Health Care Disparities and Cancer

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Health care disparities occur when a person's individual characteristics or circumstances—such as race, ethnicity, sexuality, gender identity, age or health insurance status—impact their access to health care or the quality of that care. These disparities can lead to cancer being diagnosed at a later stage, when it is harder to treat.

There has been increased attention on health care disparities, and many health-related organizations are focusing on ways to improve access to care and the quality of care. Medical institutions should abide by non-discriminatory policies, which can be posted on their website or within the care setting. Additionally, the healthcare delivery system is strengthened by the increased creativity and talent of a more diverse workforce. Administrators can promote or hire people with diverse viewpoints into positions of responsibility.

Organizations can also promote the concept of "cultural humility." Cultural humility is the ability to remain open to another person's identity. Cultural background, beliefs, values and traditions can impact how people make decisions about their health care. Being culturally humble involves reflection by the organization as a whole (and its health care providers) about their deep-rooted assumptions and being receptive to change.

It also involves recognizing power imbalances. For example, a patient may believe that they must accept health care recommendations without question. Health care providers should encourage patients and their families to discuss and collaborate on decisions regarding their health care.

Cultural humility also values institutional accountability. This means making sure the best options for care are available to everyone. Hospitals, public health administrations, insurance providers and others can take responsibility for differences in care and strive to reach health care equity.

The Power of Self-Advocacy

Self-advocacy means speaking up for yourself and what is right for you. Health care decisions are your choice. You are not required to agree to any procedure or treatment you do not want or do not understand. Be clear and open about your comfort levels and needs. It is your right to ask for the best care available to you.

Your health care team has the same goal as you do: the best possible care and quality of life. Health care professionals focus on the best medical and scientific course of action. However, your beliefs, values and traditions are equally important. You have the right and the power to make your wishes known.

It is important that you ask questions to fully understand your diagnosis and the goals of treatment, as this directly impacts health outcomes. Questions include:

- Will this treatment plan affect my ability to live on my own?
- How could treatment affect my other health issues?
- How will treatment affect my memory?
- Is the goal longer survival, which may mean a more intensive treatment, or is it quality of life?
- Do you have any material that will help me better understand my diagnosis and treatment plan?

You should not wait for your health care team to start these conversations. No medical decision should be made without your full consent and understanding. You can start advocating for yourself at any time during your cancer experience.

Based on your cultural beliefs, you may wish to avoid scheduling treatment or surgeries at certain times of the day or week or during holy times of the year. Your health care team may be able to adjust your treatment based on your needs.

Do not be afraid to seek a second opinion or to seek a healthcare provider who is a better fit for your needs, especially if you feel uncomfortable, fearful or discriminated against. It is important that you fully trust your health care provider, and share all information that is needed to receive proper, holistic care.

Social Determinants of Health

According to the World Health Organization (WHO), social determinants of health are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live and age, and the broader set of forces and systems shaping the conditions of daily life.

Social determinants of health can lead to health care disparities. Examples from the WHO include:

- Income and social protection
- Education
- Unemployment and job insecurity
- Working life conditions
- Food insecurity (see section below)
- Housing, basic amenities and the environment
- Early childhood development
- Social inclusion and non-discrimination
- Structural conflict
- Access to affordable health services of decent quality

Numerous studies suggest that social determinants of health account for between 30 and 55 percent of health outcomes. Addressing these determinants is fundamental for reducing longstanding disparities in health care. Doing so requires action by multiple segments of society.

More About Food Insecurity

Food insecurity is the lack of reliable access to sufficient affordable, nutritious food. For households facing food insecurity, the need for food competes with other needs, such as housing, utilities, medication and transportation. It is a national health problem, with underlying causes that are complex and often inter-connected. Addressing the problem requires collaboration across many sectors: businesses, federal and local government, health care researchers and non-profit organizations.

For those in immediate need, the non-profit organization Feeding America (www.feedingamerica.org) offers a network of food banks, pantries and meal programs that serve virtually every community in the United States. Other local resources can be found through an internet search or directory assistance.

