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ORIGINAL PAPER

PEARL: A Guide for Developing Community-Engaging and Culturally-Sensitive Education Materials

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Abstract

Community outreach and engagement has been a regular activity of the National Cancer Institute at its designated Cancer Centers. However, in 2016, community outreach and engagement became a required activity for all cancer centers. Yet there is a gap in the literature that provides guidelines for developing materials that resonate with communities. We developed the PEARL rubric to fulfill that gap from our work developing culturally sensitive breast cancer education materials for African American and Immigrant African women. We conducted a targeted literature review to understand the approaches that have been used for developing education materials for communities. We reviewed the literature and distilled key elements into our PEARL guide for creating culturally appropriate education materials. PEARL consists of five elements: Plain language and understandability, Explicit data, statistics, and graphs, Affirmative framing, Representative content, and Local connection. PEARL is a modern comprehensive guide that researchers can use for creating culturally sensitive materials. It is designed to guide researchers develop educational materials who have little to no experience in community engagement.

Keywords Cultural sensitivity · Cancer education · Health literacy · Breast cancer · African Americans · Immigrants

Introduction

Cancer is the second leading cause of death in the United States, claiming approximately 600,000 lives every year [1]. The four most common cancers—breast, prostate, lung, and colorectal cancer—account for almost 50% of all diagnosed cancers in men and women [2]. The widespread effect of cancer on society led to the National Cancer Act in 1971 and prompted the National Cancer Institute (NCI) to develop regional centers of excellence or designated Cancer centers [3, 4]. Currently, NCI supports 71 designated cancer centers, of which 51 are comprehensive [5]. Comprehensive cancer centers go through a rigorous peer-review process in which they must demonstrate their contributions across basic science, clinical outcomes, and population research. Many of the scientific achievements that have improved clinical care and reduced mortality come from these institutions.

NCI-designated cancer centers are a significant resource for developing research programs, faculty, and facilities for advancements in cancer prevention, diagnosis, treatment, and survivorship [6, 7]. Age-adjusted mortality rates for breast, prostate, lung, and colorectal cancer have all continued to decline, showing that primary prevention, early detection, and treatment advancements result in better outcomes [8]. However, outcomes for all populations are not the same. For all cancers combined, African Americans are more likely to die from cancer compared to other groups. African Americans are also more likely to have advanced stages of cancer when diagnosed and are less likely to receive recommended treatment than non-Hispanic whites [9]. There is consensus that Comprehensive Cancer centers can and should do more to eliminate cancer disparities [5, 10].

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Community Outreach and Engagement

Community outreach and education activities (COE) are one set of activities cancer centers can do to reduce cancer disparities. However, there is a gap in the literature describing best practice activities that can be implemented for COE. Hawk and colleagues reviewed the activities of comprehensive cancer control centers. They noted that clinical care and clinical trials, which are unique to cancer centers, only reach a small proportion of the population cancer centers engage with. Whereas COE represents a larger proportion of the activities and a greater percentage of the population within the catchment area.[5].

NCI implemented its first formal definitions of COE to increase center engagement across these activities [11]. The process began with each cancer center defining its catchment area and documenting the research activities within the catchment. In 2016, the cancer center funding renewal was updated to include community outreach and education section. The goal of this section was to align catchment area needs with scientific research being conducted in the cancer center [12]. NCI cancer centers that apply for a catchment area supplement are completing a health assessment that documents community engagement activities in their catchment, which will be used to identify and address disparities in cancer outcomes [13].

Community engagement is the process of collaborating with groups of people—affiliated by geography, special interests, or shared experiences—in the information and decision-making processes. Community engagement gives rise to more effective, appropriate, and equitable health programs and improves institutional accountability and trust [12, 14–16]. Yet currently, awareness and education interventions do not represent the majority of research projects within cancer centers. However, lack of awareness and knowledge barriers impede the uptake of cancer screenings [17]. Education interventions increase knowledge of cancer-related health behaviors [18–20], which can increase screening [21–23], and reduce morbidity and mortality through prevention and early detection. Education and awareness activities are central to a cancer center's goals and should be included in the center's portfolio. However, there is a need for instructions or guides that cancer researchers and staff could use for creating educational materials for their communities.

