Health Disparities Around the World: Perspectives From the 2012 Principles and Practice of Cancer Prevention and Control Course at the National Cancer Institute

By Neetu Chawla, PhD, MPH, Deanna L. Kepka, PhD, MPH, Brandy M. Heckman-Stoddard, PhD, MPH, Hisani N. Horne, PhD, MPH, Ashley S. Felix, MPH, PhD, Patricia Luhn, PhD, MPH, Colleen Pelsner, MS, PhD, Jonathan Barkley, and Jessica M. Faupel-Badger, PhD, MPH

National Cancer Institute, Bethesda, MD; University of Utah; and Huntsman Cancer Institute, Salt Lake City, UT

Abstract

Introduction: The National Cancer Institute Principles and Practice of Cancer Prevention and Control course is a 4-week course encompassing a variety of cancer prevention and control topics that is open to attendees from medical, academic, government, and related institutions around the world. Themes related to the challenges health disparities present to cancer prevention efforts and potential solutions to these issues emerged from facilitated group discussions among the 2012 course participants.

Materials and Methods: Small-group discussion sessions with participants ($n = 85$ from 33 different countries) and facilitators ($n = 9$) were held once per week throughout the 4-week course. Facilitators prepared open-ended questions related to course topics. Participants provided responses reflecting their opinions of topics on the basis of experiences in their countries.

A thematic analysis was conducted to explore themes emerging from the discussion groups.

Results: The varied influences of health disparities on cancer prevention efforts among > 30 countries represented prominent themes across discussion groups. Participants discussed the interplay of individual characteristics, including knowledge and culture, interpersonal relationships such as family structure and gender roles, community and organizational factors such as unequal access to health care and access to treatment, and national-level factors including policy and government structure.

Conclusion: The ideas and solutions presented here are from a geographically and professionally diverse group of individuals. The collective discussion highlighted the pervasiveness of health disparities across all areas represented by course participants and suggested that disparities are the largest impediment to achieving cancer prevention goals.

Introduction

Cancer incidence is projected to increase to > 21 million new patient cases in 2030, with approximately two thirds of all diagnoses occurring in low- and middle-income countries.¹ A recent United Nations high-level meeting on noncommunicable diseases in low- and middle-income countries signaled the heightened awareness and concern about this dramatic change in disease burden in low-resource settings.² It is increasingly apparent that cancer prevention efforts have the greatest opportunity to reduce the global cancer burden³; however, widespread formal education on cancer prevention is lacking among many health care professionals, especially in areas projected to have the largest increases in cancer diagnoses.⁴

The National Cancer Institute (NCI) Cancer Prevention Fellowship Program (CPFP) sponsors a 4-week postgraduate course in cancer prevention entitled, “The Principles and Practice of Cancer Prevention and Control” (referred to herein as the Principles course). Course participants include physicians, scientists, public health researchers, and other health professionals, with approximately half attending from low- and middle-income countries, thus providing a unique opportunity to bring together a wide spectrum of knowledge and experience in cancer prevention.⁵

During the 2012 course, interactive small-group discussions focused on topics closely aligned with the syllabus, including issues surrounding efforts to address obesity on a global level, health disparities across the many countries represented, and increasing awareness of cancer prevention in resource-limited settings. Regardless of topic area, the influence of health disparities on cancer prevention efforts was a cross-cutting theme. Health disparities, as defined by the NCI Center to Reduce Cancer Health Disparities, are “differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups.”⁶

Health disparities occur both between and within countries and represent an important area in cancer prevention efforts.⁴ Numerous organizations, including NCI, WHO, and the Centers for Disease Control and Prevention, have made reducing cancer disparities a strategic priority.⁷ Herein, health disparities influencing cancer prevention efforts and potential solutions proposed to overcome these challenges as described by the Principles course participants are summarized. The solutions proposed should be of interest to many concerned about the increase in the noncommunicable disease burden in a variety of resource settings. This report differs from others in the field for

two reasons: first, the focus was on the impact of health disparities on cancer prevention efforts; and second, the solutions were proposed by individuals on the front lines of implementing cancer prevention strategies for their regions or countries.

Materials and Methods

Sampling and Recruitment

The Principles course is offered in an in-person, classroom setting in Rockville, Maryland. Course participants with relevant training (eg, MD, PhD, public health professional) are selected on the basis of their potential to utilize the course information. The NCI Center for Global Health selects individuals from low- and middle-income countries and strives for geographic balance across the group.⁸

In 2012, 85 people representing 33 different countries participated in the course. Participants were most commonly either physicians (31.2%) or PhD-level scientists (36.4%). A majority were women (66.2%) and ranged in age from approximately 28 to 57 years.

