

Cancer Prevention in Underserved African American Communities: Barriers and Effective Strategies—A Review of the Literature

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ABSTRACT

African Americans suffer significantly more cancer morbidity and mortality than the white population. In order to decrease this differential, it is critical to understand the particular barriers to health and health care that underserved African Americans face. It is also important to identify the critical components of effective cancer prevention programs for this population. The barriers that impede care for underserved African Americans have been identified as: 1) inadequate access to and availability of health care services; 2) competing priorities; 3) lack of knowledge of cancer prevention and screening recommendations; 4) culturally inappropriate or insensitive cancer control materials; 5) low literacy; 6) mistrust of the health care system; and 7) fear and fatalism. Effective programs must incorporate community participation, innovative outreach, use of social networks and trusted social institutions, cultural competence, and a sustained approach. Programs that include these strategies are much more likely to be effective in reducing cancer incidence.

Cancer ranks second only to cardiovascular disease as the leading cause of death in the United States. For the majority population, cancer incidence and prevalence have declined in recent years and cure rates for certain cancer diagnoses have improved. This can be attributed to progress in the development and implementation of prevention, early detection, and treatment

strategies. However, despite these gains, medically underserved African American populations have not fared as well. When African American-white mortality rates are compared, African Americans are 1.3 times more likely to die of cancer than the general population.¹ Data from the Bureau of Health Information, Wisconsin Department of Health and Family Services indicate that from 1996 to 2000, cancer accounted for 33% of deaths in African Americans aged 45-64 and 34% of deaths for those aged 65-74.

To decrease the disparities in cancer morbidity and mortality between the African American and white population, it is critical to understand the particular barriers to health and health care that African Americans face. This paper is a literature review of the barriers that low-income African American populations confront in obtaining needed cancer prevention and detection and the characteristics of programs that have been effective in reaching these populations.

BARRIERS

Inadequate access to, and availability of, health care services

Poor access to health care services for African American underserved populations is due to inadequate income, unemployment, and lack of any or adequate health insurance. Many medically underserved African Americans lack a primary care physician and access the health care system only in an urgent or emergent care situation, thus missing opportunities for preventive health care.² Primary care clinics and physicians may not be conveniently available in the geographic areas where these underserved populations live, tend to be overburdened,³ and may not schedule evening and weekend hours. The underserved may also have to travel to different facilities to obtain screening tests and endure long waiting times. The cost and inconvenience

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of public transportation may also deter regular visits to a physician.²

Competing survival priorities

African American underserved patients also have difficulty prioritizing preventive and screening activities in the context of more immediate survival needs such as food, shelter, safety, and clothing.³ Low socioeconomic status and lack of insurance is a factor in the higher cancer incidence and mortality and also is a critical barrier to cancer control and prevention activities.⁴ Poor people are required to make extraordinary sacrifices to obtain and pay for health services. The stress associated with living in less-than-secure environments and existing on insufficient and unreliable resources makes focusing on preventive health care difficult.³ Many underserved patients report feeling isolated and alone, and heightened concerns about daily safety and well-being are perceived as much more prominent needs than worries about a disease they do not believe they have.

Lack of knowledge and awareness of cancer prevention and screening recommendations

The African American underserved are not as likely to be informed about the current guidelines recommended for cancer prevention and screening. Cancer prevention material that is available through the mass media may be ineffective due to literacy levels or the lack of role models and referents that relate to their culture. Television can be a source of information, but does not necessarily provide adequately extensive information.

Underwood⁵ found that the American Cancer Society recommendations for early detection in asymptomatic people were not well known by a study sample of African Americans. Although 75% of the men studied knew that annual physical examinations were recommended for cancer detection in men over 40, only 25% of the men identified colorectal exams as part of this annual physical. Seventy-five percent of the sample also believed that the number of cancer deaths would not be significantly decreased even if people were routinely screened.

Traditional cancer prevention approaches inappropriate and/or culturally insensitive

Many cancer prevention strategies are aimed at the majority class, i.e. white, educated, middle-class individuals who are presumed to be motivated by particular messages. These same messages may not carry the same influence for African American underserved populations who may not find them compelling enough to alter behavior.⁶ Most cancer education and outreach ef-

forts are insensitive and irrelevant to many poor people.⁷ They are less likely than middle-class populations to respond to usual health promotion messages delivered in the traditional format such as written self-help materials.⁸ Williams et al,² state that there "is a fundamental lack of understanding about the types of health education programs, health promotions, and communication channels that are most effective in marketing preventive health practices to African Americans." This has prompted research on why African Americans apparently ignore health education messages and do not act on health promotion messages in the same manner as whites. Cancer prevention programs need to be culturally appropriate and relevant to the population.⁹ Focus group discussions have demonstrated that some African American women think that health promotion messages should acknowledge the role of spirituality in their lives.²