Race and Ethnicity

The outcomes of cancer vary considerably according to race and ethnicity. While significant progress has been made to reduce mortality (deaths) due to cancer for all populations, there are still differences. Here are a few examples in the United States:

- African Americans experience the highest incidence and mortality rates for common cancers such as lung, colorectal and prostate. Additionally, breast cancer mortality rates are disproportionately higher among African American women than white American women.
- Compared to non-Hispanic white people, American Indian and Alaska Native (Native American) people have a much higher incidence of several cancers, including lung, colorectal, liver, stomach and kidney.

- Hispanic men and women have a higher incidence of stomach and liver cancer than white men and women.
- American Samoan men are eight times more likely to develop liver cancer as compared to non-Hispanic white people.

Genetic factors likely contribute to some of these differences. However, other factors account for these variations to a substantial degree, such as limited access to health care, lack of insurance and reluctance to seek care due to past experiences with interpersonal and/or structural racism.

Your health care team is composed of experts in medical care. However, their focus on medical issues may not account for your beliefs, values and traditions. You should feel comfortable sharing any concerns you have. These may include treatment decisions, potential side effects, financial concerns, family responsibilities and end-of-life issues.

LGBTQ+ Populations

The effects of health care disparities on the LGBTQ+ community include:

- **Fear of discrimination.** LGBTQ+ individuals may worry that disclosing their sexual orientation or gender identity will affect the quality of their health care.
- **Negative experiences.** Fear of non-affirming interactions with health care providers can limit openness, safety and trust.
- **Lower rates of health insurance.** Health insurance policies sometimes do not recognize unmarried partners. Legal protections against discrimination at both the state and federal level are inconsistent.
- **Denial of care.** While acceptance of LGBTQ+ identities is rising, homophobia and transphobia remain a reality. Some people may find themselves having to fight for the care they deserve.

Health care providers may hold biases about the LGBTQ+ community, or simply not be aware of differences in their health care needs. This affects the types of screening that are recommended.

For example:

- Lesbians are often screened at a lower rate for reproduction-related cancers, such as cervical and ovarian cancer.
- Doctors may not be aware that the human papilloma virus (HPV) is equally transmitted by anal intercourse as it is by vaginal intercourse. A growing number of health activists believe that routine screening using an anal pap smear, could reduce the incidence of anal cancer in gay or bisexual men.
- A transgender person might retain aspects of their biological sex that require certain forms of care. A trans man may need care from a gynecologist or continued breast exams. A trans woman may require care from a proctologist. However, many health care systems still rely on male-female binaries, reducing the quality of health care for non-binary or gender-nonconforming patients.

The following organizations can provide a range of resources and support to members of the LGBTQ+ community who are facing health care disparities.

- **Gay and Lesbian Medical Association (www.glma.org).** Utilizing the expertise of its diverse multidisciplinary membership to drive advocacy, education and research, the GLMA is a source of educational and informative materials. They also maintain a directory of providers dedicated to the support of the LGBTQ+ community.

- **National LGBT Cancer Network (www.cancer-network.org).** The National LGBT Cancer Network works to improve the lives of LGBTQ+ post-treatment cancer survivors and those at risk through education about the importance of early detection and screening. They also train health care professionals to provide more competent, safe and welcoming care. They have an online database to help locate care providers.
- **National LGBT Cancer Project (www.lgbtcancer.org).** The National LGBT Cancer Project seeks to improve the health of LGBTQ+ post-treatment cancer survivors with peer-to-peer support, patient navigation, education and advocacy through their online support group community, Out With Cancer.
- **Human Rights Campaign (www.hrc.org) and Human Rights Campaign Foundation (www.thehrcfoundation.org).** The Human Rights Campaign envisions a world where every member of the LGBTQ+ family has the freedom to live their truth without fear, and with equality under the law. Information and advice on a range of topics, including health care issues, is available on their website. Comprehensive programs to support individuals, allies and institutions can be accessed by visiting their related organization, the Human Rights Campaign Foundation.

Age

Due in part to stereotypes and prejudice, older patients sometimes receive inadequate health care. For example, surgery may be recommended less often, even if it is the most appropriate treatment option. Also, screening for certain cancers may be provided less frequently. Older patients may also face physical challenges, including those from existing chronic conditions, that limit their mobility (ability to get around). They may also lack reliable transportation options.

The impact of age is often more severe in people from racial minority groups. They often have a lower quality of life, shorter life expectancy and more medical conditions than non-minorities. As such, they may require a higher level of support and attention.

