

Progress in addressing disparities through comprehensive cancer control

Armin D. Weinberg · Pamela M. Jackson · Christine A. DeCourtney ·
Kym Cravatt · Joanne Ogo · Marta M. Sanchez ·
Guillermo Tortolero-Luna · Rochelle L. Rollins

Received: 28 July 2010 / Accepted: 21 September 2010 / Published online: 5 November 2010
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Abstract Cancer-related disparities are the significant differences in cancer incidence, cancer prevalence, cancer death, cancer survivorship, and burden of cancer or related health conditions that exist disproportionately in certain populations compared with the general population with respect to variables like race, ethnicity, and geography. The emergence of comprehensive cancer control efforts provides a framework to address the unequal disease burden felt by these groups. This article illustrates four distinct programs uniquely designed to fit at-risk populations. Specific examples are given that demonstrate a significant impact on the full range of the cancer care continuum. Although measureable progress has been made to improve prevention, detection, and treatment of cancer throughout the United States, many populations remain underserved, impeding our ability to achieve national healthcare goals.

Here, we reemphasize the need to sustain this progress through use of partnerships, technology, and policy.

Keywords Cancer-related disparities · Health disparities in cancer · Comprehensive cancer control

Introduction

A simple truth: We will never achieve our national healthcare objectives without eliminating cancer-related disparities. As defined by the National Institute of Health, cancer-related disparities refer to the significant differences for incidence (new cases), prevalence (all existing cases), mortality, and overall disease burden that are exhibited disproportionately in specific populations compared with the US general population [1]. Measures of disparities have traditionally focused on race, ethnicity, social, and demographic causative forces. However, we are just now beginning to recognize that there are many other important risk factors that contribute to the unequal disease burden for certain groups, i.e., age, gender, literacy, transportation, and availability of services [1].

In a previous special issue of this journal focused on comprehensive cancer control (CCC), the article *Cancer-related disparities: weathering the perfect storm through comprehensive cancer control approaches (2005)* used the “perfect” storm analogy to describe the ever-growing need for culturally competent information/services, program competition for shrinking federal, state, and local resources and the lack of access to advanced technologies and therapeutics that significantly hinder cancer prevention and treatment [2]. The elimination of health disparities is among the six priorities of the Centers for Disease Control and Prevention (CDC). As such, their National Comprehensive

A. D. Weinberg (✉) · P. M. Jackson
Intercultural Cancer Council/Baylor College of Medicine,
Chronic Disease Prevention and Control Center, Houston,
TX 77030, USA
e-mail: arminw@bcm.edu

C. A. DeCourtney
Alaska Native Tribal Health Consortium, Anchorage, AK, USA

K. Cravatt
Cherokee Nation Health Service, Cherokee, OK, USA

J. Ogo
Commonwealth of Northern Mariana Islands, Comprehensive
Cancer Control Program, Saipan, MP, USA

M. M. Sanchez · G. Tortolero-Luna
University of Puerto Rico, San Juan, PR, USA

R. L. Rollins
DHHS Office of Minority Health, Washington, DC, USA

Cancer Control Program provides for inclusion of specific objectives for a collaborative effort to reduce the burden of cancer in those underserved. The impact of these efforts spans the continuum of care from prevention through survivorship at national, state, territory, tribal, and local levels.

As our awareness has increased for the unequal cancer burden for certain groups, stakeholder (government, private, public, and local) participation in efforts to eliminate these disparities has similarly increased. Through technological advances like telehealth links via the Internet, those underserved communities are able to connect with state-of-the-art facilities and experts to share knowledge or provide specific consultation on cases. In these efforts, we continue to learn together how we can bridge these gaps in service and delivery. With these tools, cancer-related disparities are being addressed today more aggressively than ever before through the use of multi-leveled partnerships, technology, policy, and recognition of emerging issues like the social determinants of health.

