health education and literacy play a significant role in the communication with and care being provided by HCPs.^[17] Cultural differences (i.e., taboos about the word “cancer”) are also at play when discussing diagnoses with LEP patients.^[18] The use of an interpreter was found to bridge barriers due to LEP, but many HCPs report a lack of access or limited use of interpreter resources.^[15] Surprisingly, some studies found that while the use of an interpreter helped to facilitate the health education process, it simultaneously worked to further reduce patient satisfaction and interpersonal care perception.^[19] Although several barriers have been reported in these studies, there is limited research reporting strategies to promote self-management from LEP cancer patients’ point of view.

The resources and ability for self-management of cancer patients are essential to maintain the quality of life and to reduce complications. Particularly, during cancer treatment periods, to effectively manage the side effects and symptom distress brought by the treatments, a collaboration between the providers and patients is required to alleviate these symptoms and prevent them from become worsening impediments and delaying further treatments. Cancer patients need to learn how to recognize, monitor, and

control their own symptoms, and they also need to know how and when to solve problems while navigating within the complexity of the cancer treatment courses. Since most cancer treatments occur in ambulatory settings, the demand and expectation for cancer patients to engage in these self-management tasks are ever more important. For patients who are familiar with their health-care system, the journey through the course of cancer treatment and symptom management has been reported as overwhelming. As for cancer patients who are not familiar with the health-care system due to immigration or emigration, these tasks and processes of self-management during treatments can be even further daunting.^[2,20,21]

This paper summarizes the feedback on the barriers and challenges of cancer self-management reported by the HCPs and Chinese-American cancer survivors with LEP. The participants were part of a validation project to develop a cancer self-management supportive intervention for patients with LEP. The supportive intervention includes a handbook containing self-care information about managing 15 common types of cancer symptoms, physical activity guidelines, and questions to ask HCPs. The intervention handbook was developed based on the literature review and opinions from content experts. The bilingual versions (English and Chinese) were developed based on the forward and backward translation method, and the process was repeated until both versions achieve congruency. The readability of the English version is at 7 of the Flesch-Kincaid Grade Level Score.

Methods

An interdisciplinary panel of HCPs who currently or had experience providing direct patient care for LEP Chinese-American cancer patients were recruited from four different medical facilities to review the intervention handbook for its accuracy and appropriateness. A web-based questionnaire (Qualtrics®) was developed in this project and administered to these HCPs to provide their basic demographic information, their feedback on the feasibility, usefulness, and overall experience with LEP cancer patients. Provider participants were asked to comment on the feasibility and usefulness of the handbook. They were also asked to provide feedback on what type of information needed by the Chinese-speaking LEP patients, and what general barriers and challenges they experienced in practice.

Chinese-American breast cancer survivors with LEP were recruited from the community of San Francisco to participate in the project to evaluate the feasibility, utility, and relevancy of the intervention handbook.

Both language versions were provided to these cancer survivor participants. In addition to asking these survivor participants to review and evaluate the handbook content, paper-based surveys were provided to these participants to record their self-reported feedback and self-management experience. Three open-ended questions were developed in this project to ask about their information need and challenges they experienced in cancer care. Telephone follow-up was available for these participants if they were unclear about the information stated in the handbook and evaluation questions.

The study protocol was approved by the Institutional Review Board, and all participants provided their informed consent. The handbook validation and data collection process occurred during April–September 2015. The aim of this paper is to report the barriers and challenges summarized from these providers and cancer survivor participants. For the feedback on cancer care barriers and challenges, content analysis method was used to analyze the data from feedback narratives and open-ended questions collected from all participants.

Results

Provider feedback

There were seven HCPs who participated in the handbook review and provided their responses. These HCPs included two physicians, one physician assistant, one physical therapist, two oncology clinical nurse specialists, and one oncology nurse educator. Four provider participants identified themselves as Asian-Americans and three others identified themselves as Caucasian-Americans. The years of oncology-related practice experience range from 4 to 37 years. All practitioner participants had an experience in providing direct patient care to the ethnic minority patients with LEP, including Chinese-American cancer patients.

