



Impacting Health Disparities Through Community Outreach: Utilizing the CLEAN Look (Culture, Literacy, Education, Assessment, and Networking)

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Background: Community outreach programs are important vehicles for reducing the discovery-delivery disconnect by bringing cancer education and screening services directly to community members. Such programs are consistent with the priority areas of the Department of Health and Human Services' initiatives for reducing health disparities by 2010, and they support the use of culturally, linguistically, and literacy-specific approaches for eliminating cancer health disparities.

Methods: This article reviews the important tenets of culture and literacy when developing community outreach programs for medically underserved populations, examines a health education empowerment model for community program planning, and describes the use of the CLEAN Look Checklist (in which CLEAN is an easy-to-remember mnemonic of culture, literacy, education, assessment, and networking) for identifying cues and strategies to achieve relevant outreach.

Results: This article illustrates the application of this approach with an example of outreach strategies for reaching at-risk Haitian American women in our community.

Conclusions: Meeting the challenge of a strong health disparities agenda requires integration of cultural and literacy considerations in outreach program, message, and intervention development. The use of a checklist may help clinicians, educators, and researchers create a sustainable model of community outreach guided by a paradigm that incorporates a multilevel approach to address cancer outcomes for disenfranchised populations.

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Introduction

It is well recognized that we have seen unprecedented advances in translating research findings into public health practices for reducing cancer risks over the past few decades.¹ Yet, such advances are not realized by all members of society according to age, race, ethnicity, and socioeconomic group.^{2,3} While survival rates have increased, significant challenges remain to close the gaps in cancer outcomes.^{3,8} Impacting cancer disparities requires the creation of accessible, acceptable, and beneficial cancer interventions and communications as outlined by Healthy People 2010,⁹ the American Cancer Society 2015 goals, the Office of Minority Health's Standards for

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the Provision of Culturally Competent Health Care,¹⁰ and a number of Institute of Medicine reports relating to the unequal burden of cancer, cancer communications, and health literacy.^{6,11,12}

Outreach programs are important tools for bringing cancer education and screening services directly to community members and serve to contribute to reducing health disparities.¹³⁻¹⁵ They assist communities, cancer centers, and hospitals to reach mutually beneficial goals that would otherwise not be achievable for promoting accessible and equitable cancer care for at-risk and hard-to-reach groups. While culture and literacy are increasingly important areas of concern in cancer control programming, many developers of outreach programs are not aware of their audiences' literacy level as well as the major cultural norms and boundaries that support or impede community members' behaviors relating to screening, early detection, and prevention. Thus, meeting the challenge of a strong health disparities agenda in community outreach requires integration of culture and literacy in all phases of intervention, communication, and programmatic development.⁷ This paper reviews the important tenets of culture and literacy for impacting health disparities and examines a health education empowerment model for program planning. This paper also proposes the *CLEAN Look Checklist* to identify cues and strategies for culturally and literacy relevant outreach and illustrates the process with lessons learned by outreach and collaboration with an at-risk population.

Culture and Health Literacy Tenets for Impacting Health Disparities

Recommendations from the National Institutes of Health Trans-HHS Report to Reduce Cancer Health Disparities Progress Review Group¹⁶ purport the use of culturally, linguistically, and literacy-sensitive specific approaches for eliminating cancer health disparities and promote community-based strategies that move us from discovery to delivery. Carrying out these recommendations involves the design and implementation of evidence-based best practices, proven interventions, and relevant outreach strategies that take into account culture and literacy. Moreover, Meleis¹⁷ describes the delivery of culturally competent care as care that exhibits sensitivity to the differences in individuals based on their vast experiences and responses due to their backgrounds, socioeconomic status, language, literacy, sexual orientation, ethnicity, and cultural background. Thus, culturally competent providers recognize how social marginalization often increases health risks for individuals, are aware of the diversity of communication patterns, and are cognizant of how language, communication, and literacy influence trust within the relationship.

