

“Weaving Balance into Life”: Development and cultural adaptation of a cancer symptom management toolkit for Southwest American Indians

Felicia Schanche Hodge · Tracy Line Itty ·
Mary P. Cadogan · Fernando Martinez

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Abstract

Introduction Self-management of cancer symptoms has the potential to decrease the suffering of cancer survivors while improving their health and quality of life. For many racial/ethnic groups, culturally appropriate self-management instruction is not readily available. This paper reports on the first symptom management toolkit developed for American Indian cancer survivors.

Methods Part of a larger research study, a three-phase project tested a cancer symptom self-management toolkit to be responsive to the unique learning and communication needs of American Indians in the Southwest USA. American Indian cancer survivors and family members participated in 13 focus groups to identify cultural concepts of cancer and illness beliefs, communication styles, barriers, and recommendations for self-management techniques. Sessions were audiotaped and transcriptions were coded using Grounded Theory.

Results Participants expressed a need for an overview of cancer, tips on management of common symptoms, resources in their communities, and suggestions for how to communicate with providers and others. The “Weaving Balance into Life” toolkit is comprised of a self-help guide, resource directory, and video. Preferred presentation style and content for the toolkit were pilot tested.

Discussion/conclusions American Indian survivors favor educational materials that provide information on symptom management and are tailored to their culture and beliefs. Suggestions for adapting the toolkit materials for other American Indian populations are made.

Implications for cancer survivors Many cancer survivors lack effective self-management techniques for symptoms, such as pain, fatigue, and depression. The toolkit promotes self-management strategies for survivors and provides family members/caregivers tangible ways to offer support.

Keywords American Indian · Cancer survivors · Symptom management · Communication · Education · Toolkit

Introduction

Cancer-related symptoms, such as pain, depression, fatigue, and functional limitations, can be effectively self-managed by cancer survivors, thus decreasing suffering and improving health and quality of life. To effectively manage cancer symptoms, survivors must acquire an understanding of self-management techniques and, ideally, have adequate access to healthcare materials and services. Symptoms left unchecked not only create distress but also disrupt one’s social functioning within the family unit and community [1]. For members of underrepresented racial/ethnic groups, such as American Indians, who experience great disparity in cancer morbidity and mortality [2], lack of culturally appropriate cancer education materials can also act as a barrier to cancer symptom management [3, 4]. Ensuring a tailored approach to cultural appropriateness and sensitivity during the development and evaluation [5] of cancer education materials is essential for acceptability and adoptability, and must involve cancer survivors and their family members/caregivers [6, 7].

From the moment that cancer is diagnosed or confirmed, one can be considered a cancer survivor [7]. Cancer survivors are often affected by a wide array of symptoms as a result of their disease or treatment and unfortunately

F. S. Hodge (✉) · T. L. Itty · M. P. Cadogan · F. Martinez
School of Nursing, University of California, Los Angeles,
700 Tiverton Avenue, Factor Building #5-940,
Los Angeles, CA 90095, USA
e-mail: fhodge@sonnet.ucla.edu

face significant barriers to symptom management even after treatment has ceased [8, 9]. Survivors may be sent home from the hospital or clinic to manage their symptoms at home without knowing how to ease pain, fatigue, or other common cancer- or treatment-related symptoms by themselves. Impediments to effective self-management include a lack of awareness regarding symptom management techniques and resources, as well as various system barriers that include poor communication with healthcare providers, uneven coordination of cancer care, and lack of access to healthcare services [10]. Language differences, illness beliefs, cultural practices, and literacy level also have a significant impact on the acceptance and adoption of a self-management program [11–14]. With cancer being the number two health problem among American Indians [15], cancer survivors and their family members from this population are likely to experience pain, depression, fatigue, and loss of function without having an adequate understanding of or access to appropriate self-management techniques and tools.

Current research has focused on delineating risk factors and barriers surrounding cancer leaving a dearth of information on culturally appropriate and effective strategies for cancer education, prevention, and solutions to cancer symptom management in racial/ethnic communities. With rare exceptions, including the support circle curriculum by Native American Cancer Research [16], too few educational programs and materials are tailored for American Indian cancer patients. The “Weaving Balance into Life” cancer symptom management toolkit described in this paper expands upon existing cancer education materials for the general population and further tailors the materials for American Indian patients, survivors, and family members residing in the Southwest USA. This toolkit is a part of a larger study on self-management tools and techniques with the goal of reducing barriers to cancer-related symptom management among American Indians. The toolkit materials developed offer culturally appropriate solutions to facilitate, as well as improve, symptom management knowledge and skills.