Information needs from providers' perspectives

All provider participants considered providing a bilingual self-management handbook to the LEP patients which is a feasible and useful tool; it introduces self-care information of common side effects/symptoms to patients who are monolingual and in their early phase of the cancer treatment. The provider participants also expressed the strong need to provide multilingual self-management support for cancer patients coming with different ethnic and language background in their practices, not just for Chinese-speaking patients. As for what types of information are mostly needed for the cancer patients with LEP in self-management, examples of responses included: "They need basic tools

to understand the side effects of treatment, how to handle them, and to know what is dangerous. Practical information that helps them understand what side effects are expected and normal which is also very helpful." "Patients need to have detailed written instructions to refer to when dealing with new problems and symptom management at home." Other types of information suggested by these provider participants included: medication management, recognizing side effect and know how to handle them, cancer treatment information, end-of-life care, cancer staging and prognosis, and when to contact the HCPs.

Barriers and challenges from providers' perspectives

As for the barriers and challenges in giving cancer care to patients with LEP, a provider does not consider that whether there was any difference between LEP patients and English-speaking patients, which is stated as: "The main barriers and challenges to decision-making are similar to our English-speaking cancer survivors: What treatment to choose, how to manage side effects, etc., with the addition of their individual cultural considerations." Other examples of responses included: "Often times with the patients of LEP, the family member (son or daughter) is primarily directly the case of the patient and even answering for the patient in regards to assessment questions," "I think it would be very difficult to undergo cancer treatment in an environment where I could not communicate with my health-care team," "We use interpreters during the visits, but the interpreter is not present for the entire treatment time. If family members are unable to be present for translation assistance, this can be quite a challenge, especially during an emergency or even meeting simple needs," "Occasionally, I have patients who have mystical/cultural beliefs about treatments, but this is not necessary (Chinese)." Other major barriers reported by these providers also included: Unable to communicate directly to these patients' son or daughter about how to choose the treatment regimen, and discuss the proper way of managing treatment side effects. Overall, the main challenges concluded from the provider participants were that sometimes, the family member is the decision maker rather than the patient, and patients do not engage in discussion about their care and usually defer the decision to the medical providers. Another aspect of the challenge for providers was to try to understand and accommodate various cultural health beliefs about cancer and its treatments while at the same time to maintain the integrity of standardized cancer treatments.

Limited English proficiency cancer survivor feedback

There were 16 Chinese-American cancer survivors who participated in the review and provided their responses.

These survivor participants were recruited by networking method from community support groups in 2015. All the 16 participants were females, and the average age is 62.44 years (range: 47–77). Twelve of them were diagnosed with breast cancer, two were with ovarian cancer, one was with colon cancer, and one was with liver cancer. All participants have completed chemotherapy and radiation therapies and have been in post-treatment for 4 years on average (range: 1–11 years). The educational level of the 15 participants was reported as high school or less, and one participant had a college education. Fifteen participants identified themselves as monolingual and chose the Chinese version to review. One participant identified herself as bilingual and was able to review and comment in both English and Chinese versions. All participants identified themselves as foreign-born first-generation immigrants. In addition, all participants received 10–15 min of telephone follow-up with the researcher for them to further clarify questions they may have related to the handbook and feedback questionnaire.

All survivor participants expressed that it is helpful to have a self-management information handbook during the treatment period, especially during the beginning of the treatment period. In addition, all participants responded the symptom self-care information and communication questions listed in the handbook which were applicable and helpful to them, and they wished they had been provided such information while they were going through their cancer treatments.