This article highlights the achievements of several CCC coalitions, demonstrating that a broader execution of CCC plans coordinated with a national strategy would accelerate the amelioration of remaining cancer-related disparities. We illustrate four distinct populations (American Indians, Alaska Natives, Pacific Islanders, and Puerto Ricans) successfully impacting cancer-related disparities through the CCC planning and implementation process. Each has developed a customized plan specifically adapted to fit the unique health and social situation of their community. We describe the context that contributes to the disparities, how CCC efforts are making a difference and discuss goals and objectives to expand the programs and services.

Compared to non-Hispanic whites, the burden of cancer is disproportionately greater for American Indians/Alaska Natives (AI/AN), Hispanics, Asians, and Pacific Islanders [3, 4]. Reports compiling national data from 1975 to 2006 found that these underserved populations had increased long-term incidence rates for cancers of the kidney, liver, skin, bladder, thyroid, pancreas, and certain cancers of the blood and had increased mortality rates for melanoma, esophageal, pancreatic, and liver cancers [3, 4]. These measures may also be reflecting the lower rates of cancer screenings reported in these at-risk populations [3, 4]. As cancer diagnoses at later stages results in higher mortality rates, improving access to care and screening is critical to efforts aimed at eliminating cancer-related disparities.

Reports also show that the relative cancer burden of a population is affected by socioeconomic status and differs when data are stratified by regions [3–5]. Increased attention has also recently been given to the social determinants of health, factors reflecting the distribution of resources at global, national and local levels, which are a consequence of policy [6]. For example, compared with non-Hispanic

whites, AI/AN have lower prevalence estimates for income, education, insurance coverage, and access to personal healthcare providers but have higher rates of consumption for alcohol and tobacco [7]. Further complications arise from the frequency of misclassification errors found for minorities [3]. Therefore, analyses of cancer-related disparities that are not yet stratified by geographic and socioeconomic factors or not yet corrected for misclassification errors may obscure accurate national rates to identify the true cancer burden for these at-risk populations.

Efforts to date have increased our capacity to address the unequal burden of cancer and increased our recognition of the existence of cancer-related disparities. Nevertheless, data clearly point to the unrelenting toll cancers still have on certain communities. Here, we focus on four of these communities (American Indians, Alaska Natives, Pacific Islanders, and Puerto Ricans) and reemphasize the need for strategic execution of CCC plans in a context of data-driven research, treatment, and survivorship to provide a broader implementation among underserved populations.

The Cherokee Nation

In 1990, the Cherokee Nation became one of six tribes to participate in tribal self-governance and in 1994 began delivering healthcare services tailored to fit its language, culture, and geography. After 20 years, the Cherokee Nation currently provides healthcare to a population of 130,000 at eight tribal clinics and one tribal hospital within the 14-county jurisdiction in northeastern Oklahoma. With funding from the CDC, the Cherokee Nation Comprehensive Cancer Control Plan 2005–2007 was created focused on strategies for prevention, early detection, treatment, and quality of life/survivorship [8]. Partners from national networks, the Cherokee Nation healthcare system, the Oklahoma State Department of Health, and similar community-based organizations serve as an advisory board for the coalition that is responsible for the development and implementation of the plan.

National statistics indicate that AI/AN have the highest cancer-related mortality among all racial groups in the United States [9]. Nevertheless, this inequity is being addressed with help from a national organization, the Prevent Cancer Foundation, that helped initiate a successful colorectal cancer awareness campaign consisting of public service announcements, prevention guides written in the Cherokee language and English, and exhibits such as the Super Colon, an 8' high 20' long inflatable, walk-through model demonstrating colon disease to emphasize the importance of early screening [8].

Since lung cancer is the leading cause of death among AI/AN men and women [8], prevention initiatives focused

on reducing the higher prevalence of commercial tobacco use found among American Indians. The Cherokee Nation enacted a tobacco-free policy for tribal government facilities in 2007 and anticipating a tribal-wide policy implemented strategies that maintain a high level of awareness among citizens, employees, and healthcare providers, i.e., increased number of smoking cessation classes in communities and media campaigns like “Tobacco Stops with Me” and “Honor Tradition, Not Tobacco” which feature prominent Cherokee citizens that the community can relate to easily. Promotion of the Oklahoma Tobacco Quitline resulted in a 200% increase in utilization by tribe members from 2005–2007. In addition, community health promotion teams worked diligently with Cherokee Nation medical teams to increase tobacco use screening and tobacco cessation counseling to patients. As a result of programs like these, American Indians living in the Cherokee Nation show evidence of reducing their cancer burden with cancer screening rates increasing from 27.7% in 2005 to 37.5% in 2007 and diagnoses at earliest stages increasing from 1% from 1997 to 2001 to 4% in 1997–2004 [10].