Methods

Using a multi-method approach, this project adapted a content- and process-based strategy for educational materials development in the area of cancer-related symptom management specifically for Southwest American Indians. The study received Institutional Review Board approval from the University of California, Los Angeles and the Phoenix Area Indian Health Service. Toolkit development and implementation took place over three phases. Phase 1 describes the process that led to the discovery of cultural constructs needed in an educational toolkit, phase 2 reports on the methods used in developing and tailoring the toolkit

content and format (for the video, guide, and resource directory), and phase 3 describes the evaluation and dissemination of the toolkit. See Table 1 for information on the content, format, and organization of the toolkit materials.

One hundred and thirty-two American Indian cancer survivors, family members, and others (caregivers, community leaders, and friends) participated in 13 focus group discussions. Inclusion criteria were: (1) American Indian, (2) age 18 or older, (3) experience as a cancer survivor, family member, or caregiver/community leader/friend of a survivor. The majority of participants were female (95 females and 37 males). Focus groups were held in conference rooms at two urban Indian clinics in Phoenix, one urban Indian clinic in Tucson, and one reservation site in eastern Arizona. Each participant was consented prior to enrolling by a focus group facilitator with experience working with American Indians. The sessions, 1 to 2 h in length, were audio recorded with permission from the group members who were asked to use pseudonyms or numbers instead of names during discussion for confidentiality purposes. Thirty-five dollar gift cards were offered as incentives for participation. Focus group discussions were centered on the following areas: cultural constructs and personal experiences with cancer, barriers to self-management of cancer symptoms, and cancer beliefs, myths, and fears. The focus groups gathered to provide information on participants’ experience with cancer, as well as to assist in the development of the cancer symptom management toolkit. Successive focus groups built on the input of previous groups by reviewing preexisting cancer education materials and drafts of the toolkit educational materials consisting of a video, self-help guide, and resource directory. Focus group participants were asked to validate content, cultural acceptability, and presentation (readability, artwork, and size).

Audio recordings of focus groups were transcribed verbatim in preparation for analysis. Analysis used constructivist Grounded Theory techniques [17] to identify major codes and categories in the data. Transcripts were read in their entirety by one investigator, and then, excerpt-by-excerpt coding was conducted to capture the meaning expressed in each excerpt. Codes were reviewed and grouped by importance, similar concepts, and frequency in order to identify major themes emerging from the data. A second investigator independently reviewed the categorized codes and key themes. Community representatives evaluated the developing framework to assess accuracy of interpretation and provided validation of the codes and themes. Code description and categorization were discussed and modified until agreement among the entire research team was achieved.

To develop the video component, a recruitment call for videotaped first-person narratives went out to American

Table 1 Cancer symptom management content and format requested for the toolkit

Toolkit item	Self-help guide	Resource directory	Video
Information			
Cancer etiology, diagnosis, treatment, and follow-up care	X		
What to do and how to cope with cancer	X		X
Cancer awareness and risk for family	X		
What to expect post-diagnosis and treatment	X		X
Cancer facts and myths explained	X		X
Resources for specific cancers/treatments	X	X	
Strategies and tips:			
Relief of pain, body changes, and changing activity levels. Addressing concerns about practical issues	X		X
How to better communicate with providers and others—questions to ask your doctor	X		X
Resources for specific cancers—where to obtain information for specific cancer-related service (i.e., brachytherapy, wigs, prosthesis, support groups)		X	
If you have questions, think of them before your appointment	X		X
Simple and understandable tips, informative but not overly technical	X	X	X
Skills-building activities	X		
Cultural content			
Instrumental/culturally sensitive visuals of cancer survivors	X		X
Concern for the group, generosity portrayed	X		X
Culture portrayed in a way that is accurate and fair	X		X
Ensuring quality of materials that exemplify pride and show that culture is the equal of any other	X	X	X
Importance of spirituality and in balance in life	X		X
Layout and formatting			
Visual images/examples that are easy to follow	X		
Easy to read with larger font, but not a lot of words	X	X	
Pictures, colorful imagery and Indian artwork	X		
Smaller size to fit in a purse or easier to carry		X	X
Table of contents for ease in finding sections	X	X	X
Glossary for cancer terms	X		
Use Indian role models in pictures, sayings, and recommendations that reflect cultural background	X		X

Indian communities in the Southwest. Filming took place in Phoenix at a local hospital, clinic, and at scenic outdoor areas. Each participant was encouraged to “tell the story” of their cancer experience and to make recommendations to survivors and family members. Various versions of the edited film were reviewed by participants for verification and approval, and the video was pilot tested by a focus group for review and feedback for cultural appropriateness, accuracy, and for recommendations for key messages.

