

A SYSTEMATIC REVIEW OF CULTURALLY SENSITIVE CANCER PREVENTION RESOURCES FOR ETHNIC MINORITIES

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Background: Cancer prevention educational resources intended for members of ethnically diverse populations should be tailored to the specific cancer knowledge and beliefs of individual ethnic groups. Culturally sensitive printed materials on cancer prevention have been proposed in the literature.

Objectives: 1) To explore definitions of the term cultural sensitivity (CS) and their application to the development and testing of cancer prevention education materials for ethnic minority groups; and 2) to assess the use of instruments or scales used to measure the CS of cancer information resources.

Design: A list of articles explicitly on the CS of cancer prevention education materials was assembled by searching the databases of PubMed, CancerLit, PsycINFO, and Sociological Abstracts for articles published between 1994–2004.

Results: Ten studies that met inclusion criteria were included in this review. Most articles included breast cancer resources (90%) and targeted African American populations (70%). Few studies defined the term CS ($n=4$). Only three studies employed instruments to evaluate the CS of printed cancer information resources, and none of them explicitly listed standard measures of validity or reliability.

Conclusions: Best practice definitions and guidelines for culturally sensitive cancer prevention education need to be established. Ethnic minority individuals' cancer-related knowledge and beliefs must be incorporated into all printed cancer education efforts. (*Ethn Dis.* 2006;16:971–977)

Key Words: Cancer Prevention, Culture, Cultural Sensitivity, Printed Educational Resources

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INTRODUCTION

The age-adjusted cancer mortality rate in the United States is 199.8 deaths per 100,000 people (year of death 1997–2001).¹ Cancer death is not evenly distributed across ethnicity or race. The cancer death rate for African Americans (252.5/100,000) is higher than that for Caucasians (196.9/100,000). Ethnic and racial minorities experience a higher death rate from lung cancer, most notably so for African Americans (65.2/100,000) compared to White Americans (56.2/100,000). American Indians/Alaska Natives (36.3/100,000) also experience high death rates from lung cancer due to regular tobacco use.² Mortality from breast (35.4/100,000), prostate (70.4/100,000), and colorectal (28.3/100,000) cancers among African Americans is considerably higher than that for White Americans (breast: 26.4/100,000; prostate: 28.8/100,000; colorectal: 20.3/100,000).¹

Poor compliance with primary prevention (eg, diet, exercise) and screening practices (eg, mammography, Papanicolaou tests)^{3–8} is often related to late-stage cancer diagnosis and higher rates of cancer mortality for minorities.^{7,9,10} Having accurate and tailored cancer information is an important step in cancer prevention and is associated with improved quality of life, increased self-efficacy, and lower anxiety levels about the disease.¹¹ The rationale for inclusion of culturally sensitive, tailored information in cancer prevention stems from health psychology models including the Health Belief Model¹² and the Precede-Proceed framework.¹³ These models suggest that health information acts as a cue to action for taking preventive health actions and as an enabling factor

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initiating behavioral changes, leading to positive health outcomes.

Ethnic groups favor cancer information that incorporates their cultural beliefs into health messages.¹⁴ For example, African American individuals preferred cancer risk information framed specifically for them and wanted healthcare providers to consider cultural factors when making healthcare decisions.^{15,16} However, current research on the disparities of cancer coverage in ethnic minority mass media found that most cancer newspaper articles did not identify intended ethnic minority groups as being at high risk for cancer or as the target readers of the information.¹⁷ Individuals may be more engaged in preventive behaviors if cancer messages were relevant to their information needs.¹⁸

What is Cultural Sensitivity?

The term cultural sensitivity (CS) is often used to refer to patient health care, intervention programs, and/or printed information intended for particular ethnic groups. However, this term is frequently used in the literature without standardized definitions.^{14,19–21} A best

practice definition of CS has not been established.