Mistrust of the health care system

The health care system shares some of the negative perceptions that are associated with many other social institutions in the United States. Morra¹⁰ reports that African Americans have a deeply rooted distrust of our nation's health care systems. Mistrust of the medical community partially results from the history of experimentation and exploitation of ethnic minorities by medical researchers such as in the Tuskegee syphilis study.¹¹

Fear and fatalism concerning cancer treatment

Fear of pain, discomfort, and embarrassment during cancer screening and treatment may inhibit people and prevent them from receiving services.¹² A fear of radiation and concern about getting breast cancer from mammography has also been identified in African American women.¹³ A nihilistic belief that cancer cannot be avoided and/or treated can undermine an active approach to preventing cancer. Also a lack of belief about their susceptibility to cancer contributes to underutilization of early detection programs by African Americans.¹⁴ Prevailing attitudes of pessimism and general fearfulness about cancer coupled with skepticism about treatment and hesitancy to seek medical care contribute to a later diagnosis, more advanced disease, and a poorer prognosis in the African American population.⁵ Underserved African Americans are also more likely to believe cancer myths and be less knowledgeable about the relationship between high-risk behaviors and the development of cancer. Consequently African Americans often delay seeking medical care for 3 to 12 months after experiencing a symptom.¹⁰ Powe¹ states

that cancer fatalism is the result of cultural, historical, and socioeconomic factors that have influenced the lives of many African Americans. The experience of poverty affects factors such as poor nutrition, risk-taking behaviors, and the pursuit of health-promoting activities. Diagnosis at more advanced stages leads to poorer prognosis and excess mortality.

CHARACTERISTICS OF EFFECTIVE PROGRAMS

Effective programs address these obstacles when devising intervention strategies for African American underserved populations.

Community participation in the development, implementation, and evaluation of programs

In order to reach underserved communities and encourage participation and involvement in cancer prevention activities, many programs have effectively used the strategy of community involvement in the development and implementation of the programs.¹⁵ The Center for Healthy Communities in the Department of Family and Community Medicine at the Medical College of Wisconsin has used a participatory approach to cancer prevention in community-academic partnerships with public housing and a local church in Milwaukee. This approach entails community people assessing their own health care needs and developing and implementing strategies to address those needs. The social change model has been the theoretical framework for some of these programs.^{16,17} This model defines indigenous social units in a population, uses surveys and focus groups in the assessment of need, focuses on strengths in the community rather than weaknesses, and emphasizes increased community competence as well as improved health status as outcomes.

Community-directed programs rely on community perceptions about existing barriers and methods to address these barriers and increase cancer prevention and screening.¹⁸ Joint planning and participation of the community in all components of the program permits ownership of the program by the community and facilitates the involvement of community members.¹⁵ Curry et al¹⁸ report on a cancer-screening program that used a locality development model, which included a broad range of people who determined the goals and the activities for effective community change.

Community involvement has taken somewhat different forms in different programs. In an urban public housing development, the support of the community leadership was sought through the tenant councils.^{3,8}

Introducing a smoking-cessation program in this community required the support of the housing development's leadership. These people can function as a critical link between the community and the health care system. Community advisory boards have also been used by programs to ensure broad representation and input from the community.^{2,18}

Innovative outreach strategies and sites

Since the African American underserved population has not been reached by the standard delivery of health care services, many programs have developed alternative methods to reach this group. Strategies such as mass media educational messages delivered through electronic and print channels have been used.¹⁹ Community-developed videos, brochures, and T-shirts have been produced as educational materials.^{14,17} A program to reach the African American community used an African American ancestral storyteller to refine the message delivered by health educators to include key health facts in the tradition of oral storytelling.²⁰ A pictorial representation was developed that depicted the steps of obtaining a mammogram to educate low-income women about the screening process.^{2,21}

Many cancer programs attempting to reach the underserved have tried to locate and/or deliver their programs where people live and go about their daily activities. Several programs have used public housing developments as sites.^{2,8} Programs have also carried out their interventions at beauty parlors, senior centers, and laundromats.¹⁷ Strategies have focused on reaching people at church, public health facilities, business and civic groups, colleges and universities, restaurants, grocery stores, pharmacies, and dry cleaners.^{6,19}

