

Facts & Resources: Cancer Health Disparities

Overview

Health disparities result when specific groups or populations receive lower quality of health care compared to others. In the United States the sources for health disparities include income, social class, health insurance status, ethnicity, education, access to quality health care, geography, lifestyle factors, and cultural factors.

The National Cancer Institute (NCI) concludes that individuals from underserved populations are more likely than the overall U.S. population to:

- Be diagnosed with and die from preventable cancers
- Be diagnosed with late-stage disease for cancers that are detectable at an early stage through screening
- Receive either no treatment or treatment that does not meet currently accepted standards of care
- Die of cancers that are generally curable
- Suffer from terminal cancers without adequate pain control and other palliative care

Despite everyone's desire to bring the best possible cancer treatment to all children and youth, there are still factors that create differences in cancer diagnosis, access to treatment, social services and support. All of these factors can influence the short- and long-term impact of cancer and lead to disparities.

For example, several studies have shown that Black, Hispanic, and American Indian/Alaskan Native children have less chance of surviving acute lymphoblastic leukemia compared to white or Asian-American children. Children in all racial and ethnic minority groups are under-represented in cancer clinical trials. Some research suggests that parents' level of education and socioeconomic status influences their understanding of clinical trials, and their understanding of informed consent to allow their child to receive experimental treatments. Yet studies have shown that children's survival rates can be raised by 20 to 40 percent if their cancer care is coordinated by pediatric oncologists and delivered at comprehensive, multidisciplinary cancer centers that follow established clinical trial guidelines.

Who is underserved?

The NCI's Center for the Reduction of Cancer Health Disparities considers the "underserved" to be populations who lack adequate community, clinical, or individual resources to meet their needs, putting them at risk of poor health. Typically, people think of the poor, uninsured, and minorities as underserved. However, many groups have been identified who don't receive the best care options available today, including:

- Rural families and others who live great distances from health care facilities, especially those far from centers that specialize in pediatric cancer

- Families headed by single parents and other “nontraditional” families
- Families who are uninsured (sometimes even while working) or under-insured
- Young adults who no longer receive their parents’ medical benefits, but do not yet have their own or who are under-insured

What barriers do families face?

The President’s Cancer Panel and the NCI, as well as other organizations such as the Intercultural Cancer Council (ICC), have identified several barriers that prevent young patients and their families from getting the best care available:

1. **System barriers** often emphasize acute care over health promotion and illness prevention. The complexity of navigating health care services can be overwhelming for many families.
2. **Financial barriers** often hurt the working poor who have no insurance, or who are underinsured and overwhelmed by out-of-pocket expenses (such as routine transportation to treatment; high nutrition foods; non-covered medicines and related care items). According to the U. S. Census, an estimated 46 million Americans have no health insurance. In 2004, 33% of Hispanics, 20% of blacks, 17% of Asian Americans, and 11% of whites had no health insurance. For these families, cancer can lead to bankruptcy and loss of dignity.
3. **Physical barriers** are frequently faced by families who live in distant, rural, or frontier areas with no transportation system and a lack of pediatric cancer specialists.
4. **Information and education barriers** impact families whose language and/or cultural traditions may cause them to avoid screening, delay or avoid treatment, or have difficulty understanding and assessing treatment options or following complex treatment regimens. Lack of information can also affect healthcare providers, when they are unaware of newer, proven therapies or are unable to make timely referrals to specialists.
5. **Barriers related to cultural differences and biases** may prevent patients from receiving information or optimal care. Bias can occur on the part of the patient or the healthcare provider.
6. **After treatment is over, disparities continue.** The cancer experience does not end when treatment is over. Long-term survival and ability to thrive can be influenced by many factors, including those listed as barriers above.

Resources and References on Cancer Health Disparities

**Indicates organizations serving as national partners or advisors to the ITVS Community Engagement Campaign for A LION IN THE HOUSE*

This section provides key resources to assist patients, their families and caregivers in overcoming some of the barriers to care. For more information about the full range of services offered by each of the organizations listed, please visit their websites at the links provided.

