Expert Q&A: Cancer-Related Health Disparities [1]

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The oncology community continues to study the differences in the occurrence (also called incidence), frequency (also called prevalence), and survival (also called mortality) rates of cancer among different populations in the United States. These populations may include members of minority groups, older adults of any race or background, and those who are poor or geographically isolated. Cancer.Net talked with Karen Winkfield, MD, PhD, Assistant Professor, Harvard Medical School, and the Chair of ASCO's Health Disparities Committee to learn more about health disparities in cancer.

Q: What are health disparities and the contributing factors?

A: While the term "health disparities" can apply to many different populations (including groups that differ based on age, gender, socioeconomic status and sexual orientation), it is more commonly used to express differences seen among racial and ethnic minorities in the United States. For example, black men and women bear the greatest burden of disease across almost

all health conditions in the United States—heart disease, cancer, HIV/AIDS, infant mortality, asthma—to name just a few. The causes of health disparities are multifactorial and closely associated with social and economic disadvantages. However, for many illnesses racial health disparities are seen even after adjustments are made for socioeconomic status. When specific populations are so negatively affected by disease, this becomes more than just a health concern – it enters the realm of social injustice.

The World Health Organization (WHO) defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." Many factors cited as contributors to health disparities (such as poverty, lack of insurance, low literacy, and mistrust of doctors) are historically linked to discrimination and the systematic exclusion of marginalized people from the ability to achieve social and economic well-being. As such, black populations in the United States have been ascribed a state of "unhealth" for centuries. In order to begin closing racial and ethnic gaps seen in disease prevalence and outcomes, we must focus on ways to improve health equity with greater effort applied to addressing injustices that affect the health of vulnerable populations.

Q: How do health disparities affect people with cancer?

A: The same factors that contribute to health disparities in general are associated with worse outcomes for people with cancer. Poverty, lack of trust, low literacy, and inadequate health insurance are all barriers that may negatively affect the ability to seek proactive cancer screening or timely disease treatment. They may limit access to cancer specialists or state-of-the-art treatments such as clinical trials.

Cancer disparities are vividly demonstrated in black American communities. While incredible progress has been made to reduce cancer mortality for all populations, blacks continue to suffer the greatest incidence and poorest outcomes for each of the most common types of cancer. Black men are diagnosed with prostate cancer at almost twice the rate of any other racial/ethnic group. Death from prostate cancer in black men is more than twice that seen in white men. Furthermore, although historically breast cancer was more frequently diagnosed in white women, it continues to be deadlier in black women. A 2015 report from the American Cancer Society [2] suggests that the breast cancer mortality gap between black and white women has actually widened over the past few years. The same types of racial disparities also exist in other cancer types.

Socioeconomic factors play a major role in cancer outcomes and may influence major choices patients make about treatment. As part of my community outreach, I have interviewed women who elected to undergo mastectomy rather than breast conservation following a breast cancer diagnosis because they could not afford time away from work and the potential loss of pay associated with a prolonged course of daily radiation therapy. A recent article in JAMA Oncology [3] showed that poorer people are less likely to enroll in cancer clinical trials. Since black people have the highest poverty rate in the United States, the lack of access and participation in clinical trials may actually worsen racial disparities. There has been a dramatic increase in the number

of phase I and phase II clinical trials that provide early access to novel therapeutics including targeted therapies that may significantly alter cancer outcomes. This personalized, precision medicine is not being offered at every cancer center, and income or insurance may prevent patients of lower socioeconomic status from obtaining the tests required just to enroll in trials. My fear is that if policies are not put in place to provide equitable access to genetic testing and clinical trials, the divide will only widen.

Q: Can you talk about some of the current research surrounding cancer-related disparities?

A: Most of the high-profile literature related to cancer disparities is simply focused on describing the disparate outcomes. We have known for centuries that health disparities exist. Some researchers have made a career of analyzing large databases that simply show over and over again that race-based differences in outcome persist independent of cancer stage and treatment. More reporting on the problem is not needed. The research community needs to move away from the simplistic reporting of disparities and instead focus on strategies designed to change the landscape of cancer disparities.

