Reducing the Unequal Burden of Cancer

Frederick P. Li and Lisa M. DiGianni
Dana-Farber Cancer Institute, Boston, Massachusetts 02115

Cancer is second only to heart disease as the leading cause of death among Americans (1). Age-adjusted cancer mortality rates have declined over the last decade, reversing the upward trend of earlier years (2). Notwithstanding, cancer might soon be the leading cause of death in the U.S.2 because mortality rates from heart disease have declined even faster due to control of hypertension, hypercholesterolemia, and other risk factors. Moreover, the burden of cancer is not equally distributed within the U.S. population but differs by race, ethnicity, and other demographic characteristics (2–4). Compared with U.S. whites, African Americans and other medically underserved minorities have higher cancer incidence and mortality rates because of barriers to healthy lifestyles, early detection services, and quality medical care (5).

Recently, the IOM conducted an analysis of the cancer burden among ethnic minorities and medically underserved Americans, as well as the NCI research agenda for these at-risk populations. The IOM Committee, chaired by Dr. M. Alfred Haynes, issued its report in 1999 entitled “The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved” (6). The report contained a series of recommendations, including: (a) more accurate measurements of the cancer burden among minority and underserved populations; (b) quantifying and, if needed, increasing the resources committed to these high-risk groups; and (c) strengthening the Office of Research on Minority Health. Other recommendations were the expansion of behavioral and social science research to encompass diverse racial/ethnic groups, strengthening medical institutions that serve minority populations, and increasing the pool of investigators and providers interested in minority health care and research. Periodic reports would monitor progress and inform government leaders and the public of relevant activities, programs, and outcomes.

In response to the IOM report, the National Cancer Advisory Board established a subcommittee to assess and quantify NCI’s funding commitments to research on racial/ethnic minorities (7). The subcommittee developed criteria and procedures for assessing the extent of minority involvement in NCI-sponsored research programs, including those targeting minority populations. To increase minority participation in clinical trials and other research activities, study sections were instructed to consider representation of minority and underserved groups as part of the merit evaluation and priority score for grant applications. NCI also funded the Special Populations Network to assess and reduce the excess cancer burden among African-, Hispanic-, Asian-, and Native-Americans; Alaskan Natives; and Hawaiians/Pacific Islanders. These initiatives complement and strengthen programs of the American Cancer Society and professional organizations, such as the American Association for Cancer Research and the American Society for Clinical Oncology.

To increase awareness and activities to reduce cancer health disparities described in the IOM Report, Dana-Farber/ Harvard Cancer Center hosted a symposium on October 18, 2001 in Boston entitled “Reducing the Unequal Burden of Cancer.” The goals of the conference were: (a) to highlight the excess cancer burden among ethnic minorities and medically underserved populations, both locally and nationally; (b) to identify challenges and opportunities to reduce cancer risks in these high-risk groups; (c) to promote early detection and improve cancer care for the underserved; (d) to increase the numbers of health care providers and researchers from underserved minority groups; and (e) to enhance minority participation in clinical trials and other cancer control activities. The 300 attendees at the October 2001 conference included physicians in diverse clinical specialties, nurses, and community workers and other health care providers, as well as local, state, and regional health officials, patients, cancer survivors, community leaders, and advocates. The program for the day-long meeting focused on four topics: (a) avoidable cancers due to infectious agents; (b) cancer prevention and early detection; (c) advances in cancer therapy and participation in clinical trials; and (d) a round table discussion of cancer survivorship within minority populations. Our keynote speaker was Dr. Harold Freeman, Chair of the President’s Cancer Panel, who spoke of his search for information on his ancestor, a blacksmith and slave who labored to purchase his freedom in 1838 and, subsequently, the freedom of his wife. Other noted scholars described the excess cancer burden in minority communities and proposed strategies to improve care for underserved populations. Additionally, several outstanding young minority clinician-scientists presented their research findings. Success of the symposium was largely due to the many Dana-Farber/Harvard Cancer Center faculty and staff who volunteered their services (see “Acknowledgments”).