The Alaska Tribal Health System

The Alaska Tribal Health Compact, a government-to-government agreement, provides statewide services to the Alaska Native population in specialty medical care, water and sanitation, community health and research, and information technology. Levels of care include over 180 small community primary care clinics staffed by trained village residents, subregional/midlevel practitioner clinics in larger communities, six regional primary care hospitals, and one tertiary care hospital in Anchorage. Funded by the CDC, the Alaska Native Tribal Healthcare Consortium (ANTHC) cancer program staff developed the Alaska Comprehensive Cancer Plan 2005–2010 led by advisors and collaborators that include physicians, hospitals, clinics, and tribal regional health corporations, private and non-profit organizations [11, 12]. CCC programs focus on prevention, screening/early detection, diagnosis, treatment, survivorship/quality of life, and palliative education [11, 12].

Cancer has been the leading cause of death for the Alaska Natives since 1993, with breast, cervical, colorectal, lung, prostate, and bladder being the most commonly diagnosed cancers [12]. The magnitude of the disproportional cancer burden felt by the Alaska Natives is exemplified by colorectal cancer. Alaska Natives show significantly higher incidence and death rates from colorectal cancer relative to race-specific US rates, all-race Alaska rates, or all-race US rates [12]. In fact, diagnoses of colorectal cancer for Alaska Natives occur at more than twice the rate of Alaska whites. From 1996–2002, the

incidence rate of colorectal cancer for Alaska Natives was 108.6 per 100,000 compared with rates of 51.1 per 100,000 for whites [12].

Colorectal cancer screening for Alaska Natives is limited, not readily available to a third of the population [12]. Low screening rates result from a high demand for the required specialty providers and equipment located only at the tertiary hospital or regional hubs and therefore only accessible through expensive and difficult travel. For this reason, expanded colorectal cancer screening and education is being addressed through CCC programs including media projects, community health education, fundraising, and worksite activities. Efforts geared toward quality of life include survivorship conferences and creation of supportive resources like *The Traditional Food Guide for Alaska Native Cancer Survivors*, a nutrition guide of Alaska’s wild foods. The use of the guide has expanded to become a healthy lifestyle resource used in schools, tribal communities, elder facilities, and hospitals across Alaska [11]. For children in remote areas affected by cancer, *Camp Coho* offers a culturally appropriate, innovative one-day “camp” that aims to help them cope better together [11].

The ANTHC convenes annual symposia geared toward resolving the barriers to care and encouraging new initiatives to reduce the inequity [11]. For instance, to improve palliative care knowledge, skills, and education for healthcare providers of Alaska Natives, teams of providers were brought together for three palliative care symposiums with nationally recognized speakers. To balance expensive and difficult travel to such events, technological advances have allowed Alaska to become a worldwide leader in telehealth communications [11]. Through interactive features and social media networks, “virtual” consults and communities are created that can provide remote clinics access to a larger community of experts. Telehealth education services have increased remote healthcare provider knowledge about cancer-related and other healthcare issues and have reduced the need to travel to the tertiary care hospital by offering video-teleconferencing consultative opportunities for remote providers and their patients with Alaska Native Medical Center specialists.

Cost-effective access to worldwide palliative care experts via telehealth for the International Telehealth Palliative Care Symposia has expanded educational opportunities. In 2010, 670 registrants from 18 countries participated in the conference [11]. Used effectively for diagnosis, treatment, culturally appropriate programs, or simply for bringing together cancer patients undergoing lengthy treatment far away from home to their family, telehealth is changing healthcare access and education for Alaska Natives and their healthcare providers.

