

Disparities in Cancer Diagnosis, Treatment, and Survival Between African-American and Other Population Groups

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Abstract

There are currently more than 800,000 African-American cancer survivors in the US. While cancer affects all segments of the population, there are wide disparities in cancer survival rates and quality of life according to race, ethnicity, and geography. According to the American Cancer Society Cancer Facts and Figures for African-Americans, 2008, African-Americans have the highest death rate and the shortest survival of any racial and ethnic group in the US for most cancers. Social barriers to high-quality cancer prevention, early detection, and treatment services and the impact of discrimination have a direct impact on these high death rates. African-Americans consistently see disparities across the cancer control continuum. This article provides an in-depth analysis of the disparities in the African-American cancer community, as well as strategies that are recommended to address these inequities.

Keywords

Cancer, survivorship, cancer survivor, national action plan, African-Americans, disparities, Lance Armstrong Foundation, minorities, minority populations, social barriers, cancer prevention, discrimination, inequities, survival rates, quality of life

Disclosure: The authors have no conflicts of interest to declare.

Received: July 3, 2008 **Accepted:** May 6, 2009 *DOI: 10.17925/OHR.2009.05.1.93*

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Health disparities are defined as the “differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the United States. These population groups may be characterized by gender, age, ethnicity, education, income, social class, disability, geographic location, or sexual orientation.”¹ There are currently more than 800,000 African-American cancer survivors in the US.² While cancer affects all segments of the population, there are wide disparities in cancer survival rates and quality of life issues according to race, ethnicity, and geography. According to the American Cancer Society Cancer Facts and Figures for African-Americans, 2008, African-Americans have the highest death rate and the shortest survival of any racial and ethnic group in the US for most cancers. “Social barriers to high-quality cancer prevention, early detection, and treatment services and the impact of discrimination”² have a direct impact on these high death rates. African-Americans consistently see disparities across the cancer control continuum, including:

- disparities in prevention, screening, and early detection;
- disparities in treatment services; and
- disparities in survival.

Disparities in Prevention, Screening, and Early Detection

Among the African-American population, a number of factors affect prevention behaviors, access to screening, and understanding of early

detection options. Socioeconomic issues are the primary factors that influence the entire spectrum of cancer, from prevention and early detection to treatment, quality of life, and survival. Compared with 10% of Caucasians, 24% of African-Americans live below the poverty line.² In addition, 20% of African-Americans are uninsured compared with only 11% of Caucasians.² Socioeconomic factors can also affect cancer prevention and early detection, including behaviors such as avoidance of tobacco, participation in physical exercise, and maintenance of a healthy bodyweight, as well as regular access to high-quality screening tests with timely and appropriate follow-up. For certain cancer types, African-Americans experience higher incidence rates than Caucasians. African-Americans are also more likely to be diagnosed at a later stage of cancer than Caucasians, possibly due to factors such as less awareness about cancer symptoms and reduced access to cancer screening services. Cancers among African-Americans are more frequently diagnosed after the cancer has metastasized and spread to regional or distant sites.³ Other factors linked to the healthcare-related behaviors and adjustment of African-American cancer patients include limited knowledge and misinformation about cancer, mistrust of the medical community, concerns about privacy, lack of insurance, religious beliefs, and fear and stigma associated with seeking emotional support.⁴

Disparities in Treatment Services

African-Americans can also experience disparities in treatment services. As previously stated, African-Americans are more likely to

be uninsured and living in poverty. Poor and uninsured people are more likely to be treated for cancer at late stages of the disease and are more likely to receive substandard clinical care and services.² For virtually all cancer types, African-Americans continue to have less access to appropriate and timely treatment.² Cancer health disparities are also found in relation to quality-of-life issues. Minorities with cancer often suffer more pain due to undermedication. Nearly 62% of patients at institutions serving predominately African-American patients were not prescribed adequate analgesics.⁵

Disparities in Survival

The disparities in diagnosis have a direct impact on disparities in survival. Detection at later stages may result in lower cure rates and shorter survival times.² Healthy People 2010 reports that African-Americans are about 34% more likely to die of cancer than Caucasians and more than twice as likely to die of cancer than Asian Pacific Islanders, American Indians, and Hispanics.⁶

Although the racial disparity has decreased over the last 10 years, in 2003 the death rate for all cancers combined continued to be 35% higher in African-American men and 18% higher in African-American women compared with Caucasian men and women.² Five-year relative survival rates are the indicators that assess the likelihood of surviving five years from the time of diagnosis, taking into account deaths from other causes, and are commonly used to monitor progress in the early detection and treatment of cancer. The overall five-year relative survival rate among African-Americans has improved from approximately 27% in 1960–1963 to 57% in 1996–2002. However, in general African-Americans are less likely than Caucasians to survive five years after diagnosis for all cancer sites and at all stages of diagnosis.²