Few North American health and medical organizations define cultural terms in their policy statements. An exception is the American Association of Diabetes Educators,²² which explains CS in its position statement. Cultural sensitivity (CS) is based on the work of Resnicow et al^{23,24} and relates CS with health promotion interventions and educational materials: "the extent to which ethnic/cultural characteristics, experiences, norms, values, behavioral patterns, and beliefs of a target population's relevant historical, environmental, and social forces are incorporated in the design, delivery, and evaluation of targeted health promotion materials and programs." Cultural sensitivity (CS) consists of two dimensions: surface structure and deep structure. Surface structure is the extent that health resources match the social and behavioral features and appearance of the intended population. Deep structure recognizes that cultural, social, historical, and environmental variables influence health behaviors, and values ethnic differences in the perceptions of the prevention of disease.

The Office of Minority Health's National Standards for Culturally and Linguistically Appropriate Services in Health Care²⁵ also offers an explanation of CS: "the ability to be appropriately responsive to the attitudes, feelings, or circumstances of groups of people that share a common and distinctive racial, national, religious, linguistic or cultural heritage."

Review Objectives

The objectives of this review are: 1) to evaluate in depth the definitions of the term cultural sensitivity and the application of CS to cancer prevention educational resources; and 2) to examine the use of instruments used to measure the CS of printed cancer prevention materials for members of diverse ethnic populations. Other re-

searchers have systematically reviewed culturally appropriate healthcare interventions, although not related specifically to cancer.²⁶

METHODS

Literature Search Terms and Inclusion Criteria

A list of articles on CS explicitly related to cancer prevention intervention programs and educational materials was assembled by using PubMed, CancerLit, PsycINFO, and Sociological Abstracts. These databases were searched for articles written over a 10-year period (1994–2004) with the terms cancer and cultural sensitivity along with the following search terms alone or in combination: education, print, information, resources, race, ethnic group, and ethnicity. Follow-up searches were conducted by using specific terms identifying ethnic minority populations (African American, Alaska Native, American Indian, Asian, Hispanic, Pacific Islander) to ensure inclusion of all eligible studies.

For inclusion, journal articles had to be written in English, published between January 1994 and December 2004, available through the university library system, discussed printed cancer prevention education materials, and used the terms cancer and cultural sensitivity in the titles or abstracts. Studies that discussed CS as a recommendation for future cancer education programs or interventions were excluded. Non-empirical literature reviews, case studies, editorial pieces, and letters on the cultural aspects of cancer were not included. Articles using the terms cultural competence, cultural relevance, cultural tailoring, cultural suitability, or cultural appropriateness were consulted for background information.

Coding of Articles

The following characteristics were coded: year; study method (quantitative

or qualitative); cancer type (general, site-specific, or multiple cancer types); population (ie, sample size, ethnicity, age, recruitment procedure); definition of CS; tool used to measure CS (ie, name of tool, standard measures of reliability and validity testing); study objectives; outcome measures (eg, evaluation of culturally sensitive cancer information, etc); and whether objectives and/or outcomes were associated with the intended ethnic minority groups. Original or referenced definitions of CS needed to be stated explicitly to be coded as defined terms. Inter-rater coding reliability was tested on all 10 articles. Articles were read thoroughly and coded independently by two researchers to ensure consistency. We had 100% consensus in article eligibility and coding.^{27–29}

Inclusion criteria, article selection, and analysis of methods, findings, and conclusions (including sample selection, validity, and reliability measures) were based on Oxman and Guyatt's criteria for methodologic rigor of systematic reviews.³⁰

RESULTS

Number of Articles

A total of 147 citations were obtained with the search terms. Of these, nine were not relevant to cancer and culture. Of the 138 remaining articles, 25 were literature reviews or editorials; 32 were on cancer prevention networks for cancer control; 15 on cancer beliefs, belief scales, knowledge, and/or information-seeking; 4 on social support and care giving for minority patients; 4 on cancer treatment and/or patient care; 2 on clinical trials for minority patients; 6 on physician-patient communication about cancer; 18 on the health and/or cancer status of minority groups; and 9 on cancer genetics and ethnicity. Twenty-three of the 138 articles were specifically on the CS of cancer prevention education; 13

Table 1. General description of 10 studies on culturally sensitive cancer prevention resources, 1994–2004