The Gap in Community Education and Engagement

The literature describing community education and engagement have not produced recent, replicable tools that support the development of outreach or educational materials [24]. The most relevant recent review, was conducted by Hoffman-Goetz and Friedman in 2006[25]. While their paper provides a thorough review of the use of culturally sensitive materials for minority populations, it does not guide researchers on how to develop these materials. This is because, it is common to use a bespoke, interactive process to work with communities to create culturally sensitive materials. For example, a community education intervention may develop materials and then seek feedback from community leaders, finding community-specific insights used in material revision. This is good practice but may lead to the rediscovery of similar insights for every intervention. Some existing tools can be used to evaluate the quality of materials. Existing tools, largely consist of post-hoc evaluative frameworks focused on readability (reading-level), comprehensibility, or suitability of existing materials [26, 27]. A gap in the literature is a comprehensive approach for creating both understandable and culturally sensitive materials.

Creating understandable materials is essential because it facilitates connection with those across the health literacy spectrum. However, a singular focus on understandability ignores critical themes that support community engagement that extend beyond simple understanding, such as cultural sensitivity. Suitability guides, such as the Suitability Assessment of Materials (SAM) by Doak and colleagues28, do incorporate aspects of cultural-appropriateness. However, it is one factor among six [28]. A tool that supports community engagement will emphasize cultural fit, as it can be expressed in multiple domains. The current literature examining suitability of cancer education materials has been valuable in providing a foundation but needs to be updated to incorporate cultural-appropriateness into education materials.

Cultural sensitivity is a term for which it is difficult to find a single, comprehensive definition. Kreuter and colleagues state that culture is,

> *"Factors such as familial roles, communication patterns, beliefs relating to personal control, individualism, collectivism, and spirituality and other individual, behavioral, and social characteristics are not inherently "cultural" but may help define culture for a given group if they have special meaning value, identity, or symbolism to the group's members"* [29].

Therefore culturally appropriate materials are tailored to specific groups or a subgroup's culture. However, this is typically overgeneralized to race/ethnicity or gender.

Our Contribution

Our work examined the literature of cancer education for minority populations and distilled generalizable information

that can be used by health professionals and researchers seeking to conduct education projects prior to community engagement. The goal is to improve foreknowledge of common community concerns or needs for creating culturally appropriate education that could lead to more productive exchanges. This includes conducting prior work on common culturally sensitive issues that are easy to address and can build trust with community partners.

To address this gap, we constructed a guide that can be used to develop culturally sensitive cancer education materials. The development of the rubric was supported through a community outreach and education program, Breast Cancer Champions (BCC). The program aims to increase breast cancer screening among local African American and African immigrant women. A need identified by the community partners was a lack of culturally sensitive breast cancer education materials.

Compliance of Ethical Standards

BCC is a collaborative project between Sisters Standing Up to Breast Cancer, the Breast Cancer Education Association (BCEA), Sage programs ("Sage") at the Minnesota Department of Health (MDH), and the University of Minnesota. This project was deemed non-human subjects by both the University of Minnesota and the Minnesota Department of Health IRBs. We have no conflicts of interest to disclose.

Methods

PEARL Guide Development

We formed a Review Leadership Team (RLT) that consisted of five members who guided the development of PEARL. Our team was composed of two researchers from the University of Minnesota with expertise in health disparities, research staff from the Minnesota Department of Health, and two community experts who have delivered peer-to-peer education interventions for over a decade.