Culture

Culture can be conceptualized as a variably shared way of life that includes knowledge, attitudes, beliefs, customs, and values of a group of people.¹⁸ A cultural group shares an identity that shapes worldview expectations and perceptions and also guides behaviors. While many domains relating to the cancer experience are universal (eg, communication, spirituality, decision-making patterns), people experience them differently depending on their worldview.¹⁹ Kleinman²⁰ describes the health care system as one that is both social and cultural, consisting of intersecting external factors (eg, economic, epidemiologic) to internal factors (eg, behavioral, communicative). Thus, clinical realities are culturally constituted and vary cross-culturally and across the domains of health care.

Outreach interventions that are not informed by communities and do not consider culture are not understandable and are rarely successful or sustainable. However, a participatory approach to intervention design and implementation lays the groundwork for sustainable interventions and encourages community involvement and ownership of health programs, especially in cross-cultural contexts. In other words, interventions must be congruent with culturally mediated notions of what it means to be healthy and what puts a community at risk. For example, the work of Strickland et al²¹ addresses the role of religion in designing a culturally appropriate cervical health promotion program for Yakama Indian women of Eastern Washington (Wa'Shat Longhouse). Ethnographic field methods were used to discern salient cultural features to be observed as this health intervention was developed. Individual interviews with spiritual leaders and members (both men and women) of the Wa'Shat Longhouse religion revealed important religious influences as evidenced by answers to questions about their worldview, preferred channels of communication, and community tribal leadership. These data then informed the design of the intervention. In another study, Roushdy-Hammady²² included illness narrative collection and analysis as a primary method in her research among Turkish communities in Anatolian villages and migrants from these villages to other European countries. These communities had a higher-than-expected rate of mesothelioma mortality. This type of cancer is highly associated with exposure to erionite, which is a naturally occurring carcinogenic element found locally in the ground, in stucco used for house construction, and in dust. Her extensive narrative collections about people's experiences with and suffering from this cancer, as well as elicited cultural notions of cancer risk, illness categories, ethnoetiologies, and kinship, yielded unexpected information that suggested the potential for a familial risk that co-occurred with the carcinogenic environmental risk. These observed associations are currently under public health study for

epidemiologic relationships, and the ethnographic methods have informed current public health and education intervention strategies.

Health Literacy

Health literacy is defined 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.¹² It includes a constellation of skills required to function in the health care environment such as having basic reading skills, knowing when and where to go for cancer screenings, understanding public health messages about mammography, reading screening guidelines, completing health insurance forms, recognizing the role of what familial genetics has in breast cancer, and understanding expectations of prevention trials. As noted in the Priority Areas for National Action in Quality Improvement,¹¹ health literacy is a cross-cutting theme that affects care across the continuum of health and is critical in helping people evaluate health information, make informed health decisions, and potentially adopt or maintain behaviors.²³

The current US health care system has persistent reading demands for the people who use it. Studies indicate that individuals with low literacy are unable to meet these demands and thus fall behind more literate groups in adopting and using cancer control procedures and interventions.¹ Health instructions not read and screening interventions poorly understood adversely influence self-care abilities, decrease self-esteem, and increase shame, decrease the use of health care services, decrease ability to share in decision making, place individuals at risk for developing health complications, and affect receptivity of information received from websites.²⁴⁻³⁰ Hence, there is an established need to raise health professionals' awareness about the diversity of literacy levels among Americans and to focus on transdisciplinary approaches.³¹ Ramirez³² states that to fully understand the cancer information needs of diverse and multicultural groups, the learners themselves must be included in the determination of their health needs, health practices, and health programs, including communications. This practice is one component of the transcreation process in which existing English language health education materials are reformulated to meet language and literacy needs and be culturally congruent with the intended population.³³ Finally, the creation of appropriate community-centered outreach strategies within the context of cultural and linguistic considerations is key to bridging the communication gap (Figure).