Study Investigators	Cancer Type(s)	Location	Printed Materials	Sample Population/Intended Readers	Definition Provided for Cultural Sensitivity?	Inclusion of Cultural Factors?
Baty et al ¹⁴	Breast, ovarian	Utah, Louisiana	Booklet, flip chart	African American men and women, mean age of 48.5	No	Yes
Chan et al ¹⁵	Prostate	Texas	Brochures	African American, Hispanic, and White couples (men and women), mean age of 63	Yes	Yes
Coleman et al ¹⁹	Breast	Arkansas	Pamphlet, picture book	African American women mainly, mean age of 43	No	Yes
Santos et al ³³	Breast	Hawaii	Booklets	Hawaiian women (ages not specified)	No	Yes
Mohrman et al ³⁴	Breast	Arkansas	Print publications	African American women (ages not specified)	No	No
Brant et al ³¹	Breast	Montana, Wyoming	Posters, brochures, flip chart	Plains Indian women (ages not specified)	No	Yes
Guidry and Walker ³⁵	Breast, cervical, colorectal, lung, prostate, skin, general	Texas	Books, pamphlets	African American laypersons (ages not specified)	Yes	No
Guidry et al ³⁶	Breast, prostate	Texas	Pamphlets, posters, and fact sheets	African Americans (ages not specified)	Yes	No
Masset ³⁷	Breast	Massachusetts, Washington DC	Brochures, booklets, pamphlets, newsletters	Hispanic women aged ≥40	Yes	Yes
Forte ³²	Breast	California	Pamphlet	African American women aged ≥50	No	Yes

were on intervention programs and included multimedia cancer resources (eg, videos, telephone hotlines, and Internet-based education); 10 focused on printed resources and were included in this systematic review. Table 1 provides a description of the 10 studies under review. Though two studies included descriptions of intervention programs, a key component of them was the distribution of culturally sensitive printed resources. Thus these studies were included in the current review.^{31,32} One study on cancer prevention materials for Native American women also described focus groups with cancer survivors.³³ This component of the study on individuals with cancer was not included in this systematic review on cancer prevention education.

Sample Population

Most studies (n=6) focused on printed education materials for African American populations only.^{14,19,32,34–36} Two studies focused on Native Amer-

icans,^{31,33} one study evaluated materials intended for Hispanic women,³⁷ and one study targeted multiple ethnic minority groups (eg, African Americans, Hispanics, and Caucasians).¹⁵ Participants recruited for formative or outcome evaluation of educational materials tended to be women only (60%) over the age of 40; men or materials on cancer in men (ie, prostate, colorectal, lung, testicular) were included in four (40%) studies.

All 10 studies used purposive or convenience sampling to recruit participants or collect educational materials. Though Guidry and Walker³⁵ described the collection of their printed materials (total convenience sample), the recruitment strategy for African Americans to participate in focus groups was not specified.

Cancer Type

Six of the studies focused solely on breast cancer resources.^{19,31–34,37} One article was on prostate cancer only.¹⁵

Three articles mentioned multiple site-specific cancers, including breast, cervical, colorectal, gastrointestinal, ovarian, and skin cancer.^{14,35,36}

Most studies included breast cancer resources intended for African American women (60%).^{14,19,32,34–36} Printed resources for Native women (Plains Indian and Hawaiian) were also on breast cancer.^{31,33} Chan et al’s research on prostate cancer involved African American, Hispanic, and White couples.¹⁵

Study Method

Most of the studies, with one exception,¹⁹ explicitly stated research objectives, and these objectives involved cultural factors related to one or more ethnic minority groups. All studies specified outcome measures, which were also related to ethnic group. Most of the studies (n=7) did not specify evaluation of outcome measures (eg, assessment of materials using follow-up surveys or focus groups).^{14,15,32,33–36} One study