The U.S. government has funded several demonstration programs aimed at increasing cancer screening rates among low income and uninsured citizens. Much of the data from this research is published in annual reports available online on the website of the specific agency that funded the research. There has even been a surge in the number of cancer navigation programs designed to improve access to care for vulnerable populations. However, published results showing that these programs work are limited. For more detailed information, a 2011 review [4] does a great job summarizing the available data.

Access to cancer clinical trials has become a very important part of the cancer disparities literature. Earlier, I mentioned the recent *JAMA Oncology* article that discusses poverty as a barrier to cancer clinical trials. Several researchers have begun to focus on understanding the financial burden patients may face related to participation in cancer clinical trials.

However, I continue to be most excited about qualitative research that focuses on identifying social determinants of cancer-related disparities. Research methods such as semi-structured interviews and focus group data bring a wealth of information that otherwise would be difficult to thoughtfully and systematically evaluate. It is my hope that journals and institutions see the value that qualitative research brings to the complex issue of cancer disparities. Understanding perceptions, behaviors, and cultural circumstances that affect the health of communities is a major step towards developing sustainable programs to improve health equity.

Q: What is ASCO doing to reduce disparities in cancer care?

A: As described above, there is so much work to be done to improve health equity and cancer care among vulnerable populations here in the United States. I'm proud to say that ASCO has made addressing cancer disparities a key aspect of its mission and agenda for more than two

decades, since the first Advisory Group on Health Disparities was established in 2003. Today these efforts are overseen by the ASCO Health Disparities Committee, which is charged with developing programmatic and policy solutions to effectively address healthcare disparities across the cancer care continuum.

An important part of ASCO's cancer disparities work has been focused on increasing the diversity of the clinical oncology workforce [5] to improve access to cancer care for the underserved. Since 2008, the ASCO Conquer Cancer Foundation has run the Diversity in Oncology Initiative (DOI) awards program. This program is designed to help recruit and retain people who are underrepresented in medicine to cancer careers.

Two programs have proven to be invaluable experiences:

- The Medical Student Rotation [6] for Underrepresented Populations, which provides clinical or clinical research oncology rotations for medical students from populations underrepresented in medicine.

- The Resident Travel Award [7] for Underrepresented Populations, which provides financial support for residents from underrepresented populations to attend ASCO's Annual Meeting. To date, the program has provided more than $1 million in funding and has become a model for other medical groups around the country.

In addition, the DOI recently established a diversity mentoring program to provide structured mentoring for medical students and residents who are interested in oncology careers.

ASCO has also been working to educate oncology providers and patients on issues related to disparities in cancer care. This work includes ASCO University Learning Modules on Disparities in Cancer Care and Cultural Competence [8].

ASCO is also working to ensure that its growing quality assessment and improvement programs address the needs of underserved and minority populations. Strategies include increasing the participation of practices that serve the medically underserved and have limited resources in ASCO's quality programs. As part of this effort, ASCO has developed a program designed to assist these practices in participating in ASCO's Quality Oncology Practice Initiative (QOPI). The project will help practices by providing them with hands-on quality improvement assistance and mentorship from ASCO and other practices to implement QOPI, thereby measuring and enhancing the quality of care they provide.

Finally, ASCO has been especially active in addressing cancer disparities through policy and advocacy, workforce diversity and quality work. ASCO has developed numerous policy and position statements on issues including Medicaid reform, access to clinical trials, and opportunities and challenges in addressing disparities through implementation of the Affordable

Care Act. These statements provide concrete, solution-focused recommendations to guide ASCO's advocacy work in promoting access to high quality cancer care, the need for workforce diversity and education, and research.

More Information

Health Disparities [9]

Cancer Health Disparities in the United States: Facts and Figures [10]

Additional Resources

National Cancer Institute: Cancer Health Disparities [11]

National Cancer Institute: Center to Reduce Cancer Health Disparities [12]

Links
[1] http://www.cancer.net/research-and-advocacy/health-disparities-and-cancer/expert-qa-cancer-related-health-disparities
[2] http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-046381.pdf
[3] http://oncology.jamanetwork.com/article.aspx?articleid=2457394
[4] http://www.ncbi.nlm.nih.gov/pubmed/21659419
[5] http://www.asco.org/practice-research/asco-diversity-oncology-initiative
[6] http://www.conquercancerfoundation.org/MSR
[7] http://www.conquercancerfoundation.org/RTA
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