Results

Phase 1: discovery of cultural constructs needed for an educational toolkit

Identifying key cultural constructs to shape the toolkit content was a first priority. Focus groups among American

Indian cancer survivors and family members revealed that participants had very little knowledge about cancer and cancer treatment. Participants voiced that they were unsure what to believe with regard to the etiology of cancer. For example, focus group members noted certain cultural beliefs portray cancer as a “payback” disease, that others would ask “what did you do?” to deserve cancer. Witching and breaking of taboos were noted to be possible causes, along with exposure to toxic chemicals or radiation, injuries, poor diet, genetics, and smoking. The nature of cancer and what it means to a survivor to be diagnosed were also explored. It was reported that words for cancer in several American Indian languages translate to “a sore that does not heal,” which could put a cancer survivor into an “unbalanced” state. This and frequent experiences of late/misdiagnosis appeared to prompt a fatalistic attitude towards cancer, casting it as a disease that is not readily treatable by traditional Indian or even Western medicine.

Further, communication barriers and breakdowns surrounding discussion of diagnosis and treatment were noted frequently between family members and also healthcare providers. Comments such as “we never knew” that a relative had cancer were shared numerous times. Several participants reported they often left cancer treatment recommendations up to their healthcare providers and followed (or did not follow) the prescribed treatment regimens—largely with little understanding of how the treatment worked or potential adverse effects. In addition, fear of negative community response to the cancer diagnosis, myths regarding cancer and symptoms, and an inability to obtain support from patient advocates (not often available at local clinics or hospitals) prompted several cancer survivors to voice the need for health education to provide general and specific cancer facts. Basic information on the trajectory from cancer diagnosis (how and when) to treatment (surgery, medication, and radiation) and ultimately to survivorship (symptoms) was requested when asked about developing content for toolkit educational materials. In addition, participants requested that spirituality be stressed in the materials as a way of keeping balance in one’s life.

Phase 2: developing and tailoring the cancer symptom self-management toolkit

After determining key cultural themes to address in the content of the educational materials, the design and layout of the cancer symptom management toolkit began to take shape. The impetus and direction for the development of a culturally sensitive toolkit came from Southwest American Indian communities and cancer survivors. Initially, it was decided that the toolkit should consist of three items: a cancer symptom self-management guide, a motivational video, and a cancer resource directory. The purpose of this multifaceted approach was to take into account the various learning approaches (i.e., verbal and visual) and needs present in American Indian communities. Upon further probing, suggestions for including a journal for note taking and calendaring were also incorporated. Based upon the feedback from the focus groups, the toolkit components were designed to be relevant, informative, and easy to understand for both the cancer survivor and their family members. Focus groups suggested the following content and formatting (see Table 1) for each item in the toolkit:

The self-management guide

The first component of the toolkit, the guide, was designed as a self-directed guidebook to assist an American Indian cancer survivor as he/she journeys through the cancer

experience while managing cancer symptoms. Several suggestions were offered for the format of the guidebook during focus group sessions. Participants preferred a large, easily visible size with large print and colorful imagery. Focus group participants emphasized the importance of creating a sense of balance in life during and after treatment; to achieve this, they recommended imagery that used warm colors and pictures of families together to illustrate balance and strength. Participants liked the idea of having a table of contents so they could easily see what topics the guide covered. Readability was an important issue as many requested the information to be presented in a way that was simple, understandable, and informative, but not overly technical. As far as personalizing the content, focus group participants wanted to include American Indian cancer survivor testimonies and storytelling, which are a culturally important method for transmitting information in American Indian communities [18]. Tips, recommendations, and clarification of common myths and fears were also requested content. The idea to close each chapter with relevant skills-building strategies was incorporated to help learning retention. For example, a checklist was included in the chapter on loss of function to help survivors mark off what they could accomplish themselves and remember what tasks necessitate asking for help.