Social network/social influence interventions

Social network strategies have been effective in cancer prevention programs.^{2,15} These strategies emphasize the concept that human behavior is strongly affected by an individual's social networks, the availability of social support for particular behaviors, and the prevailing norms of the person's social group. In this type of intervention, respected community people are identified and trained to promote healthy behavior. These community people, who have sometimes been referred to as "natural helpers" are trusted, influential members of the community who are seen as credible by community members and can communicate cancer prevention messages and motivate healthy behavior.²² This strategy assumes that health information from mediated sources rather than from physicians and other health care professionals is more likely to be received and acted on by community

members. Social network interventions can function to “enhance existing social network linkages, develop new social network linkages, enhance networks through the use of indigenous natural helpers, and enhance networks at the community level through participatory problem-solving processes.”²⁴ The literature reports this strategy was used effectively in many programs and uses different titles for the social network change agent such as lay health advocate, lay health advisor, lay health educator, and peer health educator.^{8,15,20} These strategies have been successful with African American underserved populations both in urban⁸ and rural¹⁷ settings. Williams et al used public housing tenant organization leaders as natural opinion leaders to deliver messages and communication about screening and prevention activities.² Sadler et al²⁰ found that local community cosmetologists could be effectively used as peer health educators to promote health and early detection.

Patient navigator programs have been developed to help address the obstacles that low-income African American people face when following up an abnormal clinical finding.⁷ These navigators act as patient advocates and attempt to identify and resolve barriers to care. A role model “witnessing” intervention that uses community women who have discovered a breast lump to motivate other women to take responsibility for their health and practice breast self exam is another social network strategy that has been used.⁶

Using social institutions as entry point to the community

The use of a trusted and respected community social institution has been used by several cancer prevention programs.^{6,24} In a community with high church participation, women were effectively recruited for cervical cancer screening by lay health leaders selected by clergy.²⁵ The church, as a historically trusted institution in the African American community, was used to bridge to a less trusted structure, the health care system. Eng¹⁶ recruited lay health advisors from community-based organizations, such as church, social, and civic groups and then implemented the cancer control and prevention activities through these same organizations.

An understanding of cultural belief systems and literacy levels must inform the development of cancer prevention materials and strategies

Cultural beliefs about cancer and cancer prevention activities differ among different groups, and these beliefs need to be understood in order to develop effective strategies. Effective programs have accounted for cul-

tural differences in perceptions of health risk, effectiveness of different risk reduction strategies, and culturally specific barriers to prevention. Gregg and Curry²⁴ have found that the cancer models understood by an African American female population differ significantly from those understood by clinicians. This can be explained by the differences between physicians and laypeople, social classes, and ethnicities. Many women in a community-based screening project did not believe that cancer can be cured, and were concerned that, if diagnosed, the knowledge that they have cancer might cause mental deterioration and quicken death. They also thought that the treatment choices available if you have cancer would be harmful to their health and very costly. A program in a housing community found that smoking was not perceived as a major health threat, and this belief made it difficult to motivate individuals to quit smoking.⁸ Lack of belief in cancer susceptibility or denial also contributes to underutilization of cancer preventive services.¹⁴

Similarly, Underwood⁵ found that African American men’s perceptions of learned helplessness and lack of feelings of self-efficacy regarding control over their health negatively influenced the use of cancer risk reduction and early detection activities.

Literacy levels of the community affect whether written cancer control materials can be effectively used. Pictorial representations of cancer screening have been used successfully as a method to overcome barriers that low literacy levels present.²

Program sustainability and long-term involvement with community

One of the thorny issues that confronts community cancer control programs is whether they can be institutionalized and sustained in the community. The North Carolina Breast Cancer Screening Program had as an initial goal to facilitate countywide partnerships that could sustain the program.¹⁶ This was done through establishing community agency-based outreach positions and developing a community advisory board. This program focused on building a coalition among the providers, the populations they serve, and the communities in order to foster an enduring program. The Atlanta Project has focused on ensuring that the project’s activities are integrated into the current programs of the neighborhood health center, the local American Cancer Society office, or community-based organizations.¹⁸ The social influence model has demonstrated promise in institutionalizing the promotion of cancer control in community settings.

LIMITATIONS

Many programs have recognized that a one-time exposure to cancer education is not sufficient. Continuing exposure must occur within the community in order to change attitudes and norms.⁶ Maintaining interest in cancer prevention behaviors in the midst of more pressing survival needs also requires additional strategies. Dropout rates in prevention programs can be high in a population where mobility is high and other issues take priority. People who are unaccustomed to seeking assistance and value their privacy and independence may not avail themselves of opportunities to acquire information from community advocates. Programs that use a social network intervention are not as likely to reach community members who are social isolates and fearful of asking for assistance.¹⁶ Concerns about whether information will be kept confidential may also be a deterrent. To be truly effective, intervention programs will need to understand and address motivational issues that may differ from those prevalent in the dominant culture.⁸

CONCLUSION

When practitioners develop cancer prevention programs for the African American underserved, they must keep in mind these significant barriers: inadequate access, lack of knowledge, culturally inappropriate materials, low literacy levels, mistrust of the health care system, and fatalism regarding cancer cure. The intervention programs that can incorporate the critical elements identified in this review in their strategies are more likely to be effective in reaching and influencing the underserved.

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