Discussion Group Format and Data Sources

Nine discussion groups of nine to 10 participants randomly assigned to be regionally representative of the course population were formed. Discussion sessions occurred once per week, led by facilitators who had previously attended the course. Discussion facilitators developed open-ended questions tied to the weekly discussion topics. Each week, participants were provided discussion questions and asked to give responses reflecting their personal opinions and experiences regarding the topic. Responses were neither endorsed by nor representative of an official position of a specific government or employer. After asking permission from participants, facilitators took notes during discussions. Facilitator notes were de-identified from participant names and specific countries to maintain confidentiality. During analyses, countries were grouped by either region or income level (eg, low, middle, high). At the conclusion of the course, each group presented its collective solutions to one of the selected topics. Course participants also completed evaluations of the overall course and the discussion groups. Institutional review board exemption for this study was obtained from the National Institutes of Health Office of Human Subject Research.

Data Analysis

A thematic analysis was conducted to explore themes emerging across the discussion groups. This analytic strategy is able to capture differentiating as well as similar contexts and allows thematic content to emerge from the data in an iterative fashion.⁹ A subset of discussion facilitators examined written responses from facilitator notes, course evaluations, and slide presentations to identify key themes. In analysis of all areas, health disparities emerged as a cross-cutting issue. Facilitators worked in teams to examine the ways that health disparities were raised within each topic area and compared coding processes.

Results

Socioecologic Framework

A number of factors play a strong role in the existence of health disparities around the globe and were enumerated during the course discussions. The major themes emerging from the discussions echoed the layers of influence highlighted in the socioecologic framework (SEF) conceptual model (Fig 1). The SEF examines how multiple levels of influence affect and engender behavioral and health-related outcomes spanning from individualistic personal attributes to interpersonal and environmental factors. The framework illustrates how factors are interdependent and influenced by both internal and external factors on the individual, interpersonal, community/organizational, and national/policy levels.¹⁰ In addition to identifying sources of health disparities, participants also proposed solutions to the challenges identified (Table 1). Major themes related to health disparities and proposed solutions are categorized, according to the layers of the SEF.

Individual Factors

Socioeconomic status (SES) was an overarching contributor to health disparities. Across all discussion groups, participants raised the issue of poverty or low SES as a main contributor. As one facilitator noted, “although the countries discussed varied widely, the common denominator in all of them was that low SES was the biggest determinant of health disparities.”

Among individuals with lower SES, participants described several underlying factors associated with cancer-related health disparities, including limited access to preventive and treatment services, quality of care, lack of knowledge, geographic location, and distribution of resources. Irrespective of country of origin, a common theme resonating among participants was unequal allocation of resources. To address this issue, the proposed solution for local governments was to focus on sharing and disseminating resources both financially and intellectually (Table 1).

Education and Knowledge

Lack of knowledge related to cancer prevention and availability of services was cited as an important contributor to health disparities by multiple participants. Participants noted an obvious link between individuals with lower SES and lack of knowledge related to the importance of cancer screening and the influence of health behaviors such as diet, physical activity, and sun protective behavior. One participant from Africa noted that “screening is only really occurring in the educated population.” Another individual described differences in knowledge in urban versus rural communities by stating, “We have a national health service . . . . Some people from the countryside may have less knowledge of disease and not know that they need to come to the doctor, but they have the same access as everyone else.”

To address these knowledge gaps, participants proposed health disparities could be reduced by disseminating cancer prevention information to portions of the public who may not be aware of the importance of cancer screening or the existence

Figure 1. Socioecologic framework of factors related to health disparities. Data adapted.^{10,11} (*) Factors discussed during the 2012 Principles and Practices of Cancer Prevention and Control summer curriculum at the National Cancer Institute.

of modifiable risk factors associated with reduced cancer risk (Table 1). Participants from low-, middle-, and high-income countries all agreed that community-based programs would have the greatest impact in terms of uptake and reducing disease burden.

Cultural Beliefs

Several participants described the role of cultural beliefs as a potential barrier to accessing cancer services and treatment. Within this broader category, fatalism and the use of traditional healers or alternative practices were commonly mentioned. As one participant from South America described, “fatalist approaches” resulted in people “tending not to go the doctor” for preventive cancer care. Participants also mentioned the use of traditional healers or alternative approaches to Western medicine as reasons individuals may avoid utilization of formal health care services, particularly in lower- and middle-income

countries or among individuals with limited health care access. As a potential solution, participants suggested that local communities would be more equipped to provide information in culturally relevant programs and interventions (Table 1).