In addition, while African-American women have been found to have lower incidences of breast cancer than Caucasian women, they die from the disease at a higher rate. Although access to healthcare is a strong factor contributing to disparities in cancer rates and outcomes between African-American and Caucasian women, studies show that biological differences play important roles. Since the 1970s, overall breast cancer mortality rates have been higher among African-American women than among Caucasian women. Researchers suggest that racial disparity is not fully explainable based on socioeconomic factors. Suspected biological factors underlying this trend may be interpreted by both epidemiological and clinical perspectives.⁷

A National Action Plan for Cancer Survivorship—Advancing Public Health Strategies

The Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (LAF) joined forces to lead a public health effort to address the issues faced by the growing number of cancer survivors living with, through, and beyond cancer. Through their collaboration, a National Action Plan (NAP) for Cancer Survivorship—Advancing Public Health Strategies was developed.⁸ This article provides a review of this report, as well as of the addendum specifically related to the African-American population. The NAP represents the combined effort of almost 100 experts in cancer survivorship and public health. The NAP identifies and prioritizes

cancer survivorship needs and proposes strategies for addressing those needs within four core public health components:

- surveillance and applied research;
- education, training, and communication;
- programs, policies, and infrastructure; and
- access to quality care.

The NAP takes a public health approach, focusing on the impact of the disease on the entire population and emphasizing collaborative, community-based activities. A public health approach includes influencing the healthcare system, providers, and policy-makers who support and can make a difference in reducing the burden of cancer on survivors. In addition to the NAP, an addendum was developed that addresses the priorities of the African-American community.

Development of A National Action Plan for Cancer Survivorship—African-American Priorities

The methodology and development of A National Action Plan for Cancer Survivorship—African-American Priorities⁹ reviewed the top concerns in the African-American community related to cancer survivorship, and established a framework for actively addressing the survivorship needs of this growing population. The ultimate goal of establishing these priorities in the African-American community is improved quality of life and survival rates for survivors.

Using A National Action Plan for Cancer Survivorship, a number of African-American stakeholders in cancer survivorship participated in prioritizing the identified needs and topics specific to the African-American community. Through an Internet-based survey process, 75 respondents ranked each need in five topic areas of cancer survivorship. Respondents also provided comments on the process and cancer survivorship in general.

Access to services was identified as the top issue, but many respondents admitted that it was difficult to prioritize when there is so much that needs to be done. Culturally competent patient and provider education was a priority for many respondents, and patient navigation was the top cross-cutting issue across all areas of need. The following information summarizes the ranked priorities as identified by African-Americans regarding cancer survivorship issues. A workgroup of leaders in the field of cancer control among African-American populations guided the process and aided in analyzing and interpreting the results.

African-American Cancer Survivorship Priorities Ranking, Detailed Information, and Top Needs

These are listed in order of importance:

- access to quality care and services;
- education, training, and communication;
- infrastructure, programs, and policies; and
- applied research and surveillance.

Access to Quality Care and Services

Access to quality care and services means ensuring that survivors are able to obtain high-quality treatment and services in a timely,

competent manner. This approach must also promote good, culturally appropriate communication and shared decision-making between the cancer survivor and healthcare providers. Cancer treatment is complex and differs for each individual based on his or her specific situation and needs. All cancer patients should have timely access to the latest and most effective treatments available, including clinical trials. Quality care and services includes pain and symptom management as well as end-of-life care. The goal of pain and symptom management is to provide relief so that survivors can tolerate the diagnostic and therapeutic procedures needed to treat their cancer and live comfortably through each stage of cancer survivorship. Appropriate end-of-life care affirms life and regards dying as a natural process, neither hastening nor postponing death, in order to achieve the best possible quality of life for cancer survivors.

The prioritized needs related to access to quality care and services are:

- develop and promote a patient navigation system for cancer survivors;
- develop and disseminate guidelines that promote quality and timely service provision to cancer survivors;
- educate decision-makers about economic healthcare barriers related to cancer survivors;
- establish integrated multidisciplinary teams of healthcare providers that support cancer survivors; and
- assess and enhance palliative services for cancer survivors.

Education, Training, and Communication

Education, training, and communication include efforts to communicate with the general public as well as with policy- and decision-makers, to educate survivors and their families, and to train healthcare providers to meet the information needs of all those affected by cancer survivorship. Survivor education should be tailored to each particular stage of survivorship. Educational interventions may be most appropriate during the first five years after diagnosis, as this is the time when many of the challenges associated with the adjustment to survivorship occur. Also included is healthcare provider training, which aims to ensure that providers are aware of the medical and psychosocial needs of cancer survivors. Training should cover all services necessary to enhance quality of life throughout survivorship. Public communication about the issues surrounding cancer survivorship that aims to create a societal understanding and acceptance of the growing populations of cancer survivors and the issues they face is also necessary.

The prioritized needs related to education, training, and communication are:

- develop and promote patient navigation systems for cancer survivors;
- educate healthcare providers about cancer survivorship issues;
- educate decision-makers on the value of follow-up care and clinical trials;
- teach survivors to access and evaluate cancer survivorship information;
- train survivors in advocacy skills; and
- educate the public about cancer survivorship.