Barriers and challenges from survivors' perspectives

In addition to asking the survivor participants to provide comments on the content of the handbook, additional questions were asked about the barriers and challenges they had experienced. In the question of “What were the barrier and challenge that you experienced in communicating with the physicians/providers about treatment decisions,” examples of responses include: “The main challenges were the language barrier and medication side effects;” “I wish I have had this handbook while I got my treatment, I did not know anything and did not know how to make the decision and communicate, I could only worry about if I could survive;” “I was too worried, and I could not express my own option because of my poor English. I could only follow the doctor's direction;” “I tried to look for information myself before I talked to my doctor. There were uncertainty and risk in the different types of treatments. I can only take the risk and gamble,” “I was so scared, I did not know what questions to ask my doctor,” and “My doctor was very busy. Usually, I had not finished

my question, the doctor had already left the unit floor;” “The fear, worry, and endurance of the treatment side effects were the biggest challenge;” “My challenges were my lack of knowledge about my disease, language barrier, and these medical terms;” “I worried about the symptoms and recovery after my surgery.”

In the question of “What were the barrier and challenge that you experienced in communicating with the physicians/providers during your treatments (e.g., chemotherapy),” examples of responses include: “I was worried about all the symptoms and complications that I had to suffer from my chemotherapy;” “I just listened to my doctor. I follow everything my doctor arranged for me;” “I was not sure if my treatment would be successful. However, the doctor could not answer my question because of the language barrier. Every time my doctors and nurses only stated basic questions to me, they would not provide detailed explanation;” “I resisted the chemotherapy myself. After 3 weeks of hard-thinking and consultation with the second opinion, I accepted my doctor's treatment arrangement;” “I did not know what the side effects were from the chemotherapy, how it would do to my body, and whether it was really working or not;” “I felt very anxious when I had chemotherapy. I worried whether chemotherapy could really kill cancer;” “My chemo had 6 cycles. When I finished the third cycle, my doctor told me I could either finish the rest of the three cycles or I could stop it now. I hesitated and was not sure about it, so let the doctor made the decision. The doctor recommended me to finish all the six cycles because of the health insurance coverage. The result was pretty bad. The treatment took a toll on my body;” “The nausea, vomiting, fatigue, fear, and change of my body were the toughest things I had to endure and suffer. They were the biggest challenges from my treatment. I needed a strong will power to overcome;” “It was difficult for me to express these side effects brought by the chemotherapy to my doctor;” “I was old so I just followed everything my doctor said to me. I could still feel the pain from the surgical wound that I had from 4 years ago.”

Information needs from survivors' perspectives

In the question of “Thinking back when you discussed your treatment (e.g., chemotherapy) with your providers, what information do you wish you had been provided at that time? What question do you wish you could had asked then,” examples of responses include: “Because I do not understand English and I could not communicate well, I wish my doctor and translator could help answer all questions to help me pass through the chemotherapy;” “I wish I could had asked about how to minimize the side

effects;" "I wish I could had received more information about chemotherapy, like the good and bad parts, and how I can tolerate it;" "I wish I could had asked whether the chemotherapy is life-threatening;" " I would like to know if there is anything to prevent the problem of nausea, constipation, oral ulcer, and sleeplessness. It was also great to know about nutrition, and whether there was home visit service available to me;" "I had some symptoms and side effects experienced during the beginning of my treatment. I told to my doctor. I received no response so I thought these side effects were normal. I mentioned them again during my next visit, and still, my doctor gave me no response. Until these side effects got really worse, my doctor just started doing something to me. These side effects had caused damage to my body and I do not know if I will ever recover;" "When I had my chemo, I wish my nausea could get relieved. However, the doctors and nurses cannot help resolve this problem for me. They told me I could not afford the best anti-emetic medication. My insurance would not cover it. One pill costed 3 dollars. It was too expensive;" "When I got diagnosed with cancer, I thought it was a mistake. I thought I was dying because of all the fear, sleeplessness, and hopelessness. I barely could eat anything. I went through eight cycles of chemotherapy, I suffered lots of side effects, such as fatigue, vomiting, oral sores, and gum bleeding. I thought I was going to be dead. I did not know what to ask for help. I wish I could have gotten more information back then;" "I wish I could have asked questions such as how effective is the treatment? How long and how many times? How can I reduce the side effects? How long can I recover? Can I work during the chemo? Is there any organization which can provide assistance or support;" "I wish I did not have to worry while I had my chemo. I just let the doctor make decision."