Support from family and friends can make a significant difference. An older person should not hesitate to ask for help, such as:

- Scheduling check-ins
- Being explicit about what help is needed
- Asking for rides to health care appointments
- Reviewing medical concerns and the results of appointments
- Asking for assistance with meals, shopping or other personal care tasks

For more information, see the "Communicating With Your Health Care Team" section.

Lack of Health Insurance

Being diagnosed with cancer without having health insurance is a leading cause of health care disparities. It can also bring challenges that are stressful and emotionally difficult. There are avenues you can pursue to potentially obtain health insurance.

- **Your place of employment.** Talk to a representative from your human resources department about employer-offered health benefits that you may be eligible for.
- **Your spouse or domestic partner's plan.** If your spouse or domestic partner has a job that offers health insurance, find out if you're eligible to be covered.

- **COBRA.** If you have left a job recently and were covered by an employer's health insurance, you may be able to continue your coverage under COBRA (the Consolidated Omnibus Budget Reconciliation Act). This law requires employers to make health insurance coverage available through their plan to former employees for a minimum of 18 months after employment has ended. Beneficiaries are required to pay the premiums plus an additional administrative fee. Visit the U.S. Department of Labor website (www.dol.gov) to learn if you are eligible.
- **Your school.** If you are currently a full-time or part-time student, check with your college or university to see if they offer coverage.
- **Purchase it on your own.** You can contact an insurance broker, or visit www.healthcare.gov to find the Health Insurance Marketplace in your state.
- **Medicare and Medicaid.** Medicare is a government-provided health care plan for people 65 and older and those who have been receiving Social Security Disability Insurance benefits for a minimum period of two years. Medicaid provides health care services for people whose income falls under a certain level. Contact the Centers for Medicare and Medicaid Services (CMS) at 877-267-2323 or visit www.cms.hhs.gov to find out whether you are eligible for either of these programs.
- **Social Security.** Social Security Disability Insurance or Supplemental Security Income may be able to help with the cost of health insurance. For eligibility requirements, call 800-772-1213 or visit www.socialsecurity.gov/disability/.

Managing Expenses

Whether or not you have health insurance, here are a few things you can do to help manage your expenses.

- **Double check all bills and EOBs (explanation of benefits).** You'd be surprised how often billing mistakes are made. If you don't receive an itemized bill, ask for one. Look for incorrect dates of service (for instance, you shouldn't be billed for the room on the day you were discharged) and fees billed more than once for the same test or procedure.
- **Speak to a financial counselor in the hospital's business office.** The hospital may be able to set up a payment plan for the bills you have received. They may also be willing to consider any insurance payments to be "payment in full." Some hospitals have funds to offset medical services that aren't fully covered by insurance.
- **Negotiate payment plans** for your non-medical monthly bills with your utility company, phone provider and other creditors.
- **Seek help from nonprofit organizations** such as the Patient Advocate Foundation (800-532-5274 or www.patientadvocate.org). You can also contact Cancer*Care* to speak with a licensed oncology social worker who can help you explore your options and find appropriate resources.
- **Utilize available programs.** For many people, expensive cancer medicines pose a financial challenge. Fortunately, there are many programs to help individuals get medications for free or at a low cost, some of which are made available by the pharmaceutical company that manufactures the drug. For more information, contact the Medicine Assistance Tool, listed in the Additional Resources section of this booklet.

Communicating With Your Health Care Team

To help avoid encountering health care disparities as you seek appropriate treatment, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and the members of your health care team, including doctors, nurses, nurse practitioners, physician assistants, dietitians, social workers and patient navigators.

Here are some tips for improving communication with your health care team:

Start a health care journal. Having a health care journal or notebook (either on paper or in a digital format) will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Keep a diary of your daily experiences with cancer and treatment. You can separate your journal or notebook into different sections to help keep it organized.

Prepare a list of questions. Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, you should ask your most important questions first, and be as specific as possible.

If possible, bring someone with you to your appointments or have them be present during telemedicine sessions. Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support during your appointments. The other person can serve as a second set of ears. They may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

Write down your doctor's answers. Taking notes will help you remember your doctor's responses, advice and instructions. If you cannot write down the answers, ask the person who accompanies you to do that for you. If you have a mobile device, like a tablet or smartphone, ask if you can use it to take notes. Writing notes will help you review the information later.