Health Education Model for Cancer Education and Outreach

Central features of a successful health education model for cancer outreach include community empowerment and a recognition of social, political, and economic

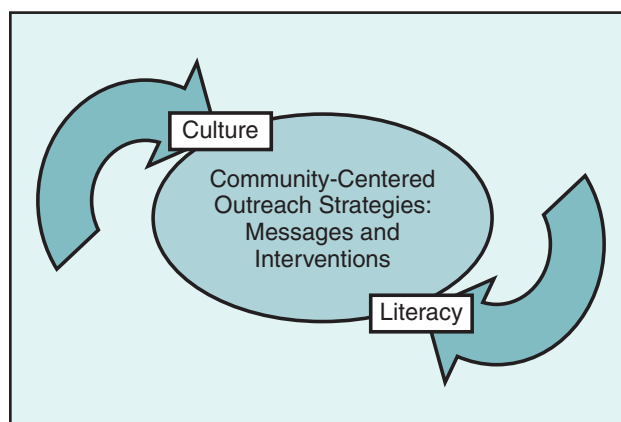


Figure. — Cancer, culture, and literacy: closing the communication gap.

aspects of health.^{34,35} Reconceptualizing health beyond the individual to the collective group moves the cancer control field from a narrower lifestyle focus to one that is informed by community-centered participation and empirical observation in order to more effectively understand the sociocultural context of health, illness, and intervention strategies.^{20,36-40} Meade and Calvo⁴¹ note that attention must be given to collective rather than individual efforts to ensure that the outcomes reflect the voices of the community and truly make a difference in people's lives. Finally, an understanding of the health care system as a sociocultural system better grounds health education and outreach interventions within sociopolitical structures, especially within local community-based settings.^{42,43}

Empowerment and literacy are two concepts that share a common history. The concept of empowerment is traced back to Paulo Freire, a Brazilian educator who sought to promote literacy among the most oppressed members of the Brazilian population.⁵⁰ Attempts to apply Freire's empowerment model to cancer prevention and other health education activities have been successful.^{38,44-49} His methodology, referred to as critical consciousness, involves not only education but also activism on the part of the educator.⁵⁰ The underlying tenet of Freire's work centers on empowerment, wherein community participation in shared dialogue elucidates key problems, increases collective knowledge and encourages action for social change.^{51,52} Freire's work speaks to a variety of action research applications, including those that relate to improving community health of marginalized populations, which have direct application for the development of community outreach programs directed for at-risk groups. Freire's work in critical pedagogy,⁵⁰ combined with a critical anthropology of health (CAH) perspective, shapes our approach to the theoretical underpinnings of a community outreach and education model that integrates social context, culture, and literacy. These guiding paradigms are complementary in that each acknowledges that structural forces differentially impact health outcomes

for disenfranchised populations. These perspectives, then, inform community-based participatory program planning as well as the development of meaningful and relevant cancer education and outreach programs.

Discovery to Delivery: Integrating Culture and Literacy into Community Outreach

Cancer control providers, researchers and educators are well positioned to impact the health behaviors and practices of individuals, groups, and community members through the delivery of culturally and literacy-relevant health activities, interventions, and roles. Communities most often consist of multiethnic and linguistically diverse cultural groups. An awareness of cues and strategies is required to effectively penetrate at the community level (Table). Here, we offer a five-pronged approach for creating a sustainable model of community outreach for at-risk populations. We have called this the *CLEAN Look Checklist*, which serves as a constant reminder to integrate culture and literacy into outreach programs to achieve a CLEAN look to the program. The *CLEAN Look Checklist* encompasses the following five cues into a mnemonic device: Culture, Literacy, Education, Assessment, and Networking.

Case Example From the Field

The Table presents cues and strategies that are important to consider in order to reach at-risk groups in consideration of culture and literacy, but the manner in which the approaches are operationalized and further implemented at the community level is what provides an “effective fit.” Community partnerships are critical to inform and implement effective interventions. The following case example illustrates our experience developing a breast health outreach program with the assistance of one of our community partners, the Haitian American Alliance, Inc, and local Haitian churches. These partnerships are the foundation of the Tampa Bay Community Cancer Network (TBCCN), a National Cancer Institute Community Network Program focused on cancer education and screening among ethnically diverse, medically underserved communities in the Tampa Bay area.

Many women from the local Haitian community are socially marginalized and medically underserved, and they face discrimination in multiple ways upon immigration to this country. Through the course of our outreach and interventions, we have been able to successfully reach women from the local Haitian community through the application of the CLEAN approach and the relationships and trust we have built through

our efforts. To date we have reached more than 80 Haitian women with mammography and clinical breast examinations and approximately 4,500 Haitian people with breast cancer education messages. The success of this program is due in part to our efforts to reach out with culturally appropriate messages and is aided by the relationships we have built with the community. We apply the *CLEAN Look Checklist* to describe these efforts and offer lessons learned.