The Commonwealth of the Northern Mariana Islands

The Commonwealth of the Northern Mariana Islands (CNMI) consists of 15 islands with 176.5 square miles of land spread out over 264,000 square miles of the Pacific Ocean [13]. The CNMI Healthcare System is made up of four private medical centers and government facilities that deliver services to the population of 69,221 residents [13]. Cancer remains a leading cause of death in CNMI [13]. In agreement with the University of Hawaii, CDC funding allowed creation of the Comprehensive Cancer Control Plan for the Commonwealth of the Northern Mariana Islands 2007–2010 dedicated to improve education, prevention, early detection, diagnosis, treatment, survivorship, data surveillance, and registries [13]. National and international partners of government, community, and tribal leaders work to reduce CNMI's high cancer burden.

Successful CCC partnerships in CNMI include the Commonwealth Cancer Association, the Breast and Cervical Screening Program, the Immunization Program, and the Maternal and Child Health Program. Since cervical cancer in CNMI is among the highest in the world but is preventable with the human papilloma virus (HPV) vaccine, the Department of Public Health began a 3-year plan in 2006 to vaccinate females aged 9–26 with public schools, non-profit and faith-based organizations engaged to achieve 100% vaccination of its target audience [14]. Students participated in focus group discussions. A mass media campaign was implemented and recognized at the National Public Health Information Coalition with Gold and Silver awards for effective communication. The HPV vaccine was also made available to girls at public health satellite clinics, which enabled vaccination of 92% of its target population [14]. Community-based events raised awareness of the high cancer burden and numerous dialogues and support meetings provided exchange of information for newly diagnosed patients, survivors, practitioners, and caregivers. Additional fundraising events like the Marianas March for Cancer, the Marianas Diva Pageant, and coin drive collections assisted in the outreach of CCC programs to CNMI residents.

Puerto Rico

Cancer is among the leading causes of death in Puerto Rico. CDC funding in cooperation with the University of Puerto Rico and the Puerto Rico Department of Health allowed the *Puerto Rico Comprehensive Cancer Control Plan 2008–2012: A blueprint for cancer control in Puerto Rico* to be launched as a framework for coordinated and integrated action [15]. Objectives include evidence- and theory-based strategies to catalyze existing and potential partnerships, address specific cancer risk factors, and

improve data availability and outcome measures. A coalition comprised of public health, government, professional, academic, medical, private, non-profit, and community-based organizations was convened in steering committees that identified seven priority areas, including (1) prevention; (2) screening/early detection; (3) diagnosis/treatment; (4) rehabilitation/survivorship/palliative and end of life issues; (5) access to healthcare; (6) data/cancer surveillance; and (7) research and training. Priority working groups developed goals and objectives into strategies aimed at reducing disparities.

The CCC program began by assessing the needs for implementation of priority goals and by promoting the adoption by state government as public policy on cancer control, i.e., senate approval, vote pending in the House of Representatives. Although still in the early stages of implementation, CCC efforts have increased awareness about healthy diet, physical activity, screening for cancer, and the effects of policy change. To address the high cancer burden in Puerto Rico, the CCC program is now focused on mobilization of resources that maintain the momentum of the planning phase and encourage support of partners and other stakeholders. By bringing these resources together, the coalition aims to identify and secure resources that will sustain and progress CCC implementation, i.e., joint grant applications, advocacy through state legislatures, and foundation resources.

Summary and future directions

Here, we celebrate four distinct groups (American Indians, Alaska Natives, Pacific Islanders, and Puerto Ricans) providing culturally specific evidence-based CCC programs designed to reduce cancer-related disparities within their communities. Although urban residents often have what appears to be readily available access to healthcare services, the challenges of transportation, child care, provider shortages, and culturally competent care are more obvious in remote populations. In both rural and urban communities, many underserved residents live under conditions so poor, i.e., without water or electricity, that fail to provide for good hygiene and overall health.