Infrastructure, Programs, and Policies

Infrastructure, programs, and policies are the means by which change can be made in public health. Infrastructure refers to basic resources and facilities to address survivorship, such as healthcare and public health systems in state and local health departments. Effective infrastructure and good relationships with public and private sectors are required to operate and manage effective programs. Programs are specific activities that aim to improve the quality of life of cancer survivors. These programs may address medical, psychosocial, legal, and financial issues related to cancer survivorship. Policies include legislation, regulations, ordinances, guidelines, and norms that establish an environment conducive to program implementation and other changes specific to survivorship. Policies may be implemented at the national, state, organizational, and community levels in an effort to advance public health.

The prioritized needs related to infrastructure, programs, and policies are:

- develop and promote patient navigation programs that facilitate optimum care;
- identify and implement programs proved to be effective;
- develop and disseminate education programs that empower survivors to make informed decisions;
- implement evidence-based cancer plans that include all stages of cancer survivorship;
- promote policy changes that support addressing cancer as a chronic disease;
- establish clinical practice guidelines for each stage of cancer survivorship; and
- develop infrastructure to obtain quality data on all cancer management activities.

Applied Research and Surveillance

Applied research and surveillance are the scientific tools of public health. They can be used to establish a solid, systematic knowledge base in cancer survivorship. Applied research includes cancer survivorship research that focuses on applying our knowledge of cancer and issues survivors face to the development of solutions and appropriate interventions. Applied research investigates health systems, public policy, and effects on individuals to address survivor needs. Surveillance is the collection, analysis, and use of cancer data. Surveillance data are critical for directing effective cancer prevention and control programs. Data come from cancer registries that collect information on each cancer patient. National surveys collect data on health attitudes, beliefs, and behaviors that are used to help understand issues related to all stages of cancer survivorship.

The prioritized needs related to applied research and surveillance are:

- identify factors associated with health concerns of cancer survivors;
- identify programs/services that best meet cancer survivorship needs;
- research preventive interventions to evaluate their impact on survivorship;
- translate applied research into practice; and
- enhance existing surveillance and applied research infrastructure.

Cross-cutting Issues

A set of five core issues ‘cut across,’ or affect, all of the main topic areas. Based on the feedback and input from stakeholders in the African-American community, these were prioritized as follows:

Develop and Promote Patient Navigation Systems for Cancer Survivors

Patient navigation can be used to ensure that survivors understand their care and to enhance the delivery of optimum care. Navigators can ensure timely delivery of care, connect survivors with appropriate resources, provide educational information on cancer survivorship, and provide general oversight to the delivery and payment of services for each survivor.

Develop and Disseminate Public Education Programs on Informed Decision-making for Cancer Survivors

Cancer survivors are faced with extremely difficult medical decisions at each stage of living with, through, and beyond cancer. Survivors need to thoroughly understand their options for care. When patients are well-informed and participate in deciding how to manage their health, the results are more positive and survivors are more likely to follow the recommendations made by their health providers.

Develop and Disseminate Clinical Practice Guidelines for Each Stage of Cancer Survivorship

Clinical practice guidelines summarize research on outcomes pertaining to one specific disease. Physicians select guideline recommendations according to the individual’s healthcare needs. Guidelines have been developed for the treatment of particular cancers, but there are not enough for cancer survivors at each stage of cancer survivorship (e.g. monitoring survivors after treatment is completed, monitoring long-term healthcare, and end-of-life care).

Develop a Comprehensive Database on Cancer Survivorship

Increasing the capacity of surveillance systems to capture information on health topics can lead to a better understanding of diseases and the people affected by them. A comprehensive database system could provide information on the ongoing health of survivors and other issues that they face.

Develop Comprehensive Evaluation Systems that Monitor Cancer Survivorship Issues and Services

The goal of evaluation is to increase program efficiency and its impact over time. Effective evaluation requires high-quality indicators that are comprehensively monitored during all steps of program implementation.

Conclusion

African-Americans are now more likely to develop and die from cancer than any other racial or ethnic group. By using reports such as A National Action Plan for Cancer survivorship—African American Priorities or Making Cancer Health Disparities History Progress Review Group¹⁰ as guides, the public health community can better respond to this disparity and effectively address the needs of African-American cancer survivors. The NAP has identified the areas of access to care, cultural competency training, and patient navigation programs as priorities for improving the survivorship infrastructure. Organizations and individuals representing healthcare personnel and the public may use this report to focus their current and future cancer survivorship activities. Local organizations may find the NAP and other reports on cancer disparities useful as a starting point or as a source for strategic planning goals for local activities. These recommendations could act as a basis for the design of local programs, especially at the early stages of planning when there is a need to prioritize objectives for cancer survivorship. Foundations, grant-makers, and other funding organizations can use this information as a guide and a credible reference source for both establishing a need for funding and setting funding priorities for the African-American cancer community.

By focusing programmatic and advocacy activities on the identified priorities, organizations and individuals can work collaboratively toward addressing the needs that will ultimately lead to improved quality of life for African-American cancer survivors, their families, friends, and care-givers. ■



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