Record your visit if your doctor allows it. Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.

Incorporate other health care professionals into your team. Your medical oncologist is an essential member of your health care team, but there are other health care professionals who can help you manage your diagnosis and treatment:

- Your primary care physician should be kept updated about your cancer treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking. Have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncologist knows of any other medical conditions you have, or any pain you are experiencing, so that they can consult with your primary care physician or your specialist if needed.
- Ask your oncologist to send a summary of your visits to your primary care physician and all doctors involved in your care.

Cancer*Care*'s Free Support Services and Programs

It can be very difficult to receive a diagnosis of cancer, especially if you are encountering disparities as you seek health care.

Cancer*Care*® can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how Cancer*Care* helps, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

You will likely also build your own personal support network composed of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store, or ask a friend who's a good listener to come over for a chat.

Remember, there is no such thing as over-communication.

Frequently Asked Questions

Q: What can I do if I feel I have been discriminated against?

A: Section 1557 of the Affordable Care Act (ACA) prohibits discrimination on the basis of race, color, national origin, sex (including sexual orientation and gender identity), age or disability in covered health programs or activities. Health insurers, hospitals, clinics and any other entities that receive federal funds are covered by this rule.

If you believe you have been discriminated against in a way that violates Section 1557, you may want to contact a patient advocate (if one exists) at your treatment facility. If none exists or you don't receive a satisfactory resolution, you can file a complaint with the Office for Civil Rights (OCR) through their online portal at https://ocrportal.hhs.gov/ocr/smartscreen/main.jsf.

Q: I have heard the term "digital divide." What does that mean?

A: The digital divide is the gap between those who have access to technologies (and the skills to use that technology) and those who don't. Examples of digital technologies include telemedicine, patient portals, mobile health applications and online appointment schedulers. For the most part, digital technologies require reliable internet access. Because digital technologies can have a positive impact on health outcomes, this divide can lead to health care disparities. The Federal Communications Commission (FCC) has launched an initiative to narrow this gap. The FCC views telemedicine care services—especially for underserved and marginalized communities—as a top priority.

Q: Can you tell me more about telemedicine?

A: Telemedicine, also called telehealth, refers to the remote delivery of health care services. Through video-conferencing technology, you can communicate with your doctors and other members of your health care team from the comfort of your home. The communication can also be via a traditional "voice only" phone call, which helps reduce the effect of the digital divide.

Telemedicine helps equalize health care disparities by providing convenient and accessible medical services to individuals who face barriers such as geographical distance, limited mobility, or lack of local healthcare facilities.

Through telemedicine, your oncologist and other members of your health care team can provide:

- A pre-visit review of your symptoms, personal health and family history
- A review of your treatment plan and expectations
- Guidance for in-person or hospital visits
- Information on relevant clinical trials
- Adherence guidance
- Symptom management (including pain)
- Education on lifestyle modification to improve your quality of life

A telemedicine visit may allow your doctor to prescribe oral medications when an in-person office or hospital visit is not possible or is undesirable from a risk perspective (e.g., exposure to COVID-19 or other viruses).

Contact your health care team about whether telemedicine appointments are available and if they are the right choice for you. Your insurance carrier can advise you about your coverage for telemedicine appointments.

Q: Can you explain clinical trials and why they are important?

A: Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer, including those who face the challenges of health care disparities, to take part in clinical trials.

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things that you should know:

- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.

Additional Resources

CancerCare®
800-813-HOPE (800-813-4673)
www.cancercare.org

American Cancer Society
800-227-2345
www.cancer.org

Cancer.Net
Patient information from the American Society of Clinical Oncology
888-651-3038
www.cancer.net

Cancer Support Community
888-793-9355
www.cancersupportcommunity.org

National Cancer Institute
800-422-6237
www.cancer.gov

National Coalition for Cancer Survivorship
877-622-7937
www.canceradvocacy.org

SAGE Advocacy and Services for LGBT Elders
877-360-5428
www.sageusa.org

Medicine Assistance Tool
888-477-2669
www.medicineassistancetool.org

CLINICAL TRIALS WEBSITES

ClinicalTrials.gov
www.clinicaltrials.gov

EmergingMed
www.emergingmed.com

National Cancer Institute
www.cancer.gov

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