Consider Alaska which is 1st among US states in land mass, 47th in roads, and 48th in doctor to person ratio with 60% of its population living in small communities not yet connected to roads [12]. When basic diagnostic tools and specialized treatment are not available within the community health system, patient care must be contracted to providers far away, depleting financial support of programs and adding emotional hardship to patients. Patients who must leave their village to travel to Anchorage for care are overwhelmed by noise, transportation, big buildings, many

Table 1 National Plan for Action (NPA) to end disparities

National plan for action to end health disparities. Goals and strategies

Goal		Strategies
No	Description	
1	AWARENESS —Increase awareness of the significance of health disparities, their impact on the nation, and the actions necessary to improve health outcomes for racial, ethnic, and underserved populations	<ol style="list-style-type: none"> 1. Healthcare Agenda. Ensure that ending health disparities is a priority on local, state, tribal, regional, and federal healthcare agendas 2. Partnerships. Develop and support partnerships among public, non-profit, and private entities to provide a comprehensive infrastructure to increase awareness, drive action, and ensure accountability in efforts to end health disparities and achieve health equity across the life span 3. Media. Leverage local, regional, and national media outlets using traditional and new media approaches as well as information technology to reach a multi-tier audience—including racial and ethnic minority communities, youth, young adults, older persons, persons with disabilities, LGBT groups, and geographically isolated individuals—to encourage action and accountability 4. Communication. Create messages and use communication mechanisms tailored for specific audiences across their life span, and present varied views of the consequences of health disparities that will encourage individuals and organizations to act and to reinvest in public health
2	LEADERSHIP —Strengthen and broaden leadership for addressing health disparities at all levels	<ol style="list-style-type: none"> 5. Capacity Building. Build capacity at all levels of decision making to promote community solutions for ending health disparities 6. Funding and Research Priorities. Improve coordination, collaboration, and opportunities for soliciting community input on funding priorities and involvement in research and services 7. Youth. Invest in young people to prepare them to be future leaders and practitioners by actively engaging and including them in the planning and execution of health, wellness, and safety initiatives
3	HEALTH SYSTEM AND LIFE EXPERIENCE —Improve health and healthcare outcomes for racial, ethnic, and underserved populations	<ol style="list-style-type: none"> 8. Access to Care. Ensure access to quality health care for all 9. Children. Ensure the provision of needed services (e.g., mental, oral, vision, hearing, and physical health; nutrition; and those related to the social and physical environments) for at-risk children, including children in out-of-home care 10. Older Adults. Enable the provision of needed services and programs to foster healthy aging 11. Health Communication. Enhance and improve health service experience through improved health literacy, communications, and interactions 12. Education. Substantially increase high school graduation rates by working with schools, early childhood programs, community organizations, public health agencies, health plan providers, and businesses to promote the connection between educational attainment and long-term health benefits 13. Social and Economic Conditions. Support and implement policies that create the social, environmental, and economic conditions required to realize healthy outcomes
4	CULTURAL AND LINGUISTIC COMPETENCY —Improve cultural and linguistic competency and the diversity of the health-related workforce	<ol style="list-style-type: none"> 14. Workforce. Develop and support the health workforce and related industry workforces to promote the availability of cultural and linguistic competency training that is sensitive to the cultural and language variations of diverse communities 15. Diversity. Increase diversity and competency of the health workforce and related industry workforces through recruitment, retention, and training of racially, ethnically, and culturally diverse individuals and through leadership action by healthcare organizations and systems 16. Ethics and Standards for Interpreting and Translation Services. Encourage interpreters, translators, and bilingual staff providing services in languages other than English to follow codes of ethics and standards of practice for interpreting and translation
5	DATA, RESEARCH, AND EVALUATION —Improve data availability, and coordination, utilization, and diffusion of research and evaluation outcomes	<ol style="list-style-type: none"> 17. Data. Ensure the availability of health data on all racial, ethnic, and underserved populations 18. Community-Based Research and Action, and Community-Originated Intervention Strategies. Invest in community-based participatory research and evaluation of community-originated intervention strategies in order to build capacity at the local level for ending health disparities 19. Coordination of Research. Support and improve coordination of research that enhances understanding about, and proposes methodology for, ending health and healthcare disparities 20. Knowledge Transfer. Expand and enhance transfer of knowledge generated by research and evaluation for decision making about policies, programs, and grantmaking related to health disparities and health equity

people, and often must communicate through an interpreter. The trip may take several days. Weather problems may cause delays, making travel difficult and cost prohibitive. When economic, geographic, and cultural barriers are compounded by additional obstacles of limited laboratory supplies and equipment and untrained staff, the infrastructure of the health system leads to incomplete care and frustration for providers and patients.