Discussion

The barriers and challenges reported by the providers and cancer survivors with LEP in this project all demonstrated the frustration and limitation experienced during the patient-provider communication and interaction as a result of language and cultural barriers. As reported by most survivors, even though a translator was available, the amount and content of the information conveyed by the providers regarding their treatments and how to manage those occurring side effects were still considered insufficient. As noted in some providers' responses, some were willing to provide information; however, they were limited by the language differences and the time they can spend with patients. All survivors recognized their limited ability in English communication; however, the desire of being informed and empowered to know what is going on

and what to expect with their health condition is undeniably warranted. The common expectation from the survivors' responses was that they all appreciate receiving information on the benefit and risk of their cancer treatment, symptoms, and side effects, and how to manage them.

Although the results from this project presented the challenges of cancer care from the perspectives of both LEP cancer survivors and providers, certain limitations are recognized. The project data were collected from a small sample of Chinese-American cancer survivors, and the generalizability of the findings can be limited. Future studies can include larger sample pool of cancer patients with LEP from other cultural backgrounds. The project results were also limited in the qualitative nature of data. Future studies can include quantitative measures of health outcome indicators to examine the impact of the challenges experienced by LEP cancer patients on their overall cancer care outcomes.

The advancement of cancer treatment has helped patients to have improved survival chance and more alternative treatment options. Cancer treatments are increasingly provided in the ambulatory setting. With this change in the cancer care delivery system, a cancer patient is required to be an "informed" client to self-manage by learning not just about the benefits and risks of their own treatments, but also how to manage the symptoms and side effects, and how to solve problems when problem arises while they are not with the providers.^[2,20] The benefit to support patient self-management has been well documented in studies.^[22] Supportive self-management interventions have been increasingly proposed and studied for their effectiveness in improving various health outcomes of cancer patients. For instance, these interventions could include strategies to help improve physical and psychosocial well-being,^[23-25] symptom management,^[26-28] coping,^[29-31] and diet and physical activity.^[32-34] While the results from these programs were supportive to cancer patient self-management, the development of such program and validation of usefulness and sustainability for cancer patients who have language and cultural barriers are still limited.^[35,36]

Conclusion

The importance of providing quality of cancer care to patients with limited language proficiency has been well documented.^[15] At the same time, the benefit of providing a supportive self-management intervention has also been validated in the literature.^[20] However, from the data reported by these LEP survivors and provider participants in this study, the discoordinance of information need and

communication was evident. The intricacy of cancer care requires orchestrated effort from both cancer patients and providers. In particular, for patients who are new to the health-care system and have barriers due to language and cultural background differences, the orchestrated effort could be significantly impeded. The cultural sensitivity of providers could be trained and emphasized continuously to increase the awareness and skills on how to work with patients who have different cultural and language backgrounds. However, as suggested by the feedback provided by these provider participants in this project, providers' attention to the need of patient with LEP could be limited due to time and resource constraints in a fast-paced and busy setting. Cancer patients who have language and cultural barriers can be empowered to access and learn information and skills on how to work with the providers, manage these side effects and symptoms, and support themselves for better physical and psychosocial well-being to have quality cancer care. Further studies are recommended to expand and explore the self-management program to multi-cultural cancer patients to evaluate its applicability and acceptability for long-term outcomes. The handbook validated in this project can potentially be expanded and tested in the future studies.

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Conflicts of interest

There are no conflicts of interest.

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