Interpersonal Factors

Participants discussed relationships within their family structures and gender roles as potential barriers to accessing cancer care, particularly with respect to services for female-related cancers. As one participant described, the interplay between culture and gender dynamics played a role in cervical cancer screening in Africa: “Women who present for Pap screenings typically ask their husbands for permission. If the procedure doesn’t seem acceptable to the husband, the woman won’t do the test. However, if there is a woman who knows about the screening and encourages her peers to participate, they typically will.” Another participant from South America similarly described the role of

Table 1. Factors Related to Health Disparities and Selected Proposed Solutions From Course Participants

Factor	Proposed Solution
Individual	
Socioeconomic status	Local governments should focus on sharing and disseminating resources, both financially and intellectually.
Cancer prevention education for public and practitioners	Disseminate cancer prevention information to members of public who may not be aware of importance of cancer screening or existence of modifiable risk factors that can reduce cancer risk.
Cultural beliefs	Local communities should provide information via culturally relevant programs and interventions and understand cultural factors that influence health decision making so that health care providers will be able to provide appropriate level of care in a manner that is well received by their patients.
Interpersonal	
Family relationships and gender roles	Maximize use of existing resources to specifically target underserved populations and increase capacity of women’s clinics so that women are more comfortable using this avenue as means for cancer screening and/or treatment.
Community and organizational	
Geographic location	Use mobile health care units as one strategy to reduce disparities.
Access to treatment and quality of care	Increase number of trained health care professionals with government investment in education and incentives for medical students to choose certain specialties and practice in specific areas of country.
National and policy	
Access to screening programs	Improve infrastructure and provide comprehensive medical coverage and incentivize local governments to implement screening programs focused on cancer prevention and control.
Cancer prevention education for policymakers	Increase interagency communication to facilitate delivery of unified message to public regarding cancer prevention and incentivize local governments to implement educational campaigns focused on cancer prevention and control.

“machismo” in a woman’s ability to access cancer screening and reproductive care, particularly among rural populations. As a proposed solution to circumvent some of the disparities arising from gender roles, participants suggested countries maximize the use of existing resources to target underserved populations (eg, increasing capacity of women’s clinics; Table 1).

Community and Organizational Factors

Geographic disparities influencing access to care. Despite the extremely diverse group of participants, a common thread that resonated as a contributor to cancer-related health disparities was geographic impediments to accessing health care facilities. One participant from Asia noted, “For rural people, medical care is very far and very rare. It may take up to one day to travel to a hospital. While in big cities, medical care is very accessible and better equipped.” Another discussion group member from Asia also described transportation issues: “In Asia, there are many small islands so transportation significantly impacts access as well as differences in quality of care depending on the location.” A participant from North America mentioned that women may start treatment for breast cancer, but they may “experience barriers such as transportation and childcare issues that limit their ability to complete treatments such as radiotherapy after lumpectomy.” Even in countries with universal health insurance, transportation was still a concern. One participant from Eastern Europe noted that “patients don’t pay for treatments, but transportation costs still affect access.” Because of these access barriers, many individuals from rural communities present with more advanced stage of disease compared with their urban counterparts, as suggested by a participant from Africa who said, “Cancer patients who live outside of the capital tend to present with advanced disease.” Participants felt utilizing mobile health care units was one strategy for reducing disparities by distributing treatment and screening resources to areas lacking access, such as rural settings or villages extremely far from national hospitals (Table 1). In addition, a participant from Asia shared an example of directly targeting high-risk areas to receive specific cancer screening programs.

Disparities in access to treatment and quality of care. Even among countries with universal health insurance programs or government-based subsidies for health care, disparities existed for covering cancer treatment costs and obtaining supplemental coverage. Several participants noted disparities were worse for individuals with public insurance or those lacking supplemental coverage to pay for treatment-related costs. As one participant described, differences in insurance type affected access to cancer treatment: “Herceptin [trastuzumab; Genentech, South San Francisco, CA] treatment is given to early-stage breast cancer cases and not late-stage cases for those with public insurance only. However, if someone has purchased private health insurance, they would have access to Herceptin treatment regardless of disease stage.” Another participant from Africa noted that individuals “without supplemental insurance tend to have longer hospital stays because they are not the priority.”