In simple truth then, CCC strategic planning has only just begun to address cancer-related disparities. This report illustrates that sustaining these efforts now requires shifting focus to strategic execution and implementation. There are thousands of underserved communities where disparities are exacerbated by further challenges. With the systematic support of the CCC programs and partners, communities are empowered to implement strategic plans to reduce their significant cancer burden through optimal use of their readily available resources. Moreover, CCC efforts in prevention and early detection will likely result in increased demand for cancer treatment, which will further stretch resources. Forecasting into future then suggests that among the main priorities for CCC plans must be the overall improvement in infrastructure to provide more comprehensive care to underserved areas.

As our plans to address disparities evolve, we find additional subgroups within these populations that are further burdened by the existing healthcare resources. The Intercultural Cancer Council (ICC) is a national CCC partner committed to reducing cancer-related disparities through innovative programs focused on public policy at a national level and healthcare service on a regional and local level. The ICC promotes educational outreach initiatives that include the identification of public policy issues affecting these communities. One example, the 1st “Men’s Health Summit: A Man’s Health is a Family Matter,” educated AI/AN men about prostate, colorectal, and testicular cancers, the importance of early screening and the effects of tobacco [16]. Participants discussed plans aimed at improving cancer issues for AI/AN men through tribal policy with regard to issues, such as, employment, housing, elder services, child welfare, and schools [16]. The ICC has also supported national partners in two major policy summits, one focused on the AI/AN population and another on Pacific Islanders.

Maintaining the momentum of CCC progress requires that these programs and partners now be linked with broader initiatives that allows for synergy of common issues rather than duplication of efforts. Health-related disparities are not unique to cancer. Recognizing the magnitude of these and other health disparities, the US Department of Health and Human Services (DHHS) Office of Minority Health (OMH) is launching a National Partnership for Action to End Health Disparities (NPA) [17].

The NPA was designed as a catalyst for collective leadership around five main goals: (1) awareness, (2) leadership, (3) healthy system and life experience, (4) cultural and linguistic competency, and (5) data, research, and evaluation. Table 1 provides a description of these five goals and 20 national strategies for action. Regional blueprints and targeted initiatives undertaken by public and private partners will increase the effectiveness of programs targeting the elimination of health disparities through the coordination of partners, leaders, and stakeholders committed to action. The NPA was developed based on a “bottom-up” approach and established with the underlying belief that local leaders are fundamental to formulating relevant community-driven solutions. Voluntary health equity entities at the neighborhood, community, state, regional, and national levels will provide a means for multi-sector organizations to plan, collaborate, and drive efforts for mutual benefit. Federal input is through OMH and a Federal Interagency Health Equity Team, which is comprised of the ten departments.

The NPA provides an exciting opportunity for a broader framework of CCC plans. If public and private resources can be strategically aligned to work together, we should be able to offer a more effective collaboration, an improved infrastructure of healthcare systems, a reduction in the gaps of service, and a breakdown of the traditional silos that limit our capacity to address inequities in healthcare. Only if national, state, and local leadership joins together with private, non-profit, and community-based organizations can we sustain and build upon the progress of CCC plans. Although we celebrate our successes to date, an increased commitment from all partners is required to continue in our current direction with a forceful look ahead to expand opportunities for action. Again, a simple truth is that national healthcare objectives can be achieved only by the elimination of disparities.

Acknowledgments The authors wish to acknowledge Grant H13/CC625012-05 for Reverse Capacity Building: Sharing our Cultural Story American Indian/Alaskan Native Educational Forum and Cooperative Agreement Number MPCMP051006-03 for the EDICT-CLAS Project. We also wish to thank Anne P. Lanier, MD, MPH, Guillermo Tortolero-Luna, MD, PhD, Nayda Figuero-Valle, MD, MPH, and Rachel Morris BA.

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