We conducted a review of academic and grey literature on cancer educational material development for guide content. Our goal was to find articles that demonstrated how to create culturally sensitive materials for cancer education or find existing materials that we could use as a basis for our model. The terms we used in our review were: 'cancer educational materials', 'breast cancer educational materials', 'cancer educational materials for African Americans', and 'creating culturally appropriate cancer education materials'. We used these terms in PubMed, EBSCOhost, and Google Scholar to identify materials and articles that used culturally appropriate materials in community engagement activities. We also examined the first five pages of results on Google. We used this search engine to determine if any materials were currently available by large cancer communities (i.e., Komen Foundation, American Cancer Society, Centers for Disease Control and Prevention).

Article selection was limited to cancer outreach and education interventions that focused on the creation of materials for breast cancer and prioritized minority or persons-of-color populations. Publications were read separately and annotated bibliographies were created for each. As a group, we discussed each publication to determine its contribution and arrived at a consensus as to the relevant aim, theme(s), and contribution of the publication. Themes were discussed and compared with the literature to determine overlap, that is, in cases where different publications came to similar conclusions. The literature was used to guide the merge of several candidate themes into larger umbrella themes. The final list of themes became the PEARL guide.

Results

The results from our search identified 346 articles, from 2000 to 2020 that matched our key words. Only 32 articles were reviewed beyond the abstract and of those only 14 publications met our inclusion criteria (Table 1). We specifically focused on articles that developed cancer educational materials and deployed them in the community.

Our review of the relevant literature facilitated the development of our guide, PEARL, a generalized and modernized framework for developing or adapting cancer education materials that are culturally appropriate. The team that reviewed the literature conferred and ultimately agreed on insights identified and organized them into five domains: plain language and understandability, explicit data and graphs, affirmative framing, representative content, and local connection (Fig. 1). To accompany the guide, we developed a formatted checklist (Supplementary I). This will allow future researchers to apply the guide during material development easily.

Plain language and understandability are some of the most common elements that emerged from our review of the literature [44–46]. Plain language refers to the removal of jargon and/or medical terms [47]. Understandability is more broadly linked to current literature on health literacy. Healthy People 2010 defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [48]." Berkman and colleague's systematic review describes that many studies show a negative relationship between low health literacy and health outcomes [49].

Table 1 Articles reviewed to compile PEARL

Article title	Population description	Article approach	Findings	Provided culturally-relevant materials
Hall et al. [30]	African American women in Mississippi	Employed a mass media campaign on black radio (both audio and print format) to educate African Americans on cancer	The experimental group scored better on Breast Cancer Knowledge than the control	Yes, they provide titles of American Cancer Society multicultural videos
Watson-Johnson et al. [31]	Hispanic women in Georgia	Developed a Spanish language educational toolkit administered by Community Health Workers (CHW), "Promotoras"	Promotoras were very knowledgeable about the cancer education materials; this translated into positive and effective education sessions	Yes, it includes a detailed description of the educational toolkit as well as pre and post educational activities
Choi et al.[32]	African Americans Men	Analyzed the cultural sensitivity and readability of 44 educational materials	Concluded that most of materials were cultural-sensitive but had reading levels above high school	No
Sung et al. [33]	African American Women in Georgia	Utilized a culturally-sensitive cancer education program taught by lay health educators	Cultural-appropriate education materials have limited effectiveness unless they also address health system barriers	No
Kline [34]	Population: African American Women	Examined the cultural sensitivity and rhetoric of education materials. Used PEN-3 model to assess breast cancer educational pamphlets targeted to African American women	Not only should pamphlets address barriers to cancer screening, but educational pamphlets should also address the context of screening in cultural values	No
Beck et al. [35]	African Americans in Wisconsin	Educational programs were held at African American churches and facilitated by community health workers; modules were previously assessed for cultural sensitivity	Community involvement is critical for developing educational outreach materials	No
Landrine and Corrall [36]	African Americans in San Francisco and Oakland, California	Participants received educational materials that highlighted disparities among Black and white individuals regarding cancer screening	They concluded it is more effective to frame disparities positively because it leaves readers feeling more hopeful	No
Robinson et al [37]	Native American Women in Navajo Nation	Created a culturally appropriate breast cancer education video in the Navajo language	Patient empowerment was a strong suggestion for future education videos and included anecdotes of women in the videos	No
Jones et al [38]	African Americans in Maryland	Used public service announcements to determine how African Americans responded to education on racial disparities	Participants responded poorly to education centering on racial "negative" disparities	No
Susan G. Komen [39]	African American Women	Created a toolkit to address breast cancer mortality disparities and they provide resources on how to educate Black women on breast cancer and prevention methods	They provide a complete guide for the breast cancer continuum of care, including communicating with Black immigrant communities	Yes, it includes example dialogues of conversations between educators and community members