A Lion in the House

a film by Steven Bognar and Julia Reichert

COMMUNITY ENGAGEMENT CAMPAIGN

***Intercultural Cancer Council, <http://www.iccnetwork.org>**

- Children/Adolescents & Cancer <http://iccnetwork.org/cancerfacts/cfs9.htm>
- Cancer Fact Sheets: medically underserved populations <http://iccnetwork.org/cancerfacts>

***National Cancer Institute, <http://www.cancer.gov>**

Cancer Health Disparities Fact Sheet/Nov, 2005

<http://www.cancer.gov/newscenter/healthdisparities>

Toll-Free Hotline Numbers

Support from specialists to direct services, including: financial and legal assistance, counseling, translation, transportation and care connections.

***American Cancer Society, 1-800-ACS-2345 / <http://www.cancer.org>**

Cancer Information Specialists and Translation Services:

- 24 hours a day/7 days a week/365 days a year
- Patient Navigators trained to link those dealing with cancer to needed programs and resources in their own community

CancerCare, 1-800-813-HOPE / <http://www.cancercare.org>

- *CancerCare Connect:* Telephone Education Workshops
- *CancerCare Counseling:* Talk to a Social Worker or email info@cancercare.org
- *CancerCare Inform:* Individualized plan to help manage day to day concerns
- *CancerCare Assist:* Financial assistance

***Lance Armstrong Foundation, 1-866-235-7205 / <http://www.livestrong.org/survivorcare>**

Call LIVESTRONG™ SurvivorCare, speak to professional oncology social workers:

- Individual counseling
- Assistance with legal, financial and/or insurance issues
- Matching to clinical trials

***The Leukemia & Lymphoma Society, 1-800-955-4572 / <http://www.lls.org>**

The LLS Information Resource Center (IRC) is a call center staffed by master's level social workers, nurses and health educators for information, support and resources to patients and their families. IRC information specialists are available Monday through Friday, 9 a.m. to 6 p.m. ET.

***National Cancer Institute, 1-800-4-CANCER (422-6237) / <http://www.cancer.gov>**

- Call the NCI Cancer Information Service (CIS) to speak with Information Specialists who are available to answer calls in English or Spanish.
- **LiveHelp** is NCI's live online assistance, <https://cissecure.nci.nih.gov/livehelp/welcome.asp>.
- The CIS Partnership Program works with nonprofit, private and other government organizations to deliver messages and materials about cancer to people who may have difficulty obtaining health information because of educational, financial, cultural or language barriers.

National Childhood Cancer Society, 1-800-5-FAMILY /

<http://www.nationalchildrenscancersociety.com/>

The National Children's Cancer Society:

- provides direct financial assistance for medical and non-medical expenses related to treatment for children with cancer
- locates cancer resources for families and negotiates solutions for a child's care with insurance companies, hospitals and other agencies
- Care to Share Cancer Connection is an online network for parents and other caregivers of children with cancer
- educational materials are designed to provide children and parents with information about cancer, healthy lifestyle habits, and survivorship

***NHPCO Caring Connections HelpLine, 1-800-658-8898 / <http://www.caringinfo.org/>**

Caring Connections is a program of the National Hospice and Palliative Care Organization (NHPCO), a national consumer engagement initiative to improve care at the end of life. The toll-free helpline is available to people looking for end-of-life information, including free brochures and advance directives or contact information for a hospice or other end-of-life organization.

Patient Advocate Foundation, 1-800-532-5274 / <http://www.patientadvocate.org>

Patient Advocate Foundation is a national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.

- Active liaison to resolve insurance, job retention and/or debt crisis matters relative to a patient's diagnosis
- Co-Pay Relief Program, <http://www.co-pays.org>
- African American Outreach

National Resource Directories

Children's Cancer Association/Kids Cancer Pages,

<http://www.childrenscancerassociation.org/>

See Resources and Programs. CCA's *Kids Cancer Pages* offers the first-ever national resource directory on childhood cancer. Recognized by the National Cancer Institute as "the most comprehensive guide for families currently available," this comprehensive directory is packed with information on all aspects of pediatric cancer. For families battling pediatric cancer – and the medical professionals who care for them—our *Kids' Cancer Pages* directory is a vital support tool.