Culture

Various cross-cultural analyses of health beliefs and perceptions about cancer reveal that expressed fatalism about cancer is largely a culturally mediated belief in need of correction via appropriate health education and prevention messages.^{53,54} While an understanding of culturally mediated health belief systems is of obvious importance, there is a lack of attention to the influence of macrosocial forces that affect people in poverty, in which a sense of fatalism reflects lived sociocultural realities and experience with cancer. Culture and structure are inextricably intertwined, and culturally competent interventions that recognize this relationship are more attuned to beliefs and material and social conditions that impact a person’s health-seeking behavior.

In our local community, many Haitian women we serve are under- or uninsured and, to some extent, linguistically isolated. It was not uncommon to learn from the women about family members and acquaintances who were diagnosed in later stages of cancer with subsequently unsuccessful treatment. Thus, expressed fatalism about cancer is not an irrational response, and it was a common theme that we addressed by incorporating culturally congruent concepts about health, ethnoetiology of cancer, early detection, and spirituality into our methods of education delivery. Programs were held in a social context and physical location (eg, women’s group meetings, churches) where the women felt comfortable learning about cancer. Messages about survival and early detection were adapted to address expressed ethnoetiological beliefs. Moreover, with grant funding from the Avon Breast Health Care Foundation, we hired an outreach worker from the local Haitian community. Her knowledge of the community informed outreach strategies that included working with local clergy, specifically clergymen’s wives, and local Haitian nonprofit organizations to create culturally acceptable outreach messages and activities. Importantly, this grant funding also allowed us to address some access barriers and develop resources linkages for mammograms and clinical breast examinations for women who met set income guidelines.

Literacy

Attention to cross-cultural literacy in the context of health is critical for creating acceptable, relevant materials that resonate with the intended population.^{32,55}