Table 1 (continued)

Article title	Population description	Article approach	Findings	Provided culturally-relevant materials
Leeks et al. [40]	African American Women	Conducted focus groups with African American women in Georgia to create culturally appropriate messaging	Participants provided feedback on the draft materials, including family and community images for messaging	Yes, it includes final print materials
Buki [41]	Latina/o women	Authors conduct formative work on the process for creating culturally appropriate materials for Latina/o women	Their main contribution is a checklist that provides lots of detail on designing messages	No, but it provides a checklist for creating materials
American Cancer Society [42]	Adults with cancer	Provided detailed information on how screening rates have decreased during the COVID-19 pandemic. They provide tested messages that will resonate throughout the pandemic	Provided a guidebook with messages that organizations could use to stop individuals from delaying screening. They also provided an example press release	Yes, messages have example imagery to compliment the text, and complete materials are provided
Coleman et al. [43]	African American women	Examined how reading levels and cultural-sensitivity impact women's ability to learn more about breast screening education	This program focused on breast cancer screening education development process, including literacy, photography, and cultural sensitivity	No, but they had images of the messages from the Ruby and Pearl picture book

Plain Language and Understandability
Explicit Data, Statistics, and Graphs
Affirmative Framing
Representative Content
Local Connection

Fig. 1 PEARL guide for creating educational materials

However, we also identified a cultural gap within the definition of understandability. Cultural understandability should also be considered when translating materials. For example, Robinson et al. discuss how the translation of the word cancer in the Navajo language becomes "the sore that does not heal" [37]. Multiple words can be used to describe an object or body part, and choosing a culturally appropriate term is important [41]. While it is beneficial that researchers provide materials in a variety of language translations, doing so without a validated cultural context has the potential to increase stigmas and detract from the purpose of the materials. Therefore, when creating materials in other languages, researchers should enlist a native speaker of the language to ensure that the translation accurately reflects the intent of the materials. Previous cancer education research has noted language as a consistent barrier, especially among immigrant populations [50].

Explicit data, statistics, and graphs are closely related to understandability but focus on the understandability of cancer data, statistics, and graphs. All of these items are increasingly common in health education materials. Often the text associated with these materials is above recommended reading levels [51], because text cannot be easily entered into software that assigns readability scores [52]. As a result, graphs and statistics are often overlooked and assumed as being easily understood for all communities. Increasingly, communities want information presented in other media formats (e.g., infographics or on the web). While there is a growing use of infographics in educational materials, we could not find any literature examining their understandability levels for communities.

Affirmative framing emphasizes positivity and empowerment. Too often, health disparities research discusses the negative health outcomes and almost exclusively focuses on a two population comparison (i.e., white to black) [34]. However, positive and affirmative messages are more effective at increasing awareness [36]. Researchers should provide

messages that demonstrate positive changes or outcomes for the community of interest [36, 38]. This can include activities like individuals sharing their authentic stories and lived experiences [37]. This is particularly important in minority communities, in which many stereotypes and stigmas exist. In these cases, positive messages can be made that affirm the individual and dispel myths [33].