Table 2. Definitions of cultural sensitivity in 4 studies, 1994–2004

Study Investigators	Definition Provided	Source of Definition
Chan et al ¹⁵	"... the extent to which ethnic/cultural characteristics, experiences, norms, values ... are incorporated in the design of targeted health promotion materials." (p. 394)	Resnicow et al ²⁴
Guidry and Walker ³⁵	"... relates to the appropriateness and representativeness of information to a particular group." (p. 291)	Friedenberg et al ⁴⁷
Guidry et al ³⁶	"address the cultural beliefs, values, and behavior of the intended audience." (p. 166)	Original definition
Massett ³⁷	"... model continuum ... a range from cultural destructiveness (ie, the purposeful destruction of a culture or the process of dehumanizing minority cultures) to cultural proficiency (ie, the conscious holding of all cultures in high esteem and the valuing of cultural differences)." (p. 239)	Cross et al ⁴⁸

indicated the need to conduct an outcome evaluation in the future with senior African American women.³²

Most studies ($n=6$) assembled a list of deep structure cultural considerations (eg, modesty, spirituality, disease stigmas, fatalistic beliefs, traditional or holistic values) for printed educational materials from the literature or through conversations with lay persons from the representative ethnic group.^{14,15,19,31–33} Cultural factors were not explicitly addressed in four evaluations of the surface features of printed cancer information (Table 1).^{34–37}

Definitions and Measurement of Cultural Sensitivity

Few studies defined the term CS ($n=4$ or 40%).^{15,35–37} One study provided an original, independent definition,³⁶ and three studies referenced other researchers' definitions.^{15,35,37} Massett's definition was on general CS and did not focus specifically on cancer.³⁷ Table 2 summarizes the definitions of CS described in these studies.

Three studies^{34–36} used the Cultural Sensitivity Assessment Tool³⁸ instruments to measure the CS of cancer prevention information. Validity testing of the Cultural Sensitivity Assessment Tool was not reported in the three studies that employed this tool, though Guidry et al's research^{35,36} mentioned that multiple testers were used to ensure inter-rater reliability.

DISCUSSION

Ten articles published between 1994 and 2004 were analyzed in this systematic review. Most articles were on breast cancer and included or were targeting African Americans. Only one study was exclusively on prostate cancer. No interventions focused solely on the prevention of colorectal or lung cancer despite higher mortality rates among ethnic minority populations.¹ A lack of attention on colon cancer has been found repeatedly in print media intended for both ethnic minority and general populations.^{17,39–41}

Common cancers in men (eg, prostate, colorectal) were included in only three studies. Men from under-served minority populations must also receive culturally appropriate cancer information. Men from ethnic minorities may experience late-stage diagnosis, poor prognosis, and rising mortality rates for prostate and colorectal cancers.^{42,43} Men often defer health- and cancer-related decisions to their physicians or wives.^{7,44} Cultural factors such as men's role as family leaders, machismo, embarrassment of receiving digital rectal examinations, and reliance on family and alternative medicine may inhibit men from seeking medical attention.^{7,15} Cancer education targeting ethnic minority men is important to encourage cancer awareness and prevention.

The use of cultural terms was inconsistent. For example, Baty et al¹⁴ defined the term "cultural compe-

tence," though the study objective was specifically to develop "culturally sensitive" communication aids for breast and cervical cancer genetic counseling in African American populations. A number of other studies used multiple cultural terms (that is, both CS and cultural competence) without distinguishing the meaning of these two terms.^{14,19,37}

Lack of Evaluation

Three studies employed instruments or scales to test the CS of cancer prevention information. Studies by Guidry et al^{35,36} mentioned inter-rater reliability testing of the Cultural Sensitivity Assessment Tool (CSAT) but did not offer statistical results. Mohrmann et al³⁴ did not report validity or reliability measures of the CSAT in the evaluation of printed resources for African American women. Although the CSAT is presented as a quick tool for the assessment of surface elements of CS (eg, appropriate graphics, physical appearance), it is less useful in measuring deeper characteristics of cultural groups (eg, beliefs and perceptions about cancer). Cultural variables regarding cancer were not addressed in the three studies that employed the CSAT. An additional Cultural Sensitivity Checklist has been developed to explore deep structure, historical, and cultural representations of health and illness for both printed and Web-based cancer educational materials.²⁸