Table. — CLEAN Look Checklist: Achieving the CLEAN Look in Your Outreach Program

CUES	STRATEGIES
<p>Culture <i>Assess Cultural Relevancy</i></p> <ul style="list-style-type: none"> • Am I currently conducting programs, services or projects that aim to reach multicultural, multilingual groups? • What are the cancer information needs of community members from their perspective? • In what way can outreach link to the group's beliefs, values, preferred language and linguistics? 	<p>Transform existing cancer control efforts into culturally relevant programs:</p> <ul style="list-style-type: none"> • Involve diverse community members in the development of programs and communications to appropriately inform the cultural and linguistic dimensions of your project. Ask questions about their background, concerns, health needs, health practices, etc. • Pretest communication/program ideas with members of the community and stakeholders. • Translate/transcreate current messages into appropriate language, eg, offer information in a language and manner culturally attuned to the population.
<p>Literacy <i>Assess Literacy Relevancy</i></p> <ul style="list-style-type: none"> • Are you currently conducting programs, services or research projects that aim to reach low-literacy populations? • How do your outreach aims require information? • What are the learning needs of the community? • What is the educational level of your group? What do the census data tell you? What do the local data tell you? • How does the group prefer to get health information (eg, print, electronic, performance education)? 	<p>Transform existing cancer control efforts into literacy-specific programs:</p> <ul style="list-style-type: none"> • Involve community members in the development of programs/materials. • Talk to community members and get to know them. Ask questions about their educational background, learning preferences, etc. Recognize that many people may hide or disguise their reading abilities. • Obtain user input on an ongoing basis, eg, what do they think about this? • Pretest cancer information and ideas with members of the community. • Employ learner verification techniques to assure understanding, acceptability, usability and efficacy. This helps verify the meaning of "words." • Translate/transcreate current information into appropriate communications using easy-to-understand terminology and drawing on a multitude of formats, channels and tools. • Provide cancer information at a literacy level matched to the population and in concordance with their preferences for acquiring information, eg, pictures, novellas, use of spokesperson.
<p>Education</p> <ul style="list-style-type: none"> • Do the messages of my outreach program work? • What changes can be made to make the programs, services and projects more culturally and literacy relevant and acceptable? • What other cancer educational tools are available? • How can I find other resources to enhance my education and outreach programs and culture and literacy approaches? • In what way is staff oriented to culture and literacy in outreach? • In what ways can I disseminate information about culture and literacy tenets among staff and colleagues and community members? 	<ul style="list-style-type: none"> • Conduct ongoing process and outcome evaluation of your program. • Conduct frequent checks of satisfaction and understanding with users. • Involve community members in the ongoing improvement of outreach programs. • Go to web sites of agencies involved in cancer education, CIS, CRCHD, ACS and/or organizations that focus on your audience of interest, eg, http://cis.nci.nih.gov/, http://crchd.nci.nih.gov/, http://www.cancer.org/docroot/home/index.asp. • View the work of others via CRISP (http://crisp.cit.nih.gov/). • Access available resources (see CCL supplements at http://www.moffitt.org/ccj). • View Cancer Control Planet (http://cancercontrolplanet.cancer.gov/). • Attend local and national meetings, eg, American Public Health Association, Intercultural Cancer Council's Symposium for Medically Underserved, Cancer, Culture and Literacy Biennial Conferences and/or meetings specific to the needs of the community, eg, National Center for Farmworker Health, National Hispanic Alliance. • Assess cultural competency awareness and implement training programs needs. Refer to CLAS for action steps (OMH, 2003). • Increase bilingual staff and diversity of team.
<p>Assessment</p> <ul style="list-style-type: none"> • What are the cancer information needs of the community? • What are the cancer program/service gaps in the community? • How would members of the intended population prefer the programs, services or projects in terms of language, literacy? • How can I foster institutional change for promoting inclusion of CLEAN approaches? • How can I assure that follow-up care is part of outreach communications? 	<ul style="list-style-type: none"> • Talk to community members and get them involved. This includes community members themselves, key stakeholders, and members of community agencies. • Review state and county cancer profiles. • Review current local community programs, services, screening and projects. • Conduct asset mapping/needs assessments. • Identify medically underserved areas. • Conduct formative research using qualitative approaches, such as focus groups, in-depth interviews, case studies, etc, to understand information gaps and to better fit the message to the population. • Involve community members in the process of program development to better match information to culturally mediated learning styles, preferences, language and need. • Create a working group to evaluate current policies about patient education. • Form a working group to evaluate current outreach follow-up care policies to assure that communications reflect follow-up linkages and that CLEAN is integrated into staff education. • Explore the use of navigation strategies to address CLEAN and follow-up linkages.
<p>Networking</p> <ul style="list-style-type: none"> • How can I get fresh ideas/feedback and learn new approaches to effectively incorporate culture and literacy into outreach activities? • How can I maximize my cancer outreach efforts? 	<ul style="list-style-type: none"> • Create a strong network of community partners and collaborators. • Seek out new partnerships from a variety of agencies, eg, media, adult education, community agencies, community social service, businesses, philanthropy, pastors in churches, doctors, etc, to assist in outreach development. • Develop collaborations with staff from the anthropology, psychology, public health, nursing and other departments in your university that work closely with similar groups that you want to reach. • Offer community workshops on developing materials to enhance shared capacity to integrate CLEAN into programs.

With the assistance of Haitian community partners, we used a participatory process to transcreate a breast self-examination (BSE) shower card with monthly reminders and included combined pictorial/written instructions in Haitian Creole on how to do the BSE. It is important to note that language use and literacy are strongly associated with power and social class in the Haitian immigrant community. Creole is largely a spoken language; that is, fewer people read Creole than speak it. French and English fluency (written and spoken) is reserved for a small portion of the population, primarily the professional social class. Additionally, Haitian Creole orthography was standardized in the 1980s, but it has since undergone many revisions. As a result, we consulted with a varied group of Haitian community members and organizations to transcreate the BSE shower card linguistically and graphically, thus ensuring a greater level of cultural acceptability and comprehension than what could have been produced through simple translation alone. The BSE shower card, as a reminder for women to take home, is used in conjunction with verbally delivered breast health education. Future projects will involve more audiovisual educational materials in Creole to accommodate literacy needs and learning preferences expressed by community members.