Representative content provides authentic community voices, images, and institutions. Essentially, the materials must capture the essence of a community and weave it throughout the materials. In the literature, this is often called "cultural sensitivity", "culturally appropriate", or "cultural awareness". At this time there is no agreed-upon definition or approach, but there is consensus to consider the experiences, norms, representation, cultural beliefs, and values of a community [53, 53–55]. Additionally, Hoffman-Goetz and Friedman suggest that cultural sensitivity is two-dimensional [25]. The first dimension is the surface in which materials match the social and behavioral features of the community. The second dimension provides depth and focuses on the values and the communities' perspectives of disease. In our guide, representative content is the first dimension.

Creating representative content can begin with simple things like visual representations of the community in the materials [40, 47]. The materials developed by Leeks and colleagues describe community members' impressions when they see culturally accurate materials. "They … stated that she looked real" [40]. In addition to education, the goal of educational materials should be to reflect their intended audience. To achieve these goals, photos of community members are preferred over stock photos. Icons and graphics that represent the culture should also be considered. The goal is to personalize the materials so that it accurately represents their community.

Creating culturally appropriate materials is a complex process because each community is different. Education materials should consider how this particular community likes to be addressed (i.e., first or third person) [34], or how decision-making is done in this community. For example, we developed materials for African American and African immigrant women. For many African immigrant communities, decision-making is done by the head of the household. Therefore it is the husband's decision if a woman can access healthcare. Understanding these cultural nuances is critical for developing culturally appropriate materials.

Local connection extends the concept of representative content to the second dimension of cultural sensitivity. Local connection involves connecting with the local community at its various sub-communities that researchers directly engage. Materials that are created should be relatable to local activities, data, people, and institutions [35]. Provide contact information for community stakeholders as a resource. Resources should be current and offer relevant support to the community that is being educated.

Discussion

Creating culturally appropriate education materials for African American and African immigrant women led us to develop the PEARL guide. PEARL is a modern comprehensive guide that was developed specifically for community engagement and uses the concept of cultural-appropriateness to galvanize engagement. The guide is designed to be a simple tool that can be used to create culturally sensitive cancer education materials. PEARL could be applied to many cancer education materials and is best suited to those in paper or digital media. The PEARL guide provides suggestions on how to best communicate complex qualitative and quantitative information to lay audiences. While concepts, like understandability are well documented in the literature, the literature examining how to effectively create cancer education materials that are cultural sensitivity for priority communities is still growing. We believe the use of the PEARL guide could speed up the creation of culturally sensitive materials, which could lead to richer engagement between cancer researchers and the community.

Limitations

We developed the PEARL guide through a literature review process while developing culturally appropriate materials for African American and African immigrant women. Therefore, there are likely to be concepts from other cultures that we did not consider during this process. Additionally, the literature search may not have been exhaustive and additional topics could be created. However, we believe that the guide has distilled relevant and useful information that researchers can use for creating community engaging materials.

New Contribution to the Literature

Our PEARL guide integrates key elements found within the literature to form a comprehensive and modern guide for creating culturally sensitive cancer education materials. The guide identified five domains, three of which (Affirmative Framing, Representative Content, and Local Connection) are directly related to concepts of cultural sensitivity. Previously the literature for creating educational materials had almost exclusively focused on understandability, and not much work had been specifically directed towards the integration of cultural appropriateness into the materials. Additionally, much of the literature on cultural sensitivity and its development in materials needed to be updated. Our generalized framework

fills a gap in the literature on how to create culturally sensitive cancer education materials.

The PEARL guide is designed to support researchers with little to no experience in community engagement. However, it is not intended to serve as an alternative for community input when designing culturally sensitive materials. Our literature review and resulting PEARL guide demonstrate that the creation of culturally sensitive materials is a complex process and consultation and co-development with the community are likely to result in better materials that are more aligned with the intended audience.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10903-022-01418-5.

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