Inconsistent quality of health care delivered was also a frequent theme. Lack of qualified staff to provide adequate services, treatment, and patient guidance seemed to be a significant problem, particularly in low- and middle-income countries. One participant from the Middle East made the following observation: “Some physicians [who] are not trained in that country and do not speak the language . . . they typically practice in poorer areas; as such, people who present for health care do not trust or do not understand the health-related advice they are given.” The lack of qualified staff was noted to have a disproportionate impact on individuals without health insurance or those accessing care from public health care facilities. Participants also stated that physicians may have financial incentives to work in urban areas and have more lucrative practices. An overall shortage of physicians resulting in a high patient-to-physician ratio was reported among countries at all economic levels.

A proposed solution for increasing the number of trained health care professionals included government investment in education and incentivizing medical students to choose certain specialties and practice in specific areas of the country (Table 1). Pathologists and cytologists are of greatest need in low-income countries, where some participants reported patients with cancer carrying their own biopsy samples to cancer hospitals to be analyzed. Oncologists are also needed to treat the increasing number of patients diagnosed by new screening programs.

National and Policy Factors

Government structure and resources determine access to screening and treatment, with wealthier nations often providing more services to their citizens and to vulnerable populations than low- or middle-income countries. As one facilitator noted, a group member commented that “improvement in infrastructure and providing comprehensive medical coverage would provide the biggest impact in reducing cancer health disparities.” Although some lower- and middle-income countries provide universal health care coverage, several participants noted variation in distribution of resources by location. Participants also noted that some nations and regions had better access to resources provided by nongovernmental organizations than others.

Participants felt that national and regional governments should incentivize local governments to implement screening and educational campaigns focused on cancer prevention and control (Table 1). Vaccination programs could be integrated into the existing infrastructure for infectious disease prevention, which governments and nongovernmental organizations have spent significant resources building. Another possible solution discussed was the need to increase interagency communication to facilitate the delivery of a unified message to the public regarding cancer prevention. In particular, the participants noted the need for existing governmental agencies and nongovernmental agencies, such as health-related nonprofit groups, to communicate at both the national and international levels to find an avenue for systematically distributing cancer prevention information and resources to educate health professionals and lay people.

Discussion

Here, participants spanning 33 different countries uniformly highlighted the pervasiveness of health disparities and the ways that disparities influence the design, implementation, and success of cancer prevention efforts (Table 1). Although participants represented different geographic regions, income distinctions, and health care systems, concerns and proposed solutions were remarkably consistent. With the exception of issues related to screening and a few comments related to treatment, the challenges discussed by participants largely focused on health care, culture, education, workforce, and infrastructure. The resulting solutions were then predominantly focused on the domain of primary prevention or promoting health with the goal of preventing cancer from ever occurring. These discussions also naturally touched on all aspects of the SEF (Fig 1) and provided further evidence to support some of the recommendations put forth by others for addressing cancer incidence in various regions of the world.^{2-4,7,12-15}

Some of the solutions presented could be implemented without additional costs or resources. For example, the groups were consistent in their calls for unified cancer prevention messages from all sources (eg, governmental and nongovernmental agencies) to promote the education of both lay people and practitioners. Although coordination could be challenging, coordinating across different groups would not require additional resources above those already being used to distribute current messages. This strategy would contribute to the goal of increasing awareness of cancer prevention efforts among both the general public and health professionals, which was echoed in our findings as well as by others suggesting strategies to address the growing cancer burden in Africa and Asia.^{4,13-15}

The contribution of unequal access to providers to health disparities, including stage of disease at presentation, was noted here and in prior studies conducted within countries considered both higher and lower resource settings.¹⁶⁻¹⁸ Participants also highlighted unequal distribution of resources by both governmental and nongovernmental agencies, especially with regard to urban versus rural settings. Within current ongoing programs, redistribution or coordination of resources to ensure access to care and information among rural populations could be considered. Discussion groups also highlighted the need to work with community-based programs in coordination of public health messages and health care delivery efforts, highlighting

the importance of local involvement.⁷ Finally, participants described the role of wider social and gender norms as an important aspect of addressing gender-related disparities in women's access to cancer screening and treatment; these norms should be addressed by community-based programs and policy-based solutions.

In conclusion, the solutions proposed should be of interest to many concerned about the increase in the noncommunicable disease burden in low-resource settings and addressing health disparities. The solutions were presented by individuals who have encountered many of these challenges firsthand in their own work. The consistency of the concerns and solutions demonstrate the cross-cutting nature of health disparities across many diverse regions. Finally, the strategies described here to address health disparities could be applied not only to reduce cancer incidence but also to address the growing worldwide burden of a variety of noncommunicable diseases.¹²

Acknowledgment

Supported by the National Cancer Institute Cancer Prevention Fellowship Program (Principles course and all authors). We thank K. Leigh Greathouse, PhD, MPH, RD, and M. Khair El Zarrad, PhD, MPH, for their contributions as discussion group facilitators and the Principles course participants for these invaluable conversations.