In its Healthy People 2010 report, the U.S. Department of Health and Human Services identified the elimination of health disparities as a major objective (8). To monitor progress, the NIH developed standards for reporting of data on gender and ethnicity of human subjects involved in its grant-funded research, including therapeutic clinical trials. In the last renewal of the Dana-Farber Cancer Center Support Grant, required data were provided on minority participation in therapeutic clinical trials and the racial distribution of the population in our catchment area. The submitted figures showed that minority cancer patients were underrepresented in our clinical trials, when compared with corresponding census data for minorities in Massachusetts. The discrepancy was interpreted as showing that we had under-accrued minority cancer patients to clinical trials.

Accepted 1/6/03.

1To whom requests for reprints should be addressed, at Dana-Farber Cancer Institute, 44 Binney Street, Boston, MA 02115. Phone: (617) 632-2508; Fax: (617) 632-3161; E-mail: fl@partners.org. Frederick P. Li is a Harry and Elsa Jiler American Cancer Society Clinical Research Professor.

2The abbreviations used are: U.S., United States; IOM, Institute of Medicine; NCI, National Cancer Institute.
However, inquiries to other Massachusetts medical centers and community hospitals showed that they also treated few minority patients with cancer. Subsequently, we found that whites in Massachusetts tend to be considerably older than nonwhites in the state (Fig. 1). The difference is due in part to the influx of young minority families from other states and abroad, as well as the tendency of certain minority groups to have more children. Massachusetts Tumor Registry data also show that cancer incidence rates increase by approximately 10-fold from ages 0–20 years to ages 30–50 years and increase by 100-fold between childhood and ages 60 years and over (9). Thus, the small number of minorities in our cancer clinical trials is partly due to the younger ages of minority populations in our catchment area. To properly assess minority representation in clinical trials, age-adjusted cancer incidence data (rather than crude rates) should be examined. Cultural, socioeconomic, and linguistic barriers also need to be eliminated so that all Americans have equal access and quality cancer care. Because recruitment of minorities and the underserved into clinical trials is costly, appropriate research support needs to be available to investigators and their institutions.

Acknowledgments

We thank the volunteers who helped plan, organize, publicize and/or staff the meeting: Faye Austin; Elizabeth Barbeau; Lynn Basilio; Edward Benz; David Bor; Karen Burns-White; Bruce Chabner; Graham Colditz; Jim Conway; Sheila Cunningham; Karen Emmons; Ediss Gandelman; Judy Garber; Norma Gerton; Bob Handin; Ed Harlow; Larissa Horbanczuk; Dirk Iglehart; Brad Kaiser; Philip Kantoff; Melissa Klumpar; Russell Leshne; Anne Levine; David Livingston; Dennis Lynch; Wanda McClain; Nancy Mueller; Lee Nadler; David Nathan; Joan Reede; Lissa Olbeter; George Pearson; Pat Reid Ponte; Stephen Sallan; Lowell Schnipper; Glorian Sorensen; Sapna Syngal; James Wall; Donna Walthall; Jane Weeks; Athene Wilson; Yvonne Witherspoon; Population Sciences Administrative staff; and Dana-Farber/Harvard Cancer Center Health Communications Core. We are particularly appreciative of the work of Nina Cardoza, who was involved in every phase of the work, from setting the agenda to the preparation of manuscripts for publication.

References

Reducing the Unequal Burden of Cancer
Frederick P. Li and Lisa M. DiGianni


Updated version  Access the most recent version of this article at:
http://cebp.aacrjournals.org/content/12/3/230s

E-mail alerts  Sign up to receive free email-alerts related to this article or journal.
Reprints and Subscriptions  To order reprints of this article or to subscribe to the journal, contact the AACR Publications Department at pubs@aacr.org.
Permissions  To request permission to re-use all or part of this article, contact the AACR Publications Department at permissions@aacr.org.