Resource directory

The resource directory was created as a reference tool to provide regionally and locally specific resources and references, such as clinic locations, cancer care, organization websites, and phone numbers where American Indian survivors or family members could access information. Also included was contact information for treatment facilities where cancer care services are offered, sites offering existing support groups, stores for wigs, rehabilitation materials, etc. The resource directory was viewed as a reference tool, and as such, participants wanted it to look complimentary in design to the guide. Recommendations were made that the directory be referenced to in the text of the guide. Participants particularly noted that they liked the technical aspect of the directory and recommended a table of contents for easier access by topic. As to the size of the directory, participants recommended a smaller size than the self-management guide, such as pocket/purse size that would be easy to carry.

Motivational video

An important component of the toolkit was the motivational video to provide visual and verbal messages to survivors and their families. The storyline of the video emphasized the experiences of Southwest American Indian cancer

survivors and provided personal tips, recommendations, and strategies for cancer symptom self-management. Again, the concept of achieving a sense of balance through incorporation of culturally important healing strategies was emphasized. It was felt that a video was an integral component for the toolkit since focus group participants thought a video might be the easiest format for sharing information with family members. Effort was made to include soothing music and written instruction following the instruction of the guide in the video to help foster learning and retention. Focus group participants also requested to see American Indian cancer survivors as role models that reflect the cultural background of Southwest American Indians in the video.

Supplementary materials

A few supplementary items were included along with the guide, resource directory, and video as part of the cancer symptom management toolkit package. As suggested during focus groups, all materials were packed into a messenger bag for ease of transporting the items. In addition, a small journal and pen were included to help survivors with journaling of symptoms (such as intensity and location of pain), medication use, and questions to ask healthcare providers. The text of the guide makes reference to recording experiences in a journal to help survivors and family members with the management of symptoms, as well as assist with communication with healthcare providers during medical appointments. A small post-it pad was also included for taking notes, making reminders, or marking pages for future reference. Lastly, a small personal back massager was placed in the bag as a tool to provide soothing touch.

Overall design

Just as it was essential to incorporate cultural beliefs and practices in the content, we discovered it was equally important to incorporate Southwest American Indian imagery throughout the design of the materials. Since creating a sense of balance in life as a cancer survivor takes patience and skill, the toolkit's cover design and language make reference to the weaving of traditional Southwest American Indian blankets. Based on feedback, the overall color scheme chosen was an earthy tan coupled with turquoise, with a woven blanket border symbolizing the "Weaving Balance into Life" title and theme. Other images and patterns reminiscent of Southwest tribal culture (woven baskets, earthen wares, desert landscapes, and artwork) were used as graphics on the pages of the guide and shown in the video, assuring the toolkit incorporated recommendations from American Indian focus group members. In

addition, all the toolkit materials were to be packed together in a complementary blue messenger bag.

Phase 3: approaches used to evaluate and disseminate the toolkit

Participants in the intervention portion of the larger study took part in the evaluation of the cancer self-management toolkit. An evaluation form measuring satisfaction, usability, and the cultural competency of the toolkit was disseminated among the participants who attended an educational talking circles intervention following development of the toolkit. Fifty-nine participants filled out and returned the evaluation form. Overall, respondents had very favorable views of the informational content of the toolkit materials. When asked about the appropriateness of the level of information for cancer survivors and for family members and friends, almost all felt the information was at an appropriate level (98% and 100%, respectively). A majority also felt the information was understandable (98%), and that the materials were devoid of any unsuitable content, including inappropriate vocabulary, language or concepts, bias, or stereotypes (86%). Skills-building activities that dealt with improving doctor/patient communication, responding to negative thinking, and learning calming, deep muscular relaxation exercises were the most favored by respondents. Respondents gave the toolkit high ratings (good/excellent) for its American Indian cultural aspects (culturally acceptable wording, American Indian artwork and images, understandable tips, etc.) and the overall quality of the products (86% and 93%, respectively).

When asked about what other types of information the toolkit could have contained, a majority responded that they would like information on counseling (56%), emotional support from family/friends (53%), and help regarding financial support (51%). Respondents also commented that they would like to see more personal/survivor stories and educational materials (pamphlets, videos, etc.). Overall, the respondents' comments expressed satisfaction with the toolkit and an appreciation for the knowledge gained.

Distribution of educational/resource materials

Participant feedback indicated that hospital and general oncology waiting rooms, clinics, and doctors' offices were the recommended locations to disseminate cancer educational materials to American Indians, with the supposition that resources that are currently available in waiting rooms are not created with American Indian populations in mind. Preferred dissemination strategies included making the materials free, easily available, and transportable (messenger bag) at outpatient and inpatient facilities frequented by American Indian survivors. Once the current research study

has been completed, the toolkit materials will be distributed to cancer centers, Indian Health clinics, and community centers in the Southwest.