In addition to the inconsistent use of cultural terms and insufficient validation of CS instruments, limited formative evaluation was done in the development of cancer education materials. Only two studies conducted in-depth inductive research with ethnic communities to gather information about cancer beliefs and knowledge for printed cancer resources.^{14,15} In order to create culturally tailored information for diverse populations, we must explore and incorporate health attitudes and behaviors of the intended audiences. A way to evaluate the effectiveness of cancer communication efforts is to work directly with ethnic populations to assess their understanding and opinions of the material and modify it accordingly. Individuals should be involved in the process of creating learner-developed materials that are reflective of their language and cultural characteristics.⁴⁵

Limitations of Systematic Review

This study has limitations. First, the sample size was small ($n=10$) and only included articles with the term CS in the titles and/or abstracts. However, the sample represented the entire set of articles on CS of printed educational resources on cancer prevention over 10 years (1994–2004) that were identified in the four databases. Relevant articles may have been missed since additional hand searching of the bibliographies for the 10 CS articles was not conducted. Second, only English-language studies were included in the systematic review. Additional published and unpublished cancer interventions in languages other than English have probably been conducted. Studies using terms other than CS in the interventions or educational materials (eg, culturally competent, culturally appropriate, culturally relevant, culturally congruent, and so forth) were not included; thus, sampling bias may have affected our interpretation of the strengths and limitations of the literature with respect to culture and cancer prevention inter-

ventions and educational materials. Finally, we focused only on studies involving cancer prevention rather than cancer treatment. More robust applications of the term “culturally sensitive” may be found in clinical studies with cancer patients.

Promoting Better Cancer Education Science: Recommendations for Practice

Though all of the studies reviewed here attempted to understand the significant influences of culture on cancer prevention, few defined CS in application to cancer education. Future research must avoid the confusion of buzzwords such as cultural sensitivity, cultural competency, cultural relevance, and cultural appropriateness and their application to cancer prevention. Development of best practice definitions and guidelines are needed to ensure greater consistency in use and implementation of CS cancer prevention programs. Nongovernmental organizations (NGO) and stakeholder organizations’ definitions of CS have been related explicitly to the delivery of health interventions or resources.^{22,25}

The authors define culturally sensitive printed cancer information as that which entails both surface aspects of culture (ie, mention of ethnic minority group, use of appropriate illustrations, font size, and wording) and embedded, deep structure components (ie, symbolic elements, historical framing, attitudes, cultural beliefs, literacy skills) of ethnic groups.²⁸ However, the focus of culturally sensitive cancer education should not be on definitions and terminology. Rather, the provision of culturally respectful and relevant cancer information to ethnic minority individuals who may be at high risk for cancer is required. We recommend a three-phase approach for developing culturally appropriate cancer prevention programs and materials: 1) a standardized definition of CS as applied to cancer prevention needs to be developed by expert groups with knowl-

Development of best practice definitions and guidelines are needed to ensure greater consistency in use and implementation of CS cancer prevention programs.

edge about cultural factors related to cancer in the intended ethnic minority communities; 2) CS of the intervention or information resources must be tested with validated and reliable instruments or scales; hence, standardized instruments to assess CS of educational components must be developed for this facet of cancer prevention; and 3) In agreement with the Intercultural Cancer Council,⁴⁶ stakeholders and lay persons from the intended ethnic minority communities should be involved in formative evaluation to ensure cultural relevance.

The Office of Minority Health²⁵ offers excellent principles for the delivery of culturally appropriate and relevant health care and resources: “... striving to overcome cultural, language, and communication barriers; providing an environment in which patients/consumers from diverse cultural backgrounds feel comfortable discussing their cultural health beliefs and practices in the context of negotiating treatment options; using community workers as a check on the effectiveness of communication and care; encouraging patients/consumers to express their spiritual beliefs and cultural practices; and being familiar with and respectful of various traditional healing systems and beliefs and, where appropriate, integrating these approaches into treatment plans.” Cancer educators, program planners, and researchers must consider the cultural aspects of cancer. Without clear identification, application, and measurement of cultural factors, cancer

education information and associated programs will remain largely etic and dichotomous ("us-them") rather than emic and inclusive ("we").

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