Education

The high religiosity observed in the local Haitian community (across multiple denominations, primarily Judeo-Christian) served as an enabling community characteristic in the context of breast and cervical cancer education. We adapted a faith-based breast and cervical cancer program, The Witness Project®, to fit the culturally mediated educational needs of Haitian women that emerged as the outreach efforts grew. Specifically, we used a participatory approach and began by working with local women's groups and with clergy members and their wives to discuss the program's applicability to the Haitian community. We translated this "live" program into Haitian Creole through the skills of the Haitian outreach worker. Because physicians are widely respected in the community, we complemented the program by bringing a local Haitian American physician to reinforce the messages of early detection and specifically address myths about cancer in the Haitian community. Collaboration with Haitian women and community-based organizations in the transcreation of cancer education messages, health events, and screenings promoted a sense of ownership and empowerment among community consultants and participants. Finally, through our community collaborations and feedback, we learned of specific social dynamics that were important and unique compared with other immigrant communities: the local Haitian community was more receptive to cancer information if its delivery also came from a non-

Haitian person to reinforce what culturally matched health educators had imparted about cancer. As a result, we included a medical anthropologist who is not Haitian but whose research focuses on Haitian culture, health beliefs, and language in all phases of our outreach and education efforts.

Assessment

An important key formative strategy that led to significant rapport development and sustained intervention impact was the use of qualitative, ethnographic methods, including participant observation in the community, to discern what women wanted in terms of education, how they wanted it delivered, and from whom. In collaboration with Haitian community partners, gaps were identified where cancer education messages were lacking, nonexistent, or otherwise not reaching the most vulnerable women in the community. This collaborative assessment drove our initial decisions to seek funding for a breast health program, and relationships developed with community gatekeepers, churches, and community-based organizations that catalyzed program acceptability and sustainability in the community.

Networking

Partnership and collaboration from program concept to implementation are critical elements in building rapport, trust, and respect. Community partnership was key to the success of this intervention, because support from community gatekeepers and organizations helped to foster broader community interest and acceptance in the program. Additionally, an extensive knowledge of the community was developed through the hiring of a Haitian outreach worker and via ethnographic methods in a fieldwork context. As a consequence, we learned of and worked through key community gatekeepers, such as clergy and their wives and local Haitian nonprofit organizations, to further facilitate our acceptance in the community and to provide the program with ideas, legitimacy, and ultimately sustainability and recognizable presence in the community. A measure of effectiveness is evidenced by the ongoing requests we receive from various local (and now statewide) Haitian organizations for cancer education and outreach activities, programs, and event sponsorships. Finally, our outreach strategies for at-risk populations are constituted by a strong and sustained web of community networks that provide breast health screening services in strategically placed locations that facilitate access for community members. Although our screening program has been effective in reaching at-risk women, we continually enhance the educational reach of the program in the community by systematically examining factors that influence screening behaviors and working with partners to improve our practices.

Conclusions

Meeting the challenge of a strong health disparities outreach agenda in cancer control requires an understanding and consideration of culture and literacy in all phases of program, message, and intervention development and implementation. One challenge is to develop effective cancer outreach programs and communications that address the optimal context, channels, and content that reflect the realities of people's everyday lives.^{56,57} It calls for inclusion of worldviews and issues that are significant to those to whom it is addressed. It also requires the use of empowerment processes, including community-based participatory approaches, that promote an awareness of social, cultural, political, and environmental forces affecting the health of community members and that integrates culture and literacy into focused outreach and education efforts. As such, the application of culture and literacy is particularly useful in efforts to impact the health disparities agenda at the community outreach level and positively influence the lives of community members. It also has potential implications for a positive impact in the clinical setting for patient education in a variety of conditions. We encourage clinical practitioners, educators and providers to incorporate the *CLEAN Look Checklist* in their practice and work to accommodate the health education and communications needs of an increasingly diverse patient population. Lastly, we alone cannot address cancer health disparities experienced by our community alone. The collective wisdom of many is needed to make a difference.

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