Discussion

The compelling need to better understand cancer symptoms (pain, depression, function, and fatigue) and management as experienced by American Indian adults in the Southwest was the impetus for the development of tailored educational materials. Developing and implementing a program to bring balance back into the lives of cancer survivors follows from these initial steps. Little is known about cancer-related symptoms, and the need exists to provide better care to American Indian survivors. The study is built on the premise that barriers to the receipt of effective palliation and symptom management faced by American Indians can be removed by taking a more survivor-centered approach to the problem. By assisting American Indians to be more assertive and effective in their communication with providers and the established health system(s), we hope to facilitate the adoption of health-promoting behaviors. The toolkit development was designed to help increase culturally appropriate information (knowledge) and improve decision-making strategies (attitudes) and skills, which will improve treatment for cancer-related symptom management and care (behaviors). The development and evaluation of a culturally appropriate toolkit is an important first step in this process.

Researchers have long documented health disparities among American Indians, including health education. Educational approaches for topics in cancer prevention and control require a broader understanding of the cultural constructs of cancer, particularly since it is considered to be a “new” disease among many tribes with the advent of chronic disease overtaking acute disease as leading causes of morbidity and mortality. Talking about cancer in American Indian communities often carries taboos (even saying the word “cancer” can be taboo as it may bring forth the disease), making cancer a difficult, stigmatized topic that is not often talked about [19]. Although cancer has been found among the remains of ancient American Indians [20], it has more recently gained attention in American Indian communities due to increased incidences of the disease, necessitating not only educational materials but also additional support for prevention, treatment, and control activities. Targeted educational materials developed in partnership with cancer survivors, their families, friends, and communities will help to ensure sustained access, education, and supportive activities. It will also help to bring “balance” back into survivors’ lives by providing tailored attention to the physical, emotional, mental, and

environmental aspects of cancer. Collaboration with cancer survivors and the community strengthens the cancer educational materials and helps to support the efforts of cancer prevention and control.

Future directions and conclusions

Information gathered on the cultural constructs of cancer and symptoms and the preferred presentation and layout of the self-management guide, directory, and video were rich with details that guided the development of the toolkit. This information could shape future work on cancer-related management topics among American Indians. Additional research is needed to capture the views of American Indians in all regions of the USA as American Indians are a group of over 500 tribes, many of whom differ in language, culture, artwork, and preferences in communication styles. The paucity of available training materials, especially those that provide culturally appropriate learning guides for self-management of cancer symptoms, suggests a growing gap in the management and control of cancer in this population. Further testing and adaptation of these materials with other tribes and communities are indicated to reduce the disparities faced by American Indian cancer survivors.

Improving communications between American Indian cancer survivors and healthcare providers, as well as with family and friends, was identified as a major focus for the toolkit. The lack of communication about cancer was described by focus group members as a cultural barrier (“we don’t talk about it”) and a preferred method for sparing additional hardship on family members (“we don’t bring our burdens home”). Without such support, cancer survivors have limited means to manage cancer pain, depression, fatigue, and functional limitations that may be associated with their illness. The cancer symptom management self-help guide developed in conjunction with survivors and their family/friends is meant to be shared and to serve as a means to self-manage symptoms with help from all co-survivors. Additional work is needed to explore areas of communication within cancer survivors’ family and network of friends so that additional support needed by survivors can be provided and received.

Implications for cancer survivors

Following primary treatment, many cancer survivors and family members lack effective self-management techniques for common symptoms, such as pain, depression, and fatigue. The toolkit components and skills-building activities help promote self-management for survivors, as well as provide family members and caregivers tangible ways to better support them. Toolkit materials offer a glossary of

terms in the guidebook to help target varying levels of familiarity with cancer symptom management.

This project demonstrated that information available from survivors living with cancer and their circle of family members, caregivers, and others could be valuable to the development of training materials and resources for racial/ethnic minorities. When training is developed in collaboration with the community of cancer survivors, it has the potential to provide the unique educational messages and skills-building techniques necessary to form culturally acceptable and adoptable materials. This is a first step in gaining a better understanding about how cultural constructs shape cancer care and how to use that knowledge to build the foundation for more effective tools to self-manage the cancer symptoms faced by American Indian survivors, as well as better equip family members in their role as caregivers.

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