Authors' Disclosures of Potential Conflicts of Interest

The author(s) indicated no potential conflicts of interest.

Author Contributions

Conception and design: All authors

Administrative support: Jonathan Barkley

Collection and assembly of data: All authors

Data analysis and interpretation: Neetu Chawla, Deanna L. Kepka, Brandy M. Heckman-Stoddard, Hisani N. Horne, Ashley S. Felix, Patricia Luhn, Colleen Pelsner, Jessica M. Faupel-Badger

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Jessica M. Faupel-Badger, PhD, MPH, Cancer Prevention Fellowship Program, National Cancer Institute, 9609 Medical Center Dr, Room 2W136, Bethesda, MD 20892-9712; e-mail: badgerje@mail.nih.gov.

DOI: 10.1200/JOP.2013.001129; published online ahead of print at jop.ascopubs.org on October 1, 2013.

References

1. Ferlay J, Shin HR, Bray F, et al: Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *Int J Cancer* 127:2893-2917, 2010
2. World Health Organization: 2011 high level meeting on prevention and control of non-communicable diseases. <http://www.un.org/en/ga/ncdmeeting2011/>
3. Thun MJ, DeLancey JO, Center MM, et al: The global burden of cancer: Priorities for prevention. *Carcinogenesis* 31:100-110, 2010
4. Yoo KY: Cancer prevention in the Asia Pacific region. *Asia Pac J Cancer Prev* 11:839-844, 2010
5. Faupel-Badger JM, van Bommel DM, Wiest JS, et al: Expanding cancer prevention education to national and international audiences: The National Cancer Institute's Principles and Practice of Cancer Prevention and Control annual summer course. *J Cancer Educ* 26:619-625, 2011
6. National Cancer Institute: Center to Reduce Cancer Health Disparities: Health disparities defined. <http://crchd.cancer.gov/about/defined.html>
7. Jones LA, Chilton JA, Hajek RA, et al: Between and within: International perspectives on cancer and health disparities. *J Clin Oncol* 24:2204-2208, 2006
8. Williams MJ, Otero IV, Harford JB: Evaluation of the impact of NCI's summer curriculum on cancer prevention on participants from low- and middle-income countries. *J Cancer Educ* 28:27-32, 2013
9. Braun V, Clarke V: Using thematic analysis in psychology. *Qual Res Psychol* 3:77-101, 2006
10. Stokols D: Establishing and maintaining healthy environments: Toward a social ecology of health promotion. *Am Psychol* 47:6-22, 1992
11. Richard L, Potvin L, Kishchuk N, et al: Assessment of the integration of the ecological approach in health promotion programs. *Am J Health Promot* 10:318-328, 1996

12. Lins NE, Jones CM, Nilson JR: New frontiers for the sustainable prevention and control of non-communicable diseases (NCDs): A view from sub-Saharan Africa. *Glob Health Promot* 17:27-30, 2010 (suppl)
13. Sylla BS, Wild CP: A million Africans a year dying from cancer by 2030: What can cancer research and control offer to the continent? *Int J Cancer* 130:245-250, 2012
14. Patel JD, Galsky MD, Chagpar AB, et al: Role of American Society of Clinical Oncology in low- and middle-income countries. *J Clin Oncol* 29:3097-3102, 2011
15. Lyerly HK, Abernethy AP, Stockler MR, et al: Need for global partnership in cancer care: Perceptions of cancer care researchers attending the 2010 Australia and Asia Pacific Clinical Oncology Research Development Workshop. *J Oncol Pract* 7:324-329, 2011
16. Engelman KK, Hawley DB, Gazaway R, et al: Impact of geographic barriers on the utilization of mammograms by older rural women. *J Am Geriatr Soc* 50: 62-68, 2002
17. Gentil J, Dabakuyo TS, Ouedraogo S, et al: For patients with breast cancer, geographic and social disparities are independent determinants of access to specialized surgeons: An eleven-year population-based multilevel analysis. *BMC Cancer* 12:351, 2012
18. Panagopoulou P, Gogas H, Dessypris N, et al: Survival from breast cancer in relation to access to tertiary healthcare, body mass index, tumor characteristics and treatment: A Hellenic Cooperative Oncology Group (HeCOG) study. *Eur J Epidemiol* 27:857-866, 2012