*CureSearch, <http://www.curesearch.org/resources/>

CureSearch unites the world's largest childhood cancer research organization, the Children's Oncology Group, and the National Childhood Cancer Foundation through our shared mission to cure childhood cancer. The *Resource Directory* includes listings for local, national and international organizations that offer resources for helping community members, parents and kids with childhood cancer. Enter your ZIP code to find local and regional organizations.

Faith Community Connections

Children's Defense Fund, <http://childrensdefense.org/>

"Engaging Faith Communities" is a resource area to connect ministers, seminarians, educators, lay leaders, and other people of faith who work with and for children to programs and advocacy networks, such as:

- The National Observance of Children's Sabbath on the 3rd Weekend in October mobilizes the interfaith community to address serious problems facing children and poor families.
- The Annual Samuel Dewitt Proctor Institute for Child Advocacy Ministry Conference, to address serious problems facing children and poor families.

*Health Ministries Association, <http://www.hmassoc.org>

Health Ministries Association (HMA) is a professional membership organization for: Faith Community Nurses, Program Coordinators, Lay Health Ministers, Clergy, Health Educators and Faculty. The mission of HMA is to encourage, support and develop whole-person ministries leading to the integration of faith and health. HMA Local Chapters are located in 27 states.

National Research and Cancer Centers, Information and Services

National Cancer Institute (NCI) / U.S. National Institutes of Health (NIH),

<http://www.cancer.gov/>

- The Center for the Reduction of Cancer Health Disparities, <http://crchd.nci.nih.gov/>
 - Research to reduce cancer health disparities
- The Comprehensive Cancer Centers, <http://www3.cancer.gov/cancercenters/centerslist.html>
 - Find a cancer center in your state

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COMMUNITY ENGAGEMENT CAMPAIGN

- The Cancer Information Service, <http://cis.nci.nih.gov/index.html>
 - National information and education network

Centers for Disease Control and Prevention (CDC), <http://www.cdc.gov/>

- Office of Minority Health, <http://www.cdc.gov/omh/>
- Cancer Prevention and Control: Health Disparities, <http://www.cdc.gov/cancer/minorityawareness/index.htm>

Department of Health and Human Services

Office of Minority Health, <http://www.omhrc.gov/>

National Center for Minority Health and Health Disparities, <http://ncmhd.nih.gov/>

Articles and Reports

President's Cancer Panel Reports/National Cancer Institute, <http://pcp.cancer.gov>

- 1) Voices of a Broken System: *Real People, Real Problems*/2000-2001 Report
- 2) Facing Cancer in Indian Country: *The Yakama Nation and Pacific Northwest Tribes* 2002 Report

Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (2003).

Institute of Medicine, National Academy of Sciences, <http://www.iom.edu/?id=4475>

Kadan-Lottick, N. S., et al. (2003). **Survival variability by race and ethnicity in childhood acute lymphoblastic leukemia.** *JAMA*, 290(15), 2008-2014.

Cancer survival gap: Progress stalls for young adults, Wednesday, July 06, 2005. By Amy Dockser Marcus, *The Wall Street Journal*.

This facts and resources sheet about Cancer Health Disparities is a resource produced by the ITVS Community Engagement Campaign for A LION IN THE HOUSE, a documentary series coming to public television on PBS/Independent Lens, June 21st & 22nd, 2006. The Campaign offers organizations, individuals and public television station partners opportunities to get involved in events that will: strengthen local care networks, educate the community, and increase local capacity to address the needs of patients and families, especially in overcoming barriers to care for underserved populations. Learn more about what's going on in your community and how to get connected.

For more information: www.itvs.org/outreach/lioninthehouse

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